



# *University of* **HUDDERSFIELD**

## **University of Huddersfield Repository**

Ralph, Penelope

OPENING THE 'CAN OF WORMS': AN INVESTIGATION INTO OCCUPATIONAL THERAPY PRACTICE IN RELATION TO SUPPORTING CLIENTS' SEXUAL CONCERNS

### **Original Citation**

Ralph, Penelope (2019) OPENING THE 'CAN OF WORMS': AN INVESTIGATION INTO OCCUPATIONAL THERAPY PRACTICE IN RELATION TO SUPPORTING CLIENTS' SEXUAL CONCERNS. Doctoral thesis, University of Huddersfield.

This version is available at <http://eprints.hud.ac.uk/id/eprint/34935/>

The University Repository is a digital collection of the research output of the University, available on Open Access. Copyright and Moral Rights for the items on this site are retained by the individual author and/or other copyright owners. Users may access full items free of charge; copies of full text items generally can be reproduced, displayed or performed and given to third parties in any format or medium for personal research or study, educational or not-for-profit purposes without prior permission or charge, provided:

- The authors, title and full bibliographic details is credited in any copy;
- A hyperlink and/or URL is included for the original metadata page; and
- The content is not changed in any way.

For more information, including our policy and submission procedure, please contact the Repository Team at: [E.mailbox@hud.ac.uk](mailto:E.mailbox@hud.ac.uk).

<http://eprints.hud.ac.uk/>

# **OPENING THE 'CAN OF WORMS':**

## **AN INVESTIGATION INTO OCCUPATIONAL THERAPY PRACTICE IN RELATION TO SUPPORTING CLIENTS' SEXUAL CONCERNS**

A thesis submitted to the University of Huddersfield in partial fulfilment of the requirements  
for the degree of Doctor of Philosophy

**Penelope Ralph**

**THE UNIVERSITY OF HUDDERSFIELD  
October 2018**

## Copyright statement

i. The author of this thesis (including any appendices and/or schedules to this thesis) owns any copyright in it (the "Copyright") and she has given The University of Huddersfield the right to use such copyright for any administrative, promotional, educational and/or teaching purposes.

ii. Copies of this thesis, either in full or in extracts, may be made only in accordance with the regulations of the University Library. Details of these regulations may be obtained from the Librarian. This page must form part of any such copies made.

iii. The ownership of any patents, designs, trademarks and any and all other intellectual property rights except for the Copyright (the "Intellectual Property Rights") and any reproductions of copyright works, for example graphs and tables ("Reproductions"), which may be described in this thesis, may not be owned by the author and may be owned by third parties. Such Intellectual Property Rights and Reproductions cannot and must not be made available for use without the prior written permission of the owner(s) of the relevant Intellectual Property Rights and/or Reproductions

# Contents

Copyright statement.....	2
Abstract.....	7
Acknowledgements .....	9
Presentations / posters .....	9
List of abbreviations .....	10
List of figures & tables .....	11
List of appendices .....	12
<b>CHAPTER 1: INTRODUCTION - A MISSING OCCUPATION? .....</b>	<b>13</b>
1.1 Situating myself / my research.....	15
Justification for research .....	16
What this research is not about.....	19
Intersecting disciplines and occupational science .....	20
1.2 Defining terms .....	22
Occupation .....	22
Sex and sexual expression .....	25
Defining taboo and stigma.....	27
Contested terms .....	28
The study question, aims and objectives .....	28
<b>CHAPTER 2: CONTEXTS / LITERATURE REVIEW .....</b>	<b>30</b>
2.1 Occupational therapy: history, professional identity and sexual concerns.....	32
Introducing occupational therapy.....	32
Occupational therapy professional identity .....	40
Sex as an occupation .....	47
Summary: Occupational therapy: history, professional identity and sexual concerns.....	55
2.2 A brief history of influences on attitudes to sex and sexuality theory.....	57
Historical influences on attitudes .....	57
Methodological context: Sexuality theories .....	64
Taboo, 'specialness' and hierarchies of 'acceptable' sex.....	73
Summary: Influences on attitudes to sex and sexuality theory.....	75
2.3 Disability theory and disabled people / clients' experiences of sex.....	77
Methodological context: Disability theories and models .....	77
Disabled people / client experiences of sex .....	82
(Re)Claiming ordinary sex lives .....	88
Summary: Disability theory and disabled people / clients' experiences of sex .....	90
2.4 Occupational therapists, healthcare professionals and client sexual concerns.....	93
Ambiguity .....	93

Attitudinal barriers .....	96
Structural/ material factors .....	99
Taboo, stigma and healthcare .....	101
Medicalisation and sex .....	102
Summary: Occupational therapists, healthcare professionals and client sexual concerns .....	106
 2.5 The concept of 'dirty work': occupation, sex and 'matter out of place' .....	109
Introducing 'dirty work' or occupational taint .....	109
Relevance to this study.....	114
Summary: 'Dirty work', occupation, sex and 'matter out of place' .....	117
 Chapter 2: Conclusion.....	119
 <b>CHAPTER 3: METHODOLOGY .....</b>	<b>121</b>
 3.1 Conceptual frameworks and theory.....	122
Paradigms, ontology and epistemology .....	122
Considering approaches and methodologies .....	124
Summary: Conceptual frameworks and theory.....	132
 3.2 Research Methods and design .....	135
Mixed methods .....	136
Research design.....	138
Summary: Research methods and design .....	148
 3.3 Ethics and rigour .....	150
Ethical considerations.....	150
Ensuring quality, rigour and validity .....	152
Summary: Ethics and rigour .....	154
 Chapter 3 Conclusion.....	155
 <b>CHAPTER 4: RESULTS, ANALYSIS AND DISCUSSION.....</b>	<b>156</b>
 4.1 Recognising sex as an occupational concern .....	157
Sex as an occupation .....	157
Defining sex and sexual expression .....	159
Sex as an occupational therapy concern .....	160
Taking an occupational approach .....	165
Recognising demand, meaning and importance .....	167
Summary: Recognising sex as an occupational concern .....	170
 4.2 Broaching sexual concerns in occupational therapy practice .....	173
Assessment and reasoning .....	173
Client goals and concerns: interventions and problem solving .....	180
Trust, rapport and therapeutic relationships .....	185
Summary: Broaching sexual concerns in occupational therapy practice .....	188
 4.3 Comfort, discomfort and barriers to broaching sex.....	191
Comfort and discomfort .....	191
Organisational and structural barriers .....	198
Client barriers.....	204
Summary: Comfort, discomfort and barriers to broaching sex.....	207

4.4 Countering occupational taint: Managing sex as ‘dirty work’ .....	210
Is sex ‘dirty work’? .....	210
Countering occupational taint .....	212
Summary: Countering occupational taint - managing sex as ‘dirty work’ .....	219
4.5 Negotiating tensions and ambiguities .....	222
Normative assumptions and reasoning .....	222
Balancing risk and autonomy .....	229
Summary: Negotiating tensions and ambiguities .....	231
Chapter 4 Conclusion .....	234
<b>CHAPTER 5: CONCLUSION - FINDINGS, IMPLICATIONS AND RECOMMENDATIONS.....</b>	<b>236</b>
5.1 Findings, implications and contribution to knowledge .....	238
Sex as an occupational (and ordinary) concern .....	238
Occupational therapy practice skills and sexual concerns .....	240
Resources - absence and creativity .....	241
Ambiguity around practice .....	242
Navigating assumptions, attitudes and acceptability .....	243
Countering taint through professional identity and values .....	244
Using Critical Realism in occupational therapy /science research .....	246
Using sexual script theory/ materialism in this research .....	248
5.2 Recommendations and limitations .....	250
Policy and practice: .....	250
Further research: .....	255
Study limitations .....	258
5.3 Conclusion .....	261
<b>APPENDICES.....</b>	<b>265</b>
Appendix 1 – Research instruments .....	265
1.1 – Stage 1: Survey .....	265
<b>QUICK SURVEY: AN INVESTIGATION INTO OCCUPATIONAL THERAPY (OT) PRACTICE IN RELATION TO SUPPORTING SERVICE USERS’ SEXUAL CONCERNS IN PHYSICAL SETTINGS. ....</b>	<b>266</b>
Consent form .....	267
Quick survey .....	268
1.2 – Stage 2: Questionnaire .....	269
1.3 – Interview guide – pre-pilot .....	275
1.4 – Interview guide – post-pilot .....	277
1.3 - Stage 3: Interviews .....	279
1.4 - Support information provided to all participants .....	281
Appendix 2 – University of Huddersfield School of Human and Health Sciences Ethical approval form .....	282
Appendix 3 – Risk assessment .....	284

<b>Appendix 4 – Flyers and advertising research .....</b>	<b>286</b>
<b>Appendix 5 – Data analysis .....</b>	<b>288</b>
<b>REFERENCES.....</b>	<b>289</b>

## Abstract

**Introduction:** Sex is an important aspect of health, wellbeing and identity (Couldrick, 2007), yet it is an often overlooked, ignored and omitted aspect of healthcare due to feelings of stigma, taboo and discomfort (Couldrick, 1998; Yallop and Fitzgerald, 1997; Jones et al, 2005). Occupational therapy uses occupation to enable and support people engaging with activities that matter to them (COT, 2015). Within occupational therapy, there has been debate as to whether sex is an occupation and within the remit of occupational therapists. In practice, occupational therapists rarely address sexual health concerns due to attitudinal and structural barriers (Couldrick, 1998). This research sought to explore the work of occupational therapists who address the sexual concerns of their client in order to find out more about experiences, thoughts and feelings, in order to support future practice.

**Methods:** This research used a mixed-methods approach to explore the practice and experiences of occupational therapists who do address sexual health concerns in predominantly physical and neurological settings. This study was undertaken using a purposive sample in three phases; a scoping survey which sought to identify eligible participants who include sexual concerns in their work (105 respondents), a questionnaire focussing on the practice and background of those who broached sexual concerns (14 participants), followed by semi-structured qualitative interviews focussing on their thoughts, feelings and experiences of broaching sexual concerns (12 participants). This research gained ethical approval from the University of Huddersfield's School of Human and Health Sciences.

**Results:** The participants recognised sexual health as a meaningful occupation, an activity of daily living and an important aspect of client lives, viewing sex as an occupation and therefore part of their remit. They adapted and applied their core professional skills and knowledge such as reasoning, activity analysis, building rapport, creativity and problem-solving skills. The participants reported using a range of interventions including advice, adaptive equipment/ aids, motivational interviewing, and client education. Drawing on their occupational focus, several participants indicated they felt well-placed to view sexual concerns holistically, considering the impact on the client's role/ identity and body image as well as practical, functional considerations around impairment. The participants also indicated they faced barriers similar to those found in the literature such as issues around lack of resources, education and training, negative attitudes to sex and organisational constraints (Haboubi and Lincoln, 2003; Dyer and Das Nair, 2013; McGrath and Lynch, 2014). At times, the participants indicated they made assumptions about their clients based on reasoning. The participants recognised sex to be a sensitive, taboo subject, which can be described as occupationally 'tainted' or 'dirty work', and used strategies based on their professional values to counter this. Limitations to this study include the lack of representation from those working in trauma and orthopaedics and other areas of occupational therapy practice, and the low number of quantitative data responses, which mean that this study is not generalisable and the quantitative data is not statistically significant.

**Conclusion:** This research indicates that occupational therapists could recognise sexual concerns as meaningful and important occupational concerns, and an important aspect of health, wellbeing and



identity, and that there is a role for occupational therapists in supporting client sexual concerns as part of holistic and client-centred practice in accordance with the values of the profession. Occupational therapy skills and knowledge were transferable and could be applied to sexual concerns, whilst education, training, previous exposure to sensitive subjects and a strong sense of professional values were important facilitators for raising confidence and competence. By addressing sexuality occupational therapists can normalise the legitimate concerns of their clients and ensure that support for sexual needs is provided or available for all, in accordance with the profession's core holistic and client-centred values.

## Acknowledgements

I would like to thank the many people who have supported me in this research.

I am extremely grateful to my supervisors, Prof Surya Monro and Dr Jo Stead, for their guidance, support and encouragement – thank you!

Sincere thanks go to the people who took the time to participate in this research and without whom this research would not have been possible; the survey participants and particularly the questionnaire and interview participants who took time out from their busy lives to share their knowledge and experience.

Thanks also go to the RCOT Specialist Sections and SHADA for their help in recruiting participants.

I would also like to thank my friends and family for their continued support and encouragement, with special thanks to my mum as always, to Safeena and Lorraine for their diligent cheerleading, and to Steve for his role as sounding-board.

## Presentations / posters

*It's the elephant in the room": Sex and occupational therapy.* Presentation at 9th annual RCOT Northern and Yorkshire regional student conference. 1 June 2018. Huddersfield, UK.

*Occupational Therapists and 'dirty work': sex as a tainted occupation.* Presentation at the British Sociological Association 49th Medical Sociology Annual Conference 2017, 13-15 September 2017. University of York. York, UK.

*Sexual Health and Occupational Therapy: a missed opportunity?* Poster at the College of Occupational Therapists Annual Conference. 19-20 June 2017. Birmingham, UK.

*Recognising sexual health as a meaningful activity in occupational therapy.* Oral / poster at the 23rd World Congress of Sexology. 28-31 May 2017. Prague, Czech Republic.

*Professional identity in occupational therapy and the sexual issues of clients: A review of the literature.* Presentation at University of Huddersfield PGR Festival. 1 April 2016. Huddersfield, UK.

*'A can of worms?' Occupational therapists and the sexual expression of clients – a review of the literature.* Poster at University of Huddersfield PGR Conference. 13 November 2015. Huddersfield, UK.

## List of abbreviations

ADL – Activity of Daily Living

AHP – Allied health professionals

AOTA – American Occupational Therapy Association

COT / RCOT – Royal College of occupational therapists (receiving royal assent in 2017)

CR – Critical realism

HCPs – Healthcare professionals

HCPC – Health and Care Professions Council

HIV - Human immunodeficiency virus

ICF – International Classification of Functioning, Disability and Health

LTCs – Long Term Conditions

MDT – Multi-disciplinary Team

NHS – National Health Service

NICE – National Institute for Health and Care Excellence

OT – Occupational therapy

SHADA – Sexual Health and Disability Alliance

STD / STI – Sexually transmitted disease / infection

UPIAS - Union of the Physically Impaired Against Segregation

WHO – World Health Organisation

## List of figures & tables

Figure 1 – Drivers for this study

Figure 2 – Department of Health (2012) outcome framework

Figure 3 – Underlying professional beliefs (Creek, 2003)

Figure 4 – Personal and socio-institutional factors

Figure 5 – Influences on sex since the Middle Ages

Figure 6 – Simon and Gagnon's three levels of sexual scripts

Figure 7 – Rubin's hierarchy of sex

Figure 8 – Barriers to disabled people accessing sex and sexual expression

Figure 9 – Barriers to HCPs/OTs in broaching sexual concerns

Figure 10 – Pawson and Tilley's CR model

Figure 11 – Dalkin *et al*'s (2015) CR model

Figure 12 – Applying Dalkin *et al* (2015) to Robson's gunpowder analogy

Figure 13 – Summary of study methodology

Figure 14 – Mixed method strategies: Concurrent nested

Figure 15 – Mixed method strategies: Concurrent exploratory

Figure 16 – Demographic: Age range

Figure 17 – Demographic: Gender

Figure 18 – Demographic: Sexuality / orientation

Figure 19 – Demographic: Work sector at time of study

Figure 20 – Demographic: occupational therapy experience in years

Figure 21 – Data collection process

Figure 22 – Template Analysis process

Figure 23 – Survey question: Do you feel that sexual function / intimate relationships are occupations?

Figure 24 – Questionnaire question: Do you include sexual concerns / intimate relationship needs of the client as part of your role as an occupational therapist?

Figure 25 – Questionnaire question: If so, how often do you include it?

Figure 26 – Questionnaire question: How do you go about assessing client needs?

Figure 27 – Questionnaire question: Who raises the concern first?

Figure 28 – Concerns arising during the interviews

Figure 29 – Questionnaire question: Types of interventions used

Figure 30 – Examples of interventions used (interviews / questionnaire data)

Figure 31 – Questionnaire question: Levels of comfort / discomfort

Figure 32 – Questionnaire question: Pre-registration training

Figure 33 – Questionnaire question: Post-registration training

Figure 34 – Meaning and importance of sexual concerns

Figure 35 – Dalkin *et al* (2015) in relation to this study

Figure 36 – Mechanisms for broaching sexual concerns

## List of appendices

### Appendix 1 – Research instruments

- 1.1 – Stage 1: Survey
- 1.2 – Stage 2: Questionnaire
- 1.3 – Interview guide – pre-pilot
- 1.4 – Interview guide – post-pilot
- 1.5 - Stage 3: Interviews
- 1.6 - Support information provided to all participants

### Appendix 2 – University of Huddersfield School of Human and Health Sciences Ethical approval form

### Appendix 3 – Risk assessment

### Appendix 4 – Flyers and advertising research

### Appendix 5 – Data analysis

## Chapter 1: Introduction - A missing occupation?

The roots of this research lay in a realisation during my undergraduate occupational therapy degree that discussions and support related to sexual concerns were missing from day-to-day practice. Everything I had learnt about 'occupation'<sup>1</sup> as defined in occupational therapy (discussed further in chapter 1.2) suggested that sex and sexual expression were occupational, linked to meaning, identity, function and activity, yet during my pre-registration education sex had been absent from my experiences of practice and those of my cohort. I wondered about the implications this omission may have had on clients and for occupational therapy as a profession. As will be discussed in chapter 2.8, this omission is not unusual; sex is often missing not just within occupational therapy practice but within healthcare generally. After talking with my then cohort, and considering previous research on occupational therapy attitudes, it was clear that sex and sexual expression were seen as occupational concerns but due to a variety of attitudinal and structural reasons were missing from day-to-day practice. Despite occupational therapists broaching other sensitive concerns such as toileting, end of life care and suicidal ideation, and being potentially important to clients as a meaningful part of their lives and identity, sex seems to be perceived as exceptional and taboo. This omission has not gone completely unnoticed - for example the excellent work by Lorna Couldrick (1998/9, 2005, 2007) examining occupational therapist practitioner views on sex and sexual expression, but there has been little research specifically exploring the thoughts and activities of occupational therapists who do broach sexual concerns. Sex in healthcare is often perceived through a prism of negativity; problematised (for example, unwanted pregnancy, sexually transmitted Infections (STIs)), pathologised (for example, penile dysfunction, female sexual arousal disorder), or couched in terms of risk, vulnerability or potential harm. This research sought to contribute towards a shift in perspective to consider sex as a positive part of sexual health and as an ordinary part of client lives.

Based on this, I was motivated to examine the experiences of occupational therapists who do broach client sexual concerns, and how they felt about this part of their roles. The literature indicates that occupational therapists and HCPs generally are unclear and unsure of what to do regarding sexual concerns, therefore by capturing this information I could shine a light on and provide a useful insight

---

<sup>1</sup> As will be discussed further below, 'occupation' in occupational therapy and occupational science is defined more broadly than in common usage as activities, tasks and roles which people as individuals, groups or communities engage in. This can include a wide array of activities including necessary day-to-day tasks such as eating, mobilising and toileting, active pursuits such as work, hobbies and leisure or passive activities such as sleeping.

into what occupational therapists do and how they manage an occupation which may be described as taboo or tainted (as discussed in chapter 2.5). I sought to generate knowledge that could encourage and support occupational therapists generally in acknowledging, reflecting and ultimately including sex as just another occupation.

This study seemed timely as there have been indications in recent years of a shift in societal attitudes towards disabled people and sex, and a gradually increasing demand from occupational therapists for knowledge and support. Television programmes such as *The Undateables* (Channel 4) and advertising such as those used in the 2017 *Maltesers* campaign suggest disability is becoming more visible and that society is perhaps finally beginning to accept disabled people as sexual beings. This is reflected in increasing media attention such as a *Metro* feature (2018) on sex toys aimed at disabled people and articles on sex and relationships relating to disabled people on *BBC* (2016), *BBC Ouch* (n.d), *Vice* (2016), and *The Guardian* (2016) suggesting disabled people - who could be current or potential occupational therapy clients – may be seeking information and support about sexual issues. Based on speaking to practitioners and Facebook forums such as *Intimacy4OT* there were anecdotal indications from occupational therapists themselves that they would like to support their clients but had difficulty in finding information and ways to do so. The literature on disabled people's experiences suggests a demand for support exists (discussed in chapter 2.3). This study sought to fill this missing knowledge, seeking to open the 'can of worms' - as broaching sexual concerns is often referred to (Gott *et al*, 2004, p,528; Dyer and Das Nair, 2013, p.2658) - and contribute in making sex and sexual concerns less discomforting and daunting.

## 1.1 Situating myself / my research

All research is subject to the opinions and prejudices of the researcher and this study is no different. It was important for the study that I acknowledged any bias to ensure transparency and rigour (Robson, 2002). Here, I will set out some of my attitudes, influences and standpoints in relation to this subject. Firstly, I can relate to the awkwardness and discomfort many people feel about talking about sex, especially in a professional healthcare context (see chapter 2.5) and part of my personal motivation for undertaking this research was an attempt to reduce that discomfort; the greater exposure to sensitive, discomforting subjects can lead to more competence and confidence in dealing with them personally and professionally (Hecimovich and Volet, 2011; Wilding *et al*, 2012). I could empathise with the discomfort reported in the literature by many occupational therapists and HCPs who omit or avoid sexual concerns, especially when it may feel difficult to justify in an age of time and resource scarcity.

From the outset I thought, and continue to think, that sex is an occupation and as such it should be part of the remit of occupational therapists if they are to truly adhere to professional values of holism and client-centeredness. This question of whether sex is the remit of occupational therapy has been contested and will be examined in chapter 2.1. Personally, I feel it is potentially marginalising to omit an occupation which may be important to clients. Sex and sexual expression are occupational; they are part of who some people are, how some people see themselves and what they want to be and do, imbued with meaning and identity, as well as a potential source of fun, pleasure, purpose, closeness to others, self-esteem and self-worth, and therefore a valuable part of many people's lives. For some people sex may be central to their lives, for others - for example people who may identify themselves as asexual - it may be of no interest, with a spectrum of attitudes in between. Therefore it should be acknowledged in order for assumptions to be avoided and to recognise the person as an occupational whole. For many people, sex relates or contributes to other parts of their lives; their sexuality, identity, relationships, work and life roles. It is not vital and omission is not life threatening, but it is important for many people (Jackson and Scott, 2010a).

Although I consider sex to be important for many people, I also understand the sensitivity around discussing sexual concerns; when asked about my research I felt some unease regarding other people's reactions, implying a sense of sex as a tainted subject or as 'dirty work, that is, necessary but societally rejected (Irvine, 1990, citing Hughes 1958 and 1962, discussed further in chapter 2.5). A participant, Carol, also commented on the difficulty of researching the subject whilst Irvine (2014) suggests that sexuality research is stigmatised within academia. Sexual imagery is described as



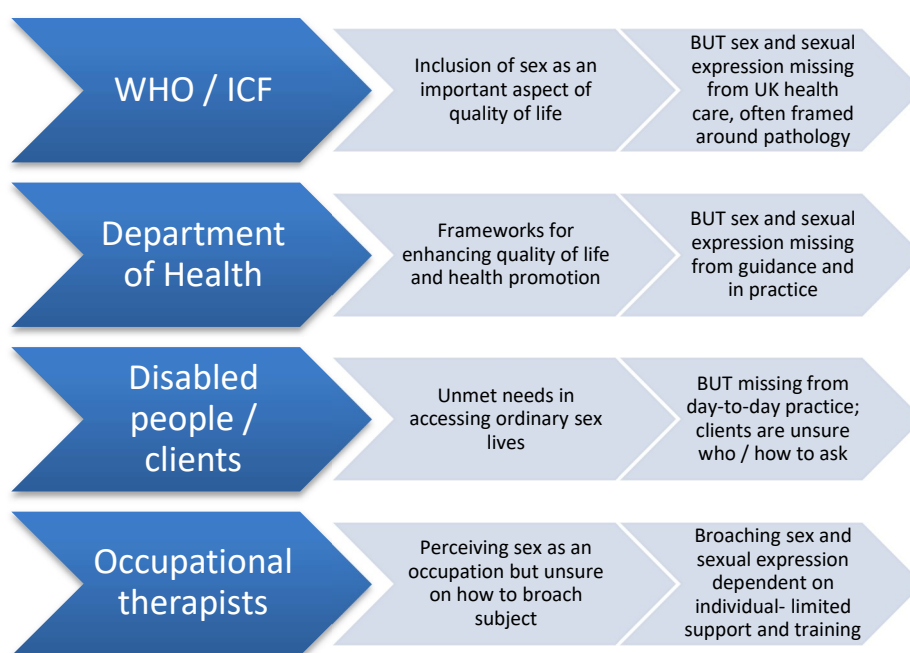
pervasive in Western culture and yet exceptionalism around sex reinforces its continued 'taboo' (Jackson and Scott, 2004). For example, sex education remains contested and imbued with a sense that it is somehow dangerous or may encourage promiscuity (Jackson and Scott, 2004). Whilst sex workers are seldom perceived as 'ordinary' workers undertaking what some people may see as 'undesirable' work but instead they are often subject to moral judgements whereas many people undertaking other 'undesirable' work are not subject to these moral judgements (Sanders *et al*, 2018). Sex, then, is laden with baggage from individuals and society which can influence how it is researched and how that research is perceived (discussed further in chapter 2.2).

With regards to my background, I share some of the dominant traits that the occupational therapy profession is often criticised for (Hammell, 2011; Clare Taylor, 2007): I am white, I identify as female, as heterosexual (although I perceive sexuality as unfixed and on a spectrum); I am non-disabled (although I see this too as unfixed as I may face permanent or temporary impairment, illness or disabling barriers throughout my life). Unlike the predominant occupational therapy 'middle class' stereotype I am from a working class background and identify myself as such. Most of these attributes put me in a relatively privileged position and can impact on my views and analysis during the research process. An account of how I have countered and reduced my conscious opinions and unconscious biases can be found in section 3.3 on rigour and quality, as part of the Methodology outlined in chapter 3.

### **Justification for research**

As the literature indicates that occupational therapists perceive sex as an occupation but often feel they lack the knowledge and competence to include it, this study sought to provide knowledge derived from experienced practitioners which can help others prepare, support them in practice and provide a foundation for reflection to help engage with a subject often described as sensitive and difficult. There were several drivers for this study which I have outlined below in figure 1:

**Fig 1 – Drivers for this study**



(WHO<sup>2</sup>, 2001; DoH<sup>3</sup>, 2012; Northcott and Chard, 2000; Couldrick, 1998; Shakespeare *et al*, 1996)

As will be discussed below, despite there being several drivers for the inclusion of sex and sexual expression within UK healthcare and occupational therapy practice, it remains an unmet and missing need, and arguably an occupational one.

### ***An unmet health concern***

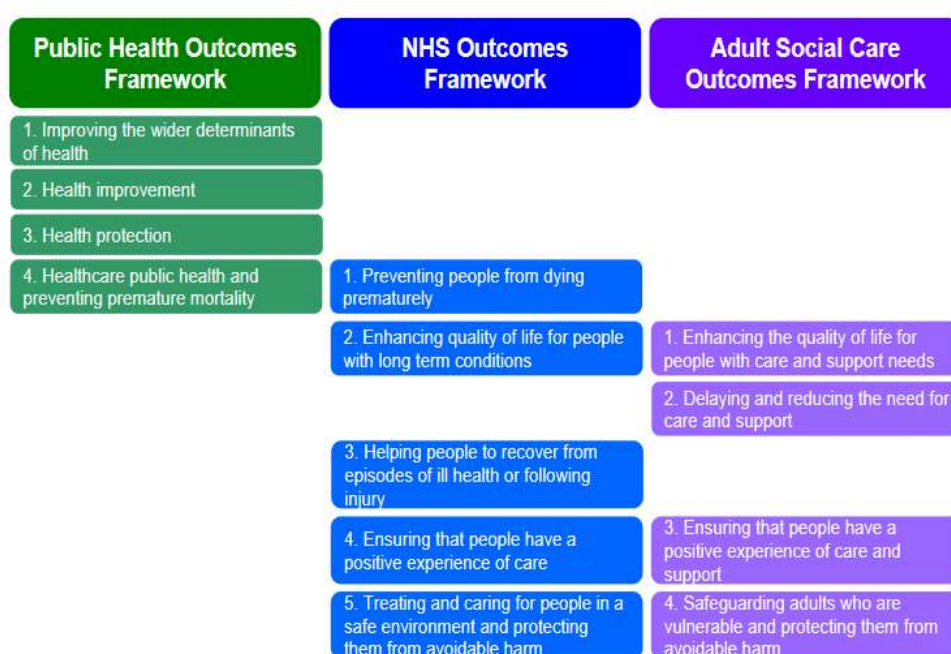
Research indicates that when sexual concerns are addressed within medical and healthcare practice this can support health and aid self-esteem, emotional well-being and overall quality of life (Tepper, 2000). McCabe and Taleporos (2003) found that failing to address sex can have a negative impact on self-esteem and body image whilst Hassounah-Phillips and McNeff (2005) suggest omission could lead to an increased vulnerability to abuse. The US NGO Planned Parenthood (2007) sets out evidence for a host of health benefits in their report *The Health Benefits of Sexual Expression*, including improved cardio-vascular health, general wellbeing, and immunity to disease and pain management. By addressing sexual concerns the general health of disabled people can be sustained by reducing stress and improving feelings of wellbeing (NHS Choices, 2017), improving body image and self-esteem, and aiding adjustment to changes in life circumstances (McCabe and Taleporos,

<sup>2</sup> World Health Organisation

<sup>3</sup> UK Department of Health

2003). Research indicates that disabled clients want these issues to be acknowledged and addressed (Shakespeare *et al*, 1996) but they do not know who to ask (Northcott and Chard, 2000), suggesting a demand for input and support; the experiences of disabled people are examined further in chapter 2.3. Drivers for further exploration can also be found in national and international policy; the World Health Organisation [WHO] (2001) states that access to sexuality is a healthcare issue and should be supported for all. Sexual expression is a domain in the *International Classification of Functioning, Disability and Health* (ICF), and arguably an Activity of Daily Living (ADL) (Couldrick, 1998). Whilst the Department of Health (2012) Outcome Framework for quality of life and health promotion (figure 2) has several indices around quality of life and health promotion which could arguably include consideration of sexual concerns due to the link with health and wellbeing, for example quality of life for people with lifelong conditions, enhancing quality of life and helping people recover.

**Fig 2 – Department of Health (2012) Outcome Framework**



Sex, then, can be seen as an unmet concern, missing from day-to-day practice despite suggestions that clients would like these concerns met, indications of positive links to health and wellbeing and links to national and International policies.

### ***Missing occupation = missing knowledge***

As sex and sexual expression are often missing from occupational therapy education, training and even informal discussion, there remains a huge gap in knowledge in this area. Other aspects of clients' lives around returning to work, access to leisure and hobbies, therapeutic use of arts, crafts and creativity and day-to-day self-care such as washing, dressing, mobilising and food/drink

preparation, as well as a host of widening practice activities are given attention in occupational therapy professional literature whilst therapeutic-related 'trade' fairs such as Naidex and The OT Show advertise services and equipment to support mobility, self-care and leisure activities but provided no information or support for sex and sexual expression. I could find only one (online) UK service which provides specialist adaptive equipment to support sexual activity (who import equipment from the US), and anecdotally I learnt of a UK specialist sex worker who specifically worked with disabled people. As sexual health interventions in the UK are often aimed at the negative repercussions of sex or on sexual dysfunction (Department of Health, 2013; Public Health England 2015), there appears to be nowhere to turn for clients and practitioners for more positive and supportive interventions, and limited means for finding information and widening knowledge. Whilst sex remains missing from occupational therapy consideration and out of sight from day-to-day practice, useful and important knowledge remains hidden and unexplored, taboos are reinforced and sex remains something framed as exceptional rather than an ordinary part of clients' lives.

### ***Sex as an occupational concern***

As will be discussed in 2.1, sex is arguably an occupation and should be considered part of the remit of occupational therapists. Failing to address sexual concerns is potentially problematic and contrary to the philosophy and values of the occupational therapy profession as it misses aspects of the client's life which may be meaningful and important to them. It also potentially reinforces a traditional, medical model of disability by reinforcing barriers to clients in engaging in all aspects of their daily lives; societal, physical / environmental, emotional and psychological. As such it could be seen as potentially marginalising by leaving what might be an important issue for clients aside. I wondered how clients might feel if this part of their lives were omitted; it may be the last thing on their minds but for some people it may be a huge concern or an extra worry to have an important activity and part of their lives ignored, one which the client may be unsure about raising (Northcott and Chard, 2000).

### **What this research is not about**

Although this study draws on sociology, gender, sexuality and disability theory, these were not the primary foci of this research. Nor was this research about human or sexual rights issues which are discussed in more focus by Richardson (2000) and McGrath and Sakellariou (2016). This research also omits occupational therapy and sexual concerns in the areas of mental health or learning disability. Instead, I aimed to keep the focus of this research quite narrowly concentrated on occupational therapists who worked in predominantly physical settings. This was to limit what could

easily have turned into a huge project. I wished to avoid framing the study around issues of mental capacity and legal debates although these are hugely important and impinge on all areas of occupational therapy practice. This is not to say that practice in mental health and learning disability in relation to sex and sexual expression do not deserve attention – far from it. There has been discussion about access to sex and sexual expression within learning disability services, often framed around concerns around safeguarding and inappropriate behaviour. Increasingly, though, there has been acknowledgement that people with learning disabilities have sexual rights and should be supported in expressing them (Keywood, 2003; Dukes and McGuire, 2009; Mencap, 2016). For people using mental health services, the issue of sex seems to be invisible; there is very little literature or discussion on the subject and the experiences of the participants in my research who had worked in mental health indicated it was an issue that was largely ignored or ‘swept under the carpet’. There is, then, absolutely a need for more open discussion and research about the sexual needs of all clients generally, but in learning disability and mental health services the combination of complex concerns around safeguarding and capacity, the still prevalent stigma around these conditions and overstretched resources, clients’ needs continue to be ignored and omitted, and unfortunately due to aims of a deeper focus on practice around physical impairment this research was also unable to address this. In the event, due to the difficulty in finding participants and the blurred boundaries between some areas of occupational therapy practice, issues around learning disability and mental health did arise and I have referred to these in chapter 4, but I have actively omitted a deeper discussion around legislation, legal frameworks, mental capacity and safeguarding in order to keep the focus on occupational practice and experience, and the participants’ feeling about that practice.

## Intersecting disciplines and occupational science

As noted above, this study drew on several disciplines; sociology, health sciences, disability studies and human relations studies. These disciplines intersect under the auspices of occupational science, a relatively new discipline which focuses on ‘humans as occupational beings’ (Yerxa, 1990). Occupational science helps draw these multiple disciplines under a unifying umbrella and ensure the centrality of occupation within this study, drawing on several foci of occupational science (see box). Placing this

### Foci of occupational science

‘The human need to be occupied;  
The purpose of occupation in survival and health;  
The effects of occupation or occupational deprivation;  
Why humans strive for occupational competence and mastery;  
Understanding what prevents or enhances occupational performance;  
How social, cultural and political structure affect occupation;  
How occupation provides biological and sociocultural needs;  
How occupation was necessary in the development of human capacities’.  
(Wilcock, 1993, in Jones, *et al.* 1998)

research under the auspices of occupational science helped maintain an occupational focus and ensure its relevance to occupational therapy theory and practice. Wright St-Clair (2012, p.140) suggests that 'occupational science may only flourish in a context in which divergent views are voiced and debated and knowledge development is celebrated as being continually in flux'.

This study both draws on and contributes to occupational science literature, congruent with the aim of making 'a connection between engagement in occupation and human development, wellbeing and health' (Kristensen and Peterson, 2016, p.241). Occupational science is an 'essentially human science' (Whiteford and Pereira, 2012) which encourages the investigation of the nature of occupation in society, incorporating a variety of approaches to strengthen critical reflection and the investigation of the relationship between occupation, occupational therapy, culture and society, and to provide knowledge to encourage a focus on social change and occupational injustice (Kristensen and Peterson, 2016). A key feature of occupational science literature is its concern for occupational justice and social change which aligns with the view that the omission of sexuality from practice is an issue of justice (Sakellariou and Simó Algado, 2006). This study contributes to the call within occupational science to investigate specific occupations to widen knowledge and help achieve greater understanding (Twinley, 2013).

The focus of this study was to investigate the work of occupational therapists in practice with a view to sharing their practice as well as exploring the participants' thoughts and feelings. The intention was to encourage occupational therapists – and healthcare practitioners more generally - to reflect on sex as part of their practice, and to open discussion and reflection on the limits they may be unwittingly placing on their perceptions of occupation. Anecdotally, when sex was discussed in practice, sex was often spoken of as an amusing anecdote or an embarrassing aside rather than a part of daily occupational practice. This research sought to explore and fill the gap in knowledge, to provide basis for reflection and preparation for when occupational therapists may need to broach the subject, shining a light on what for clients and disabled people may be an unmet need.

## 1.2 Defining terms

This section will define and briefly explore some of the key terms used within this study such as occupation, sex and sexual expression, and taboo and stigma.

### Occupation

The concept of 'occupation' within occupational therapy and occupational science is defined more broadly than in common usage; dictionary definitions allude to paid work or the holding of an area or country (for example, 'your job or profession', occupying a house/ space, military occupation - Collins dictionary, 2017). The definition which is more congruent with occupational therapy is less prominent, for example 'something you spend your time doing, either for pleasure or because it needs to be done'. Definitions of occupation in the occupational therapy literature include:

- 'Occupations are the daily living tasks that are part of an individual's lifestyle' (Golledge, 1998, p.102)
- 'Occupation is engagement in activities, tasks and roles for the purpose of productive pursuit, maintaining one's sense of self in the environment, and for the purposes of relaxation, entertainment, creativity and celebration' (Christiansen, Baum and Bass-Haugen, 2005. p.548)
- 'Occupation is the doing of work, play or activities of daily living within a temporal, physical and sociocultural context that characterises much of human life' (Kielhofner, 2008, p.5)
- '(Occupation) comprises of all the ways in which we occupy ourselves individually and as societies' 'our occupations are all the active processes of looking after ourselves and others, enjoying life, and being socially and economically productive over the lifespan and in various contexts' (Townsend, 1997, p.19)
- 'Specific 'chunks' of activity within the ongoing streams of human behaviours which are named in the lexicon of the culture' (Yerxa *et al*, 1989, p.5)
- 'An occupation is a specific individual's personally constructed, non-repeatable experience' (Pierce, 2001, p.139)
- "Occupation' as a term refers to practical and purposeful activities that allow people to live independently and have a sense of identity. This could be essential day-to-day tasks such as self-care, work or leisure'. (RCOT, 2017)

(Adapted from Molineux, 2009; Leclair, 2010; Twinley, 2013; RCOT, 2017)

The definitions above include key aspects in common such as a focus on doing and active

engagement, often incorporating meaning and purpose. Reed and Sanderson (1999) outlined several assumptions regarding the person and the importance of occupation:

- that persons are biopsychological, spiritual and should be viewed as a 'unified whole';
- they react, interact and are able to change and adapt within their social, cultural and physical environment;
- that the person has needs which may be helped or hindered by their environment, and that the person has choices, responsibilities and roles.

(Reed and Sanderson, 1999).

Occupation can be ordinary or special, can refer to practical and purposeful activities that can facilitate a sense of identity and can be undertaken consciously or unconsciously without awareness of them (Dickie, 2013, p.2).

Hagedorn (1995b) notes that definitions of occupation have been problematic, suggesting definitions are subject to personal predilections and fashionable mores. This has contributed to confusion about occupational therapy (Molineux, 2009) which is discussed further in chapter 2.1. Definitions of occupation have at times lapsed into tautology and reductionism as theorists have used interchangeable and undefined expressions around function and activity whilst attempting to marry meaning and function. The word 'occupation' has been used interchangeably with expressions such as 'function' or 'activity' due to concern that it may be 'misunderstood by others' (Wilding, 2009, p.4). Several definitions reduce occupation to constituent parts, conjuring up an image of human-as-machine and reflecting a Westernised, systems-oriented outlook (for example Pierce, 2001; Evans, 1987). Evans (1987) discusses 'mastering' the environment and the world; aspiring to be perfect and a focus on 'productive' activities - suggesting a medicalised view of the client as 'faulty', who may use occupation to become whole or part of society as long as it is in an 'appropriate' way. Other attempts to define occupation involve a taxonomy of key characteristics in order to help recognise occupation (Molineux, 2009, p.18), which arguably appear to be a sort of occupation 'spotters guide' (see box on p.23).

Moving away from more abstract definitions of occupation, Roberts (2011) ascertained how occupational therapists themselves define occupation. She outlines several themes:

- Social connectedness
- Self-identity
- Accomplishment, fulfilment and purpose



- Satisfaction and fun
- Feelings of health and well-being
- Routines and structures
- Recognition of role of environment

These themes indicate that occupational therapists themselves are less inclined to take a reductionist approach to occupation but instead consider meaning and purpose.

These definitions reflect the challenges the profession has had in understanding and conveying occupation as a widely encompassing concept. Clouston and Whitcombe (2008) suggest that definitions of occupation within occupational therapy are inward-looking, 'nebulous and incoherently defined' (p.317) making the concept difficult to articulate, hard for those outside the profession to objectively understand and making it subject to different interpretations depending on culture, setting and focus. Ultimately, occupation is a 'complex and multi-faceted phenomenon that cannot be succinctly defined' (Molineux, 2009, p.18) and may be conceptualised differently across cultures and languages, or even within the occupational therapy profession. Being ambiguous and multifaceted has opened the profession to a wide range of opportunities and experiences, but has also impeded understanding and development (Molineux, 2009, p.18), creating confusion in clients and wider society. Although a universal definition may be elusive, Roberts (2011) suggest that occupational therapists themselves know occupation when they see it. This may be both a strength and weakness, potentially leading to some occupations being included or omitted in practice according to the perceptions and experiences of the practitioner. This may be particularly problematic in relation to sexual concerns which are often omitted from occupational therapy literature and practice (Couldrick, 1998), which

### **Taxonomy of occupation**

The challenges of finding a satisfactory definition of occupation are indicated by a tendency to list its characteristics. Although useful in identifying occupation there was a danger of reducing it to a 'tick list' of attributes. For example:

Molineux (2009, p.18):

- active engagement
- purposeful
- meaningful to individual engaged in it (unique and dynamic)
- contextualised (physical, social, personal, cultural, and so on)
- human (non-human animals may not be engaged in the same way)

Yerxa (1993, in Dickie, 2013):

- Self-initiated
- Goal directed (inc. fun/ pleasure)
- Experiential
- Behavioural
- Socially valued / recognised
- Organised
- Essential to quality of life
- Influences health
- Made up of adaptive skills

may lead to assumptions that sexual concerns are not occupations. Practitioners, then, may not perceive sex as part of their remit

Despite these definitional difficulties, occupation has been recognised as an important aspect of human life as 'occupation provides the mechanism for people to fulfil basic human needs essential to survival and health; to adapt to environmental changes; and to develop and exercise genetic capacities in order to maintain health and experience physical, mental and social well-being' (Wilcock, 2006, p.51). The influential *International Classification of Functioning, Disability and Health* (ICF – WHO, 2001) recognises occupation as a key aspect of health and wellbeing, suggesting that all HCPs should have an 'understanding of the occupational impact of health conditions and in gauging the value of their assessments, interventions and research agenda in terms of occupation or in ICF terms participation' (Hocking and Nicholson, 2007, p.43), this may give occupation greater attention and legitimacy.

## **Sex and sexual expression**

The use of terms such as sex, sexuality, sexual health and sexual expression are complicated by how various disciplines, conceptual frameworks and individuals use them. Sex and sexuality have been examined through a variety of disciplines - for example, psychology, sociology, medicine, physiology - and each has brought a variety of applications of language, definitions and explanations. To some extent, each attempts to exert control over the subject and how it is discussed. At times terms such as sex and sexuality have been used interchangeably – for example 'sex' has commonly been used interchangeably with gender or as shorthand for sexual intercourse, whilst 'sexuality' has been used to refer to the general subject of all things sexual, sexual orientation or attraction between genders. Definitions of terms such as sex and sexuality have been affected by the dominance of either essentialist<sup>4</sup> (nature) or constructivist (nurture) interpretations.

A starting point in defining terminology, before the existence of Wikipedia, would be to use a dictionary; the Shorter Oxford Dictionary (Little *et al*, 1987) provides definitions of sexuality as being related to sex, or to the sexes, or 'relations' between them, or of having a gender. The word 'sexuality' could encompass various aspects of sex including 'sexual orientation', 'sexual activity', the 'capacity for sexual feelings' (Oxford Dictionaries, 2015), and 'of being sexual, including sexual activity, expression of sexual interest' (Merriam-Webster, 2015). The WHO defines sexuality as:

---

<sup>4</sup> The idea – discussed in chapter 2.2 - that 'things have a set of characteristics which make them what they are...; the doctrine that essence is prior to existence'. The attributes are 'natural', innate and unchanging. (Oxford Dictionary, n.d.; Wikiepedia, n.d.)

...a central aspect of being human throughout life [and] encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality was experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships. [...] Sexuality was influenced by the interaction of biological, psychological, social, economic, political, cultural, legal, historical, religious and spiritual factors.

(WHO, 2015)

Bremner and Hillin (1994, in Bywater and Jones, 2007) state that sexuality is made up of 'sex, sexual practices, sexual orientation, sexuality, social relationships and political dimensions' which 'all adds up to how we define ourselves' (p.3). Although sex and sexuality have been contested in terms of meaning and where they are derived from (as discussed in chapter 2.2), it is generally accepted that sex and sexuality are important for many individuals. Victor (1980) outlines 3 dimensions of human self-conceptualisation in which sexuality is important as an essential part of the self; physical, social and personal; the physical being attitudes to and experiences of functions of the body, the social being attitudes about attractiveness and desirability in relation to others and the personal being feelings towards their own sexuality (for example pleasure or guilt). Weeks (1995) suggests that these dimensions could also shape the self, as sexuality has been used by the State and the powerful (mainly white heterosexual men) as a means of exerting power over those considered as 'other' such as women and non-heterosexual people. This has led to sexuality being invoked as a means of asserting power in a struggle for identity and self (Weeks, 2003).

For the term 'sex', the Shorter Oxford Dictionary (op cit, 1987) provides three narrow, essentialist and gender-oriented meanings: '(i) either of the two divisions of organic beings as male and female respectively..., (ii) quality in respect of being male or female, (iii) the distinction between male and female...'. (p.1958). The World Health Organisation [WHO] (2015) defines sex as 'the biological characteristics that define humans as female or male'. The Oxford dictionary also provides this dual definition for the word 'sex'. However, the WHO definition also acknowledges that 'the term sex is often used to mean 'sexual activity'' reflecting that sex can incorporate multiple and complex aspects of an individual including reproduction, relationships, erotic activity, fantasy, intimacy, love, pleasure, desire, personal and political identity, a sense of being individual and part of a collective, and negatives attributes such as sin, violence and disease.

For the purposes of this study, I have used the WHO definition of sexual health as a basis for considering sex and sexual expression. The WHO (2015) definition suggests that sex should be seen more broadly in a more positive and holistic way incorporating emotional, mental and social well-being, identity, sexual orientation, pleasure and relationships and seen as an ordinary part of a client's life and health:

...a state of physical, emotional, mental and social well-being in relation to sexuality; it was not merely the absence of disease, dysfunction or infirmity. Sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence. For sexual health to be attained and maintained, the sexual rights of all persons must be respected, protected and fulfilled.

(WHO, 2015)

Seen in this way, sexual health can be perceived as congruent with the values of occupational therapy. Couldrick (2005) uses the term 'sexual expression' as encompassing sex and sexuality – which she defines as 'role and gender identity'. It was this terminology I favoured in discussing sexual concerns during the study as it includes a broad interpretation of sexual expression incorporating, whilst avoiding, a too narrow focus on sexual intercourse as a purely functional activity.

## **Defining taboo and stigma**

This section briefly defines these terms. The Oxford dictionary (2017) defines taboo as 'a social or religious custom prohibiting or restricting a particular practice or forbidding association with a particular person, place or thing'. Taboo originated from the Tongan meaning forbidden or to set apart. Stigma, originating from the Greek for 'mark branded on the skin' (Oxford Dictionary, 2017), has evolved into meaning a mark of 'social disgrace', 'associated with a particular circumstance, quality or person' (Goffman, 1963, p.13). Health and medical literature tend to focus on stigma rather than taboo, and therefore - although distinct - these will be discussed as interlinked phenomena (Chelvanayagam, 2014) throughout the thesis. Stigma can be physical, social, cultural, psychological (for example disability, homelessness, joblessness, criminality, mental health concerns). These 'signify an individual's failure to live up to social and cultural ideals' (Goffman, 1963, p.14). Erving Goffman's symbolic interactionist perspective on stigma and deviance has remained hugely influential. He suggests that people who are 'spoiled' ceased to be seen as individuals, instead viewed, treated and ultimately devalued as a 'stigmatised entity', giving rise to feelings of discomfort in the non-stigmatised. For Goffman 'the normal and the stigmatised are not persons but rather perspectives' (Goffman, 1963, p.138), the stigma arises from the interaction of

the 'spoiled' person with the rest of society. According to Goffman (1963), stigma is derived from discrepancies between assumed social identity and actual social identity and deviation from prevalent norms. Therefore the 'stigmatised' fall into a gap between who they are in reality and what is expected of them as a 'normal' person. Taboo gives rise to feelings of discomfort and leads to the avoidance of stigmatised subjects 'deemed inappropriate' (Chelvanagamon, 2014). Rather than dissecting the concepts of stigma and taboo, for the purposes of this study I have accepted these terms on face value, focussing instead on their impact in terms of experiences and feelings of the participants such as sensitivity and discomfort.

## **Contested terms**

This study touched on several areas where the terms used are contested and subject to debate. Cameron (2015) states that 'language is important – it is through language that we come to understand and relate to ourselves and other people around us'. Some terminology is weighted with oppressive assumed values and negative connotations around 'normality', paternalism and condescension, for example the use of the terms 'patient', 'client', 'service user' or 'customer' have been subject to both advocates and critics (McLaughlin, 2009; McGuire-Snieckus *et al*, 2003, Hammell, 2006). For the purposes of this thesis I have used the word 'client' due to readability rather than any particular fondness for the expression. Labels such as 'the disabled' or 'the handicapped' disempower and dehumanise, and have been avoided. Throughout this study I have attempted to use respectful language and the terms generally preferred within the disabled rights movement (Miller *et al*, 2004). For example, I have used 'disabled people' rather than 'people with disabilities', 'non-disabled' rather than 'able-bodied'. This reflects 'Crip' ideas around disability – discussed further in chapter 2.3 - challenging the tendency to see 'non-disability' as the norm or neutral (McCruer, 2018) and disability as 'other'. There is still debate around some of these terms, for example, expressions such as 'illness' and 'impairment' can have negative connotations. This study is not intended to settle the debate around these contested terms.

## **The study question, aims and objectives**

Having introduced and outlined the drivers for this study, I reviewed the literature and context (explored next in chapter 2). From that I formulated the research question and the aims and objectives for this research around which I framed my study. These are set out below:

### **Research question:**

**Does current occupational therapy practice support clients' sexual concerns and, if so, how?**

### **Aims and objectives:**

**Aim 1: Identify existing UK occupational therapy practice relating to in sexual concerns****Objectives:**

- To identify individuals who incorporate sexual concerns in their occupational therapy practice.
- To identify the scope of this practice.

**Aim 2: Explore occupational therapy practice regarding sexual concerns;**

- To explore this practice by occupational therapists.
- To investigate practical aspects, such as assessments and interventions, used in relevant practice.

**Aim 3: Explore occupational therapy practitioner attitudes to and experiences of practice broaching sexual concerns;**

- To investigate the attitudes and influences on individual occupational therapy practice in this area.
- To explore and examine the barriers and facilitators to this practice, as perceived by the individual occupational therapy practitioners.

The study focusses on the practice, attitudes and experiences of occupational therapists, concentrating predominantly on physical settings. The following chapter will expand on the context and literature which led to these aims and objectives, whilst chapter 3 will outline the methodology used both in theory and practice. Chapter 4 outlines the results, analysis and discussion. The final part, chapter 5, concludes the thesis, highlighting the key messages, limitations and suggestions for further research.

***A short note on thesis structure***

To aid navigation of this thesis, the beginning of chapters which explore the themes found in the literature and data in parts 2 and 4 are summarised with diagrams which outline the subjects covered. These have been omitted from the list of figures as they are intended to signpost the reader.

## Chapter 2: Contexts / Literature review

This chapter explores the key themes of the thesis; that UK occupational therapists, and HCPs generally, find client sexual concerns challenging due to prevailing taboos and expectations around sex within UK society, despite clients with illness /impairments and disabled people being sexual beings who face significant barriers to fulfilling their sexual needs and wants due to societal and cultural attitudes, the physical environment and internalised attitudes, as well as barriers due to their conditions /impairments. Occupational therapists have historically struggled with their professional identity due to ambiguity around defining occupation, eclectic influences and the variety in practice areas and roles, which may contribute to their discomfort around occupations which fit uneasily in dominant conceptualisations and assumptions around occupation. This may be exacerbated by the dominance of the medical model and medicalisation of sexual concerns which may impact on how clients concerns are perceived. This chapter explores this context and background of this study, combining a review of relevant literature.

In order to examine these, this chapter is separated into five sections:

- Occupational therapy - history, professional identity and sex: this briefly outlines the history of occupational therapy and how eclectic influences have impacted on its professional identity, leading to challenges and debate. This has also led to assumptions around the nature of occupation which have led to the querying of sex as an occupation, which may have contributed to the omission of sex as an occupational concern;
- A brief history of influences on attitudes to sex - which outlines some of the influences on attitudes and taboos affecting how sex is seen within society and in healthcare, leading to exceptionalism and medicalisation and in turn affecting the perceptions of clients /disabled people and occupational therapists. This chapter includes methodological context to sexuality theories, providing an outline of theories around sex;
- Disabled people / clients' experiences of sex - disempowerment and taboo, examining disabled people's experiences and barriers in accessing sex and sexual expression as well as outlining disability theories which impact on the perceptions of clients /disabled people and occupational therapists;
- Occupational therapists, HCPs and the sexual expression of clients - looking at some of the attitudinal and structural barriers to practice which have affected the omission or inclusion of sex;

- The concept of occupational taint or 'dirty work'- providing an overview of the concept and its management, and relating this to both occupational therapy and taboos around sex within occupational therapy.

In order to search and explore the literature, I used Boolean search strategies combining key words and using MeSH<sup>5</sup> features (where relevant) to find related work; for example (impairment OR disability) AND ("sexual expression") AND ("health professionals"). Databases used included the University of Huddersfield information search Summon, the University of Manchester library catalogue, publisher Science Direct, the UK NICE search database Evidence Search, Allied Health Professionals (AHPs) / nursing database CiNAHL and the specific publisher websites for occupational therapy and occupational science journals.

These chapters outline and define the context, terms and ideas underpinning this study, and review the literature around occupation, professional identity, sex and sexual expression, healthcare and taboo. They are not exhaustive but provide an overview of the debates and how these might influence practice.

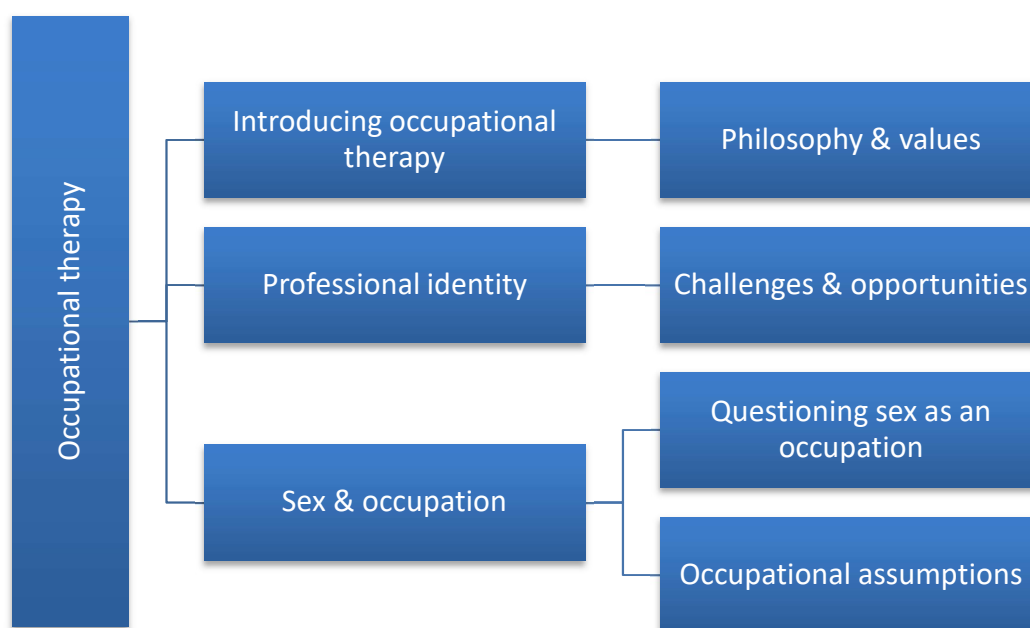
---

<sup>5</sup> MeSH (Medical Subject Headings) is a thesaurus of terms controlled by the US National Library of Medicine to ensure the indexing of subjects which are relevant to one another, predominantly used in US databases



## 2.1 Occupational therapy: history, professional identity and sexual concerns

This chapter provides background on occupational therapy as a health profession in the UK, including a brief history, an outline of underpinning philosophy and values, and examining some of the challenges the profession has negotiated regarding its professional identity. This is important for the study as an understanding of the context of occupational therapy underpins comprehension of what occupational therapists do and why. The interview participants who are the focus of this research chose to broach sexual concerns whilst many of their peers do not; the history and values of the profession contributed to their reasoning around this, as well as providing an explanation of some of the ambiguities which may have led to why many do not. It is beyond the scope of this study to provide a detailed examination – this section is intended to provide context, giving an overview to aid understanding of some of the contradictions within the profession which have contributed to ambiguity around sex and sexual expression as occupations, discussed later in this chapter.



### Introducing occupational therapy

Occupational therapy is a healthcare profession which focusses on occupation as key to health and well-being, using an array of skills and knowledge to support clients in achieving their goals, focussing on participation in 'occupation' in its widest sense - as defined in chapter 1.2. Occupational therapy is now global in scope although access varies across the world (Pattison, 2018), whereas in the past it was arguably considered a luxury (Spashett, 1981; Punwar, 1994). In the 'developing' / majority world occupational therapy may still be seen as a luxury within healthcare, but often

underpins projects tackling societal inequalities (for examples, see Kronenberg *et al*, 2001-*Occupational Therapy Without Borders*). In the UK, occupational therapy has a protected title and is therefore regulated by the Healthcare Professions Council (HCPC), which means that in order to practice as and use the title of 'occupational therapist' an individual must have successfully completed a validated course and be registered with the HCPC. The professional body for occupational therapy is the Royal College of Occupational Therapists (RCOT), which promotes the profession and approves courses validated by the HCPC. Occupational therapy is available in a wide-range of settings; in social care, health services, the 'third sector'/NGOs<sup>6</sup> and beyond, for people with physical, learning and mental health conditions, and working with clients from all age groups and abilities. The profession has also been actively widening practice beyond the NHS and social care, introducing entrepreneurial and role-emerging elements to the pre-registration courses (Thew, 2011). Although predominantly employed by the NHS and local authorities, occupational therapists are increasingly working in independent private practice - for example, in insurance and court work - and non-traditional roles, for example, working in fire services, working with trans-gender clients and with refugees.

Below are the Royal College of Occupational Therapy (RCOT) and World Federation of Occupational Therapy (WFOT) descriptions of 'what is occupational therapy?':

Occupational therapy provides practical support to empower people to facilitate recovery and overcome barriers preventing them from doing the activities (or occupations) that matter to them. This support increases people's independence and satisfaction in all aspects of life.

(RCOT, 2017)

Occupational therapy is a client-centred health profession concerned with promoting health and well-being through occupation. The primary goal of occupational therapy is to enable people to participate in the activities of everyday life. Occupational therapists achieve this outcome by working with people and communities to enhance their ability to engage in the occupations they want to, need to, or are expected to do, or by modifying the occupation or the environment to better support their occupational engagement.

(WFOT 2012)

---

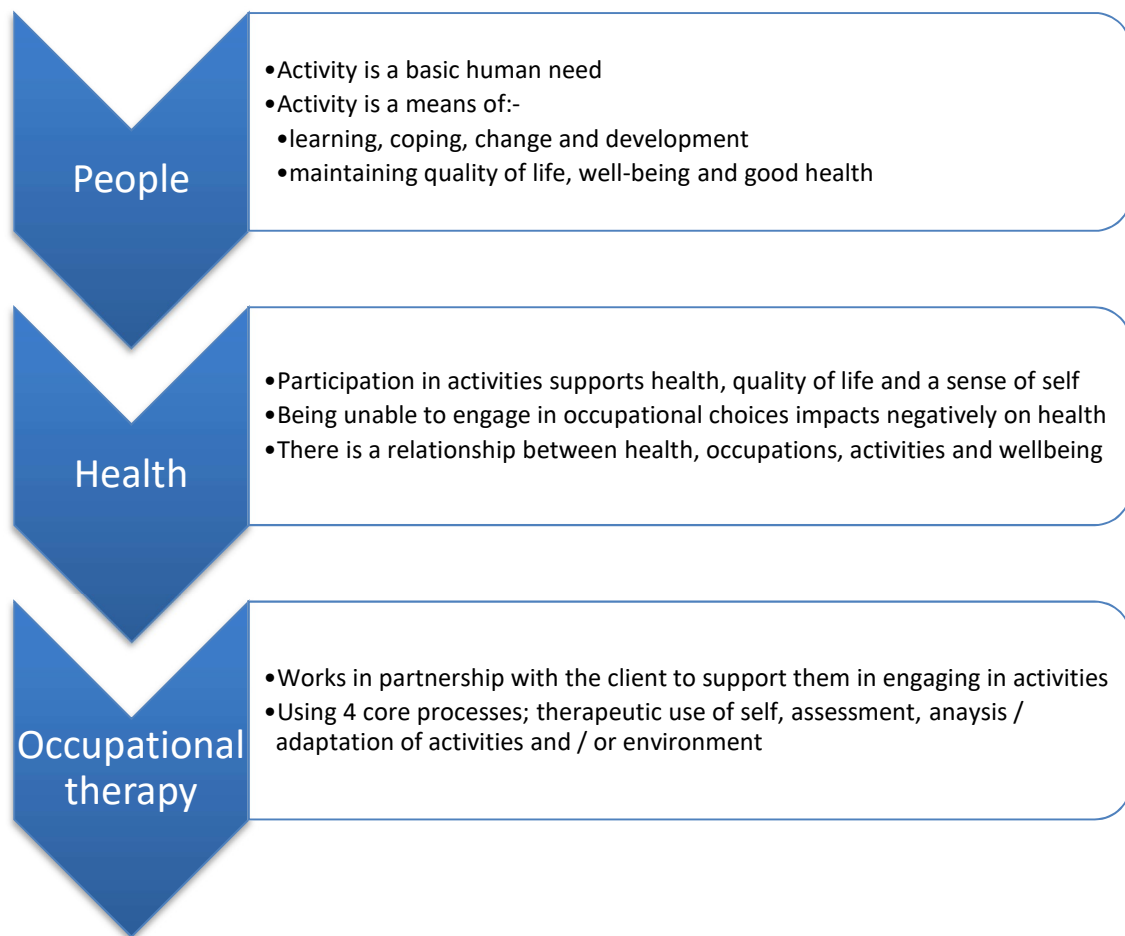
<sup>6</sup> Non-Governmental Organisations

Both descriptions reiterate supporting people and communities in engaging with activities which are important to them. Creek (2003) describes occupational therapy as a complex intervention requiring the weaving of beliefs, values, knowledge and skills. This is 'based on biomedical, social and humanistic theory', emphasising choice, control, and engagement as influential on health and wellbeing (Kristensen and Peterson, 2016, p.240), centring on occupation as a method of achieving this as a means (developing health and wellbeing, used therapeutically) and / or an ends (the goal or outcome) (Wilding, 2009). Occupational therapy uses occupation as a 'therapeutic agent' (Turner *et al*, 2002, p.13) to enable and support people in their recovery from or management of illness and impairment, helping them overcome barriers which may be preventing them from doing the activities or occupations that matter to them in order to increase satisfaction and quality of life (COT, 2015), 'enabling occupations and engaging people in health-restoring occupations' (Wilding, 2009, p.11). The central philosophy of occupational therapy is the 'professional belief in the impact of occupation on health and well-being' (Turner and Alsop, 2015), based on a 'whole-person approach' (Creek and Loughter, 2008, p.35). Occupational therapy encompasses core values of 'altruism, equality, freedom, justice, dignity, truth, and prudence' (AOTA, 2015, Kanny, 1993 – see below):

Altruism -	Unselfish concern for others' welfare
Equality -	Equal rights and opportunities
Freedom -	Choice and autonomy
Justice -	Fairness, equity and moral / legal principles
Dignity -	Values inherent worth, empathy and respect
Truth -	Facts and reality, honesty
Prudence -	Discretion, diligence, managing judgement through reason
(AOTA, 2015; Kanny, 1993)	

Although the professional has developed significantly, these values remain evident in the theory and practice of the profession. Creek's (2003) influential UK work setting out occupational therapy as a complex intervention suggests that professional beliefs and values are factors occupational therapists draw on during the 'therapeutic encounter' (p.27), based on beliefs about the nature of people, health and occupation therapy (see figure 3):

**Fig 3 –Underlying professional beliefs**



Taken from Creek (2003)

A subsequent report by Pentland *et al* (2018) revising Creek's (2003) document in order to reflect current practice takes a more systems-oriented approach to the occupational therapy process mapping out the complexity involved. There is less emphasis on professional beliefs, instead it identifies necessary personal and socio-institutional factors (see figure 4).

**Fig 4 – Personal and socio-institutional factors**



Taken from Pentland *et al* (2018)

The new document appears to have a less explicit focus on client-centeredness and uses systems-thinking to retain a commitment to holism (p.47), however by focussing on complexity from a systems perspective the language of the document omits the more the empathetic aspects of holism which are embedded in Creek's (2003) report. Being a more recent document, the influence of Pentland *et al*'s (2018) updated examination on the complexity of occupational therapy on current and future practice is yet to be seen. Pentland *et al* (2018, p.1) suggest that Creek (2003) has been useful in 'describing occupational therapy within education, practice and research'.

Creek (2003) suggests that the therapist should value and respect the rights of clients including their individual experiences, diversity and beliefs (p.29) and should always take a client-centred approach. The influence of Creek (2003) can be seen in the RCOT statement on occupational therapy that:

Occupational therapy takes a whole-person approach to both mental and physical health and wellbeing, enabling individuals to achieve their full potential.

Occupational therapy provides practical support to enable people to facilitate recovery and overcome any barriers that prevent them from doing the activities (occupations) that matter

to them. This helps to increase people's independence and satisfaction in all aspects of life.

(RCOT, 2017)

There are flaws in this outline of professional beliefs; for example, this arguably can be interpreted as a Western-centric and neoliberal approach to human occupation focussing on individual potential and a humanistic striving towards self-actualisation, which has been criticised by some disability activists and academics for being a narrow and oppressive view of what it is to be human (for example, Goodley and Runswick-Cole, 2016) and emphasise individualism and independence, where challenges arising from society and the environment are seen as barriers which must be overcome by individuals rather than broken down and changed within and by society. The new document on complexity places more focus on the interrelationships between the person, therapist, environment and context (Pentland *et al*, 2018). However, it is not the remit of this study to dissect these beliefs and values. Despite being potentially problematic if accepted uncritically, Creek's (2003) analysis has provided a powerful and positive foundation for occupational therapy practice (Bryant, 2010). Commissioned and supported by the RCOT, Creek's (2003) work is referenced extensively in occupational therapy literature and has arguably been influential on the self-perception of UK occupational therapists, it will therefore be taken on face value for the purposes of this study.

### ***A brief history of occupational therapy***

What follows is a brief account of the development of occupational therapy within the UK as this provides context for the study and highlights how the profession has been influenced by diverse ideas and practices which may have contributed to ambiguity around identity. Deeper and fuller accounts can be found elsewhere (for example Wilcock, 2001; Duncan, 2011; Creek and Lougher, 2008). Occupational therapy is regarded as a relatively new profession within the field of healthcare (Turner, 2011; Thew, 2011) although the therapeutic use of occupation to support health and wellbeing has a long history, appearing in writings from Ancient Egypt, Greece, Rome and Arabia (Wilcock, 2001). The development of occupational therapy has been shaped by an array of historic influences including the rise in moral treatment in the 18th and 19th centuries, pragmatism, the Arts and Crafts movement, the Quakers, progressive movements in the treatment of illness and mental health, and the development of rehabilitative equipment during the First World War (Reed and Sanderson, 1999).

The treatment of people with illness and impairment, particularly mental illness, prior to the Enlightenment period was underlined with confinement and punishment based on fear and

superstition (Turner *et al*, 2002). During the Enlightenment period of the 18th and 19th centuries there was an increasing understanding of disease and impairment, and practitioners such as Phillipe Pinel in France and William Tuke in the UK advocated a more moral and humane basis to treatment, including releasing clients from shackles and prescribing 'physical exercise and manual occupation' (Turner *et al*, 2002). This became known as the Moral Movement which challenged 'traditional medical thinking' of the time, developing a link between occupation and health as a 'treatment or therapy' (Clouston and Whitcombe, 2008, p.315). By the 19th century acceptance of occupation as a treatment was widespread in mental health 'care', although this was largely based on anecdotal evidence rather than a scientific approach. Turner *et al* (2002, p.5) suggest that this emphasis on anecdotal rather than scientific evidence is a situation that has continued to 'dog [...] the profession'.

Although writings and practice which could be described as 'occupation-based' had increased during this time (Turner *et al*, 2002), it was not formalised as a specific and specialised area of practice until the early 20<sup>th</sup> century. In the US, the development of occupational therapy was largely derived from reformist and progressive movements of the early 20th century, seeking to address a variety of social problems (Schwartz, 2009). The founding membership of what was to become the American Occupational Therapy Association (AOTA - initially known as the NSPOT; the National Society for the Promotion of Occupational Therapy) was made up of a key figure in the development of OT in the US, social welfare reformer Eleanor Clarke Slagle, two architects, a nurse and a teacher. The development of occupational therapy widened; at around this time George Barton, having worked with William Morris in the UK, became interested in the relationship between environment and social problems. Barton had personal experience of illness and impairment; he had contracted tuberculosis and had had surgery to remove a gangrenous foot, finding hospitals to be 'deplorable' (Schwartz, 2009). His experiences led him to create a space for convalescence where 'he could be happy, get well, and become self-supporting' as opposed to the 'sick' atmosphere of hospital; whilst Dr William Dunton, a physician and later psychiatrist who was also interested in crafts was promoting, practising and writing about the use of occupation with his clients.

In the UK, occupational therapy became available informally after the First World War in the form of 'curative workshops', usually run on military lines to support the treatment and rehabilitation of soldiers, and was introduced formally in Bristol by Dr Elizabeth Casson in 1924 after a visit to the US. Occupational therapy was initially undertaken by nurses under supervision, the occupations being prescribed by doctors (Clouston and Whitcombe, 2008). After the Second World War, the

development of occupational therapy in the UK was influenced by the founding of the National Health Service (NHS), still dominated by the medical profession and subject to military influence based on the pre-war 'curative workshop' model (Turner *et al*, 2002). Large numbers of predominantly young men returning from war with impairments or injuries added 'impetus to the development of occupational therapy' (Turner *et al*, 2002). Most occupational therapists became employees of the new NHS although occupational therapy training remained private. Turner *et al* (2002) suggests that these early occupational therapists felt the link to the medical profession gave their work credibility and encouraged clients to accept occupational-based treatment; this deference to the doctors' 'aims of treatment' (Turner *et al*, 2002, p.12) rather than patient needs remained into the 1960s. Although this gave the profession 'credibility', it also meant a move away from the more socially progressive, person-centred, multi-disciplinary, moral and social welfare orientation that had underpinned its earlier development (Schwarz, 2009), leading to a prescriptive approach whereby the occupation or activity satisfied a doctor's opinion on particular symptoms or the disease / impairment (Molineux, 2004).

State registration of occupational therapists was introduced during the 1960s. Hagedorn (1995a) suggests that as at this time the economy grew stronger, hospital facilities improved and care focussed more on large institutions in both physical and mental health. During this time the medicalisation of healthcare became more embedded, with science and technology oriented developments in drug therapy and improved surgery techniques, as well as the introduction of behavioural interventions in mental health. Hagedorn (1995a) suggests that the occupational therapy profession desired to be seen as 'scientific' and emphasis continued to fit clients into rehabilitation rather than *vice versa*. Further improvements to medical techniques in the 1970s led to a push to shorten hospital admissions and reduce the rehabilitation journey, marking the beginning of discharge as the main objective (Hagedorn, 1995a). At this point the profession began to question its direction; there was increased introspection in writings about occupational therapy having become difficult to distinguish from physiotherapy (Turner *et al*, 2002, p.15). Turner *et al* (2002) suggests that occupational therapy theorists during this period felt that the profession had lost its way, and there were anecdotal instances where the action of an activity had become devoid of meaning either to the client or as an activity in itself (for example, using a loom without cotton/wool to weave - Molineux, 2004) - the client literally going through the motions of an activity rendered meaningless. Clouston and Whitcombe (2008) described these as 'successive identity crises' (p.315) in the focus and purpose of occupational therapy.



Since the 1980s, the predominant employer of occupational therapists in the UK – the NHS – has undergone numerous changes, including increased managerialism (Learmonth, 1997), the 1990s introduction of ‘internal markets’ (NHS Choices, 2008) and more recently the extension of private and ‘third sector’ involvement in service provision through the Health and Social Care Act 2012 (UK Gov, 2012). During this time there has been a move from larger institutionalised ‘care’ towards community initiatives (Killaspy, 2006), greater emphasis on clients taking personal responsibility (Hunt, 2015), improved life expectancy and longer term management of conditions (Public Health England, 2017). These have led to more opportunities for occupational therapists but have run parallel to changes in the structure of UK health services and budgetary constraints, and an increasingly business-oriented approach to healthcare with the primary focus on measuring outcomes and discharge. Emphasis has shifted towards health promotion and education, and a greater push for both personalised care and individual ownership, whilst the focus on client discharge has remained, and there has been greater emphasis on proving value and effectiveness through outcome measurement and Evidence Based Practice (EBP). Proving outcomes, focussing on discharge and providing evidence in a background of time and resource pressures have been challenges for occupational therapy where outcomes around quality of life and wellbeing, being qualitative, can be difficult to prove and measure in quantitative terms (Bowman, 2006).

As this brief history shows, occupational therapy has drawn on an eclectic array of disciplines and ideas, encompassing social, moral, spiritual and humanistic influences and movements, whilst influenced by bio-medical and functional approaches as well as medical and military structures. These have been both opportunities and threats to the profession and have led to some of the reported challenges around its professional identity.

### **Occupational therapy professional identity**

Historically, the profession has struggled with its professional identity, due to the multiple influences and ideas underpinning its development, theory and practice, confusion around roles, the nebulous concept of occupation, dissonance between practice and values, and issues around hierarchy within health service structures (Molineux, 2004). These challenges around identity have been explored extensively in the literature, for example Finlay (1998), Mackay (2007), Clouston and Whitcombe (2008) and Molineux (2004) to name a few. The variety and diversity of their roles has led to some occupational therapists to feeling that they are a ‘jack of all trades, master of none’ (Drummond, 2010). This issue of professional identity is relevant to this study because it may impact on what occupational therapists do and how they see themselves, their perceptions of what are occupations, their ability to retain occupation as central to their practice and their unique contribution within

often medicalised organisations. This has arguably impacted on the parameters and confidence of occupational therapists, which may have contributed to the omission of sex and sexual expression as occupational concerns. As will be discussed later in chapter 4, the data indicated that the participants who broached sexual concerns drew on their professional identity and values in order to justify and support their practice and manage the sensitivity and taboo around the subject.

### ***Defining professional identity***

This section will briefly describe professional identity in general. Again, this is a subject that has been examined extensively, particularly within psychology and organisation / management studies. The concept of professional identity has been described as difficult to define (Jones *et al*, 1998). In general, it is a form of social identity related to how groups interact and how people distinguish themselves from other groups within work (Adams *et al*, 2006), and how a person assimilates professional aptitudes and knowledge in order to define themselves as a member of a professional group (Kvåle and Rambø, 2015). The label 'professional' can have several meanings; it may indicate a high level or quality of service, it could be used to distinguish a paid occupational group as distinct from an unpaid 'hobbyist' or amateur, it can be an occupational group which shares certain identifying features, traits and characteristics (functional approach), or a grouping derived from the attainment of status, behaviours and power wielded in relation to others (interactionist approach) (Jones *et al*, 1998 p.131; Clouston and Whitcombe, 2008). Briefly, professional identity is described as a 'set of beliefs and attitudes and understandings about ... roles within the context of work' (Adams *et al*, 2006). Similarly, Slay and Smith (2011) describes it as 'one's professional self-concept based on attributes, beliefs, values, motives and experience'. Mackey (2007, p.95), taking a more functional approach describes it as a 'collective entity and project' including a definable knowledge base, autonomy and monopoly of control over a specific area of work. It is linked to and is part of personal identity (Slay and Smith, 2011, p.87) suggesting it fixes a person's place in society in relation to others through self-adopted meanings. Therefore professional identity is defined by how an individual sees their profession and is influenced by how others see it. Professional identity, then, is a dynamic and contested social construct, rather than a static concept, evolving and re-defining as professions are influenced by society, culture, workplace practice and governing professional bodies.

### ***Tensions or eclecticism: Professional identity challenges within occupational therapy***

The literature indicates a 'well-documented' struggle and 'uncertainty' around professional identity within occupational therapy (for example, Mackay, 2007; Finlay, 1998; Wilding and Whiteford, 2008)

since the 1970s. This has been attributed to a combination of internal and external factors; the diversity and lack of uniformity of roles and practice, a lack of clear definition of 'occupation' (as discussed on earlier), organisational constraints and demands, and client expectations and perceptions (Mackey, 2007). For some occupational therapists, these have created tensions between professional practice and philosophy, doubts around status, and compromises around professional values (Mackey, 2014). These tensions can be seen in the struggles some occupational therapists have had in maintaining their professional identity and values, occupational focus and their exasperation that the general public can still be unclear about what is occupational practice (Turner and Knight, 2015). Arguably these challenges have been diminished for professionals by the adoption of occupational science as an underpinning epistemology (Stead, 2016), but tensions can still be problematic for some occupational therapists and public misunderstandings continue (Turner and Knight, 2015).

### *Confusion and ambiguity*

As stated earlier, the literature indicates that historically some occupational therapists have felt confused and insecure regarding their identity, struggled to articulate who they are and their value (Finlay, 1998; Molineux, 2004; Mackay, 2007) and felt themselves to be undervalued (Turner and Knight, 2015). This has undermined the profession and its development (Molineux, 2004). The reasons behind this confusion and ambiguity are derived from the eclectic array of influences and ideas which have contributed to development, competing demands, and the seemingly contradictory epistemologies underpinning the profession. Finlay (1998) found concerns regarding role identity derived from a lack of clarity of what is occupational therapy, the clash between ideals and practice, negative stereotyping and role misunderstanding by others outside the profession, the challenges of role blurring and changing practice, and a sense of inadequacy and failure regarding the legitimacy of roles. Turner and Knight (2015) suggest professional identity has been impacted by varying interpretations and potential misunderstandings around the word 'occupation'. Despite the 'concept of occupation hold(ing) centre stage within the philosophy of the profession' (Molineux, 2004, p.2), occupation remains unclear and nebulous with little 'consensus on a universal definition' (Leclair, 2010, p.17) and presupposed assumptions of shared meanings. The diversity of occupational therapy practice is said to have contributed to a 'sense of confusion' (Finlay 1998) about the nature of occupational therapy. Changes in focus and purpose, and a lack of professional consolidation (Turner, 2002) led the profession to have a 'disparate rather than...uniform identity' (Clouston and Whitcombe, 2008, p.315). Clouston and Whitcombe (2008) suggest professional identity is undermined by being about 'everyday life' and activity based on 'common sense', meaning it is 'taken for granted....habitual and therefore not highly valued' (p.318). The literature also suggests

that due to the lack of confidence or clarity in their professional identities, occupational therapists are more likely to be dominated by other professional colleagues. Wright and Rowe (2004) suggest that when professional groups 'feel the need to protect energetically and maintain their professional boundaries, they are more likely to be exclusive and excluding' (p.46), resulting in 'defensiveness'. Finlay (1998) suggests that conflict over roles and professional rivalry leads to the client being 'inadvertently caught in the middle' between healthcare professional groups.

These internal tensions are derived from, and at times compounded by, material, organisational and structural pressures which can both compromise and constrain occupational therapy professional values and identity. These pressures include organisational changes such as increased generic working and boundary blurring, and increased private sector involvement in health and social care leading to 'traditional' occupational therapy roles having differing titles (Mackey, 2014). Kinn and Aas (2009) suggest that occupational therapists are uncertain in articulating what they do and attempt to distance themselves from historic, stereotypical views of occupational therapy held by other health professions as being the 'knitting' / 'basket weaving' / 'tea making' people, in favour of higher status activity (p.118). Whilst attempting to clarify and explain their roles to colleagues and clients, Wilding and Whiteford (2008) found that occupational therapists in some settings adopted language focussed around function, but in doing so this impacted on their professional confidence and identity. Their research indicates this has contributed to occupational therapists undermining a sense of themselves as occupationally-focused, encouraged a narrow and limited conception of Activities of Daily Living (ADLs), and constrained occupational therapists distinctive contribution to service provision (p.186). Further pressure on professional identity arises from movements led by disabled people and client groups, questioning the occupational therapy role around creating dependence or narrow interpretations of independence, of overlooking the role of inter-dependence (Haraldsdóttir, 2015), focussing on individual change whilst failing to address social barriers (Jones *et al*, 1998), and normative assumptions around disability (Hammell, 2004; Chacala *et al*, 2014).

Turner and Knight (2015) note that tensions between 'medical, social and occupational aspects of health' lead to difficulties for some occupational therapists in describing what they do, misunderstandings around practice, perceived lack of status, and a lack of consistent occupational paradigms which are exacerbated by generic working patterns (p.667). This led to an 'inability to react strategically to change on a personal, local or national level' (Turner and Knight, 2015, p.668). These challenges gave rise to a tendency to lack of clear messages and coherence about

occupational therapy due to the lack of a 'single discourse' (Turner and Knight, 2015, p.667), a tendency to under-rate occupation-based knowledge in comparison to knowledge which is perceived to have a strong evidence base, a difficulty in verbalising value and the rationale for practice, and a perceived lack of status (Turner and Knight, 2015). This may lead to feelings of being undervalued and unappreciated, a tendency to detach practice from underpinning theory, an overemphasis on skills building rather than knowledge development in Continuing Professional Development (CPD) and a tendency to be influenced by other professions and non-occupational perspectives (Turner and Knight, 2015).

The literature indicates that a key tension for occupational therapy professional identity is the dissonance between values and practice. Occupational therapists shared values and beliefs around client-centred and holistic practice may be compromised by the realities of practice, dominant medicalised approaches to health and 'tension between medical, social and occupational perspectives' (Turner and Knight, 2015, p.665). This can lead to practitioners attempting to balance seemingly contradictory positions. Finlay (1998) indicates that being an occupational therapist involves some degree of 'doublethink' whereby seemingly contradictory views are held simultaneously, finding that occupational therapists believe in what they do but did not fully understand it, have a desire for recognition and to be valued but have problems in articulating their roles, and are confident in practice but lack professional esteem. This discord has been reflected in the literature as a 'conversation' (Hooper and Wood, 2002) between two cultures (Turpin and Iwama, 2011, citing Mattingly and Fleming, 1994) or two epistemologies (Creek, 2010); art and science (Turpin and Iwama, 2011, citing Mattingly and Fleming, 1994); 'pragmatism and structuralism' (Hooper and Wood, 2002) or romanticism and rationalism (Hocking, 2008). This combination of both art (manifested in creativity, meaning and spirituality) and science (such as function, activity analysis, systems-thinking, anatomy and physiology) has been an on-going tension within occupational therapy. The potential problems from these dichotomies reiterate the importance of placing occupation at the centre of occupational therapy practice and the development of occupational science as an epistemology underpinning the profession (Stead, 2016), which can support the drawing together of these concepts.

Molineux (2004) suggests that these professional identity crises derive from being caught between medical and mechanistic approaches and the desire to be holistic and client-centred, reflecting a dissonance between the art of occupation and the bio-medical dominance within healthcare into which practitioners fit as a profession, and against which they may feel themselves to be judged and

measured. Hocking and Nicholson (2007, p.41) suggest that by focussing more on impairment and performance components<sup>7</sup>, occupational therapists may lose sight of occupation, whilst Leclair (2010) suggests that the changing focus of occupational therapy over the decades from holism to a reductionist, medical model and back has impacted on the perceived importance of occupation within the profession. Mackey (2014) refers to this as a 'living tension' between the occupational therapist's values and the valuing of both their relationship with clients and their empathetic advocacy of the client's view, versus compromises towards their working environments which focus more on 'product' and 'process' healthcare (p.171). Her research suggests that occupational therapists have the sense that the real clients are managers and service commissioners rather than their clients. Kinn and Aas (2009) suggest that there is a 'tension between the strong sense of self-value within the occupational therapy profession and the lack of recognition by others' (p.112), and that the internal 'mental management' of being an occupational therapist appears to involve a dualist approach between fixing the body of the client and restoration of the client to a satisfying life (p.113). This 'doublethink' highlights the difficulties for occupational therapists when working within organisational and societal expectations which may conflict with their professional beliefs and desires around advocating for client-centred choices.

### *Opportunities from eclecticism and occupational science*

From its inception, the profession sought to influence, change and improve the lives of clients, yet confusion regarding professional identity, overt introspection and the seeming desire for higher professional status appear to have undermined professional confidence and in doing so the profession has been influenced by a medicalised approach, at times losing sight of its client- and social- centred roots. Much of the literature has focussed on how multiple influences have created tensions within occupational therapy and have had a negative impact on professional identity. Turner and Knight (2015) suggest strategies to broach these challenges by using this eclecticism and the adoption of occupation as a central epistemology in itself as an opportunity for taking ownership of occupational therapy's unique philosophy, values and beliefs around occupation-based knowledge and engagement, accepting the professional discourse around occupation and using communities of practice to support these occupational discourses. For example, Wilding and Whiteford (2008) indicate that embracing occupational language aides occupational therapists in gaining confidence in their professional identities. Molineux (2004) suggests the profession needs to go back to basics, refocussing their identities by remembering the history of the profession and the

---

<sup>7</sup> Aspects of functional ability required to undertake an occupation, grouped into sensorimotor, cognitive, and psychological subcategories. (*Medical Dictionary for the Health Professions and Nursing*. (2012). Retrieved April 11 2018 from <https://medical-dictionary.thefreedictionary.com/performance+components>)

centrality of occupation. This entails embracing occupational science as a foundation for practice and identity.

The perceived 'crisis' of identity need not be a hindrance but can be seen as supportive of occupational therapy practice. Mackey (2007) questions whether a unitary professional identity is really necessary, finding that occupational therapy professionalism is a reflective ethical concept. Rethinking the diversity of occupation could facilitate professional identity rather than hinder it, as occupational therapists have reason for professional cohesion under the unifying epistemology and focus on occupation. Clouston and Whitcombe's (2008) negative assertions on professional identity do not address whether professional 'worth' involves greater compliance with the dominant power of either the medical model or with consumerist values, which arguably could involve losing core aspects of occupational therapy identity and values such as client-centeredness, holism and the centrality of occupation to human beings. They also fail to address who this power and dominance is for as it appears that both the client and occupation are lost in this narrative where the status of the profession takes precedence.

Mackay (2007) suggests this flexibility of occupational therapy professional identity is an opportunity not a threat, as the profession can 'redefine' professional identity. The tensions between eclectic aspects of occupational therapy are not necessarily negative but instead highlight flexibility and an ability to find common sense solutions to problems, bridging the gap between biomedical approaches and client wants and needs, filling the gap between science and lived experience, function and 'art'. These criticisms and identity crises which the profession seems to have borne suggest it has been preoccupied with using scientific and quantitative methodologies rather than embracing its qualitative strengths. Molineux (2001, p.6) suggests this has been reactive and dictated by circumstances, however it could also be seen as evidence that the profession has been evolving in recognition and acknowledgement of client needs – in this way perceptions of 'role blurring' indicate adaptability and flexibility rather than failings in professional identity.

The tensions around professional identity within occupational therapy are relevant to this study due to the potential impact they may have on broaching sexual concerns. Ambiguity around roles and tensions between approaches may contribute to a lack of confidence and defensiveness around the profession. The lack of clarity around defining occupation may explain why some occupations may be omitted, making it harder to confidently engage in work that is sensitive and contentious such as broaching sexual concerns, especially for some occupational therapists who may feel it is not part of

their remit or are unsure about how to broach this subject (see chapter 2.4). Tensions between medicalised versus client-centred approaches may contribute to sex being omitted or may lead to a practitioner taking an overly functional approach when considering sexual concerns. This will be explored further later in this chapter.

## **Sex as an occupation**

A combination of factors may make the broaching of sexual concerns a difficult area to negotiate, including the stigma and taboo around sexual concerns, ambiguity around perceptions of sex and sexual expression as occupations, tensions within professional identity outlined above, set against a climate of discharge-orientation and stretched resources, the low priority given to sexual concerns (McGrath and Lynch, 2014; Gott *et al*, 2004) and limited dedicated support and resources to deal with concerns. Despite these pressures and the negative aspects of professional ambiguity, as indicated above, I feel the flexibility and eclecticism of occupational therapy, based on occupational science as an underpinning epistemology can be positive and supportive to the inclusion of sexual concerns, and – as will be shown - this is evident in the data. I would argue that the ability of occupational therapists to negotiate the lines between values and practice, encompassing science and art by including biomedical, spiritual, social, cultural, common sense and practical aspects, are attributes which make occupational therapy ideally placed to deal with complex and sensitive subjects such as sexual concerns.

The literature indicates that sex and sexual concerns have largely been omitted from occupational therapy theory and practice. This section will explore the debate around whether sex can be considered an occupation and therefore the remit of occupational therapy, and examining sexual concerns in relation to assumptions around acceptable occupations. These issues are relevant to the study as it connects to potential reasoning behind the omission of sex, examining sex as an occupation, assumptions around occupations which may not be perceived to fit with how occupation is conceptualised around self-care, productivity and leisure, and how the challenges of professional identity discussed above might impact on the inclusion of sex as an occupational issue.

## ***Questioning sex as an occupation within occupational therapy***

Although sexual concerns are often omitted in practice, they have not been completely ignored in occupational therapy literature and there has been some debate around whether sex can be seen as an occupation. Among occupational therapists themselves, the majority see sexual concerns as occupational (Couldrick, 1998; Sakellariou and Algado, 2006; Hyland and McGrath, 2013); quantitative research indicates the majority felt that sex should be part of their remit - Hyland and McGrath (2013) found that 88.1% agreed it is a legitimate concern for occupational therapists,



Parkin (2014) found 87% and Couldrick (1998) 90% of their participants. Anecdotally, on online discussion forums such as #OTTalk on Twitter, many occupational therapists indicate that they feel sexual concerns are occupational, citing reasons such as sex being a domain in the *American Occupational Therapy Association* practice framework as an ADL<sup>8</sup> (AOTA, 2008), its meaning to individual clients, its role in culture, identity formation and the maintenance of roles and its relationship with self-esteem.

The RCOT's (2015) position statement on occupation-centred practice states that 'occupation is defined as all the activities we do in our daily lives, for example eating a meal, walking the dog, looking after family, going to work' and that 'occupation-centred practice is where the occupational therapist places the occupations that are of most importance to the person in a central position'. This statement takes an encompassing approach to what occupational practice should include and from this it could be inferred that sex and sexual expression should be included. Despite this, these subjects are largely absent from the RCOT website (the only reference being a suggested reading list from the RCOT library service) and, as Couldrick (1998) notes, remain invisible in many occupational therapy texts. When sex has been included in the literature it has tended to be either continuing the debate on why sex should be considered an occupation (Sakellariou and Algado, 2006; Pollard and Sakellariou, 2007; Couldrick, 2005) or focusses on sex in functional terms (Tipton-Burton, 2013). This indicates a conflict between the inclusive statements of the RCOT, the ideals of occupational therapists themselves and the reality of practice as many practitioners recognise sex as an occupation and yet continue to omit and ignore it. Whilst the idea of sex as an occupation has been accepted by many practitioners there remains a dearth of information and lack of policy and support. For example, the most recent RCOT conferences have had few references to sex (one in 2018, two - including my contribution - in 2017), and remains largely missing from the literature; during my visit to the RCOT conference it was notable that most of the interest in my research came from students who were keen to know more and learn how to engage with the subject.

Conceptualisations of sex as an occupation are based on two key premises; that sex is an ADL<sup>9</sup> (Couldrick, 1998, p.439; Yallop and Fitzgerald, 1997, p.54) and that it is part of the whole person and thus a constituent of holistic, client-centred practice. One of the few writers to provide any detailed practice information on supporting sexual activity in occupational therapy, Tipton-Burton (2013,

---

<sup>8</sup> Activity of Daily Living

<sup>9</sup> Activity of Daily Living – activities which are necessary for daily self-care 'independent community living', including 'using the toilet and grooming, dressing, and feeding oneself', and so on (*Mosby's Medical Dictionary, 8th edition*. (2009). <https://medical-dictionary.thefreedictionary.com/ADL>)

p.29), states that 'sensuality and sexuality are important aspects of everyone's activities of daily living (ADLs) and directly relate to the quality of each person's life'. Tipton-Burton (2013, p.396) suggests that sex is an occupation because it is an integral part of all human beings and human experience, important for self-esteem and self-concept, and influences adjustment to impairment. Fouché (2014, p.225) suggests that sex should be viewed as an occupation 'if he/she truly practices within a holistic framework', whilst Hyland and McGrath (2013, p.73) state that 'occupational therapists are concerned with promoting occupational participation, inclusion and engagement by enabling clients to partake in meaningful occupations'. Several writers concur with these views including Yallop and Fitzgerald (1997), Couldrick (1998, 1999) and Jones *et al* (2005).

These views contrast with those of the late US occupational therapist Gary Kielhofner, an important figure in occupational therapy whose theory the 'Model of Human Occupation' widely underpins practice and education. He suggests that sexual activity should not be seen as an occupation and therefore is not the remit of occupational therapy. Kielhofner (1993, p.137 in Couldrick, 1998) specifically excluded 'survival, sexual, spiritual and social activities' from his conceptualisation of occupation, deeming sexual activity a 'biological requirement of the individual and the species' (p.538) and stating 'occupation refers to human activity; however, not all activity is occupation' (Kielhofner, 1993, p.138, in Couldrick, 2005). Couldrick (2005) cites email communications Kielhofner had with students in 2003 where he enlarges on this view, suggesting that sex is not an occupation because the purpose of sex is 'to bond relationships and perpetuate humankind' based on 'tissue needs', that it is akin to hunger or pain aversion, and therefore akin to a primary function like eating. He also seems to suggest that if an activity does not fit in with the categories of 'self-care, productivity or leisure' then they cannot be deemed occupations. This view is problematic; Kielhofner's (1993) view of sex as a purely functional 'tissue need' reflects a reductionist approach to sexual activity, at odds with the WHO and the views of many occupational therapists themselves.

Sexual activity is arguably more than a 'tissue need'. Sakellariou and Algado (2006) suggest that sexual activity is an 'indispensable part of a happy, meaningful and balanced life and an integral component of the individual', an aspect of self-discovery and spirituality, instils meaning into occupations, helps reconnection and is a 'ritual of daily life' (p.353). Sakellariou and Algado (2006, p.352) argue that sex and sexuality are expressed through activities which may be seen as occupations (for example, personal grooming, dating or having sex). They suggest that in reducing sex to 'lust', 'satiation' of desire, and 'a mere physical process' is 'tantamount to suppressing ideals of beauty and physical performance' and 'oppressive and meaningless for many', arguing that sex is

'more than a carnal affair' (p.356). Vance (1999, p.46) suggests that to describe sexuality and sexual expression only in terms of essentialist biology or physiology is akin to describing music purely in terms of the structure and capacity of a person's hearing ability. Kielhofner's view is a surprisingly narrow and rigid conceptualisation of occupation from a highly respected figure within the profession, taking an essentialist approach to sex and ignoring spiritual dimensions around its importance and meaning. This view is neither holistic nor client-centred, nor congruent with the values of the profession discussed in chapter 1.2. Even if sexual concerns are reduced to a basic, functional 'tissue need' - aside from inherent motivations and meanings - sex could still be described as an occupation as it involves active doing, movement and activity. Sex is different from eating; whilst eating is necessary to survive, individuals can survive without sex. Yet whilst eating may be described as a purely 'tissue need' it too has occupational dimensions such as food preparation, mobility, the activity of getting food into the body, availability and usability of implements to eat, as well as social and cultural aspects of eating which bestow it with meaning or impact on food available (for example, dining with friends, affordability, religious considerations).

Suggesting occupational therapy should be restricted to rigid categories of occupation and omitting 'survival, sexual, spiritual and social activities' would seem to limit the array of occupations remaining for practitioners to consider. Several activities which may be deemed as within a 'traditional' occupational therapy scope of practice may be precluded based on this view; for example is food preparation an occupation or an aspect of survival? Are social activities tackling social exclusion and marginalisation occupations? Is the spiritual, regarded as a component of the Canadian Model of Practice (Polatajko *et al*, 2007), relevant to occupation? By limiting the conception of what is an ADL and focussing on function, Kielhofner's view could contribute to the exclusion of sexual concerns and a focus on the most basic functions necessary for discharge from medicalised care (Wilding and Whiteford, 2008), potentially reducing practice and narrowing the scope of occupation. In adhering to Kielhofner's view (1993) excluding 'survival, sexual, spiritual and social activities', the practice of occupational therapy could be severely limited. This debate is important as the literature and views of key theorists influence and direct debate around occupation; for a major influential theorist like Gary Kielhofner to dismiss sex may have contributed to its continued omission throughout the literature and in practice.

### ***Making occupational assumptions***

This debate around whether sex is an occupation provides an example of how occupational therapists can make assumptions around occupation, and which occupations are assumed to be 'positive and productive' (Twinley, 2013, p.301) linked to restoring 'good' and positive correlations

to health and wellbeing, and therefore more acceptable aspects of practice. By making these assumptions there is a danger of omitting occupations which do not fit with an individual occupational therapists' 'worldview' of what are positive or appropriate occupations, and may unintentionally reinforce power and privilege over a client. This may be particularly problematic given the dominant sexual scripts discussed later in chapter 2.2, as the profession tends to be made up of predominantly white, middle class, non-disabled women (Clare Taylor, 2007, p.277), who may apply narrow interpretations of what are acceptable occupations and adhere to dominant heteronormative views around sex and sexuality.

Kantartzis and Molineux (2012) suggest that understanding of occupation is dominated by a 'western, Anglophone and middle class view of reality' (p.39). Kantartzis and Molineux track the historical-political influences on definitions of occupation from religion and the Protestant work ethic, imperialism, capitalism and industrialisation which in turn influenced educational and political / economic structures, leading to activity having a 'central place in western society' (p.45). The value placed on occupation became viewed in economic terms, with some occupations valued more than others. They suggest the 'emergence of neo-liberalism has reinforced the importance of individual responsibility and the dominance of independence and productivity' (p.45). This economic productivity-oriented conceptualisation may explain why certain occupations such as sex and sexual expression are deemed less valid, acceptable or important than others.

According to Gerlach (2015, p.247), occupational therapists generally have failed to recognise and challenge power and privilege, potentially making them complicit in disempowerment 'as we exert normative assumptions'. Gerlach (2015, p.247) suggests the 'influence of the top-down flow of western power and knowledge in occupational therapy theorising' models and practice are deemed universal 'yet privilege certain occupations and sociocultural and economic realities' finding persistent 'taken-for-granted discourses and routine occupational therapy practices'. Davis (2005, p.29) suggests that rehabilitation adheres to a 'tyranny of the norm', with Hammell (2006, p.22) suggesting a 'normalising judgement is always a value judgement' against which an individual client is measured and compared, and – in her critique of the ICF (WHO, 2001) - that impairment is viewed as a 'deviation from socially defined norms'. This debate raises questions on how occupations are often categorised around self-care, productivity (including work and play) and leisure (including rest) (Dickie, 2013; Kantartzis and Molineux, 2012, p.47). These categories can be problematic as occupations may be classified according to their purpose, defined in units of activity with 'work,

productivity and 'serious' leisure occupations' given central importance (Kantartzis and Molineux, 2012, p.47).

Sexual concerns may not fit easily in these classifications. Reed and Sanderson (1992) suggest that sex is an important aspect of self-care, whereas Kennedy (1987) suggests sexual activity 'may be included within occupational performance area of recreation / leisure' and cites Mosley's (1981) definition of 'activities for the sake of amusement, relaxation and self-actualisation' (p.189). Work may be an obligation but some people enjoy their work, leisure can also be draining and not always pleasurable. For some sex may be work, it may be productivity, self-care or leisure, or none of these. If occupational therapy is to be client-centred then the client should dictate the meaning and purpose of an occupation and how, as Hammell (2009) suggests, if - at all. Hammell (2006) questions the categories of 'self-care, productivity and leisure' underpinning much of occupational therapy theory, as an 'ideology of normality serves to reinforce professional power' (p.23) by fostering acceptance of certain norms a profession can 'perpetuate its viability' and return to or gain 'new economic niches'. Norms are cultural judgements and are therefore fluid and flexible according to dominant values. Hammell (2006, p.20) states that 'dominant groups hold the power to legitimate their own values, portraying these as neutral, natural and objective' whilst there is an overt focus on 'individuals' experiences, ... sanitised by middle class values' (Hocking, 2012, p.61) rather than consideration of social, cultural and structural/ material challenges. Hammell (2009) suggests these categories are a 'privileged triad', stating they are 'simplistic, value-laden, decontextualized and insufficiently descriptive of subjective experience', and that the most meaningful occupations in people's lives (among which she included 'making love') 'do not fit in this privileged triad', suggesting it is dogmatic to adhere to these categories, nor into notions of wholly positive, productive and/or enabling activity.

Another approach to critiquing the limited notions of occupation comes from Twinley (2013) who suggests that there has not been enough consideration for 'non-health-giving, anti-social or unproductive occupations' which can be 'self-damaging, deviant or disruptive' (p.302). These have been referred to as being on the 'dark side' of occupation (Twinley, 2013), a metaphor for occupations which may be meaningful to clients but conflict with professional perceptions as they are dissonant with ideas around occupation as purely healthy and 'good'. Twinley (2013) framed these occupations which might not promote good health or be productive but 'may provide a sense of well-being' (p.301). These 'dark side' occupations include those considered 'anti-social' and are assumed to be negative, unacceptable and taboo, however Twinley (2013) suggests that these

occupations have meaning and importance to the individuals and groups undertaking them. Twinley, (2013) refers to her work on violence as an occupation (Twinley and Addidle, 2012) and the work of Kiepek and Magalhaes (2011) on negative occupations. By 'dark side' she suggests that this is not a 'side' as such, but a means of thinking about occupation as something complex and multi-dimensional which remain 'less acknowledged, less explained and less understood' (Twinley, 2013, p.302); occupations of which we are aware but are on the margins of practice. Among these occupations she included: anti-social, criminal, deviant, violent, disruptive, harmful, unproductive, non-health-giving, non-health promoting and/or addictive occupations, and occupations which are deemed politically, socially, culturally or religiously extreme (Twinley, 2013, p.302). Despite being less socially acceptable, these are still occupations as they have meaning and purpose, involve creativity and engagement, could be relaxing, entertaining and enjoyable, and could contribute to well-being - congruent with definitions of occupation. In order to be truly holistic she suggests that occupational therapists need to consider 'the whole picture in terms of what occupation is' (Twinley, 2013, p.301) in order to widen understanding of what is meaningful and what people perform and participate in.

Sexual concerns again do not fit easily with this concept of 'dark side' occupations; they are not generally perceived as illegal, immoral nor unhealthy activities, although they can be. They are not 'dark side' occupations in the same way as, for example, random violence or smoking. However due to taboos and sensitivity around sex, its incongruence with 'values and definition with moral character' (Kiepek and Magalhaes, 2011, p.266) and questions around acceptability, they have been marginalised as occupations, despite their importance to many clients as ordinary aspects of life. Sex remains 'in the shadows', generally missing from the day-to-day practice of a majority of occupational therapists. The feelings of discomfort and stigma described by Couldrick (1998, 1999) and others suggest it is an occupation that many practitioners struggle with. Yallop and Fitzgerald (1997) and Jones *et al* (2005) suggest that occupational therapists are more comfortable with scenarios around sex which required practical, 'common sense' or straight-forward responses, admitting to their discomfort with scenarios outside a 'normal' range of experience or based on personal attitudes around societal and cultural norms. It would seem that even when sex as an occupation is not in some way perceived as 'disordered' (for example, an addiction or deemed deviant), aspects of sexual expression can be outside what is deemed 'normal' are still taboo.

Kiepek and Magalhaes (2011) suggest that these marginalised, 'dark side' occupations indicate a spectrum in how occupations should be characterised; occupations cannot simply be seen as good

or bad, healthy or unhealthy. They provide the examples of football or ballet – occupations which are deemed socially acceptable and healthy, linked to creativity and physical endurance but in the longer term can lead to negative physical and mental health consequences. They explore ‘disordered’ activities such as problem gambling, sexual addiction, workaholism, eating disorders, internet usage disorders, compulsive shopping and exercise addiction; all problematic versions of occupations which are more socially acceptable in less extreme iterations. They also note that some occupations which are seen as unhealthy could also be positive for individuals, for example drinking alcohol, smoking, opiate use for pain alleviation or the use of medical marijuana. Kiepek and Magalhaes (2011) suggest that although occupation is ‘necessary for health and well-being ... not every occupation enhances health and well-being’ (p.266), contending that this may be ‘attributed to modern societal values and definitions of moral character’ (p.266). Kantartzis and Molineux (in Whitehead and Hocking, 2012) do not dispute the conceptualisation of occupations as purposeful but suggest the purpose is ‘enfolding, interwoven, emergent and complex....individual, familial, societal, intrinsic or extrinsic’ (p.47) and the importance of value is ‘relative and flexible’ (p.47). Hammell (2009) contests assumptions around occupations that they are always meaningful and that being meaningful is always a positive, arguing that people are autonomous in their participation in occupations. She suggests that people’s meanings may also be of ‘boredom, humiliation and frustration’. Occupations are not always good for health and wellbeing in the context of occupational therapy (Dickie, 2013), and therefore occupational therapists should recognise that occupation can be ‘passive, anti-social or pleasurable / relaxing and not be health giving’. Kiepek and Magalhaes (2011) suggest that in practice the dominant healthy / unhealthy dichotomy is simplistic and has a negative impact on the client, giving the example of a person with a history of heroin use who felt their complex ‘personal path’ was overlooked as their recovery was measured by the ‘presence or absence’ of drugs (p.267). Considering the ‘dark side’ aids reflection on how certain occupations may be ambiguous and difficult to categorise as good or bad, health or unhealthy, or fits with occupational performance areas such as self-care, productivity and leisure.

An occupation such as sex is difficult to categorise. In a sense it is on the ‘dark side’ as it evokes feelings of stigma and taboo associated with sensitivity and discomfort, and yet it is arguably an ADL - an ordinary, ‘normal’ part of existence. Its place on the ‘dark side’ is drawn from the feelings of discomfort and taboo it may invoke, based on sexual scripts around historical questions of morality discussed in chapter 2.5. Although sex has specific cultural ‘baggage’ I sought to explore other occupations which may provoke similar feelings of discomfort but there were few examples in occupational therapy literature, reflecting the lack of critical examinations of potentially unhealthy

or less acceptable occupations Twinley (2013) and Kiepek and Magalhaes (2011) discuss. Sex and sexual concerns are not like the more obviously 'unhealthy', 'dark side' occupations like smoking or violence. I considered occupations which may induce feelings of taboo or discomfort; occupations which are not always illegal and/or deemed immoral such as gambling, drinking and smoking may be problematic due to their negative unhealthy associations; an issue which is similarly sensitive to broach such as toileting is one which is a necessity and one occupational therapists do not tend to deem as inappropriate to their roles; in the literature 'cross-dressing' was one of the few occupations discussed in terms of the discomfort it invokes and not be seen as appropriate to some occupational therapists despite its meaning and importance to some clients (Curtis and Morris, 2015). These occupations may carry some degree of sensitivity and taboo due to preconceived notions of acceptable and unacceptable occupation based on dominant sexual scripts, class, upbringing and experience.

### **Summary: Occupational therapy: history, professional identity and sexual concerns**

This section explored occupational therapy, issues of professional identity and explored sex as an occupation. The literature indicated occupational therapists have found their place in healthcare practice challenging due to eclectic influences, ambiguity around occupation and dissonance between professional beliefs and values, and dominant medicalised approaches within healthcare. This has problematised professional identity as occupational therapists have attempted to maintain an occupational focus whilst desiring to retain credibility in the eyes of colleagues and clients. In the literature, this is often viewed through a prism of negativity, however this has also created opportunities for occupational therapists and benefitted clients, providing occupational therapists a flexible and adaptable foundation to their practice.

This part of the thesis also looked at the debate as to whether sex can be described as an occupation. Gary Kielhofner indicates that sex is outside the remit of occupational therapy due to being a 'tissue need'. Although sex and sexual expression have been largely missing from key occupational therapy texts and UK occupational therapy education, occupational therapists themselves seem to agree that sex and sexual expression are occupations and therefore part of their remit, believing them to be ADLs and part of the whole person, having meaning and importance to individuals. They have, however, struggled to put this belief into practice. Sexual concerns appear to have been marginalised within occupational therapy due to the discomfort associated with it arising from cultural and social taboos, questions of acceptability and the difficulty for occupational



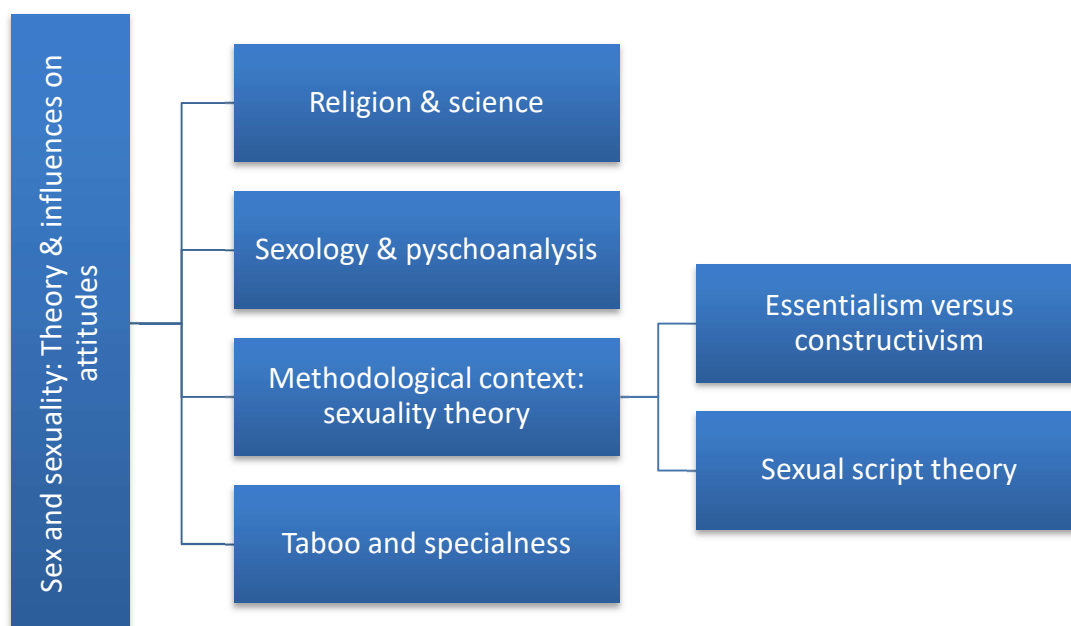
therapists in finding practical solutions to sexual concerns when they arise. Sex does not fit easily into the 'privileged triad' of self-care, productivity and leisure nor into notions of wholly positive, productive and enabling activity, but despite being what may be described as being a 'dark side' occupation, for many people sex and sexual expression makes a positive contribution to their lives and it is often an important unmet need for disabled people and clients.

The comparatively privileged background of many occupational therapists (Hammell, 2009) may blind them to the importance and difficulty in accessing sexual opportunities. Practitioners need to navigate a path which recognises their own 'taboos' as well as those for their clients and society. This might require recognising sex as ordinary ('normal') and the difficulties clients may face in exercising and accessing an ordinary sex life. It may be difficult to make sex an ordinary social experience for clients whose access to other social experiences is restricted (for example work, public spaces) and for whom everyday sexual experience may require planning and organisation. Taboo and stigmas around acceptable occupations, as well as around sex and disability (discussed in chapter 2.3) may add to these difficulties.

The RCOT (2015) published a position statement on occupation-centred practice, citing the WFOT (2012) that the 'focus of the practitioner *in any setting, with any service user group* is to maximise occupational performance and participation' (original italics), reiterating the importance and centrality of occupation as the core of the profession, and could also be seen as reiterating that occupation is central to occupational therapy professional identity. This section has highlighted some of the difficulties around defining occupation and how the profession of occupational therapy has faced challenges around identity whilst a definitive definition for professional identity has remained difficult and 'elusive' (Mackay, 2007, p.96). This has led to occupational therapists facing a dissonance between the 'art and science' of occupational therapy, and between their core beliefs and values, and the realities of practice. Despite this being viewed as problematic for occupational therapists, there are positives to be found from the unique occupational perspectives of occupational therapy. Basing professional identity on the flexibility and inclusiveness yet centrality of occupation, occupational therapists could reinforce the foundations of their professional selves.

## 2.2 A brief history of influences on attitudes to sex and sexuality theory

In this section I explore some of the historical ideas, theories and movements which have influenced perceptions of sex and which have resonated both in wider culture and in healthcare provision in the UK. These theories have been widely discussed elsewhere (for example, Nye, 1999; Weeks, 2003; Parker and Aggleton, 2007; Monro, 2015), and so rather than an extensive review of the history and theory, this overview will be a broad-brush examination of some of the key influences which have impacted on attitudes within society and a short examination of sexuality theory, particularly sexual script theory which is used to underpin this study. Rather than provide a definitive discussion on the nature of sex and sexuality, I will provide an overview of some of the historical and theoretical influences on how ideas around sex have influenced how sexual concerns are perceived and understood within society. This is relevant to this study as these contribute and influence how occupational therapists, clients / disabled people, HCP colleagues and people in general in the UK consider, interact, accept and respond to sex and sexual expression, form attitudes and sexual scripts (discussed later in this chapter), and develop and manage associated discomfort, sensitivity, taboo and a sense of 'dirty work' (discussed in chapter 2.5).



### Historical influences on attitudes

At its most simplistic, the path of ideas which have influenced perceptions of sex and sexual expression in society reflect a perpetual motion between conservatism and progressive reforms; control to apparent liberation and back (see figure 5 below). This is seldom a linear process; often contradictory views have been held concurrently (Jackson and Scott, 2004), and ideas and individual

theorists may have contradicted dominant trends. However for the purposes of this research I have stepped back to look at ideas which have generally impacted and influenced popular perceptions and taboos, as these are likely to have affected the attitudes of occupational therapists, and their clients and colleagues within wider society. These changes have influenced socio-cultural attitudes to sex around what is acceptable or taboo and on who should 'access' sex and sexual expression.

Evans (1998, p.3) suggests that 'society is preoccupied with sexuality...the rapid sexualisation of modern societies cannot be doubted'. The history of sex and sexuality has broadly swung from essentialist concepts of the body and the need to police sex (through religion, science and medicine/psychoanalysis) to constructivism and activism (marked by a de-medicalisation of sex) and a recent divergence with both the resurgence of essentialism (for example, re-medicalisation through technology - see later in this chapter), alongside an increased awareness of sex as socially constructed (for example the querying of gender roles and sexual expression around feminist and transgender narratives). Padgug (1999) describes the history of sexuality as one in constant flux, a history of changing preoccupations and influences, highlighting how sex and sexuality have been susceptible to changing socio-cultural mores (Weeks, 2003).

**Fig 5 – Historical influences on attitudes to sex and sexuality**



(Jackson and Scott, 2010a; Padgug, 1999; Cacchioni, 2015; Seidman, 2011 and 2015; Nye, 1999; Parker and Aggleton, 2007)

### ***Church to Enlightenment***

Prior to the dominant influence of Christianity, the literature often focusses on ancient Greek and Roman attitudes to sex (more detailed accounts can be found in Nye (1999) and Foucault (1981)). Nye (1999, p.3) suggests that 'sexuality in the west has usually been portrayed in an antagonistic relationship to society'. In the UK, the predominantly verbal pre-Christian culture was often interpreted through Christian eyes when subsequently written. This brief account, then, will begin in the Medieval, early Christian period, prior to industrialisation. At this time, the sexual lives of most people in the UK were subject to religion, the family and the local community. People lived comparatively static and public lives in predominantly rural populations, under the inherent surveillance of living with limited privacy (Cacchioni, 2015). Regardless as to which religion was dominant, Catholic or Protestant, prior to the Enlightenment sex was policed by the twin pillars of Christian doctrine and property rights in which heterosexual marriage between men and women for the purposes of procreation was hegemonic. This policing loosened as the UK entered the industrial revolution, work increasingly centred within factories rather than the home, with the rural population rendered landless and jobless in a changing society, gravitating to areas around those factories. This meant that the informal surveillance that existed within smaller communities became more difficult as urban populations grew, leading to a growth in sex work as social policing reduced (Cacchioni, 2015). This eventually led to moral panic among the growing middle class, who had concerns regarding behaviour and 'degeneracy' among working people (Seidman, 2011).

Industrialisation arguably led to the reduction of the power of the Church, both in terms of an increasingly urbanised and difficult to police UK population and the questioning of Christian doctrine associated with the Enlightenment in the late 17<sup>th</sup> to 18<sup>th</sup> centuries. The Enlightenment meant greater emphasis on science, rationalism, reason and individuality (Bristow, 2017). Although this led to a greater questioning and loosening of cultural beliefs around sex, science became the greater authority on sexual matters, and sexual behaviours other than intercourse for the purposes of procreation became pathologised, labelled as sickness, hysteria or madness (Nye, 1999). What the Church had deemed as immoral became translated as sick or abnormal in Enlightenment thinking, making immorality a risk of future degeneration (Cacchioni, 2015). As science took over from the Church as the arbiter of morality, unacceptable sexual desires/behaviours became considered as 'sick (rather) than merely morally corrupt' (Roberts, 2006, p.67). During this time Foucault (1981) suggests that the general discourse about sexuality and sexual behaviours was repressed, moving away from religion and the Church to fall under the jurisdiction of judicial and medical bodies. Discourses on sexuality were not concerned with the experience of sex but on the impact of what

was seen as deviant or degenerate behaviour on children or concerns around the mentally ill, criminals, homosexuals, and anyone deemed as 'obsessive' or 'perverted'.

During this period of scientific and technological development, disciplines such as medicine, psychiatry and sexology emerged. Sex became central to identity and 'essential' being, norms were established and individuals were increasingly measured against them (Foucault, 1987 cited by Roberts, 2006, p.68). For example, in the burgeoning middle class population, the ideal for women was 'passionlessness'; sexual desire or any non-heterosexual behaviours were seen as deviant or degenerative (Cacchioni, 2015). Although some perceived deviancy was punished as criminal, explanations were increasingly sought from the newly developing sciences (Roberts, 2006, p.67), and a growing focus on physiological differences was seen as a means of explaining 'deviancy'. By the late 19<sup>th</sup> century / early 20<sup>th</sup> century, ideas around eugenics - that is, 'selective breeding' based on desirable or undesirable traits - gained traction amid these increasing concerns around degeneracy and the moral and economic fitness to have children (Dabhoiwala, 2012), often based on class, race and/or ability.

### ***Sexology and psychoanalysis***

Emerging from the rise of science and reason of the post-Enlightenment / Victorian era, yet often retaining or influenced by the conservative and moral underpinning of the Christian church, ideas derived from sexology and psychoanalysis began to gain dominance, and arguably remain significant in socio-cultural ideas around sex, taboo and accepted norms. Sexology is the study of sex as a scientific subject, it first gained a foothold in the late 19th and early 20th centuries, whilst psychoanalysis, specifically the works of Sigmund Freud, developed around the same time. Freud's ideas moved away from physiological explanations of sex and sexuality towards theories of the unconscious. Although sexologists did not reach what might be called the 'brand' status of Freud (except perhaps the later proponent, Alfred Kinsey), the scientific approach to sex and the essentialist underpinning inferred by it have remained influential. The psychoanalytic tradition and sexology share the view that sex is biological in nature but disagree regarding the focus of the sexual Instinct; Freud focussing on pleasure rather than reproduction and heterosexuality, accepting non-reproductive sexual expression as normal if within social norms (Seidman, 2011, p.4).

Despite criticisms, Freud has been influential on academic and everyday language, reinforcing 'taken for granted assumptions that sexuality is a natural force albeit one constrained by social norms' (Jackson and Scott, 2010a, p.5). Aspects of Freud's terminology and theories of the unconscious - including the role of repression, denial, sublimation, and projection - have remained in the popular

imagination despite later criticisms. Sexology has also been to some extent influential; Seidman (2011) suggests that sexology has shaped western sexual culture and the idea of a natural sexuality. Sexologists attempted to discuss sexual behaviour more openly, and to show how sexual behaviour occurred naturally (Parker and Aggleton, 2007), regarding sexuality as a 'natural drive' or 'given fact' which is both universal and biologically determined (Vance, 1999), and defined what was natural in terms of sexual identity and behaviour (Abbott *et al*, 2005). Although the early sexologists were not in concord regarding the nature of sex, Seidman (2011, p.3) states that the key ideas of sexology were:

- Humans are born with a sexual nature
- Sexuality is core to being human
- Sexuality is a powerful driving force in behaviour
- Sexual instinct is by nature heterosexual
- Sexology aims to find 'laws of sexuality' using a rigorous scientific approach

Seidman (2015) suggests that from the outset sexology had a 'social purpose' (p4) to expand tolerance and to contribute to creating a 'healthy fit population', although it tended to reflect contemporary intolerances, for example Krafft-Ebing (1896) deemed non-heterosexual sex a pathology. One of the negative connotations to this was that sexology lent itself to eugenics, which gained momentum in the late 19<sup>th</sup> and early 20<sup>th</sup> centuries (Democracy Now, 2016 – interview with Adam Cohen) focussing on racial and class purity (Seidman, 2011). In the mid-20<sup>th</sup> century, as eugenics became discredited due to its association with Nazism and the Holocaust, sexology shifted its social purpose towards supporting the institution of marriage and the family. Although the intentions of several sexologists may have been progressive and attempted to challenge prevailing orthodoxies, they also often reflected those orthodoxies.

By the middle of the 20<sup>th</sup> Century, the social purpose which had underpinned sexology had largely diminished in favour of more empirical approaches such as by Kinsey (1948 / 1953) or Masters and Johnson (1966), who employed 'scientific' methods to questions of sexual behaviour. Their work had differing influences on perceptions of sex. Kinsey's US research *Sexual Behavior in the Human Male* (1948) and the later *Sexual Behavior in the Human Female* (1953) were the first to recognise that people did not fit into a heterosexual/homosexual binary and that sexual orientation was not fixed, and although Kinsey was initially 'wedded to the notion that sexuality is natural', his later work on women acknowledged the influence of social factors (Jackson and Scott, 2010a, p.6). Masters and Johnson's work also in the US reinforced more essentialist perceptions of what is 'normal' sexual

function, having set about empirically determining the 'normal' physiology of sexual function by observing, measuring and describing physiological events during sexual activities within laboratory conditions. Although criticised for his sampling method, much of the controversy around Kinsey's research was devoted to the perceived 'immorality' of his findings around sexual behaviours such as pre- and extra-marital sex and behaviours seen as 'deviant', which he suggested were within the range of normal sexual behaviour (Brown and Fee, 2003). Whilst Kinsey's work was deemed controversial, Potts (2002) suggests Masters and Johnson's (1966) more medicalised study, the *Human Sexual Response*, was 'readily accepted due to its reduction of sexual response to physiological goals'. The impact of Masters and Johnson on perceptions of sex and sexual expression, particularly in healthcare, has been long-lasting as their research provided the basis for criteria used in the diagnosis and treatment of sexual problems. Masters and Johnson's work led to increased physiological emphasis replacing psychoanalytic tradition, leading to a focus on behavioural and physical treatments and the ignoring of socio-cultural influences on sexual expression and dysfunction. Sexual 'deviance' became pathologised as mental illness (for example, in the first attempts to categorise mental illness in the *Diagnostic and Statistical Manual of Mental Disorders* (DSM) in the 1950's, homosexuality and nymphomania were included). Sexology treatment also became more biological / medical including the use of hormones and Electric Convulsive Treatment (ECT) to 'treat' perceived sexual 'problems' - for example, to 'cure' homosexuality until it was eventually removed from the Diagnostic and Statistical Manual of Mental Disorders (DSM-II, 1973 version) after intensive campaigning by LGBT activists (Cacchioni, 2015, p.439).

The influence of sexologists may be reflected in both medicalised approaches to sex and reactionary responses to attempts to redress gender inequality, for example Havelock Ellis's contention that sexual energy was stored and needed to be released are reflected in assumptions in popular thinking around (the male) sexual 'drive' (Tiefer, 2001), whilst his advocating of traditional gender roles as being natural – that 'woman breeds and tends; men provide' (Ellis, 1894 in Weeks, 1989, p.189) would not have been out of place in the now notorious 2017 James Damore memo (Wikipedia, 2018) questioning Google's attempt to improve gender diversity within the company. Scientific, sexological and psychoanalytical traditions have been contentious and yet remain influential on attitudes to sex around perceived 'normal' sexual functioning and the importance of penetrative sexual intercourse and orgasm. Sexual norms as categorised by sexologists entered popular culture; Weeks (1991, p.4) suggests that people increasingly measured themselves against them, with some perceiving a need for treatment for their 'pathologies' whilst others resisted pathologies by forming



sexual identities (for example, homosexuality) (Roberts, 2006, p.68). Despite claims of rejecting Victorian views of women as secondary to men, early sexology could be used to reinforce institutions of marriage and monogamy, and failed to examine issues of sexual identity, cultural norms, power, context and lived experience. As Weeks (1991, p.4) suggests 'sexology, then, is not simply descriptive. It is at times profoundly prescriptive, telling us what we ought to be like, what makes us truly ourselves and normal'. Attitudes and theories derived from sexology and psychoanalysis remain influential in mainstream and popular culture, despite having been challenged and being poorly evidenced; their work remains embedded in the ways western society perceives and categorises sexual issues and on which experiences have become perceived as acceptable, deviant or problematic.

Sexology, the psychoanalytic tradition and Christian ideas around sex have influenced mainstream Anglo-phone/ western cultural attitudes and thinking on sex and sexuality (Seidman, 2011, p4) and remain dominant societal views despite having been refuted. The ideas of Freud can still be found reflected in language usage and widely held cultural ideas around the 'id', 'ego' and 'Oedipus complex' remain, and Christian ideas around sex and sin still underpin popular attitudes and taboos despite the diminished role of the Church in most people's lives in the UK (Bullivant, 2016). Conversely they have provided the basis to responses which have rejected these essentialist ideas (for example, feminism and LGBTI+ activism).

These various and sometimes contradictory ideas around sex are relevant to this study as they have influenced the sexual scripts of occupational therapists, clients / disabled people healthcare colleagues, and organisational and societal attitudes in general. The box on page 71 highlights some of these potential current influences. Occupational therapists, then, must navigate societal conventions and taboos as well as managing their own perceptions of acceptability and discomfort, and the sensitivity derived from these influences. These may be reflected in heteronormative thinking and unconscious biases around relationships and the (nuclear) family, assumptions around gender roles, sexual drives, morality and around independence (and its inherent spontaneity) as a primary goal.

### **Methodological context: Sexuality theories**

Sex and sexuality have been considered through the prism of a variety of theoretical viewpoints including essentialism, constructivism, feminism, interactionism, queer theory and intersectionality. This section will provide a brief description of sexuality theory, focussing predominantly on sexual script theory which was used as a lens in this study. As discussed earlier in this chapter, sexual scripts

are relevant in the context of the study as they have influenced the practice of occupational therapy and general societal attitudes. As discussed, up until the mid-late 20<sup>th</sup> century, essentialist approaches dominated western thought on sex, initially based on Christian religious doctrine and later based on scientific and Enlightenment principles of 'reason', reinforcing notions around sex as biological and based in nature. Socio-cultural influences were seldom recognised. The dominance of these essentialist ideas suggesting that sex and sexual expression were pre-social and 'native to the human constitution', derived from God, evolution or nature were increasingly questioned (Connell and Dowsett, 1992, p.188) initially due to the work of anthropologists (for example Mead, 1928; Malinowski, 1929), whose empirical observations undermined essentialist views that sex is the same across cultures and whose findings supported ideas around the social construction of human lives.

Anthropologists gathered extensive evidence indicating there were in fact diverse sexual attitudes, beliefs and practices across cultural settings. They highlighted the importance of culture in sexual and social life (Jackson and Scott, 2010, p.9), and that essentialism failed to explain differences in the meaning of sexual acts, did not account for variations within or across cultures and ignored mainstays of culture such as 'desire and pleasure' (Connell and Dowsett, 1992, p.191). By raising questions over deviance as being socially constructed, the findings of anthropology led to 'thinking of sexuality itself as socially constructed' (Jackson and Scott, 2010a, p.5).

Proponents of constructivism eschew essentialism suggesting that sex and sexuality are products of diverse influences and social interventions which do not exist outside history (Weeks, 2003), acknowledging the 'intricate and multiple ways in which our emotions, desires and relationships are shaped by the society we live in' (Weeks, 2003, p.19). Therefore 'sex cannot be seen as a simple biological phenomenon but socially and culturally shaped' (Couldrick, 2007, p.29) as 'it only exists through social forms and organisation' (Weeks, 2003, p.29). Anthropology shows that the acceptance of sexual practices and orientation varies across cultures and that there is diversity in cultural norms which suggest sex is 'not a given, it is a product of negotiation, struggle and human agency' (Weeks, 2003, p.18). Sex and sexual expression are therefore not fixed but subjective, dynamic and fluid, influenced by and derived from interpretations of biology, psychology, socio-cultural and political identity and identifiers, constantly shaped and constructed (Evans, 1998). If sex, sexuality and sexual orientation were determined by biology they would be concrete, simple and unchangeable, however they involve 'many facets of human behaviour and being, which in turn are influenced by historical, social, cultural and political context' (Bywater and Jones, 2007, p.3).

There have been several criticisms of constructivism; that it is relativist, unstable, that it trivialises matters such as sexual identity and orientation by suggesting individuals may change (Vance, 1989, p.162), conversely that social constructivism 'assigns a passive role to the individual', whilst 'leav(ing) little room for individual initiative and creativity' and having 'limited explanatory or predictive power' (Delamater and Hyde, 1998, p.16). However, constructivism has been useful in critiquing 'notions of biological essentialism' contributing to feminist and Queer theory (Monro, 2015, p.33) and has helped delineate differences in biological sex and gender roles, deconstruct sex and gender identity binaries, aid acceptance of multiple complex identities, discourse production and deconstruction, and the unpacking of formations of LGBT identity discourse from heteronormative discourse. Thus contributing to changing mainstream attitudes towards gender equality and non-heterosexuality, helping deconstruct and question dominant essentialist ideas around sex and sexuality. Although these movements have been powerful for activists and in academia, it is less clear how much influence they have exerted on popular societal ideas around sex. As Jackson and Scott (2004; 2010a) observed, there has been increased tolerance and mainstreaming of sexual diversity and various sexual activities and sexualities, but this has occurred alongside simultaneous conservatism around sex.

### ***Interactionism and sexual scripts***

In a nutshell, interactionism is a branch of constructivism, a sociological theory which suggests that how people act within society is the product of social interactions (Merriam-Webster, 2018). Whilst sexual script theory is an interactionist metaphor which examines sexual behaviour, suggesting that human sexual activity is based on social and learned interactions (Wikipedia, 2018). Jackson and Scott (2010b, p.820) suggest interactionism provides a tool to 'link culture and subjectivity to everyday interaction and practice' and a 'mode of theorising', rather than a solution to all questions of sex and sexuality. Interactionism is useful for understanding the construction of sexuality at 'the level of everyday interactions between people' (Monro, 2015, p.31). Sexual script theory was developed by Gagnon and Simon (1973), who questioned the Freudian notion of innate sexual desire, contested the idea of 'sexuality as an overwhelming force' (p.13), and disputed Freud's emphasis on the childhood development of sexuality, instead locating sex in the social and mundane (Jackson and Scott, 2010b). Gagnon and Simon (1973) saw sex and sexuality as social products and so extensions of human sociality, suggesting that feelings and body parts 'are not sexual in themselves, but become so only through the application of socio-cultural scripts which imbue them with sexual significance' (Gagnon and Simon, 1973; Jackson and Scott, 2010b, p.814). For the purposes of this study, I felt that this branch of constructivism was a useful approach to aid understanding of how sex and taboo are perceived, accepted, processed and enacted. I felt the

dualism between predominantly essentialist medicalisation, sexology and psychology versus constructivism could limit the study; constructivism can disembodify the person, ignoring the real physical impact of impairment and illness, whereas the essentialist position can focus entirely on the body encouraging an unchallenged focus on function, omitting social and cultural factors and meanings which can impact on perceptions of sex, sexuality and health.

### *What is sexual script theory?*

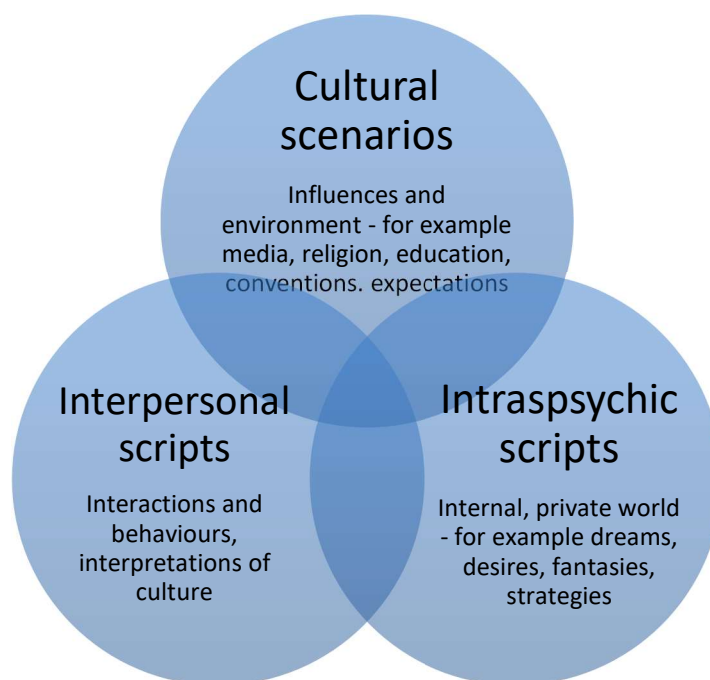
Sexual script theory is a means of conceptualising behaviour and is described as a metaphor for understanding sexual activity and conduct, based on social and learnt scripts. These are entirely historical and cultural, relative, acquired, maintained and organised by social structures and culture, and differ according to culture. Sexual script theory suggests gender and sex are linked but learnt. A central tenet is that the interpretation of reality is derived from a 'shared belief within a particular social group' (Gagnon and Simon 1986, 1987, 2003, in Wiederman, 2015). Sexual behaviour is the result of social scripts and interactions which set out expectations of what is socially accepted (Gagnon and Simon, 1973) 'reinforced' by social interaction (Monro *et al*, 2017). Gagnon (1977) and Gagnon and Simon (1973) suggest there is no sex drive or instinct, but that people learn to be sexual in the same way that they learn to be and do other aspects of their social lives. Scripts involve both external, interpersonal factors such as mutually shared conventions and internal, intrapsychic factors such as motivations and attitudes. This is a multi-way process between the individual and society. Scripts are invoked in learning meanings, organising the sequencing of acts, understanding situations, setting limits and linking meanings between sexual and non-sexual lives (Wiederman, 2015, p.7). Simon and Gagnon (1984, p.262) contend that 'all human sexual behaviour is socially scripted'; sex is not different from other kinds of behaviour, and sexual feelings no more powerful and uncontrollable than any other feelings. Gagnon (2004) suggests that sex is a 'local phenomenon with specific meanings and purposes in particular cultural-historical contexts'; that sexology and science are also products of historical / cultural contexts; that sex and sexual experience result from 'particular learning circumstances' and are influenced by engendered expectations. Mitchell *et al* (2011, p.541) describe sexual scripts as conventions or shared understandings that guide sexual interaction and behaviour, based on the 'scripted nature of social interactions generally'. For Jackson and Scott (2010b) sexual script theory challenges biological determinism and the 'concept of repression'.

### *Three levels of sexual scripts*

Sexual scripts are made up of three interrelated levels: Cultural scenarios, interpersonal scripts, and intrapsychic scripts (Wiederman, 2015) – see figure 6 below. These three levels are complex and in flux, dynamically interacting with one another, blurring and changing. Drawing on the work of several authors; Gagnon (2004), Mitchell *et al* (2011), Simon and Gagnon (1984) and Weiderman (2015), the key relevant aspects are:

- Cultural scenarios – the context for roles, including institutions, instructions and symbols. Cultural scenarios set the scene of what is desirable or undesirable, and the boundaries for what is appropriate and inappropriate behaviour or taboo. These included media, education, religion, health, and so on – the ‘general context for sexual activity’ (Wiederman, 2105, p.8), and provide ‘guides that exist at the level of collective life’. Cultural scenarios (or narratives) do not determine sexual conduct but are cultural resources which influence or help people make sense of situations.
- Interpersonal scripts – these are social interactions and structural behaviours between people and involve the adaptation of general, culturally derived concepts of sex based on experience by each individual, which can clash or match others people’s scripts. This is changing and dynamic according to context / situation, and are about meeting expectations and acting as expected; the interface between ‘interaction and mental life’. The interpersonal shapes cultural scripts into individual contexts, linking between the abstract (cultural) and the concrete (reality), and how cultural scripts are interpreted to make ‘congruent with desired expectations’ (Gagnon and Simon, 1984, p.31).
- Intrapsychic scripts - the individuals’ private world, internal processes and perceptions including desires, plans, strategies, fantasies, memories, and so on. This is the space where an individual works out difficulties with interpersonal scripts within the cultural context. These are unique and are not necessarily a linear narrative or communicable; it involves ‘the symbolic reorganisation of reality in ways to more fully realise... many layered and sometimes multi-voiced wishes’ (Simon and Gagnon, 1984, p.54). This mental life is a result of cultural scenarios and interpersonal scripts but is also partly independent, connecting culture (meaning) and action (social interaction), ‘ought’ behaviours, memories, desires, leading to an internal dialogue and ‘symbolic reordering of reality’ from which motivations lead to action (interpersonal scripts).

**Fig 6 –Levels of sexual scripts**



The relevance of the three areas varies according to cultural rules and conformity; in cultures which have fewer shared meanings and therefore fewer cultural scenarios to use as a template for behaviour, the individual is required to adapt differently drawing on intrapsychic scripts (Wiederman, 2015, p.9) as these are required when it becomes difficult to use cultural scenarios. Blumer (1962, cited in Monro, 2015, p.32) suggests that:

human beings act towards things on the basis of the meaning that things have for them; the meanings of such things is derived from or arises out of the social interaction that one has.... these meanings are handled in and modified through an interpretive process.

Jackson and Scott (2010b, p.821) note that 'normative constructions of sexuality may still dominate common-sense understandings of the sexual, but competing cultural scenarios are now available', this was reflected by the participants in this study who negotiated societal and personal normative constructions but in broaching sex challenged these normative assumptions but could also, unconsciously or not, acquiesced to them.

Sexual script theory appears congruent with occupational therapy as scripting is derived from complex interactions between person, environment and occupation (Gagnon, 2004, p.136) – for example between motivations, learning, contexts, situation and activity. I found it a useful metaphor

to help understand how behaviour is produced; 'an operating syntax' (Simon and Gagnon, 1984, p.31 in Parker and Aggleton, 2007) to help navigate and understand the narratives, constructs and discourses which impact on the self-reported conduct of the participants in this research as 'examining sexual conduct from the perspective of scripting allows one to organise and link together what people think, what they do and how they are affected by the socio-cultural context in which they live' (Gagnon, 2004, p.169). This corresponds to occupational therapy conceptualisations of the relationship between the person, the environment and the occupation. Cultural scenarios may equate with the socio-cultural environment of the person, their expected behaviours and how they feel they should behave in a given situation; intrapsychic scripts equate to the desires and meanings a person may apply towards a given occupation; interpersonal scripts relate to occupations and can also be further environmental factors, affecting the persons' interactions and behaviours. Sexual scripts are for processing engagement with sexual occupations within a physical, social or cultural environment. For example a person going on a date may have differing sets of behaviours depending on what they want from the date, the person they are meeting, where the date takes place and how that person (and their date) may be feeling, all based on interactions between the three levels of sexual scripts.

Perceived reality, then, is interpreted through meaning, arrived from experience and interaction with others, and therefore sex and sexuality are neither determined, essentialist nor fixed. Scripts involve learning the 'meaning of internal states' (Gagnon and Simon 1973, p.17), organising the sequence of acts, decoding and understanding strange or novel situations, setting the limits of response and the linking of meanings of non-sexual to sexual experience. Gagnon (2004) suggests that for a response to be sexual, a person has to actively give sexual meanings to the event/stimuli in question. Individuals go through a process of learning that suggest particular things in certain contexts are meant to be sexual, before they are understood to be sexual for those individuals. Scripts are socialised or learnt and when a new situation develops individuals adapt them. Mitchell *et al* (2011, p.541) contend that 'cultural scripts are increasingly conflicting and ambivalent' therefore a 'greater burden is placed on individuals to generate and employ interpersonal and intrapsychic scripts' to make sense of situations.

There have been several criticisms of sexual script theory; Wiederman (2015, p.18) suggests it can be difficult to operationalise in research and that when operationalised the focus is often given to a fraction of intrapsychic scripts (for example, attitudes), which incorrectly synonymises 'attitude' with the intrapsychic as a whole, for example, a participant may not articulate their fantasies or may

suggest the script that is expected of them rather than their 'real' script. A further criticism is that it is not a theory as such but a metaphor, and therefore it cannot be tested nor explain and answer questions but merely helps to describe what is happening. Although advocating sexual scripts, Jackson and Scott (2010b) also outline some of the criticisms from a feminist perspective; that the theory has been described as simplistic, that it reinforces current patriarchal structures – for example, the orientation around marriage and male-centricity. Gagnon and Simon (1973) also fail to address where scripts are derived from and there is too much onus on 'socialisation' which may be seen as deterministic. Jackson and Scott (2010b) suggest hostility among feminist thinkers of anything which implied determinism, essentialism or overemphasized individualism. They suggest that the theory is often misunderstood and written off as being 'insufficiently radical', with some feminists not prepared to dismiss the view that sexuality is based at heart on 'the product of innate drives' (McIntosh, 1978, in Jackson and Scott, 2010a, p.38). Despite these criticisms, Gagnon and Simon's social scripts theory concurs with people's experiences of sexuality over their life span - the many and changing meanings of sexuality shaped and influenced by life experiences, resulting in 'sexuality meaning different things to different people at different stages of their lives' (Hordern and Street, 2007, p.E14). Wilmoth (1998, p.905) suggests that 'sexuality is like pain or fatigue: It is what a person says that it is'.

I felt that sexual script theory was useful for this study as it reflects the complex interactions between the occupational therapist-participants,

#### **Potential influences on current sexual scripts:** (see pages 64 & 72)

Stigma and taboos were derived from predominant cultural ideas. Considering current trends in popular thinking about sex, sexuality and sexual health there were several often conflicting ideas that may be observed and identified as:-

##### **Traditional / social:**

- Monogamous, heterosexual coupling /marriage remains the standard /'norm despite greater acceptance on 'non-standard' relationships;
- Going on to have a family being the 'natural' and 'normal' narrative arc;
- Men and women still predominantly have defined gender roles, those who 'contravene' or 'transgress' those roles remain seen as different, even abnormal, and treated accordingly.

##### **Austerity & neo-Eugenic / 'alt-right' influences:**

- Moral and economic judgements about the rights, abilities and whether certain group / individuals should have relationships and/or had children (for example the poor, women over 40, disabled people);
- Concerns around over-population, often with socio-economic, racial and/or neo-colonial undertones.

##### **Neo-biomedical / aesthetic:**

- Idealised concepts of the body and mind, and the embracing of technological and pharmaceutical 'solutions' to perceived 'problems';
- Pressure to conform to perfect, spontaneous, penetrative heterosexual sexual intercourse as the 'norm' / ideal.



their clients, environmental and socio-cultural influences and occupational needs at an everyday level (Monro, 2015), such as the possible influences I have outlined in the box (page 71). I found this useful as a means of recognising my own 'baggage' as a researcher, and helping me recognise the influences and interplay between multiple cultural scenarios, interpersonal and intrapsychic scripts of the participants, and how they in turn negotiated and re-constructed sexual scripts depending on their roles, their environment and the wants and needs of their clients and the organisations they worked within. For the purposes of this exploratory study it was not necessary to draw on a theory which explained but one which aided comprehension - as a metaphor, this theory aided understanding of the attitudes to sex on a macro level within society and a micro level in the internalised attitudes of occupational therapists and disabled people/ clients, and how these might be adapted or re-invented according to their environment and experiences without my needing to explain where these attitudes came from, which was beyond the scope of this study. Jackson and Scott (2010b) suggest that as sexual scripts are not distinct from other social scripts, this aids an understanding of how sexuality is shaped by gender, social differences and division, (such as age, ability, religion). Jackson and Scott (2010b) admired Gagnon and Simon's emphasis on the 'everydayness' of sex; that sex is not special 'outside and apart', 'uniquely exciting nor transforming' nor a powerful, 'dangerous force' with the power to undermine civilization or lead to barbarity. Instead sexual script theory views sex as just part of the routine sociality of human life, part of our past and present, changing throughout our lives - not instructions but narratives of good or bad behaviour which are dynamic and changing, with elements of behaviour or performance given meaning from the scripts' context (Jackson and Scott, 2010b). Using sexual script theory helps understand how the participants navigated a subject which is both taboo and sensitive and yet ordinary.

### ***Combining interactionism (sexual script theory) with materialism***

To aid interpretation of the data I followed Jackson and Scott (2010b) by combining Gagnon and Simon's (1973) interactionist sexual script theory with materialism. Essentialist and constructivist theories fail to explain the whole picture of how the occupational therapists, their clients, their social and cultural environment and the

#### **Materialism in a nutshell**

Materialism is the view that all facts are 'causally dependent upon physical processes' (Encyclopaedia Britannica, n.d.), perceiving all matter is 'the fundamental substance in nature, and that all things, including mental aspects and consciousness, are results of material interactions' (Wikipedia, n.d.).

occupation of clients and occupational therapists interact; essentialism because of its omission of socio-cultural influences and a tendency to support a more medicalised view of sex, and constructivism because it omits the real, concrete concerns which disability, health conditions and

impairment may have on the client and the structural and institutional issues that occupational therapists faced. Monro (2015) suggests that a materialist turn helps acknowledge the structural factors which shape lived experience whilst avoiding becoming dehumanising and politically repressive, and ensures that the examination of sex and gender is inclusive of sexual orientation and cross cultural differences (p.254). Jackson and Scott (2010b, p.818) advocate using sexual script theory in combination with materialism, suggesting that materialism could counterbalance the insufficient attention given to historical and social conditions in sexual script theory, arguing this combination is not a contradiction as 'they illuminate different dimensions of society and address the activities of social life, the former at the macro-social level the latter in terms of everyday social practices' (Jackson and Scott, 2010a, p.3). The core concern of materialism is with structural inequality from social institutions and the forces which structure such as racism, ableism, and sexism (Monro, 2015, p.52). Sexual script theory and materialism were useful lenses for examining how the participants navigated structural and societal pressures, cultural scenarios and their own and their clients' perspectives and feelings around sex and disability/ impairment. Materialism aids understanding of the structural contexts and constraints in which the occupational therapists operate. Using sexual script theory and materialism, providing a more complete 'bigger picture' of socio-cultural influences and the individual process by which sense is made of them.

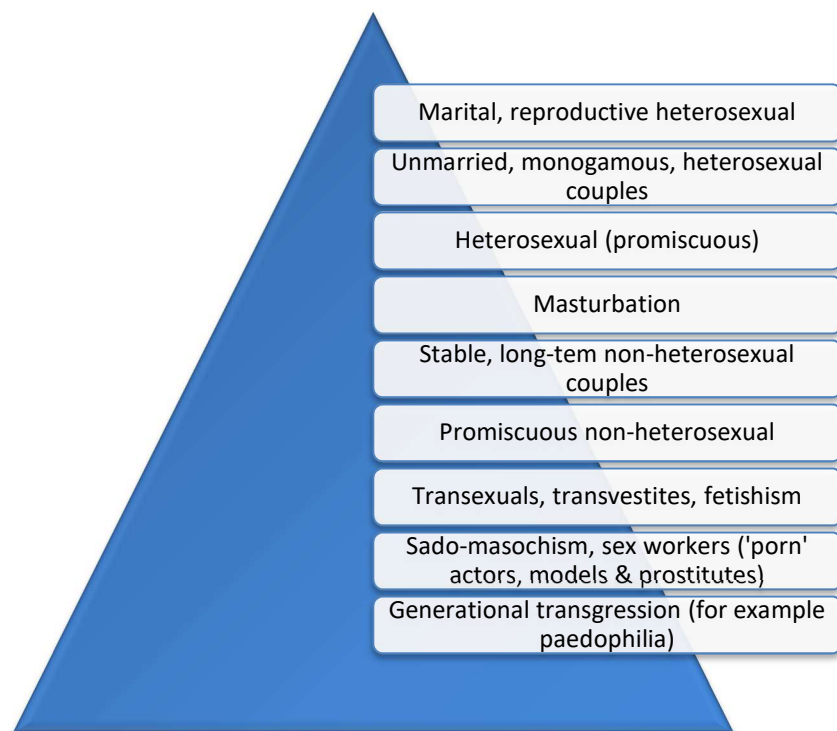
### **Taboo, 'specialness' and hierarchies of 'acceptable' sex**

This section looks at how sexual scripts relate to taboo and ideas of what is acceptable sexual behaviour. As discussed, attitudes to sex in Anglophone / western societies have been influenced by religion, science, identity, medicalisation and activism, which have in turn influenced the sexual scripts individuals use to negotiate sex and sexuality within different contexts and socio-cultural environments, as well as taboos around 'acceptable' sex. Gagnon and Simon (1973) suggest that to learn about sex is to learn about taboo, guilt and its management. Their sexual script theory 'established the legitimacy of ordered sets of behaviours' as well as providing a foundation for 'sexual responses' and conventional strategies for managing guilt (p.199). These have raised sex into a position of 'specialness'. Rubin (1984, p.144) suggests that 'great 19<sup>th</sup> century paradoxes' impact on attitudes to sex, medical practice, child-rearing, parental anxieties, police conduct and sex law' leading to ideas around sex as something taboo being 'chiselled into extensive social and legal structures' in order to protect those deemed vulnerable. As a result, essentialism has become 'embedded in the folk wisdom of western societies' (Rubin, 1984, p.149). Gagnon (2004) argues that the special status given to sex in society is a self-fulfilling prophesy; that is, people experience sex as special because they have been taught to believe that it is special. Jackson and Scott (2004, p.242) suggest that sex has become loaded with connotations around excitement, danger,

something beyond the everyday or even barbarous. They suggest that the term ‘better than sex’ has become a benchmark for pleasure, it is not ‘simply an everyday activity or just a pleasant pastime’ (Jackson and Scott, 2004, p.242), but instead must be spontaneous, passionate, not every-day, with normative assumptions of something shared between a couple, privately.

Taboo and stigma around sex are complex; Rubin (1984, p.151) suggests that there is a hierarchical system of sexual values where the ‘charmed circle’ of ‘good’/ acceptable sexual practice such as the heterosexual monogamous family within or at the top of the hierarchy and trans\* people and sex workers at the bottom (see figure 7 below):

**Figure 7 – Rubin’s hierarchy of sex**



Adapted from Rubin (1984)

Arguably, there have been several changes since 1984; stable long-term non-heterosexual relationships, ‘transvestites’ and fetishism appear more readily accepted whilst transgender and bisexuality are absent in the original. Placement within the hierarchy is also determined by gender orientation, race and dis/ability (Bywater and Jones, 2007). Rubin (1984, p.151) suggests that the lower down the hierarchy, the more likely an individual’s activities will be ‘subject to a presumption of mental illness, disreputability, criminality, restricted social and physical mobility, loss of

institutional support and economic sanctions’ and that stigma maintains ‘some sexual behaviours as low status’.

Whilst narratives regarding sexuality suggest society is more sexually liberal or permissive, Jackson and Scott (2004, p.233) suggest this ‘progress’ has been uneven, centring around the specialness of sex as separate from the everyday and beyond the mundane –as a source of pleasure or joy, and as disgusting and revolting. Reinforcing Rubin’s (1984) hierarchy, Jackson and Scott (2004, p.236) indicate a dominance of ‘institutionalised heterosexuality’ and that ‘basic citizenship rights are based on a heterosexual norm’ with ‘highly conventional lifestyles’ based on monogamy, stability, longevity, and dominant ‘family values’ as a standard to ‘aspire to’. Value is placed on the heterosexual and heterosexual coupledness over other relationships.

Perceptions of sex and sexuality appear to have been dominated by numerous binaries; for example, male or female; heterosexual or homo-sexual (with bisexuality invisible); monogamous or promiscuous; married or unmarried. Usually one of these binaries is regarded as ‘normal’ and therefore privileged, whilst the other is regarded as ‘abnormal’, at best deemed inferior, at worst immoral, stigmatised and taboo (Caplan, 1987). This reflects the Christian / western dichotomy between the mind and body, spirit and flesh, which ‘disavows’ yet is preoccupied with the body (Weeks, 2003, p.21). In attitudes to sex a sort of dualism can be perceived; sex is seen as simultaneously ‘creative, pleasurable, benign and enriching, (yet) also destructive, risky, threatening and dangerous’ (Coultrick, 2007, p.29; Jackson and Scott, 2010a). This dualist orthodoxy has been a barrier to perceiving sex and sexuality as a whole. Sex involves mind and body; sex and sexual expression are not detached from other aspects and experiences, completely free-floating, but are grounded in social and material structures, embodied, arising from the ‘experience of living in, perceiving and experiencing the world from the physical and material place of our bodies’ (Fahs and Swank, 2015).

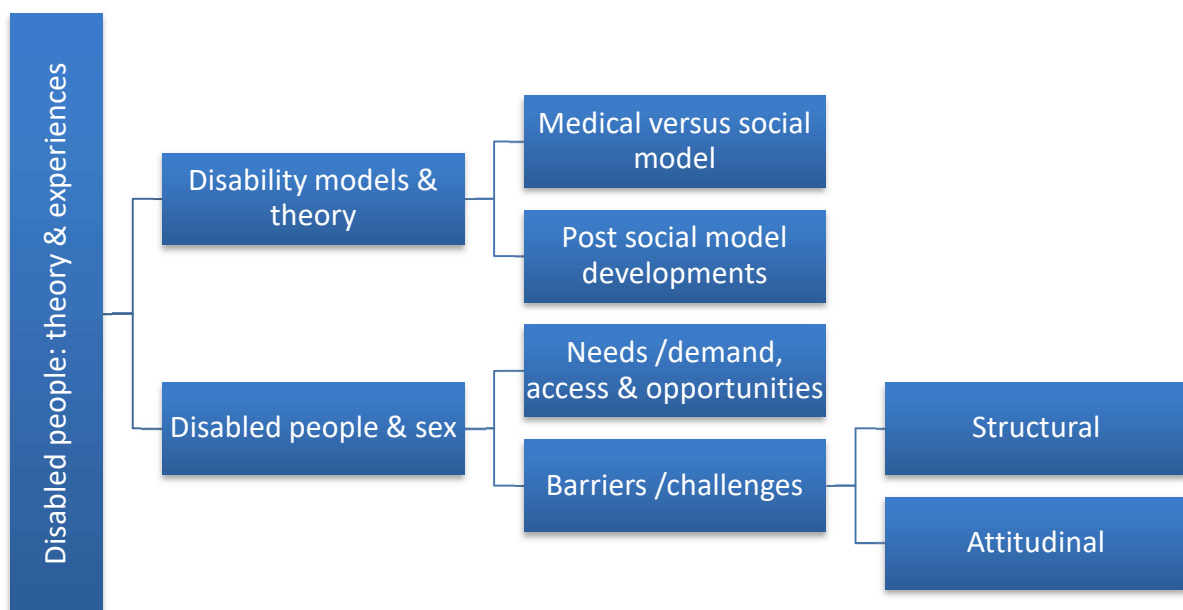
### **Summary: Influences on attitudes to sex and sexuality theory**

This section provides an outline on sexual history and theory, exploring multiple influences on ideas and attitudes of sex, sexuality and sexology. As discussed, sex and sexual expression are complex and contested aspects of human experience and existence, subject to historical, social and cultural contexts (Weeks 2003) and impacting on various aspects of people’s lives such as interactions, relationships, identity, sensuality, decision-making, self-awareness, intimacy, private behaviours and public presentation. Ideas around sex and sexuality and their associated sensitivity, stigma and taboo, are the product of socio-cultural constructs derived from history, religion and essentialism,

which combine with personal and private experiences and negotiations with others. These provide the foundations for sexual scripts which help individuals navigate the complex social behaviours involved in and around sex, sexuality and sexual expression. This social and historical context is important for this study as it provides background to dominant societal ideas about sex and sexuality, explaining the sensitivity around sex which occupational therapists must navigate for themselves, their clients and within wider society. Although, as Gagnon and Simon (1973) and Jackson and Scott (2010a) indicate, sex is an everyday part of society but it is also weighted with long-standing challenges around morality and taboo. This has contributed to the difficulty HCPs and occupational therapists have had in broaching sex which will be discussed in chapter 2.4, and the barriers disabled people / clients have faced when accessing sex and sexual expression, discussed next.

## 2.3 Disability theory and disabled people / clients' experiences of sex

This section will look at both disability theory and the lived experiences of disabled people in accessing sex and sexual expression as found in the literature. Disability theory is relevant to this study as it explains and explores how disability is perceived and how that impacts on disabled people and society, providing a means of understanding how disability is seen and underpinning the attitudes and behaviours of occupational therapists and disabled people themselves. An understanding of the experiences of disabled people themselves is also relevant and important: it shows that there is a demand from disabled people to access to sex and sexual expression and highlights how disabled people are often disempowered, their sexual lives subject to barriers and taboos within society, leading to their wants and needs being omitted and ignored within healthcare (as discussed next in chapter 2.4), an omission which was an important motivating factor for undertaking this study, and one which should be a concern for HCPs and occupational therapists in particular.



### Methodological context: Disability theories and models

This first section outlines disability theory, derived from the field of disability studies, which explores how disability is perceived in society and how disability studies challenged dominant models, as well as outlining the model used to underpin my research. Disability studies is an interdisciplinary field examining the social, political, cultural, environmental and economic intersections and factors which

define and impact on disability and disabled people (Oliver, 2013). Disability studies emerged predominantly in the UK and the US as a distinct academic discipline in the 1980s with roots in the disabled activist movements of the 1960s and 1970s and the experiences of disabled people (Priestley, 2004, p.12). The predominant 'big idea' (Hasler 1993, in Swain *et al*, 2004) has been the social model of disability. Prior to its development the treatment and perception of disabled people was dominated by medical and personal tragedy models<sup>10</sup> which led to disabled people being seen as either problems to be fixed or tragic victims to be pitied. Both of these models are based on historical perceptions of disability as 'otherness' either as a metaphysical anomaly (that is, caused by a 'curse' or magic - Barnes, 1997) or an unproductive use of social and economic resources (Barnes, 1997) - a person who is not contributing to society and therefore an economic drain. Through the lens of the medical model, the disabled person is 'sick' and is required to adapt, adjust or rehabilitate to society. According to the medical model as set out by Parsons (1951 in Barnes and Oliver, 1993), good health is 'normal' and sickness is deviant from the norm. The disabled person has a responsibility and is expected to become 'well' or 'normal' (that is, non-disabled) and seek the support of professionals to help them do so. The onus is on the disabled person to adapt to society and to the environment around them. The medical model suggests that impairment inevitably leads to inability and difficulty in living and fulfilling 'normal' social roles, therefore it is an individual problem which must be either corrected or adapted to (Priestley, 2004, p12). The personal tragedy model is a form of cultural stereotyping related to the medical model (Cameron in Hambrook, 2009). Through this model, disability is perceived to be a personal tragedy, with disabled people seen as objects of pity; tragic yet heroic figures, objects of derision or horror, or a burden on society.

Proponents of the social model of disability reject these views. It marked an important shift in how disability was seen by highlighting the problems of these models and proposing a radical change in how disability was viewed and defined. In the social model, the onus shifts to the disabling factors of society in terms of physical environment and cultural, political and economic attitudes (Oliver, 2004). Using the social model, disability is seen as the 'relationship between people with an impairment and a disabling society' derived from Marxist, materialist concepts which define capital and labour as relationships rather than things (Shakespeare, 2004, p.4). Disability is defined as the result of these factors and the impact of society, distinct from the impairment of the individual (Oliver, 2004), shifting focus away from the individual and out to the social, political and environmental structures within which the individual exists. In the social model, society is seen as

---

<sup>10</sup> Also known as the traditional or individualist model.

having failed to accommodate individual impairment therefore disability is a 'social problem caused by social processes' (Priestley, 2004, p14).

The social model has been subject to extensive and intensive scrutiny, uncovering both strengths and weaknesses. In terms of its strengths it is simple and easily explained, it provides a clear agenda for social change, politically straightforward; it distinguishes allies from enemies (Shakespeare and Watson, 2002), its supporters perceived it to be a 'practical tool' (Oliver, 2004), it has helped challenge discrimination and was instrumental in removing barriers to disabled people by underpinning changes in legislation such as the Disability Discrimination Act (1995). It has also had a profound psychological impact in raising the esteem of disabled people - helping people recognise external barriers rather than perceiving themselves as the 'problem', building a collective identity, changing the perceptions of non-disabled people and disabled people themselves by advocating and encouraging political responses to social and cultural barriers (Shakespeare and Watson, 2002, p.215-6). This model provides a theoretical tool for empowering disabled people, on which to take a civil rights /anti-discriminatory approach to change within society. Disabled people are citizens with rights within a disabling social and physical environment where the responsibility to overcome, change or maintain disability rests on society rather than the individual (Dewsbury *et al*, 2004).

However, there have been several criticisms of the social model; it can be seen as being reductionist - drawing an unsophisticated distinction between impairment (individual) and disability (social) and failing to recognise the complexity of both. It is based on the narrow experiences of a group of white, well-educated, heterosexual men (Shakespeare and Watson, 2002) and therefore fails to account for intersections of race, gender, sexuality and age. Postmodernist critiques suggest the model is too dualistic (Thomas, 2004), based on a fallacy that society can be explained by a split between two opposing dichotomies and failing to recognise the complex multidimensional factors and 'truths' affecting the individual within society. The social model can conform to the personal tragedy model in that disabled people may be cast as victims of oppression (Shakespeare and Watson, 2002). The model has also been criticised for being Utopian and for failing to recognise and address the potential conflicts between the requirements around different disabilities (for example the ideal design of a pavement edge for a person with limited mobility would be different from a person who is blind) (Shakespeare and Watson, 2002), undermining practical common sense approaches and real world development of interventions, or ignoring the realities of lived experiences (Dewsbury *et al*, 2004). Dewbury *et al* (2004) suggest that it neglects the impact of impairment, implying impairment is not a problem, and could be interpreted in such a way that



medical intervention should be rejected. In the social model, the body is missing and 'blame' is shifted to society, whereas 'blame' may be irrelevant for an individual's lived experience.

Despite these criticisms (Oliver, 2013; Shakespeare 2003), the social model achieved some success in changing social and cultural attitudes towards disabled people, and has become the 'dominant paradigm in research and understanding disability' (Dewsbury *et al*, 2004). It provides a key political framework behind disabled activism (Shakespeare and Watson, 2002), and it has been incorporated into the education of HCP groups leading to a change in the understanding of disability and impairment by professionals - although in practice, the medical model has remained dominant. Although occupational therapy has attempted to move away from the medical model and adopt the social model, Chacala *et al* (2014, p.108) suggests that occupational therapists may draw from the medical model where disability is viewed as an 'impairment, limitation, inferiority, deviance from the norm, warranting discomfort, pity, charity and concern'; the focus being on individual deficit and that disability is 'undesirable' with rehabilitation 're-inscrib(ing) notions of normal and abnormal ways of doing things'. They found that rehabilitation models assumed the need to 'fix' something which, from the client's perspective, may not be seen as 'broken', reflecting the continued tensions between the art and science of occupation which have been problematic for professional identity (see chapter 2.1).

### ***Post-social models of disability***

The social model has been the basis for the development of several models of disability, either as amendments to or a rejection of the original Oliver model. These include the affirmation and social relational models, and 'crip' theory which are outlined here. The affirmation model (or personal non-tragedy view) (Swain and French, 2000; Cameron, 2010) recognises that if the social model were to be applied throughout society, there may remain a perception of disabled people as tragic victims of their impairments (Hambrook, 2009) and that disabled people may still be patronised within society. Proponents of the affirmation model value difference and diversity, and have sought to have impairment accepted as part of an individual, both as positive and negative attributes. It challenges the roles disabled people may be obliged to take within society, as well as the barriers society creates which prevent disabled people from doing and being, and accepts 'impairment as an ordinary rather than an extraordinary characteristic of human experience, and for inclusion within ordinary life on that basis' (Cameron, 2010).

Influenced by feminist critiques of the social model, the social relational model revisited the social model suggesting that the original Union of the Physically Impaired Against Segregation (UPIAS)

document<sup>11</sup> implies greater emphasis on the interrelationships between the person and society (Thomas, 2004), and that the disabling impact of society on the individual extends to include psycho-emotional responses to both impairment and societal barriers. Thomas (2004, p.11) contends that the social model focuses too much on the public and ignores the private and personal. Proponents of the social relational model recognise the differences between disabled individuals, and that impairment itself has an impact which needs to be acknowledged, and therefore extends the definition of disability (Reeve, 2004) beyond the boundaries of the more orthodox proponents of the social model such as Oliver and Finkelstein (Shakespeare, 2004, p.16). Shakespeare (2004) questions whether a relational aspect within the social model could be redeemed; he argues that there may be little gain in breaking down the effects of impairment, societal barriers and oppression on an individual's feelings of distress (p.19).

Lastly, 'crip' theory took its name from the derogatory term 'cripple'. Crip theory's chief proponent McCruer (2012) refers to it as a 'will to remake the world, given the ways in which injustice, oppression, and hierarchy are built (sometimes quite literally) into the structures of contemporary society'. Crip theory challenges the view that the bodies of non-disabled people should be perceived as normal, perfect and/ or ideal, paralleling queer theory by appropriating the language of abuse, embracing stigmatisation and questioning the hegemony that 'straight' equates to 'normal'/ 'queer' as abnormal. In crip theory this equates to contesting the hegemony of non-disabled as normal/ disabled as abnormal, questioning notions of perfection and 'correct' function, and the positive acceptance of impairment (Löfgren-Mårtenson, 2013).

?DELETE PARA? The overt emphasis on independence may also be problematic, reinforcing a disempowering view of the human and potentially blinkering practitioners to alternative interdependent and cooperative or collaborative solutions to the barriers disabled people may face. Haraldsdóttir (2015) challenged my own notions of what are perceived as positive interventions to support disabled clients, particularly those undertaken to adhere to societal perceptions of 'normal' rather than the client; she terms surgical procedures undertaken during her childhood to make her 'look more normal' as 'beauty treatments' and the electric wheelchair which health professionals and her family saw as facilitating independence, she perceived as a frustrating liability.

Whilst disability studies and its 'big idea', the social model of disability, have been important milestones in changing attitudes towards impairment and illness, and changing perceptions of

---

<sup>11</sup> UPIAS was an early UK disability rights organisation founded in 1972.

impairment by recognising how people are disabled by society, despite the progress made through the social model and the increased acceptance of disabled people in the 'mainstream', both the medical and personal tragedy models remain dominant, particularly in healthcare. Whilst the social model remains an important move away from, and challenge to, dominant medical and personal tragedy models, the reality of the body and the impact of impairment on the lived experiences of disabled people is missing from the social model and I felt this impact, both positive and negative, should be acknowledged. Whilst I found 'crip theory' engaging with its underlying politic of empowerment and societal change, I also felt that it may be challenging for some disabled people to accept the positives of their situation in a normative society, and thus rather than empowering may inhibit their individual identity. The social relational model revisits the social model but advocates greater emphasis on the interrelationships between the person and society. This model extends the inter-relationship beyond the disabling impact of society on the individual with impairment to include their psycho-emotional responses to both the impairment and the societal impact. The social relational model recognises the private and personal as well as the public, acknowledges differences between disabled individuals, and the impact of the impairment. It also extends the definition of disability to encompass and empower all with an impairment or illness, temporary or permanent, congenital or acquired, and therefore can extend to occupational therapy clients in any setting. Adopting the social relational model acknowledges both the disabling impact of society whilst acknowledging the role of impairment body on lived experience.

Although both crip theory and the affirmation model are useful tools for examining the lived experiences of disabled people, they are less congruent with this study as the focus is the interaction between occupational therapists, clients and taboos rather than the lived experiences of disabled people and clients. For the purposes of this study I found the later development on the social model, the social relational model useful as it acknowledges the personal impact of impairment or illness on an individual whilst reflecting the principles of occupational therapy by recognising the interaction of the person, their illness or impairment, and disabling aspects of their environment and society. Therefore, it most closely related to the perspectives of the participants in this study as they negotiated the impairment and illnesses of the clients, their wants and needs, as well as the disabling impact of society.

### **Disabled people / client experiences of sex**

This section looks at the experiences of disabled people, as outlined in the literature. Although the primary foci of this study is the practice and attitudes of occupational therapy practitioners

regarding sexual concerns, client perspectives are fundamental to occupational therapy practice and therefore an examination of the literature discussing client's perspectives, their needs and wants and the challenges and barriers they face in accessing sexual occupations and activities is necessary.

### ***Barriers to sex: disempowerment and taboo***

The literature shows that disabled people/ clients are sexual beings who face significant barriers to fulfilling their sexual needs from societal and cultural attitudes, the physical environment and internalised attitudes, as well as from impairment and illness. Much of the literature focusses on disabled people and therefore this term is used to examine the perceptions of clients generally. The literature suggests that the sexual lives of disabled people remain on the margins; disabled people often lack support and access to sex, sexual expression and sexual health despite evidence indicating a demand exists and that access to those supports general quality of life, health and wellbeing. As the discussion in chapter 2.2 tracing perceptions of acceptable and unacceptable sexual conduct indicates, historically sex and sexual expression in western societies have been restricted by patriarchy and the dominance of heterosexuality as the 'norm' and all other forms of sexual expression deemed deviant or abnormal (Shakespeare, 2014). This section will look at both quantitative and qualitative primary research regarding the sexual expression of disabled people, focussing on physical disability. Key themes are the comparative lack of sexual knowledge and experiences of disabled people and non-disabled people, the lack of agency, choice and control in their sexual expression, the unacknowledged sexual needs of disabled people, and the barriers placed on disabled people's sexuality derived from social and cultural attitudes, the denial of formal and informal sex education, the physical environment, and the internalised attitudes of disabled people themselves.

Comparative studies tended to use quantitative approaches based on standardised and/ or Likert scales to compare disabled and non-disabled samples. Vansteenwegen *et al's* (2003) Belgian research compared disabled and non-disabled women's experiences of sexual expression. It found that disabled women have more negative attitudes towards sex, are less knowledgeable, have less sexual experience and are less satisfied with their sexual experiences than non-disabled women. Similarly, McCabe and Taleporos (2003) and McCabe (1999) also undertook comparative studies regarding experiences, knowledge and needs regarding sexuality and sexual expression. McCabe (1999) compares physically disabled, people with learning disabilities and non-disabled people's experiences and knowledge, taking into account whether the respondents' had received sex education - although the author acknowledges the nature or source of this education is not accounted for. The scale examines a variety of aspects of sexual life including friendship, dating and

intimacy, marriage, identification of body parts, sex/ sex education, menstruation, sexual interaction, contraception, pregnancy/ childbirth, sexually transmitted diseases masturbation and homosexuality) separated into measurements of knowledge, experience and needs of the respondents. McCabe and Taleporos (2003) also used a variety of standardised and Likert scales to examine various aspects of sexuality, sexual expression, body image and self-esteem comparing disabled and non-disabled men and women. These studies found results similar to those of Vansteenwegen *et al* (2003); McCabe (1999) suggests that in all areas of the scale used, physically disabled people have 'lower levels' of knowledge than non-disabled people, even in areas such as contraception which are emphasised in sex education programmes. Respondents with disabilities seemed to have limited access to sex education – only 50% experienced any form of sex education and of those who had they had received it from 'other sources' rather than family and friends, compared to the non-disabled population, who had predominantly received education from family and friends. This reinforces the findings of Shakespeare *et al* (1996) that disabled people can be excluded from discussions about sex and sexual expression in family life and with their non-disabled peers.

In terms of experience, McCabe (1999) found that disabled people have lower levels than non-disabled people in all the areas of the scale, particularly in dating/ intimacy and sexual interaction. McCabe (1999) suggests that the disabled respondents have higher levels of sexual need than in the non-disabled population, particularly in dating/ intimacy and experience, speculating that this may be due to lack of knowledge, lack of 'normalisation' of sexual expression and a lack of opportunity - although being quantitative the research did not provide further information to support this. Despite this, Shakespeare *et al* (1996) suggest that access to dating, intimacy and sexual interaction are seen as important for the interviewees in their research.

Several studies used quantitative methods including research instruments which are considered to be validated scales (for example, McCabe ,1999; McCabe and Taleporos, 2003, and Vansteenwegen *et al*, 2003), which arguably fail to record or measure more nuanced information or ascertain qualitative experience and feelings, wants and needs. They are also dependent on how respondents may have interpreted the quantitative categories presented to them. These more quantitative articles also tended to take more medicalised and heteronormative approaches, for example defining sexual experience in terms of intercourse and coitus, and failing to provide more nuanced information on individual experience, and the feelings and experiences which may lie beneath the responses of all the respondents, disabled or non-disabled. There are also tendencies in the

language of the studies to discuss the disabled people involved in terms of 'otherness'; McCabe (1999) referred to non-disabled people as the 'general population', whilst in McCabe and Taleporos (2003) the sample of disabled people is referred to as the 'experimental' group. This reflects the perceptions of participants in Bahner (2012), who indicate that disabled people feel they are 'living in an exclusive society where [there] is no place for people' who did not fit with normative ideas.

Vansteenwegen *et al* (2003) found no difference in the level of desire or fantasy between non-disabled and disabled women in their comparative study. These studies support the view that disabled people have the same sexual needs and desires as anyone else, and yet their needs and desires continue to remain unacknowledged or supported by HCPs. For example, Shakespeare (2014) discusses the experience of an interviewee who found her GP expressed 'shock and surprise' in her medical notes at her active sex life; generally professionals failed to value intimacy, focussing instead on medical aspects (Shakespeare, 2014).

Shakespeare *et al* (1996) indicates that opportunities for the sexual fulfilment for disabled people are limited, as are their choices. Accessing social opportunities could be challenging for disabled people due to physical barriers (Shakespeare *et al*, 1996) as well as receiving either unwanted or even offensive attention or by being 'openly ignored or dismissed' (Bahner, 2012, p.344). Santos and Santos (2017) indicate that there is a 'tendency to be portrayed as a child (helpless, vulnerable, naïve)' (p.314). Bahner (2012) suggests that disabled people could struggle for 'sexual recognition' (p.344), often lacking knowledge which led to low self-confidence, low esteem and limiting possibilities. For disabled people sexual expression remains controlled, often viewed in terms of asexuality, a problem to be medicalised or considered as too risky and dangerous (Shakespeare, 2014). Esmail *et al* (2009, p.1148) suggest that disabled people are seen as asexual due to 'predominant heteronormative ideas of sex and what is considered natural'. Even after the publication of Shakespeare *et al*'s (1996) landmark research on *Untold Desires: The Sexual Politics of Disability*, primary research continued to focus on negative and medicalised aspects of sex, for example individual sexual problems and sexual function (Shuttleworth and Sanders, 2010), rather than the broader issues of sexual expression within a disabling society. This indicates that the medical model has continued to prevail in the attitudes of health professions and the general non-disabled population in the intervening 20 years. Even with the wider acceptance of the social model in disability studies, the focus has remained on areas such as employment, education and society (Shakespeare *et al*, 1996). This omission of sexual expression and sexual politics in disability studies was initially challenged by feminist authors (Liddiard, 2014), who began discussing their own

identities and lived experiences of sexual expression with impairment, and recognised the significance of the oppression of sexual expression in disabled people's lives (Shakespeare, 2014). Although western societies have progressively become more tolerant of non-heterosexual or alternative sexual expressions since the latter 20<sup>th</sup> Century, disabled people remain oppressed and the early 21<sup>st</sup> Century pre-occupation with physical and emotional perfection could be said to prolong that oppression.

Shakespeare (2014, p.218) notes that society is fixated with views of 'asexuality or dangerous sexuality' instead of 'ordinary sexuality', promoted through media, education, health promotion of non-disabled people, disabled people and their families. He also perceives a tendency to discuss sexual expression in terms of vulnerability, protection and abuse. This may have increased as society has become more risk averse and where there has been greater publicity of cases of abuse. The literature reflects this concern; Sakellariou and Simo Algado (2006) found challenges to independence and compromises to identity (in their research, in the participant's sense of 'manhood', p.314), and social disapproval from being perceived as inappropriate in terms of dependence and family /sexual lives, whilst McCabe (1999) indicates there is resistance from caregivers to participation in their research who felt the content of the scale used was 'irrelevant' to the disabled respondents and may disturb them.

Socio-cultural barriers of stigma, assumed asexuality and lack of education are compounded by physical and environmental barriers to sexual expression. Shakespeare (2014) found access to sexual expression barred due to poor transport, poor access to work and public spaces, limited access to employment and education, and limited opportunities for privacy. For example, even post-Disability Discrimination Act, public transport can still be limited (there may be only room for one wheelchair user) and on transport chartered for people who are disabled there may be rules on allowing passengers which deny opportunities to develop relationships or ordinary casual experiences of sex which non-disabled people take for granted. Public buildings may provide access but social venues such as clubs and pubs may be more restricted. This is compounded by the lack of privacy or access to private space due to living in residential care, rehabilitation care or with the presence of PAs, family and/or carers (Shakespeare, 2014). Access to love, lust and sex are not rational and controllable in the same way as access to employment, education and public space (Shakespeare 2014), although access to the former can be impacted by the latter. Access to sexual expression is difficult to legislate for in the same way as other aspects of ordinary life. Emens (2009, cited in Shakespeare, 2014) describes sexual opportunities as 'accidents' relying as they do on access to

people and places. Being restricted in their access to social, cultural and physical space, disabled people's opportunities for sexual expression are limited.

Shakespeare *et al* (1996) found that disabled people are often barred from sexual expression and sexual aspects of ordinary life. They are excluded from ordinary sexual 'chat' with peers, do not receive informal sexual education from family and receive persistent negative images and representations of disabled people, often subject to assumptions that aspects of sexual life from attractiveness and presentation to pregnancy, reproduction and family life are 'taboo', unattainable or to be avoided (Shakespeare, 2014). For example, Esmail *et al* (2010) suggest that stigma and lack of education underline socio-cultural barriers to sexual expression. This reinforces the view that either the disabled person is not interested or able to partake in sexual expression, unlikely to be sexually active (Esmail *et al*, 2010; Howland and Rintala, 2010) or that they must be protected from harm (Shakespeare, 2014).

These barriers could be further compounded for disabled people who are also LGBT and/ or from an ethnic or racial minority group. Drummond and Brotman (2014) suggest a growing acknowledgement of the challenges of accessing sex and sexual expression for LGBT disabled people who are subject to normative assumptions combined with heteronormative attitudes. Fraley *et al* (2007, p.17) suggest that LGBT disabled people 'come to the sexual arena with a host of social constraints' as multiple identities converge to complicate access. Difficulties could arise from the lack of 'positive sexual role models, meeting sexual partners and locating resources' (Fraley *et al*, 2017, p.17). Drummond and Brotman (2014, p.534) suggest they are at increased risk of health disparities and disengagement which result from concerns around disclosure to HCPs and 'because of the intersection of both marginalised identities'. Disabled LGBT people experienced 'multiple sources of discrimination, barriers to participation within minority communities and challenges of intersecting affiliations (Drummond and Brotman, 2014, p.535), leading to feelings of not fitting in (Shakespeare *et al*, 1996).

It is no surprise then that these socio-cultural and physical barriers along with negative messages due to lack of discussion in formative years, exclusion from education, exclusion from peer sexual discussion, protection from sexual aspects of growing up, and lack of media representation of positive images of disability and sexuality have led to many disabled people internalising negative feelings about their bodies and their sexuality. Liddiard (2012, p.10) found that disabled people have been bullied, abused, ridiculed or humiliated in their sexual and intimate experiences; at best



disabled people have been excluded or assumed to be asexual, adding further to internalised feelings of being less than others, devalued and of low self-regard. In her qualitative research, Liddiard (2012) suggests that disabled people are 'significantly disempowered by sexual norms' derived from 'media, culture and science' (p.7); interviewees in her qualitative study internalised these as norms, making them feeling 'sexually inadequate'. McCabe and Taleporos (2003) found that people who perceive their disability to be more severe are less likely to be in a relationship, married or have a partner. Being single correlates with a higher need for assistance or higher level of objective indications of severe physical disability, suggesting a physical disability limited opportunities to form intimate relationships. McCabe and Taleporos (2003) suggest this may be due to stigma or the perception of burden on the part of potential partners. Santos and Santos (2017, p.314) indicate that internalised feelings of stigma manifest in 'shame, fear of abuse, the postponement of sexual life'.

### **(Re)Claiming ordinary sex lives**

Although, as outlined above, there are many negative aspects of disabled people's sexual experiences of disregard and rejection (Peta *et al*, 2015), omission and marginalisation, the literature also indicates positive stories of agency, and disabled people creating spaces and claiming sexual lives, often 'redefining' (Sakellariou and Simo Algado, 2006, p.314) themselves and their sexuality, accepting the loss of spontaneity and changing their relationships with their bodies by putting aside internalised normative assumptions. Despite the complex relationships between social, physical, psychological and internalised barriers, research also documents attempts by disabled people to retain or regain agency and sexual expression, either by adapting, creating individual sexual scripts outside traditional cultural roles or by attempting to normalise to dominant heteronormative views, with individuals attempting to create their own sexual identities and space for sexual expression (Shakespeare *et al*, 1996; Taylor, 2011; Liddiard, 2012 and 2014, Kattari, 2014).

Both Kattari (2014) and Liddiard (2012) suggest interviewees are conflicted in their attempts to create sexual identities; some sought to normalise whilst others embraced their impairment as part of their sexuality. Several disabled people worked to maintain a façade of apparent normalisation and of fitting in with the dominant ablest society around them, which Liddiard (2012) describes as creating further oppression and disablism. Liddiard (2012) found those who challenged these norms finding liberation and pleasure yet also feelings of shame and abnormality (p.8). Some disabled people perceived themselves as defined by their disability (Kattari, 2014). Santos and Santos (2017) indicates some disabled women 'did not portray or consider themselves passive victims' (p.314), despite experiencing stigma in the attitudes of family, friends and HCPs, and found disabled people

were challenging normative assumptions, countering norms and expectations and struggling for 'sexual and reproductive fulfilment and recognition' (p.315). Drummond and Brotmond (2014) indicate that 'agency and resistance' are important in the identity of their participants and for challenging social and cultural norms.

Liddiard (2012) suggests that normalisation is a double-edged sword, demonstrated by attitudes to intimate relationships. On the one hand, relationships are seen as a means of self-validation, the reassurance of self-worth and a challenge to ableist perceptions of asexuality; it is a symbol to others of being like non-disabled people or of being 'normal' – both challenging and fitting in with the non-disabled world. However, several disabled people suggested this led to 'putting up with' unfulfilling relationships and infidelity in order to remain in a relationship. Those with congenital disabilities internalised that sex and relationships were unobtainable to them from the attitudes of family, whilst others with acquired disabilities maintained relationships with people they are not attracted to believing that this to be the 'only opportunity for a relationship', the alternative being 'isolation and loneliness' (Liddiard, 2012, p.12). Women describe attempting to counter-balance feelings of being less sexually attractive or feeling sexually inadequate due to their impairment by feeling obliged to undertake sexual acts they did not particularly enjoy or offering partners' opportunity to be unfaithful. Liddiard (2012) also describes tensions when a partner is also a carer, leading to disabled people often putting up with poor, incorrect or unsatisfactory care in order to preserve the relationship or avoid conflict. These feelings of being reluctant to create conflict are also found by Howland and Rintala (2010). Even those who identified their disability as a positive defined their disability in a negative way in relation to sexual experience at some point (Kattari, 2014).

Liddiard (2012) challenged the social model within sexuality as she found that impairment played a significant role in the participants' thoughts and feeling, and has a practical impact on sex and sexual expression. Although some, like participants in Kattari's (2014) research, have found ways around their impairments or found impairment enhances their sexual expression and experiences. Kattari (2014) suggests that the importance of the partner, communication, negotiation and confidence are important in disabled people's exploration of sexual expression. Her US research found that disabled people used negotiation and creativity learnt from exposure to 'kink' experiences (Kattari, 2014) which involve what is perceived as alternative or 'marginalised' approaches to sex (for example, sado-masochism) gave disabled people greater honesty and confidence in their attitudes to sex and sexual expression. Although it should be noted that, as the author acknowledges, there is an unintentional sample bias towards people who are 'kink-identified' (Kattari, 2014). The

experiences of disabled people who are exposed to alternative sexual lifestyles suggest it leads to increased communication, openness and honesty, in turn leading to increased sexual satisfaction (Kattari, 2014). 'Kink' aids communication due to the need for clarity in negotiating and obtaining needs and concerns (Kattari, 2014). Although, it could be argued that the interviewees may need to be more open with partners due to their impairment and this may be easier with partners who have more experience in 'kink' sexual experiences and therefore were more open in terms of negotiating and discussing needs and concerns clearly. Non-disabled people may have learnt these negotiations through exposure to ordinary sexual discussion and experience, to which disabled people had been largely excluded. For the interviewees in Kattari's (2014) research, many found that 'kink' experiences provided an alternative to ordinary sexual discussion.

Despite the barriers disabled people have experienced in exploring their sexual expression and identities and feelings of being viewed as less 'whole', disabled people have sought to reclaim their sexual expression and re-define their sexuality, for example disabled men liberated from 'macho' socialisation had created alternative masculinities, and women exploring different practical ways of sexual expression and sexual experience (Shakespeare, 2014). This could be seen as a 'crip-oriented' response to challenges to sexual expression; challenging traditional roles of masculinity and femininity, a distinct disabled sexuality as 'ordinary' yet different which moves on from the social model of disabled sexuality and normalisation by acknowledging both barriers from society and the barriers created by impairment, and creating alternatives. Plummer (1999, cited in Shakespeare, 2014) advocates that 'intimate citizenship' - meaning choices, access and control regarding all aspects of sexual expression, access to public, social and cultural space and control regarding experiences, identity and attributes - should run concurrent with civil, political and social rights. This may help remove some of the social and physical barriers which disabled people are faced with, however internalised barriers may be more difficult to overcome.

### **Summary: Disability theory and disabled people / clients' experiences of sex**

This section looked at disability and impairment from two perspectives; the theory that underpins how disability is perceived within society including how dominant medical models have been challenged by disabled people, and the reality of disabled people's lived experiences of accessing sex and sexual expression. Theory has influenced how disabled people are seen – despite the acknowledgement that medical and personal tragedy models are reductive and disempowering, the experiences of disabled people indicate their lives are still subject to these dominant normative ideas around asexuality, vulnerability and risk, subject to physical, social, financial and attitudinal barriers. Despite this, disabled people themselves have sought ways to re-write these dominant sexual scripts,

seeking ways of challenging or working around societal and bodily barriers, reflecting the social relational model which underpins this research.

Disabled people face significant barriers to engaging in sexual expression, sexuality and intimacy (see figure 8 below). For disabled people the issue is not whether they could be sexually active but that they are often denied the opportunity to express themselves sexually due to the external and internal barriers preventing them from doing so (Shakespeare, 2003).

**Fig 8 – Barriers to disabled people’s access to sex and sexual expression**

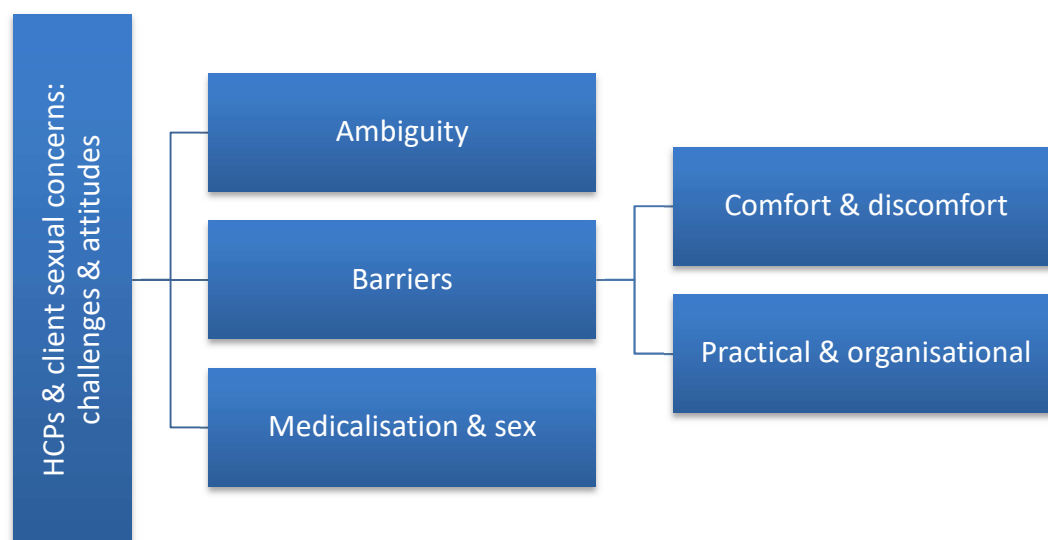


Disabled peoples sexual expression is impacted by a sense that they have had control of their bodies taken away; denied agency they are excluded from the physical, cultural and social spaces where sex and sexual expression are explored, whilst they are rarely represented as ‘positive and sexual beings in everyday culture’ (Shakespeare, 2014, p.213). The experiences of disabled people provide important context to this study, showing that disabled people are sexual beings who are being denied an important, meaningful aspect of their lives, one which they would like to access and

which, as indicated in chapter 2.1, one which can be described as an occupational concern. The following section looks at some of the reasons why sex and sexual concerns continue to be omitted in healthcare.

## 2.4 Occupational therapists, healthcare professionals and client sexual concerns

This section examines the literature looking at attitudes and experiences of occupational therapists and HCPs generally (focussing on AHPs and nurses) when broaching sexual concerns. This is relevant to the study as it uncovers the barriers and facilitators faced by occupational therapists, providing context for why sexual concerns are often seen as challenging and often omitted or ignored. The literature reviewed is a mixture of qualitative and quantitative research looking at the attitudes and experiences of practitioners and students. Due to the limited literature in this area, older research has been included which specifically focuses on occupational therapists as well as literature on nurses, other AHPs<sup>12</sup> or HCPS generally. Previous research often focusses on specific areas of pathology, patient group, diagnosis or dysfunction (for example, stroke or older people – Mellor *et al*, 2013; McGrath and Lynch, 2014), a geographical locale or a specific professional group (for example, nurses). Several articles focus on the attitudes of nursing staff, with limited research specific to occupational therapy, physiotherapists and speech and language therapists - although these professional groups are referred to in more general research.



### Ambiguity

There is a strong indication of ambiguity between the attitudes and the practice of HCPs in relation to client sexual expression, as well as institutional ambiguity regarding policy and responsibilities. Haboubi and Lincoln (2003), Vershuren *et al* (2013) and a systematic review by Dyer and Das Nair (2013) found that HCPs feel sexual expression is important, that it is part of their professional

<sup>12</sup> Allied Health Professionals

responsibility (Vershuren *et al*, 2013), that sexual expression should be recognised in order to view the client as a whole person and that sexual concerns may be a symptom revealing other medical problems (Saunamaki and Engstrom, 2014). Quantitative research by Haboubi and Lincoln (2003) suggest that 90% of HCPs agree that sexual expression should be addressed as part of the holistic care of a client but only 66% are prepared to address it. This research was undertaken within a small geographical area in the UK and little detail on obtaining the sample participants is given. Being quantitative, this research only provides a statistical snapshot and does not provide an explanation. Dyer and Das Nair (2013) systematic review of qualitative research suggests that the majority of participants feel it is important to discuss sexual concerns but did not routinely address them.

As indicated in chapter 2.1, within occupational therapy both Couldrick's (1998) and Parkin's (2013) research found that occupational therapists consider sexual expression important, however their research pointed to what Couldrick (1998) refers to as a conflict between 'ideology and practice' whereby practitioners recognise sexual expression as an occupation and an important aspect of practice yet feel either uncomfortable or lacked the competence to discuss it. Only half of the respondents included sexual expression in their assessment of clients, a quarter routinely and this appeared to be dependent on the setting (Couldrick, 1998). Parkin's (2013) quantitative survey of occupational therapists found that 87% feel it is a valid domain of occupational therapy yet most never broached the subject. This dichotomy between ideals and practice is also found regarding other health professions, for example Saunamaki *et al*, (2010) found that 66% of nurses feel it their responsibility yet 80% of them did not make time to discuss it. Later qualitative research (Saunamaki and Engström, 2013) suggests that most nurses feel broaching sexual concerns is their responsibility, with nurses describing an 'inner battle' between what they should do and what they wanted to do. However both these articles are focussed on relatively small samples within a specific Swedish hospital. The dichotomy between ideals and practice did not appear to be affected by the gender of the participants; Dyer and Das Nair (2013) indicate the gender of HCPs is not a barrier in their systematic review of eight articles, however in much of the research examined for this literature review the participants are predominantly female which may have had an impact on the results and limits the generalisability.

For many HCPs there is a lack of clarity regarding who should take responsibility for addressing sexual concerns. In Mellor *et al*'s (2013) research into the attitudes of staff working within a stroke team, the acute staff indicate it is not within their role or remit whereas community staff suggest it is up to the client to raise the issue - although they indicate they try to build rapport in order to ensure the

client could feel comfortable in doing so. This research suggests that staff working for the *Stroke Association* were more likely to discuss the issue. Haboubi and Lincoln's (2003) survey found respondents feel that nurses, doctors and clinical psychologists are best placed to do discuss sexual issues, whereas few feel it is the remit of therapy staff such as occupational therapists. This may reflect the tendency of HCPs to view client concerns in terms of a set of dysfunctions which need to be fixed (Mellor *et al*, 2013) rather than a concern linked to occupational factors such as meaning and identity. Couldrick (1998) found that addressing sexual concerns are not attributed to any particular professional group and as a result are either shared or ignored. The occupational therapist participants in Couldrick's research indicate a lack of clarity regarding where their roles began or ended in relation to sexual concerns, although they felt it appropriate for occupational therapists to address it rather than being the remit of a sexual specialist. However as this research is based on semi-structured interviews around a specific location it could be said to lack generalisability. Yallop and Fitzgerald (1997) found Australian occupational therapy students and early career occupational therapists lacked clarity regarding their role around sexual concerns. This ambiguity regarding whose responsibility may contribute to its omission in healthcare practice.

Aside from a lack of clarity regarding roles and responsibility, HCPs perceive a lack of demand from clients regarding addressing sexual expression and presume that sexual issues are a low priority. Haboubi and Lincoln's (2003) survey found that 57% of the respondents had not been asked about sexual issues within the previous 12 months, whilst Verscheren *et al*'s (2013) participants perceived a lack of demand or concern on the part of the clients, and Mellor *et al* (2013) found that participants thought clients rarely raised the issue until after discharge, making assumptions that sexual concerns are not a priority. Conversely, qualitative research into client perspectives of sexual aspects of rehabilitation by Northcott and Chard (2000) based on the views of seven interviewees found that six felt that their condition affected sexual function but only two received advice from a health professional, both having sought that advice. Although one of the client respondents felt that they should not receive advice from a health professional as it was a private matter, the remaining four believed they should either receive or be offered advice, or be directed to where to seek advice from if required. Five of the interviewees felt it should be discussed as part of rehabilitation and preferred it if the HCP broached the subject first. However the interviewees did not expect that sexual aspects should be addressed nor 'consider(ed) it to be a right' (Northcott and Chard, 2000, p.417). Taylor (2011) also found that sexual concerns of clients with Motor Neurone Disease were not addressed by occupational therapists or any other HCP. This perception of low demand for support runs



contrary to the findings of the previous section, which suggests that disabled people have unmet sexual concerns which should be acknowledged.

Several qualitative research articles provide insights into the barriers and facilitators HCPs identify in their practice. These can be seen as internal, affective factors such as the feelings and attitudes of the HCPs or external, institutional factors such as policies and procedures, time and space, and the dominance of a biomedical approach, as well as societal perceptions of sexual expression, illness and impairment.

### **Attitudinal barriers**

Discomfort and embarrassment regarding the discussion of sex and sexual expression is found in all the research regardless of professional group, specialty and geographical location (Yallop and Fitzgerald, 1997; Couldrick, 1998; Verschuren *et al*, 2013; Saunamaki and Engstrom, 2014). Jones *et al* (2005) found high levels of discomfort reported by occupational therapy students although due to the quantitative nature of their research, no context or variables are given to explain why this discomfort is prevalent. Stead *et al* (2002) observed that some participants appeared uncomfortable discussing the topic even during focus groups, suggesting discomfort in discussing the topic is not exclusive to client interactions; other research suggests that sex and sexual expression are not discussed with colleagues (Saunamaki and Engström, 2013) nor with the wider Multi-disciplinary team (MDT) (Verschuren *et al*, 2013) either formally or informally. East and Orchard (2014) found fear and anxiety in approaching the issue, although this research is centred on a service for adolescent clients in Canada, where the age of the clients and the sensitivity of carers and parents may have added to the discomfort in discussing sexual issues. Gott *et al* (2004, p.528) and Dyer and Das Nair (2013, p.2658) found some HCPs regard discussing sexual expression as a 'can of worms', reflecting the sensitivity of the subject

Embarrassment and discomfort regarding sex could be seen to arise from sexual scripts based on individual and societal perceptions of sex and sexual expression, taboos and stigma, value judgements, a fear of being misinterpreted and perceived inappropriate client behaviour, which add further to the affective barriers to exploring sexual expression with clients. Yallop and Fitzgerald (1997) undertook qualitative research on the comfort of student and early career occupational therapists based on responses to scenarios, measured using a Likert scale. They suggest that the participants are less comfortable with scenarios outside what could be perceived as a 'normal' range of their perceived experience, based on personal attitudes or societal and cultural norms (Yallop and Fitzgerald, 1997). For example, participants expressed personal discomfort with scenarios which

related to pre-marital sex, masturbation or non-heterosexuality. They are more comfortable with scenarios which require practical, 'common sense' or straight-forward responses. This research may be flawed due to possible respondent bias with the participants providing views they feel may be correct rather than being honest, and the use of a quantitative Likert scale applied to qualitative and difficult to objectively define data (such as level of comfort) means that respondents may have given differing scale points to their perceived level of comfort. Despite this, respondents admit to their discomfort with scenarios outside the 'norm'. This may be a reflection of the practical, problem-solving orientation of the occupational therapy profession rather than the level of discomfort with the context of a scenario, particularly for an early career or student occupational therapy who may lack a broad range of experience to draw on. Jones *et al* (2005) also found that experiences that fell outside 'usual' client/ clinician activity evoked discomfort in their quantitative research using a standardised measure of comfort and a range of situations, however, despite the apparent objectivity of a standardised measures such as Comfort Scale Questionnaire (Cohen *et al*, 1994 in Jones *et al*, 2005) or the Sexual Attitudes and Beliefs Survey (SABS - Reynolds and Mangan, 2005 in Saunamaki and Engstrom, 2014) it can be difficult to quantify qualitative feelings such as comfort, and it provides little nuanced explanation on what causes discomfort. As Jones *et al* (2005) suggest, the concept of comfort is complex. McGrath and Lynch (2014) note that occupational therapists sometimes use a narrow interpretation of sex and sexuality often limited to orientation and tend to respond to sexual concerns around behaviours rather than from an occupational standpoint (p.656).

Knowledge and experience are identified as facilitating higher levels of comfort in discussing sexual concerns (Yallop and Fitzgerald, 1997). Couldrick (1998) notes that comfort, attitudes and competence in relation to sexual concerns seem to improve with age and with education and training, indicating that age and experience could lessen discomfort (Haboubi and Lincoln, 2003). Saunamaki *et al* (2010) suggest that older nurses feel more confident in their ability to discuss concerns with clients. This increased confidence may be due to increased self-awareness in the individual HCP, increased self-knowledge and life experience. Yallop and Fitzgerald (1997) suggest that self-awareness could mitigate the impact of societal and cultural 'norms' as well as personal attitudes of the respondents. They feel this knowledge and experience could increase comfort in discussing sexual concerns by giving an occupational therapist more control over the situation and an improved ability in considering client needs and wants based on that therapists' personal life experiences and attitudes.

Several articles indicate a tendency in HCPs towards making value judgements on whether a client

may be sexually active. Saunamaki and Egstrom (2013) suggest that nurses are less likely to discuss sexual expression with older people or with people who are immobile, considering the clients to be 'too ill' or 'too old', with the systematic review by Dyer and Das Nair (2013) suggesting that a minority have ageist, racist or homophobic attitudes. East and Orchard (2014) suggest that some HCPs found it challenging to balance maintaining the independence of their clients and the recognition of the client as a sexual being, set against the client's medical complexity and potential physical fragility. HCPs are particularly uncomfortable with broaching matters pertaining to sex and sexual expression with clients from minority or ethnic backgrounds (Dyer and Das Nair, 2013) with one participant expressing surprise when a client of Pakistani background was willing to discuss sexual issues, reflecting the social and cultural assumptions that can impact on healthcare practice (Gott *et al*, 2004 in Dyer and Das Nair, 2013). McGrath and Lynch (2014) suggest cultural-based barriers in the decision-making regarding the inclusion of sex impacted by dominant social norms and expectations around age and sex /sexuality.

The literature identified concerns HCPs have about the impact of discussing and addressing sexual expression on the relationships and rapport they have with their clients. Couldrick (1997) found that occupational therapists fear damaging the relationship with their clients and their carers, whilst McGrath and Lynch (2014) note that occupational therapists working with older clients fear causing embarrassment or offence. This concern is also identified in other HCPs by Mellor *et al* (2013), East and Orchard (2014) and McCabe and Holmes (2014). Dyer and Das Nair (2013) suggest that this may be a perception based on anecdote rather than a common occurrence, referring to a team member had been told to 'mind their own business' when the issue of sexual expression was addressed but it was unclear whether this was a regular experience. Saunamaki and Engström (2013) suggest nurses are concerned about sparing their client's feelings whilst Mellor *et al* (2013) indicate that HCPs in stroke felt there may be a potential negative impact on their clients. Both Couldrick (1998) and Saunamaki and Engström (2013) found that nurses and occupational therapists feel the subject to be 'taboo', reflecting that this barrier remains across geographical locations.

There are also indications that some HCPs are concerned about the potential for inappropriate client behaviour; one participant in an exploration of attitudes to sexuality within community and acute stroke services in a UK area perceived client manipulation or 'grooming' of a healthcare assistant (Mellor *et al*, 2013), other participants in this research feel that the loss of inhibition which can be a result of stroke may lead to inappropriate behaviour. Jones *et al* (2005) suggests there may be issues regarding inappropriate sexual behaviour by clients, which may explain high levels of discomfort in

their participants. Perceived inappropriate behaviour on the part of a practitioner is also a concern, expressed by a participant on Canadian research regarding a community service for adolescents with physical disabilities (East and Orchard, 2014); being male the practitioner expressed concern regarding being misconstrued and the social stigma of being a man working with children. Couldrick (1998) also found that some occupational therapists express concern about misinterpretation, distortion or manipulation.

The literature indicates several attitudinal barriers to the broaching of sexual concerns which appear homogenous across a wide range of professionals, including occupational therapists, in a variety of settings and geographical locations. These barriers include feelings of discomfort around discussing sex, concerns around the impact on rapport and relationships with clients, fears around inappropriate behaviour, and judgements and assumptions around disability and the priorities of the client, and to a lesser extent around age and race. The literature indicated that these barriers could be mitigated by greater knowledge and experience in broaching sexual concerns which helped overcome discomfort and embarrassment.

### **Structural/ material factors**

Several structural barriers are identified by participants in the literature including insufficient support, policies and procedures (locally or nationally), the lack of specialist provision or referral pathways and issues around lack of time, space and privacy (Dyer and Das Nair, 2013; Couldrick, 1998; Saunamaki and Engström, 2013). Dyer and Das Nair (2013) note that the HCPS suggest a comfortable environment is required for the client to raise the issue themselves, however this places the onus on addressing concerns on the client. Mellor *et al* (2013) found that even when sexual concerns are included in assessment documentation, it is often omitted due to time constraints.

A lack of education and training in issues relating to the sexual concerns of clients is identified as an important barrier to addressing issues (Couldrick, 1998; Mellor *et al*, 2013; Saunamaki and Engström, 2013; McGrath and Lynch, 2014). Haboubi and Lincoln (2003) found that 86% of their respondents have had little or no training; of those who had 46% felt it improved their knowledge and practice, 27% felt it improved their knowledge only and 20% felt it made no difference. Being quantitative the survey provides no description of the training provided and as the respondents were from an array of HCPs the training undertaken may have been provided from a variety of sources. East and Orchard (2014) found their participants felt unprepared and misinformed regarding the 'correct' provision of information. This concern is also reflected in the systematic review by Dyer and Das Nair (2013) which found HCPs felt ill-equipped to follow up should concerns arise. In their review, education and

training is discussed in all 8 articles reviewed and is seen as a potential facilitator to overcome these concerns, but the reviewed articles also identified barriers to training such as a lack of time and resources. Saunamaki and Engström (2103) suggest that nurses are unsure how to broach the subject of sexual expression with clients whilst Jones *et al* (2005) found occupational therapy students lack information on different client groups and issues with regards to sexual concerns. Mellor *et al* (2013) also found a lack of awareness of resources. Saunamaki *et al* (2010) found those who have received further education are more positive about addressing sex and thought that further education and guidelines would help them address sexual issues.

The literature reveals that there appears to be a lack of institutional support in relation to sex and sexual expression reflected in the lack of clarity regarding roles and responsibilities and the apparent lack of institutional support in terms of policy, procedure, resources, client records and referral pathways. This discouraged the inclusion of sexual concerns. Saunamaki and Egstrom (2013) found that nurses perceived a lack of support regarding sexual expression but suggest that when highlighted as a legitimate concerns as an entry in electronic client records, nurses are more likely to ask their clients about their sexual concerns. Dyer and Das Nair (2013) and Mellor *et al* (2013) found no local policies on sexual expression whilst their respondents expressed a need for such policy guidance. McGrath and Lynch (2014) found limited resources for broaching sexual concerns. Mellor *et al* (2013) also note a lack of specialist provision, resources and a lack of formal support or referral pathways. Couldrick (1998) found that occupational therapists felt there is inadequate support and supervision, and expressed concerns about legal issues.

Previous research indicates the dominance of a biomedical approach within the practice of HCPs in relation to sexual expression, with the focus on basic care (Mellor *et al* 2013) and dysfunction (Couldrick, 1998) despite the recognition that sexual issues as important in the holistic care of clients. This is expressed particularly by occupational therapists (Couldrick, 1998) and nurses (Saunamaki and Engström, 2013). Both Couldrick (2007) and East and Orchard (2014) found that clients are concerned with not only the functional and practical implications of their impairment, disease or disability but sought social and emotional support. East and Orchard (2014) suggest that HCPs need to gain an understanding of the misconceptions, anxieties, knowledge and confidence of the client.

Despite the heterogeneity of the research – a wide mixture of approaches with few similarities in sampling and method - the findings of research in this area are extremely similar. Overall the

research gives a negative picture of occupational therapy and HCPs generally regarding addressing sexual concerns. Arguably, this may be due to a tendency to accentuate the negative; as Dyer and Das Nair (2013) suggest it is not clear whether this may be due to examples of good practice not being found or not reported in the research rather than sexual concerns being persistently omitted and ignored. However, the literature extensively indicates sexual concerns create discomfort, embarrassment and difficulty by many HCPs, leading to the omission of sexual concerns for a host of attitudinal, practical and institutional reasons, and ambiguity around what HCPs wish to do and practice, and this pervasive omission was reflected anecdotally and in the experiences of myself and my cohort during pre-registration education..

## **Taboo, stigma and healthcare**

Feelings of discomfort and embarrassment may derive from cultural scenarios around sex but may also be derived from taboo and stigma around illness and impairment and around the lives of clients. This may impact on occupational therapists and HCPs, as well as in the internalised attitudes of clients themselves. The impact of stigma and taboo on individuals has increasingly been seen as a healthcare issue, particularly around mental health and HIV (Mind, 2017; Terrence Higgins Trust, n.d; National AIDS trust, 2016), but also taboo and stigmas have been associated with client groups (for example homeless people, Roma), and other aspects of healthcare such as end of life care, reproductive health, sexual health, HIV and STIs, conditions affecting certain parts of the body (for example bowel, prostate), disabled people, or issues such as self-harm, obesity, anorexia, dementia, incontinence and sex in care/ nursing homes. These were concerns which invoked discomfort due to associations with difference or 'otherness', metaphoric or actual 'dirt', death or sex. Green (2009, p.5) suggests that sickness and disability challenge 'normal' society by being seen as:

- unfortunate / tragic
- useless /unproductive
- different
- oppressed /marginalised
- sick and suffering

Any associated stigma may be derived from blame, deviance, threat / danger (for example infection/ contagion) or difference, anything which deviated from the healthy 'norm'. Shiloh *et al* (2011) notes that attitudes towards impairment or illness could be impacted by their visibility and / or the cause, with impairment caused by injury eliciting a more positive attitude than those caused by illness, suggesting a hierarchy of acceptable 'impairment' (Tringo, 1970; Corrigan *et al*, 2000; Deal, 2003). Tringo's (1970) research indicates that non-disabled people's 'least preferred' impairments are learning disability, mental illness and alcoholism whilst the most preferred are ulcer, arthritis and

asthma. Deal (2003) suggests this hierarchy has remained stable within Western society in the intervening period; Thomas (2000) repeated this study and found only cancer had moved further up the hierarchy. Deal (2003) suggests that this hierarchy exists for both disabled and non-disabled people, reflecting the stigma attached to certain conditions. Although much of the literature focussed on client experiences of stigma and taboo, they may also lead to a sense of 'dirty work' in perceptions of and attitudes towards clients (see chapter 2.5).

A person may be stigmatised by others or they can internalise the stigma. Larsson and Grassman (2009) suggest that illness and impairment impact on identity disrupting self-perception and leading to a loss of self, changing or vanishing roles, a sense of dislocated identity (that is, the person not knowing who they are anymore) and a sense of marginalisation as others take over their roles. This is related to physical changes and leads to isolation. Illness and impairment lead to a 'biographical disruption' whereby a persons' narrative is forced to change, disrupting patterns, lifestyles and the persons' worldview, and requiring 'narrative reconstruction' whereby the person rebuilds who they are around their post-illness/impairment reality (Green, 2009). Stigma can be seen to affect the lived experiences of clients and may lead to social oppression, discrimination, exclusion from social structures and marginalisation. Green (2009, p.31) suggests that an 'understanding of stigma must take account of power differentials as these are a prerequisite to stigmatisation'. This view has been criticised for reinforcing a personal tragedy view of illness and impairment, and failing to recognise how 'disruption' to the self and how the person sees themselves may be impacted by barriers placed on them by a disabling society, and medicalised attitudes to illness and impairment (Green, 2009). Link and Phelan (2001) suggest that power and hegemony are key ingredients in the production of stigma (p.29). People who are stigmatised are considered to have lower 'social value', therefore access to opportunities are restricted and they are deemed 'less entitled' to resources (Link and Phelan, 2001, p.27).

## **Medicalisation and sex**

The inclusion of sex and the attitudinal and organisation barriers faced when broaching sexual concerns has arguably been impacted by medicalised approaches to sex. The history of sex and sexuality outlined earlier in chapter 2.2 underscores the ebbing and flowing dominance of essentialism (figure 5 in chapter 2.2). Tracking the influence of essentialist to constructivist conceptualisations, attitudes to sex within healthcare have shifted from medicalisation, to de-medicalisation in the mid-20<sup>th</sup> century to re-medicalisation and these have impacted on how sexual concerns have been considered and managed. Cacchioni (2015) suggests the Enlightenment expansion of practice (and incomes) by physicians led to the formation of medical profession

associations, the legal barring of women from the use of developing technologies, new technologies giving the impression of progress, and the shift from treatment and interventions at home to hospitals (for example, births) as hospitals became seen as safer. This ran parallel with the biological determinism of sexology of the late 19<sup>th</sup> century /early 20<sup>th</sup> century and the popularising of essentialist Freudian / psychosexual development models which underpin the medicalisation of sexuality. This shift towards medicalisation led to behaviours seen as immoral or unnatural being labelled as diseases or disorders; dysfunction became pathologised, medicalised and treated accordingly (Evans, 1998). It also led to the categorising of perceived disorder, for example systems of medical and legal sexual benchmarking which measured and rated what is 'normal' and appropriate, against which people and their bodies are measured, 'their inadequacies hopefully rectified by exercise, diet or plastic surgery' (Evans, 1998, p.3). Cacchioni (2015, p.435) suggests there has been 'classification, treatment and monopolisation' over 'deviance', reproduction and sexual functioning. From the mid-late 20<sup>th</sup> century, feminists and other grassroots movements challenged this medicalisation which they saw as maintaining inequality, with the male-dominated medical profession exercising power over women's bodies and health, and pathologising non-heterosexual people (Cacchioni, 2015). Although purporting to be scientific and objective, medicalised approaches have been subject to change under the influence of 'social, political and economic factors' (Cacchioni, 2015p.435) and as a result perceptions of sex and sexuality became de-medicalised.

Despite this later de-medicalisation, those experiencing sexual difficulties often sought (and continue to seek) medical help (Roberts, 2006, p.68). Jackson and Scott (2004, p.241) suggest that sex and sexuality has become an arena where individuals feel they must strive for perfection, leading to mental management and a constriction of liberation where sex must be perfect and, if not, denotes failure as a human being. Sexual fulfilment becomes 'a life goal in itself and a key to personal happiness' (Jackson and Scott, 2004, p.241), leading to increased re-medicalisation to 'fix' perceived problems. This has two dimensions; that sexuality is 'innate, objective, measurable and physiological - something to be diagnosed as functional or dysfunctional', and fix-ability – that perceived problems may be corrected or cured through surgery or chemistry. Cacchioni (2015) suggests the rise of what she describes as bio-medicalisation. For example, although de-medicalised in later editions of the DSM, there was a return to essentialist approaches with regards to homosexuality in the late 20<sup>th</sup> century with the much publicised but ultimately refuted discovery of the 'gay gene'; an idea which - despite being refuted – seems to have remained within elements of popular culture (p.439). The current DSM (2013) has reduced 'paraphilic disorders' so that mental



illness can only be indicated when the individual feels 'personal distress' not just 'distress resulting from society's disapproval' (Cacchioni, 2015, p.439), although there is debate as to whether any sexual activity between consenting adults should be listed as 'paraphilic'. This approach also seems to have disassociated 'personal' distress from societal disapproval.

From the late 20<sup>th</sup> century to date there has been a growth in bio-medicalisation or re-medicalisation based on genetic / pharmacological 'discoveries' and increased commodification of solutions to 'dysfunction'. This has coincided with a neo-liberal orthodoxy which places the onus on the individual as both source of 'dysfunction' and arbiter of answers, either in their choices or lifestyles, or the source of 'dysfunction' due to genetic / pharmacological determinism (for example, chemical imbalances as causal factors in dysfunction), a narrow idea of what is 'normal' and attractive, and of what may or may not be dysfunction through the media and society. Evans (1998, p.3) suggests 'we are driven to achieve perfect fulfilment and happiness through the realisation of our personal 'innermost unique sexual souls' (Evans, 1993, p.19). Cacchioni (2015, p.426) suggests this as an example of Foucault's concept of 'biopower'; the social control and management of bodies and life, noting the increasing role of the pharmaceutical industry in the bodies and lives of those with purchasing power; currently largely aimed at monogamous, heterosexual couples. She suggests that LGBTQI people may be future demographic targets and that society should guard against a simplistic view of 'individual choice' as promoted by pro-bio-medicalisation figures (Cacchioni, 2015, p.450), who advocate purely pharmacological answers to perceived 'dysfunction', ignoring the cultural, social and interpersonal factors which may contribute to feelings of concern around sex.

Bio-medicalisation responds to attitudinal pressures to conform to western sexual scripts leading individuals to seek 'perfect bodies' and 'perfect sex', promoting medical and technical solutions for those who do not match checklists for how these idealised individuals 'should' feel and look. The medicalisation of sex and sexuality goes beyond the medical professions, reinforced by advertising agencies, public relations and industries which dominate the promotion of drugs, technologies and lifestyles to clients as consumers and often dictate the clinical research agenda, as well as consumers themselves. The use and profitability of products depends on an essentialist and biological understanding of sex, sexuality and desire rather than a socio-cultural one, which is also free of psychosocial aspects of sexuality such as pleasure, desire, and so on. This bio-medicalisation is reflected in examples such as Viagra, a medication for erectile dysfunction and the on-going search for a female equivalent. Roberts (2006, p.68) suggests that Viagra is a simplistic 'solution' to a complex problem, which underlines and privileges a narrow script around penetrative sexual

intercourse, using direct advertising to client-customers by linking an erection with life satisfaction, masculinity, virility and high workplace performance (Roberts, 2006, p.69). There are also attempts to define female sexual dysfunction and the marketisation of 'solutions' to it, which involve co-opting feminist rhetoric to support a 'solution' (Cacchioni, 2015, p.448). Rather than acknowledging changes which occur over the life course or the impact of social, interpersonal or cultural factors, treatment for sexual concerns suggest maintaining usually heteronormative and monogamous sexual drives as essential to healthy aging which can be biochemically managed and supported (Cacchioni and Wolkowitz, 2011). Roberts (2006, p.68) suggests these discourses around Viagra, the search for a female equivalent and Hormone Replacement therapy (HRT) 'reproduce a narrow idea of sex, sexuality and gender relations, reinforcing culturally prevalent connections between sex, happiness and success' (Roberts, 2006, p.70) as well as being a 'profitable and ever-growing market' in an aging population. Re-medicalisation or bio-medicalisation is challenged by both activists and evidence; Karshak and Tiefer (2001, in Cacchioni, 2015, p.448) suggest the answer to sexual 'dysfunction' lies in challenging social inequality, the deconstruction of sexual norms, recognition of sexual variations over the lifespan and between individuals, support for sexual human rights and access to accurate informative sexual education.

Hill (1998) suggests that medical professionals themselves should think philosophically with regards to sexual health, stating that philosophy helps question the pre-held concepts of practitioners to remove 'bias and dogma' (Hill, 1998, p.55) and challenge assumptions, recognising sexual health as a 'multifaceted construct', it helps assess the merits and justifications of assessments and interventions (for example, technology use), it can help recognise 'competing claims to knowledge', that there are questions beyond the physiological which need to be recognised, and that philosophical theory can underpin understanding of problems and issues. Cacchioni (2015) also advocates social science as a means of challenging medical dominance of sexual health, sexual lives and sexual diversity.

Roberts (2006) acknowledges that medicine has made improvements to sexual lives as it has 'contributed to making sex safer and more pleasurable' (p.73), treatments for sexually transmitted diseases (STDs), prevention of unwanted pregnancy and the diagnosis and treatment of reproductive problems and dysfunction, but states that medicalisation may have also limited sexual expression, pathologised 'biological and sexual diversity' and contributed to intolerance of those deemed to be outside sexual 'norms', producing a space for 'fear, suffering and unnecessary and painful treatment' (p.74), which Tiefer (2006, p.0436) describes as 'disease mongering'. Although Cacchioni (2015,

p.450) suggests caution in rejecting bio-medicalisation and in making negative assumptions on what technology may offer, she suggests this could impede the potential for medicine to empower, for example sexually marginalised groups such as disabled people. This medicalisation may have impacted on the sexual scripts underpinning occupational therapists' attitudes and practice in relation to sex. As discussed in chapter 2.2, occupational therapists have struggled with their sense of professional identity and have been influenced by their place within healthcare hierarchical structures. They may also be influenced by cultural ideas around sex; for example, the feminist and activist movements which led to the de-medicalisation of sex in the 1960s and 1970s may arguably have influenced the recognition within occupational therapy of its own medicalisation in the 1970s, and the subsequent push-back towards more occupational roots of the profession. Arguably, the overt medicalisation of sex may lead some occupational therapists viewing sex as a medical or pathological issue and therefore not part of their remit, rather than a concern linked to identity and meaning and therefore an occupational concern. This may have contributed to the omission of sex in practice discussed earlier in this chapter.

### **Summary: Occupational therapists, healthcare professionals and client sexual concerns**

This section explored the literature which discusses occupational therapy and healthcare practice in relation to broaching sexual concerns, looking at barriers to inclusion and outlining issues of medicalisation which may have impacted on perceptions of sexual concerns within healthcare. Research indicates that occupational therapists and HCPs are failing to acknowledge or address sexual concerns of clients (Couldrick, 1998) across a wide range of service settings. The assessment and subsequent addressing of these concerns is often dependent on the attitudes, confidence and priorities of the individual professional involved in the clients' care. The research reveals the reasons sexual concerns are omitted are complex yet similar regardless of profession, setting or nationality. These reasons are a mixture of attitudinal and structural barriers (see figure 9 below).

**Fig 9 – Barriers to HCPs / Occupational therapists in broaching sexual concerns**



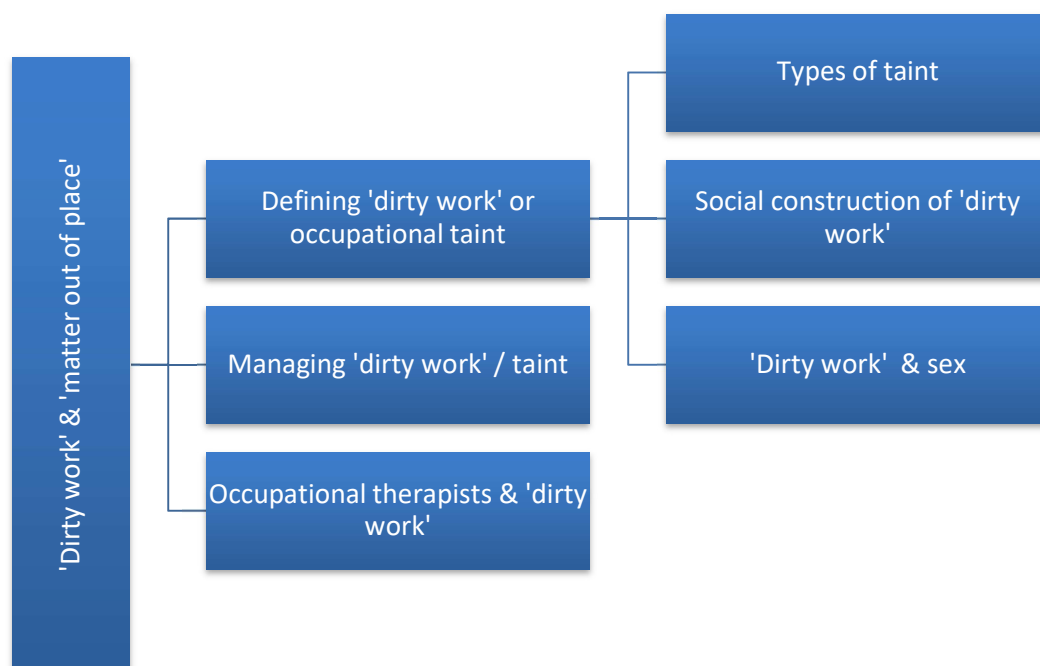
Research specifically on occupational therapists found the issue is avoided due to lack of institutional policy and support, limited time and resources, feelings of discomfort in discussing these needs with clients, a tendency to assume sexual concerns are not a priority for clients, lack of confidence, personal prejudices and values, concerns about ‘opening a can of worms’ and fears regarding inappropriate behaviours (Couldrick, 1998; Yallop and Fitzgerald, 1997). Research indicates that discomfort may be alleviated and confidence increased through gaining knowledge, training and education, experience and the opportunity to explore values and attitudes (Couldrick, 1998; Yallop and Fitzgerald, 1997; Dyer and Das Nair, 2013; Haboubi and Lincoln, 2003). These barriers and perceptions are relevant to this study as they impact on the attitudes and practice of occupational therapists generally and outline some of the issues the participants who do broach sexual concerns have to negotiate. Although from varying backgrounds, the literature indicates that many occupational therapists and HCPs reported similar views in terms of the barriers they face in

broaching these concerns. The participants in my study are subject to similar pressures and influences.

This part of the thesis also explored how changing attitudes towards sex within healthcare have led to sexual concerns being viewed through a changing prism of medicalisation, de-medicalisation and re-medicalisation. Medicalisation places the onus on the individual client as dysfunctional and in need of medical intervention in order to fit in or adapt to societal expectations (cultural scenarios) rather than accepting diversity and changes throughout the life course. This pattern of medicalisation may have influenced the practice of occupational therapy and HCPs generally in their perceptions of sexual concerns and how to broach them, adding to feelings of ambiguity and discomfort or reinforcing a view of sex as a dysfunction /problem to be medically fixed.

## 2.5 The concept of 'dirty work': occupation, sex and 'matter out of place'

This section explores the concept of 'dirty work' or occupational taint – the view that certain occupations are seen as taboo and stigmatising to the person undertaking that work. As will be explored below, 'dirty work' can take on various forms. This concept is relevant to the study due to associations with taboo, stigma, discomfort and sensitivity (for example, the ambiguity and discomfort discussed in chapter 2.4 and disabled people's experiences discussed in chapter 2.3). Perceptions of 'dirty work' reflect societal attitudes towards particular occupations which are deemed as taboo such as sex and sexual expression, and groups who are marginalised such as disabled people. In this section, I will examine the concept 'dirty work' according to previous 'dirty work' researchers, outline how it is perceived as a threat to identity and how perceived 'dirty workers' attempt to manage this.



### Introducing 'dirty work' or occupational taint

The concept of 'dirty work' or 'occupational taint' comes from research on work, organisations and human relations. It has not been specifically discussed in relation to occupational therapy or occupational science<sup>13</sup> but has been considered in relation to aspects of healthcare (for example,

<sup>13</sup> Although Twinley's (2013) concept of the 'dark side' of occupation appears to be related and led me to look into 'dirty work' in relation to this study, they are distinct concepts and Twinley does not appear to specifically

Bolton (2005) on gynaecological nursing; White and Mortensen (2003) on working in sexual health). 'Dirty work' was developed in the US by Everett Hughes and Mary Douglas in the 1950s and '60s, with Blake Ashforth and Glen Kreiner later building on their foundations. 'Dirty work' relates to how certain occupations (in the literature, usually using a narrow definition of occupation as paid work) are seen as 'polluting' or 'dirty' to the individual undertaking them, and can therefore impact on their personal meanings and identity. Activities which have been explored as 'dirty work' include work which may be perceived as directly tainting or dirty such as cleaning (Hughes *et al*, 2016) and working in sex shops (Tyler, 2011); work which has moved from untainted to tainted due to changed working conditions (such as pilots – Fraher, 2017) or social rejection (such as bankers - Vaast and Levina, 2015); unpaid activities such as working with the Samaritans (McMurray and Ward, 2014) and tainted research into taboo subjects such as sex work (Irvine, 2014) and Far Right groups (Sanders-McDonagh, 2014).

### ***Defining 'dirty work' and 'matter out of place'***

'Dirty work' includes occupations or activities which are seen as tainting within society (Ashforth *et al*, 2007), deemed unpleasant or illicit, perceived as disgusting and degrading (Hughes, 1962; Ashforth and Kreiner, 1999; Ashforth *et al*, 2007) and therefore ascribed as stigmatising or taboo. Douglas (1966, p.35) extended this to include 'matter out of place' or 'disorder within a system of cultural and moral norms' (in Jensen, 2016, p.3), therefore 'dirty work' is constructed, existing 'when people think it does' (Ashforth and Kreiner, 2014, p.85). 'Dirty' occupations 'spoil' the identity of the individual involved, making them blemished, devalued or flawed and therefore less fully human (Goffman, 1963; Kreiner *et al*, 2006). McMurray and Ward (2014) state that categorising something as 'dirty work' distinguishes the 'worthwhile, acceptable, clean, pure, orderly, unblemished and good' from the 'worthless, unacceptable, tainted, polluted, chaotic, stigmatised and bad'. Non-dirty work is deemed inherently 'good work' where there is an 'absence of proximity to dirt' and 'offers intrinsic rewards such as job satisfaction, enjoyment and opportunities for career progression' (Simpson *et al*, 2012, p.2). Ashforth and Kreiner (2014, p.83) suggest that taint comes from not only direct contact with stigma or dirt but also from 'mere association'. McMurray and Ward (2014, p.1126) suggest that dirt is defined by four factors; its context, its relation to the preferred order, the perceived threat to order and a persons' desire to keep a distance from it. 'Dirty work' or taint, then, disrupts how people see themselves, and is a threat to their identity and meaning.

---

discuss 'dirty work' or occupational taint.

In Hughes original formulation of dirty work, three types of taint are outlined (Ashworth and Kreiner, 1999, p.4); physical, social and moral. McMurray and Ward's (2014) later study added emotional taint.

- Physical taint includes dirty and/or dangerous activities, relating to effluent, grime, death and unpleasant working conditions (for example refuse collectors, miners, morticians or street cleaners);
- Social taint includes occupations requiring regular contact with and 'association with stigmatised publics or servility to others' (McMurray and Ward, 2014, p.1127) (such as domestic cleaners, prison officers, social workers or customer service roles);
- Moral taint derives from activities deemed sinful or outside social norms; a 'proximity to notions of sin, dubious virtue or deceptions' (McMurray and Ward, 2014, P1127). Ashforth and Kreiner (2014, p83) suggest that moral taint is equated with dubious virtue and/or 'deceptive, intrusive, confrontational or that otherwise defy norms of civility'. This can include debt collectors and all types of sex worker.
- Emotional taint comes from activities which require dealing with emotions outside of preferred order within organisations and 'seen as marginal and disruptive to the functioning of a modern organisation' (McMurray and Ward, 2014, p.1128). These are emotions outside preferred behaviours (for example client distress, difficulty or burdensome behaviours) which are therefore 'out of place, contextually inappropriate, burdensome or taboo' (McMurray and Ward, 2014, p.1136). This can include customer service work, flight attendants, mental health workers and support workers.

Those involved in 'dirty work' or tainted occupations may be exposed to one or a combination of these types of taint, which may be attributed to the occupation (work) as a whole or just aspects of the occupation, and can affect low or higher status occupations. Ashforth and Kreiner's (2014) later development of typologies of taint suggest that different types of taint have differing impacts on identity; moral taint being a greater threat whilst physical and social taints are seen as lesser threats due to being perceived as more necessary and noble, suggesting that 'if physical taint is a blemish on one's 'body' and social taint is a blemish on one's relationships, then moral taint is a blemish on one's character' (Ashforth and Kreiner, 2014, p.84).

Taint, then, is not fixed nor absolute; some activities may be wholly or only partially tainted, others may have 'dirty' aspects which are counteracted by the high status of the individual undertaking it (for example, medical doctors), or may become 'dirty' due to changes in societal attitudes (for



example, working in banking - Vaast and Levina, 2015). Hughes (1951 cited in Simpson *et al*, 2012, p.4) suggests that 'dirty work of some kind can be found in all occupations [as in work] – if only because at some point the worker is likely to have to do something that undermines a sense of personal dignity or because the work involves contact with a stigmatised group'. Taint exists on a spectrum and 'almost all jobs may involve some component of stigma at some point' (Kreiner *et al*, 2006, p.241). 'Dirty work' is not a stable or 'monolithic construct' (Ashforth and Kreiner, 2014, p.82); there are differences between physical, social and moral forms and how 'occupational members...attempt to counter the particular stigma associated with each' (p.83). Douglas (1962, in McMurray and Ward, 2014, p.1125) suggests 'there is no such thing as "absolute" dirt, rather dirt is in the eye of the beholder' who, 'having perceived it, shuns it because it offends against a preferred order'. This indicates that dirt is socially constructed, being 'not inherent in the work itself or the workers but it imputed by people' based on subjective standards (Ashforth and Kreiner, 1999, p.415). Because it is socially constructed, Simpson *et al* (2012, p.2) suggest that the concept of dirty work is fluid; it alters in different 'contextual conditions' not just the material task or role but in how it was perceived. They suggest that dirty work is influenced by 'diverse, contingent and fluid occupational meanings' (Simpson *et al*, 2012, p.8). What is deemed as tainted varies; particularly social and moral taint as these are influenced by 'cultural, geographical and historical context' whereas physical taint is deemed more 'innate and universal' (Ashforth and Kreiner, 2014, p.85).

Despite being socially constructed, Simpson *et al* (2012, p.8) contend that it is grounded in the material and embodied as 'dirt is productive of feelings (for example abhorrence, disgust) that are corporeally experienced'; an emotional and sometimes physical response to a constructed concept of dirt. Jensen and Sandström (2016) question the predominance of constructivist approaches in research on 'dirty work' which they describe as 'discursive abstraction'; they also suggest that dirt exists materially as well as symbolically and that 'esteem enhancing strategies' which draw on the 'moral and symbolic can be both supported or undermined by the materiality of dirt' (p.2). Jensen and Sandström (2016) offer a relational approach whereby the material and discursive (constructivist) co-exist, neither given primacy.

### ***A threat to identity***

'Dirty work' threatens an individual's ability to see themselves positively and can incur the negative judgement of others (Ashforth and Kreiner, 2014, p.82) because it impacts on the individual physically, 'morally and materially' (Southgate and Shying, 2014, p.224). 'Dirty work', then, is problematic for individuals as it is a threat to identity and therefore needs to be managed by those undertaking it. Simpson *et al* (2012, p.8) suggest that there is a need to 'understand the intersection

between “dirty work” and identity’ as doing ‘dirty work’ may impact on the sense of personal and professional identity of the person undertaking the tainted occupation. Kreiner *et al* (2006, p.620) suggest that ‘people care what others think of them, and occupations often serve as prominent identity badges to oneself and others’. Petiglieri (2011, in Fraher, 2017, p.137) suggests that ‘identity threat’ is experienced as potentially harmful ‘to the value, meanings or enactment of an identity’ and challenges individual or group ‘preferred identity narratives’. Undertaking or being involved in a tainted occupation requires some degree of identity management which is ‘likely to be dependent on the individuals’ ability to mobilise social and cultural resources to support (or resist) a particular sense of self’, therefore identity is ‘fragile, emergent and ongoing’ (Simpson *et al*, 2012, p.10). It involves a degree of mental management on the part of the ‘dirty worker’ in order to protect and conserve a sense of identity. Due to this potential threat to identity there may be a ‘preoccupation with outsiders and how the work is perceived’ (Simpson *et al*, 2012, p.9).

### ***Managing the threat***

Sanders-McDonagh (2014, p.242) suggests that managing taint requires emotional work and identity work as ‘meanings about how we understand ourselves and others ... [are] constructed, negotiated and managed by the individual in relation to various external and internal experiences and pressures’. Tyler (2011, p.1495) describes these as coping strategies to ‘create and sustain positive...role identities’ in order to counter feelings derived from a lack of recognition or validation. Ashforth and Kreiner (2014) suggest that in order to manage or counter the potential taint of ‘dirty work’, individuals use a variety of strategies or ‘normalising tactics’ (p.101), by invoking occupational ideologies around how they conceptualise their occupations by ‘reframing’, recalibrating’ or ‘refocussing’ their professional identities in order to manage or deflect stigmatising elements (Ashforth and Kreiner, 1999).

- Reframing – the most widely used countering strategy whereby the meaning of the occupation is altered to turn the stigmatising element into a ‘point of pride’ (BBC, 2007); a ‘dirty job but somebody’s got to do it!’ or ‘badge of honour’. This changes the meaning attached to stigma either ‘by infusing it with positive value’ (Simpson, *et al*, 2012, p9), or ‘neutralising’ the negative’ (Ashforth and Kreiner, 1999). The ‘dirty workers’ taking a pride in their specialness / otherness in doing a job they feel others could not do (Ashforth and Kreiner, 1999).
- Recalibrating - whereby the non-dirty / untainted elements of an occupation are reinforced and highlighted, ‘magnify(ing) their redeeming qualities’ (Ashforth and Kreiner, 1999, p.423) and minimising the tainted components (Simpson *et al*, 2012, p.9), for example a hospital cleaner highlighting the health-supporting / hygiene element of their work.

- Refocussing – involves actively downplaying and overlooking tainted aspects of an occupation and highlights non-stigmatised elements, shifting attention from stigmatised to non-stigmatised features (Ashforth and Kreiner, 1999; Simpson *et al*, 2012, p.9), for example, a farm worker involved in ‘muck-spreading’ highlighting the outdoors aspect of their role or a street cleaner highlighting their relative autonomy.

### ***Criticisms of the concept of ‘dirty work’***

The concept of ‘dirty work’ can be problematic. Ashforth and Kreiner (1999; 2004) do not explain how countering ideologies are activated nor how occupations which do not fit into the fairly simplistic countering strategies they describe might invoke these strategies. For example, a predominantly physically tainted street cleaner might not see their role as one of ‘heroic self-sacrifice’; an exotic dancer might not see their role as essential or necessary regardless of the appreciation of their audience. Jensen and Sanström (2016) argue that Ashforth and Kreiner’s theories overemphasise the discursive and ideological, and ‘privileges positive constructions’ around occupational taint, overlooking the individuals’ negative experiences (p.2). Jensen and Sanström (2016, p.100) also point out that the emphasis on managing or countering taint based on the membership of groups excluded people who are tainted ‘but do not feel that they belong to a collective of dirty workers’.

### **Relevance to this study**

Although ‘dirty work’ or taint has been almost exclusively related to occupation in the narrow sense of the word (paid work / employment), it may also be applied to occupation in the wider sense used in occupational therapy. This concept of ‘dirty work’ seemed relevant to definitions of occupation in the wider sense as defined within occupational therapy, and a potentially useful tool for exploring sexual concerns and how they were managed by the participants in this study. Jensen and Sanström (2016) suggest that the wider implications of taint should be considered in other aspects of people’s lives, not just within the context of paid work. The feelings of discomfort around certain occupations, such as sex (Yallop and Fitzgerald, 1997; Couldrick, 1998, among others) or those described as being on the ‘dark side’ indicate that these too are occupations which invoke feelings of physical, social, moral and/or emotional taint. That some occupations may be seen as ‘dirty’ is inferred by Twinley (2013) and Kiepek and Magalhaes (2011) in their questioning of the concept of wholly ‘good’ or ‘bad’ occupations, Hammell’s (2009) querying of the occupational ‘triad’ of self-care, productivity and leisure discussed in chapter 2.1, indicating that occupations may not always be categorised in a binary of acceptability, of clearly good or bad/ healthy or unhealthy, but exist on a spectrum.

The concept of 'dirty work' also resonated for me personally as a researcher undertaking this study – although taint felt too strong a word, I had felt some degree of awkwardness and discomfort in discussing my research in some contexts, feeling a sense of discussing something that is perceived as less socially unacceptable, similar to feelings discussed by Irvine (2014). Although I found the terms 'dirty work' or occupational taint problematic as they invoke what I perceive as stereotypical and classist ideas around work, hierarchy and class, the concept of 'dirty work' seemed relevant to this study as a means of understanding how the participants managed potential discomfort and taboo around sex and their clients, whilst the majority of their occupational therapy colleagues did not.

### ***Sex and 'dirty work'***

The literature indicates that sex, and occupations which pertain to sex, may be perceived as 'dirty work'. This is explored in several studies including Irvine (2014), Bolton (2005), Tyler, (2011) and White and Mortensen (2003), whilst Irvine (2014) suggests that sex-related research is stigmatised within academia, tainting the researcher. In her research on sex shop workers in Soho, Tyler (2011, p.1487) indicates that although the taint is symbolic the workers are exposed to taint due to the 'physically intimate nature' of sex; they are indirectly tainted due to their work being associated with the body. Sex may be conceptualised as 'dirty work' due to sex negative attitudes which reinforce sex as a dangerous, destructive, negative force, where genitalia are deemed 'intrinsically inferior' along with the lower digestive system (Weeks, 1981, p.22 – in Rubin, 1984). As discussed in chapter 2.2, sex remains subject to moral judgements, influenced by cultural and historical ideas around what is acceptable or taboo.

### ***Occupational therapy and 'dirty work'***

How, then, might the concept of 'dirty work' or occupational taint relate to the work of occupational therapists? 'Dirty work' arguably intersects with occupational therapy both in terms of theory and practice. As it relates to identity and how people see themselves, occupational therapists are working with their own and their clients' ideas about what is tainted and what may be threats to how they see themselves. In a sense, occupational therapy focusses on what Douglas (1966) calls 'matter out of place'; occupational therapists consider the fit between the person, environment and occupation and disruption in that fit could be described as 'matter out of place', with the occupational therapist concerned with supporting the client in either returning the 'matter' 'into place' or finding alternative ways of managing the disruption. In practice, occupational therapists may engage, directly or indirectly, in tainted or 'dirty' tasks and activities. For example, these may be aspects of their role which could be perceived as directly tainted such as dealing with bodily

functions, toileting, end-of-life care or suicidal ideation, or indirectly tainting such as supporting clients who wish to return to activities which may be perceived as 'dirty work', clients who wish to take part in potentially 'dark side' occupations (Twinley, 2013) which are meaningful to them but deemed tainted to others (for example gambling, smoking or drinking), taint from perceptions of occupational therapy from outside the profession (for example, occupational therapists seen in terms of professional stereotypes around tea making / basket weaving by HCP colleagues), or taint from finding their role has been devalued due to organisational changes or changes in working practices.

Despite these potential links between the concept of 'dirty work' and occupational therapy, I was unable to find any theoretical explorations of occupational taint or 'dirty work' in relation to the profession (other than explorations of the 'dark side' of occupation) and there have been no studies into whether occupational therapists themselves consider themselves to be undertaking 'dirty work' or whether their roles may be considered wholly or partly tainted. This may be due to - despite the well-documented concerns about professional identity discussed in chapter 2.1 (Mackey, 2007; Finlay, 1998; Molineux, 2004) - anecdotally there are few indications that occupational therapists feel themselves to be directly tainted or doing a 'dirty job', and they generally appear to obtain satisfaction from undertaking their work. It may be that practitioners do not perceive taint or that practitioners are adept at countering or managing the 'dirty' aspects of their professional identities, they do not acknowledge stigma or taboo associated with it.

Considering occupational therapy through the lens of 'dirty work', three of the four taints arguably materialise: physical taint relating to activities around toileting, incontinence and bodily functions, where there is potential exposure to sticky and messy bodies and bodily fluids; social taint from working with societally stigmatised and therefore socially tainted groups - for example, people in prison or forensic mental health settings, refugees, people with learning disabilities or severely disabled people, dealing with bereavement or suicidal ideation, as well as the potential directly social taint from perceptions of being 'servile' to medicine and being lower down the professional hierarchy within healthcare (see chapter 2.1); and emotional taint similar to that outlined by McMurray and Ward (2014, p.1130), whereby therapists find themselves dealing with difficult or challenging emotions deemed 'out of place' - for example, anger, crisis, stress, emotional lability, depression, anxiety, and so on. An occupational therapist's exposure to moral taint appears more limited, however the concept of 'dark side' occupations (see chapter 2.6) suggest there may be exposure to occupations deemed less socially acceptable, which may give rise to feelings of taint for

some occupational therapists. 'Dirty work' and 'matter out of place', then, can be seen as a concept worthy of consideration for occupational science and in relation to occupational therapy, as it may impact on their work, their clients and conceptualisations of occupation.

### **Summary: 'Dirty work', occupation, sex and 'matter out of place'**

This section explored the concept of 'dirty work' or occupations which are tainting to the people who undertake them, and how this taint is managed or countered using an array of strategies. 'Dirty work' offers a tool for examining what makes certain occupations more acceptable than others. The concept appears relevant to occupational therapy and occupational science in exploring occupations which give rise to discomfort, stigma/ taboo or are on the 'dark side' of occupation (Twinley, 2012). 'Dirty work' can be seen as embodied, classed and engendered. It can be both material and symbolic; materially it induces 'feelings of repulsion and disgust' (for example sticky, smelly, slimy) and symbolically it reflects Douglas's (1966) description of being something 'out of place', 'when there are violations of cultural norms or of the social order'. As dirty work involves this sense of 'matter out of place' it can be seen as transgressive (Simpson *et al*, 2012, p.3), with dirt symbolising a 'contravention of the social order – a transgression of particular boundaries – triggering a desire to avoid or remove it and stigmatising those who were involved in it' (Simpson *et al*, 2012, p8). Despite several potential intersections with taint, occupational therapists and occupational science seem to have had limited consideration of it. Searching the occupational therapy and science literature, I found no work on occupational taint, 'matter out of place' and how they may be managed by practitioners themselves, in relation to client occupations, or on the potential impact on clients, reflecting Simpson *et al* (2012, p.2) who suggest that 'dirty work' is under-researched and invisible. 'Dirty work' or occupational taint are relevant to this study as sex and sexual concerns can be seen as sensitive and taboo (Couldrick, 1998; Saunamaki and Engström, 2013), transgress social and cultural boundaries of what is acceptable within healthcare and occupational practice, despite many occupational therapists accepting sex is an occupational concern. The participants in this study were undertaking work which many of their peers avoided, which as discussed in chapter 2.4 invokes feelings of discomfort and taboo, which – as will be discussed in chapter 4.4 – suggests they were managing 'dirty work', indicating the concept was worthy of further exploration.

Despite feeling that the concept of 'dirty work' or occupational taint could be related to the activities of the participants in my study, there were aspects of the concept I felt uncomfortable about. This theory appeared to reflect white, male and class-ist perspectives of occupation and therefore fails to consider the intersections of race, sexuality, religion and disability. I perceived what could be seen as classist notions of 'clean' and dirty work, which seem laden with assumptions about what is good

or bad work. I have also avoided some of the aspects of Ashforth and Kreiners work around engendered ideas of work despite the well-documented acknowledgement that occupational therapy is often undertaken by white, middle class women, instead using the concept as a lens to explore the work of the study participants.

## Chapter 2: Conclusion

This chapter outlined the contexts and key areas of exploration of this study. The literature highlights that sexual concerns in healthcare involve a distinct set of challenges which set it apart from other concerns in practice due to the exceptionalism, stigma and taboo associated with sex derived from historical socio-cultural influences. The literature indicates a complex picture for occupational therapists and their clients, further complicated by the debate regarding whether sex is an occupation and whether it should be part of the remit of occupational therapy. This raises questions regarding occupation and how it has been conceptualised around productivity, self-care and leisure. I also wondered if the ambiguity around occupation and questions of professional identity suggested by Molineux (2004), Mackey (2007), Finlay (1998) and Turner and Knight (2015) may have contributed to uncertainty around sexual concerns.

Previous research indicates that sex and sexual concerns are challenging for HCPs and occupational therapists who often ignore or omit them from their practice, and are problematised for disabled people and clients who found their sexual wants and needs rarely acknowledged or supported. Dominant sexual scripts assuming the asexuality and vulnerability of disabled people (Shakespeare, 2014) and around acceptable sex and who should access it (Rubin, 1984), as well as taboos around illness and impairment, appear to have influenced attitudes towards the sexual concerns of clients, reinforcing omission or a tendency to medicalise concerns when they were acknowledged. Cultural scenarios around acceptable sex have also been internalised by disabled people themselves, although the literature indicates positive stories of disabled people re-claiming their sexual lives (Liddiard, 2012; Santos and Santos, 2017).

Throughout the literature, themes of stigma, taboo, discomfort and sensitivity recurred; in the attitudes of HCPs, in the development and control of sex and sexuality throughout history, in the barriers and challenges faced by disabled people and in the debate around sex as an occupation. Sex has been viewed in terms of exceptionalism and specialness (Rubin, 1984) rather than as an ordinary day-to-day part of people's lives. This led me to consider sex as 'dirty work' or a tainted occupation (Ashforth and Kreiner, 1999), as it carries a historical weight of socio-cultural, religious and medicalised control due to being deemed immoral, polluting and transgressive (Bolton, 2005; Tyler, 2011). Tainted occupations require countering strategies by the person undertaking them. This idea of occupational taint has not been explored in relation to occupational therapy or science before and seemed pertinent to the subject of this study, providing a theory to aid exploration around how more sensitive occupations are or could be managed.



There were several gaps in current knowledge which I sought to explore in this study. Research on practice is limited, as existing studies are often focussed on why occupational therapists omit sex rather than how and why they include it. There is very little literature on what occupational therapists actually do when broaching sex; what issues arise and how practitioners deal with these concerns – which is the type of information practitioners often seek when they are considering including sexual concerns. Following on from this there is little research on how practitioners feel about broaching sexual concerns or around the assumptions and barriers to practice occupational therapists negotiate and navigate.

This study provided an opportunity to explore the work of occupational therapists and how they manage the impact of dominant sexual scripts in order to broach sexual concerns. This study, then, sought to fill in the details around sex as an occupational concern which are often missing from practice, with a view to help current and future practitioners (both occupational therapists and HCPs generally) recognise sex as an ordinary part of their client's lives, albeit one which requires consideration and sensitivity, which with reflection and management may be included in their practice. This subject has not been explored in relation to occupational practice before and makes an important contribution to the inclusion of sex as an ordinary part of the lives of clients, informing future education, training and practice and encouraging occupational therapists in incorporating sexual concerns as part of their occupational remit.

## Chapter 3: Methodology

The previous chapter examined the context and reviewed the literature relating to this study regarding occupational therapy, occupation, the sexual concerns of clients and disabled people, HCPs attitudes to these concerns, and an overview of occupational taint. This review identified gaps in current knowledge and culminated in the development of the research question, aims and objectives set out in chapter 1 (see box) for exploring this subject further. This chapter will outline my methodological considerations and approaches, and the research methods used in this study, both in theory and in practice.

Firstly I will outline the theoretical aspects of this research, setting out the approaches I used and how I chose them. Then I will outline the practical research instruments used to collect and analyse the data. Lastly I set out how I ensured

my study was ethical and rigorous. During this study I have used methodologies mirroring occupational science, using multiple epistemologies which reflect the material reality of practice and the relativist thoughts, feelings and experiences of the practitioners.

### Study research questions, aims and objectives

#### Research question:

Does current occupational therapy practice support clients' sexual concerns and, if so, how?

#### Aims and objectives:

Aim 1: Identify existing UK occupational therapy practice in sexual expression and intimacy;

- *To identify individuals and organisations which incorporate sexual needs / issues within their practice.*
- *To identify the scope of this practice.*

Aim 2: Explore occupational therapy practice regarding sexual expression and intimacy;

- *To explore this practice within the occupational Therapy process.*
- *To investigate sexually related occupational Therapy practice and its fit within the organisation / institution and the wider MDT.*
- *To investigate practical aspects, such as assessments and interventions, used in relevant practice.*

Aim 3: Explore occupational therapy practitioner attitudes to and experiences of practice concerning sexual expression and intimacy;

- *To investigate the attitudes and influences on individual occupational therapy practice in this area.*
- *To explore and examine the barriers and facilitators to this practice, as perceived by occupational Therapy practitioners.*

### 3.1 Conceptual frameworks and theory

In considering a research question, theory provides a framework for development and an explanation of decision-making in order to provide strength and depth (Rubin and Rubin, 2012). This section will discuss the theoretical and philosophical paradigms, ontology and epistemology to this research. This process is complicated by the multiple and interchangeable definitions of terminology throughout research methodology literature; Morgan (2007) notes that even Kuhn's (1970) seminal work on the concept of paradigms *The structure of scientific revolutions* used several differing definitions for 'paradigm'. The language used to describe and define specific theories and ideas can be inconsistent between different authors (King, 2015), rendering the research journey confusing for a novice researcher. The beliefs, values, ideas and theories a researcher holds and the nature of the research question also influence the types of data collected, how it is collected and how the data is analysed, interpreted and presented. The researcher must therefore be aware of philosophical underpinnings not only for the structure it provides but also for the potential bias these values and theories may introduce. What follows outlines and explains the theory used in this research, followed by how this was applied in the research method.

#### Paradigms, ontology and epistemology

Research is underpinned by the paradigm, ontology and epistemology used. A paradigm or worldview is a set of values and beliefs about the world (Creswell and Plano Clark, 2007) – these are represented by:

- ontology - what is the nature of reality/ of being (Crotty, 1998),
- epistemology - how we know the world / theory of knowledge (Guba and Lincoln, 1994), and,
- methodology - how we find out (Crotty, 1998).

Broadly, paradigms are characterised on a realist (the world is real and directly knowable) to relativist (the world is not real and only known through interpretation) continuum (Ballinger, 2004), although the labels given - as with the definition of paradigm itself - can vary; for example, Guba and Lincoln (1994, p.193) sets out four paradigms - positivist, post-positivism, critical theory and constructivism, whereas Creswell and Plano Clark (2007) defines a paradigm as a worldview and provided a differing four worldviews on their version of the continuum; post-positivism, constructivism, advocacy and pragmatism. Wisker (2008) outlines 6 paradigms; positivist, interpretivist, constructivist, structuralist, poststructuralist and postmodernist; further muddying already opaque waters. The adoption of a particular paradigm is dictated by the researcher, the needs of the research question or even the diktats of a University. Bergman (2010, p.100) suggests

that paradigms can be subject to fashion and convention, whereby an influential figure or group adopt a paradigm whom others follow. When considering theories, philosophies and methodologies there can be a danger of 'methodolotry', that is the 'privileging of methodological concerns over all other considerations' (Chamberlain, 2000). Chamberlain (2000) describes this as a form of 'fundamentalism' where researchers adhere to 'one true way' (p.288) and posits instead that 'researchers must be free to develop and apply methods that are appropriate for finding answers to the research question and... not be constrained in the methodological straitjacket' which could otherwise lead to an overemphasis on method to the detriment of answering the research question (p.291). Therefore the researcher should be cautious, using reflection and consideration to avoid dogma, and use methodologies as tools rather than belief systems to avoid the wholesale adoption of 'paradigms' which can prevent discussion and interaction (Biesta, 2010, p.99). With this in mind, I sought to apply a methodology which could be flexible and adaptable to my needs whilst retaining a firm foundation. Rather than becoming mired in definitions of paradigms or worldviews which is not the remit of this study, I will outline the reflection and processing which contributed to my decision-making for the methodology of this research.

In choosing an appropriate approach for this research, three key considerations were borne in mind; the ontological and epistemological position of myself as the researcher; how best to answer the research question, aims and objectives, and the rationale for the research – why this research was being undertaken. This involved self-reflection, examination of the research process to question and formulate ontological, epistemological and methodological positions, and exploration around adopting possible methodological theories. This research will not resolve the ongoing debate between realism and relativism - a paradigmatic 'end of history' was not reached here - but to seek the appropriate best methodological fit for my study.

My initial philosophical position was inclined towards the world being only knowable subjectively, therefore taking an interpretivist or relativist view; that the world is viewed and interpreted from the prism of the individual's subjective viewpoint, derived from values, opinions and experiences of the world. However, this was tempered by a 'common sense' perception that there is an empirical reality - a world beyond the subjective gaze which is knowable, albeit only subjectively. For example, my view is that objectively material/ structural issues such as time and resources can impact on occupational therapy activities as well as practitioners' perceptions and values. This acknowledgment of an objective reality behind the subjective view is congruent with occupational therapy, which recognises the perceptions and values of the client as well as the realities of their

environment and occupations. This placed the ontological position of this research as post-positivist which accepts that there is a 'real world' that is knowable but that knowledge is subjective and imperfect.

In research, post-positive paradigms are used for theory generation; using small samples, subjective, with low reliability but high-validity and generalisable from setting to setting (Robson, 2002). Robson (2002, p.27) states that unlike positivism, post-positivism accepts that the 'researcher can influence what is observed' but retains a commitment to objectivity; that there is a reality but it can only be known imperfectly. However, Robson (2002) posits that post-positivists still 'hanker' after positivism, that is, pure objectivity. To temper this, I adopted a post-positivist paradigm tempered with a 'hankering' reflection for the subjective, lived experience. Having set out this post-positivist ontological position, the epistemological and methodological foundations are laid out below.

### **Considering approaches and methodologies**

This study used a critical realist (CR) approach which will be set out in detail below. Prior to adopting this, several methodological approaches were considered for this study which I ultimately felt were inappropriate as the focus of the research developed. Choosing an approach is dictated by the nature of the issue being researched, the context or setting, the researcher perspective and the philosophical stance of the researcher (Wisker, 2008). Wisker (2008) suggests that in order to find a framework of best fit the researcher must look at the issues to be examined and the reasons for wanting to investigate them; recommending reflective self-examination on the project, reasons for doing it and personal preferences in terms of theory. As indicated above, I sought a methodology which could provide foundation for the study but which could also be flexible in order to accommodate the types of data I wished to uncover and examine, as well as avoiding dogma and potential bias. I considered a variety of approaches from models which relate directly to occupational therapy (such as Person-Environment-occupation – PEO, Model of Human Occupation - MoHO or Kawa - Boniface and Seymour, 2013; Curtin *et al*, 2010) to approaches associated with qualitative methods (such as phenomenology and grounded theory). I decided against using occupational therapy models as I wanted to ensure this research would be accessible to those outside the profession and to consider ideas from outside the profession. For the qualitative aspects of the data I considered several approaches, including;

- Grounded Theory - which is grounded in data would be a useful structure but felt that the process was too rigid for my purposes;

- Phenomenology - which explores the lived experience was considered which seemed relevant to occupational therapy but as I wanted to examine practical as well as affective experiences I felt this would be too narrowly focussed on feelings;
- Ethnomethodology - which is about how people go about their daily activities and make sense of their world, where meanings are not shared by all but felt that, like Grounded Theory, it was too rigid and too oriented towards conversation analysis which was not relevant in this study;
- Phenomenography - which is about how people conceive phenomena was also considered but seemed too oriented towards collective experience rather than individual meanings;
- Critical theory - which encourages the search for 'truth' beyond reality by critiquing established reality in order to instigate change, recognising connections 'between and human interest' (May and Powell, 2008, p.45), which seemed compatible with occupational therapy but I also found the technical language dense, opaque and alienating.

(Best, 2003; May and Powell, 2008; McCabe and Holmes, 2009)

I also considered but ultimately decided not to use, despite its potential relevance, a Foucauldian approach. Foucault is strongly associated with considerations of sexuality and the body due to his work on the history of sex and biopower, and his concept of dominant discourses, knowledge and power seemed particularly relevant to the sexual scripts which prevail in how sex and sexuality is perceived. Using Foucault may have provided a means of examining relationships between scientific knowledge and social practice, looking at the techniques and power relations through which they developed and applied. His concept of discourse connects knowledge and power (Mackey, 2007), a discourse being a set of 'common assumptions'. A dominant discourse is the accepted, important 'true' discourse at any one time – the 'norm' – whilst those discourses that criticise or divert from the dominant discourse may be said to be 'other' or even 'deviant'. The dominant discourse is not static or fixed, it can change over time, it is related to culture, history and 'power relations' and different groups may have a different dominant discourses which are unaffected by one another. Allen and Carmody (2012) suggest these are 'normalising discourses [which] attempt to suppress, control and police the sexual activity of communities and subgroups within them' (p.461). For example, occupational therapists are regulated by a socially constructed professional identity discourse into which they are normalised through education and practice, what Foucault called 'technologies of the self' (Mackey, 2007, p.99), regulating their 'bodies, thoughts and conduct'. A Foucauldian approach on the relationship and relations between practitioners and clients suggests that there can be no neutrality in this relationship, that 'every relationship is a relationship of power'

(Mackey, 2007, p.99). I could see that Foucault's concept of power and dominant discourses was relevant and a potentially useful lens with which to apply to my investigation but as this is an area of practice which has not been researched before, I wanted to be free to explore what the participants did and how they felt about it, rather than focus on how knowledge is produced and how power is enacted when occupational therapists broach sexual concerns. Jackson and Scott (2010b, p.818), although acknowledging the importance of Foucault, suggest that the dominance of his views in exploring sex have led to the loss of 'focus on the sexual meanings and practices embedded in everyday social life and conversely on the social relations and meanings that shape sexual practice', ignoring the interaction between material and social. I therefore felt that the use of sexual script theory was pertinent in this exploratory study, focussing on the 'what' rather than the 'how'. Therefore this study is underpinned with critical realism (CR) founded on pragmatism seemed a more pertinent approach to achieve my research aims, with a post-positivist paradigm of imperfect objectivity. This involved taking a pragmatic approach to the study, which will be discussed next.

### **Pragmatism**

Pragmatism developed as a philosophy in the US of the late nineteenth century to mid-twentieth century with the work of James, Peirce and Dewey (McDermid, n.d.), the primary focus of pragmatism is on 'what works'. Pragmatism has had a recent resurgence due to its congruence with the increasingly popular use of mixed methods in research. Pragmatism rejects the 'either/or' dualism between positivist and interpretivist paradigms, known as the 'paradigm wars' from which was derived an 'incompatibility thesis' which posited that paradigms are rigid and cannot work together (Creswell *et al*, 2011; Tashakkori and Teddlie, 1998 p.22). Instead pragmatism suggests that what is practical and real constitutes both meaning and truth (McDermid, n.d.), and that 'what works' is true. Creswell *et al* (2011) suggest that pragmatism values both the subjective and objective, embracing methodological diversity.

Pragmatism has been criticised for failing to address metaphysical aspects of reality, for being incompatible with subjective and objective views, and for its lack of a common language (Teddlie and Tashakkori, 2009; Creswell *et al*, 2011). There have also been criticism of the focus on 'what works' and that what is true is what works, with respect to who and how it is decided 'what works', as well as questions regarding the ethics of this in practice – an early critic, Randolph Bourne suggests that sometimes what is true is what does not work, (Blake n.d). Adhering to the view that 'what works is true' also undermines the possibility of research which is transformative and can reinforce normative and constructive approaches and ideas. Hall (2012) questions whether it is possible to determine what works, suggesting that this cannot be known until a project is

completed. The incompatibility of subjective and objective views continues to be debated, and the criticism regarding a lack of common language may be directed to research methodology generally given the lack of consensus in the terminology.

Despite these criticisms, pragmatism was useful and applicable to this study, being practical, flexible and realistic - it reflects both the research process and how humans exist in the world, and makes it possible to utilise the strengths of both qualitative and quantitative approaches to give a fuller picture. By using pragmatism, paradigms could shift according to the needs of the research question using a 'pluralistic pragmatic approach' (Creswell *et al*, 2011, p.279). In practice, as pragmatism rejects either/or dualism it can incorporate the pluralistic possibility of different perspectives. It utilises the relevant worldview for each stage of the research (Creswell *et al*, 2011) which can be either convergent - which is an overall pragmatist approach - or sequential - which involves multiple worldviews (that is, a pluralistic use of research design which is most appropriate to answer the question). Morgan (2007) suggests there has been overt focus on philosophical theory, stating that paradigms can be compatible if rigid adherence to theory is rejected in favour of a focus on the research question itself. Biesta (2010, p.97) suggests that pragmatism should be understood as 'a set of philosophical tools which can be used to address problems' as opposed to what Dewey describes as system building which 'conflate the outcomes of specific enquiries with antecedent ontological conditions' (Biesta, 2010, p.99).

I used this approach as I felt that pragmatism was congruent with both the practical, 'common sense' reality and the holistic, problem solving ethos and values of occupational therapy. Libscombe (2008) suggests that reflection is needed as 'explicitness and clarity' can be 'compromised when a pragmatic approach to methodological use is combined with an indifferent attitude to theoretical dispute(s)' (p.36). He advocates the use of critical realism as a means of underpinning reflection and addressing this concern.

### ***Critical realism (CR)***

Originated by Roy Bhaskar in the 1970s, who criticised the overt positivism of natural science, CR states the world exists outside of human awareness (Clark *et al*, 2008), that 'there is no objective and certain knowledge of the world and accept[s] the possibility of alternative valid accounts' (Maxwell and Mittapalli, 2010, p.150). Initially I rejected CR for this study despite it most closely reflecting a post-positive position useful for answering the research question. Readings of Bhaskar made CR seem too abstract, the language too opaque, dense and scientific to be useful for this exploratory study. I had a sense that CR attempted to "have its cake and eat it" in its synthesis of

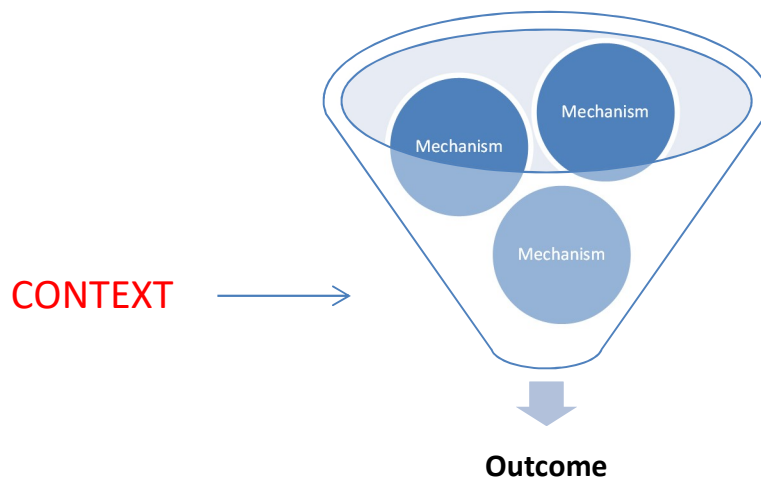


both positivism and interpretivism. However, returning to CR through the work of Maxwell and Mittapalli (2010), Maxwell (2012) and Clark *et al* (2008) I saw the practical application of CR in research and how it could apply to this study.

Clark *et al* (2008, p.E69) state that CR accepts that 'physical and social entities' have independent existences regardless of 'human knowledge or understanding'. This means social phenomena exist as a result of humans but can also be independent of individuals (for example, discrimination may exist within an organisation whether or not it is recognised by its members - Clark *et al*, 2008, p.E69); CR 'acknowledges the possibility of science but recognises the social dimension of humans and science', being neither reductionist nor relativist it represents the 'middle ground' which allows the possibility and potentiality of human meanings and experience to be incorporated and recognised as influential on behaviour and external social structures, whilst still acknowledging the possibility of empirical reality. Maxwell and Mittapalli (2010) state that CR acknowledges that 'all knowledge is partial, incomplete and fallible', it sets out a commitment to a real but not objectively knowable world (p.153), retaining 'an ontological realism while accepting a form of epistemological ... constructivism' (p.151). It is therefore congruent with a post-positivist ontology alongside my "hankering" to reflect on lived experiences.

CR represents the world as an open system that involves a complex and changing set of factors in various contexts at different times. It also recognises that individual factors (agency) and contextual or structural factors need to be taken into account. Robson (2002, p.20) provides an analogy for this using the example of gunpowder; gunpowder explodes when exposed to flame, but only in the right conditions. In CR terms, the outcome (the explosion) of an action (applying flame) which can only happen following certain mechanisms (composition of gunpowder) in a particular context (conditions which allow for the explosion such as oxygen and dry gunpowder). This is illustrated below based on a diagram by Pawson and Tilley (1997, p.72 – see figure 10):

**Fig 10 - Critical Realism diagram**



(Adapted from Pawson and Tilley, 1997, p.72)

A CR approach allows for differing contexts and 'mechanisms' which may affect outcomes, rephrasing questions such as 'what will produce the greatest overall change?' to 'what works best, for whom and under what circumstances?' (Robson, 2002, p.39). Clark *et al* (2008 p.868) suggest that CR has merits for nursing research by utilising positivist approaches to provide wider knowledge of the world which can be developed and built systematically, whilst also utilising relativist/interpretivist approaches to ensure the 'centrality of human experiences, social and cultural constructs, values, perspectives and languages' (p.868) and I felt this view could also be applied to occupational therapy. It can be systematic without being dominated by a reductionist systems approach. Maxwell (2012, p.255, citing Pawson and Tilly, 1997) suggests that by acknowledging the mechanisms and processes between cause and effect a 'mechanism is...not a variable but an account of the make-up, behaviour and interrelationship of those processes'. CR places emphasis on context; Maxwell (2012, p.156) sums this up with the equation: 'mechanism plus context equals outcome' or  $C+M=O$ .

CR offers an alternative to the qualitative versus quantitative debate; it recognises the context without reducing phenomena to a set of variables, and the mind is considered as part of reality, so mental and physical perspectives are not two distinct, separate realities. Rather than multiple realities there are multiple perspectives, and recognition of the importance of meaning as well as physical and behavioural phenomena. CR 'treat(s) both individuals' perspectives and their situations as real phenomena that causally interact with one another' (Maxwell, 2012, p.157).

CR is not without criticism; Smith and Deemer (2000) suggest how CR is positioned serves no useful function and that accepting reality has no bearing on our understanding of knowledge or how we get to it. Reading the work of researchers who have adopted CR they, ironically, can appear to lack criticality of their own position, tending towards a zealous and enthusiastic adoption of the theory, suggesting a paradigmatic 'fad' as alluded to by Bergman (2010). It can be overly relativist (Maxwell, 2012) and it can feel that CR is almost too open to interpretation as indicated by the 'cake and eat it' impression I initially found. Despite these criticisms, Lipscombe (2008) suggests CR can help refocus the researcher on the links between their pragmatic research back to their ontology, epistemology and methodology (p.43) and allows mixed methods research to overcome the tensions which can arise from using divergent qualitative and quantitative methodological traditions which can be seen as 'incommensurable' (p.43), that is lacking in common measurables and language.

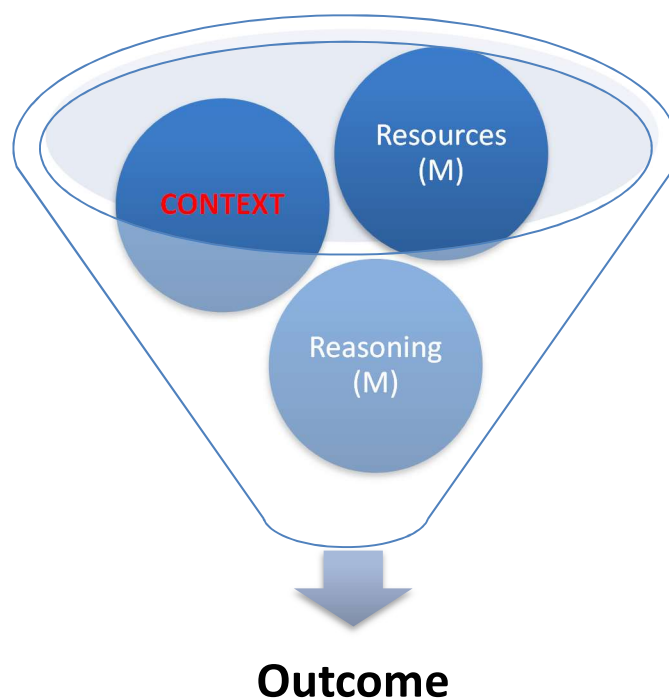
Using CR was congruent with fulfilling both the aims and objectives of this research and adhering to the occupational perspective and underpinning I sought to retain. It acknowledges multiple epistemologies, the melding of art and science and the practical and affective aspects of occupational therapy. It provided a framework for exploring the practice of individual practitioners within institutional, social, personal and attitudinal contexts, and for observing mechanisms used to reach outcomes in the variety of settings that were explored. CR provided a fluid and adaptable framework which supported the recognition of pragmatism and the realities of practice, and the holistic ethos of occupational therapy, incorporating both quantitative and qualitative data, allowing my study to explore agency, mechanisms and contexts. In essence, I felt that CR reflects how the occupational therapy process works in looking at the person, environment and occupation, which may be loosely correlated with context, mechanism and outcomes, and how those aspects intersect and interrelate. Applied to the broaching of sexual concerns, for example, the literature review indicates that context (the attitudes toward client sexual expression and fears or otherwise of the occupational therapists involved) and mechanisms (structural factors such as time, resources and the lack of clear referral pathways) impacted on an occupational therapist actively engaging the client on this issue – the outcome. CR allowed me to keep a pragmatic and occupational focus on 'what works' both in terms and content of the study, and meant I could explore practice, experience and feelings the participants had about that practice. It also meant I could apply several theoretical lenses simultaneously; the social relational model of disability, interactionist sexual script theory, materialism and occupational science without conflict with the overall ontological and epistemological paradigms. CR combines art and science (realism and relativism) (Christiansen and Townsend, 2009) and therefore permits the 'integration of... subjective and objective approaches'

(Maxwell, 2012), recognising the objective character of society, the subjective context and causal role of agency.

### *Operationalising CR*

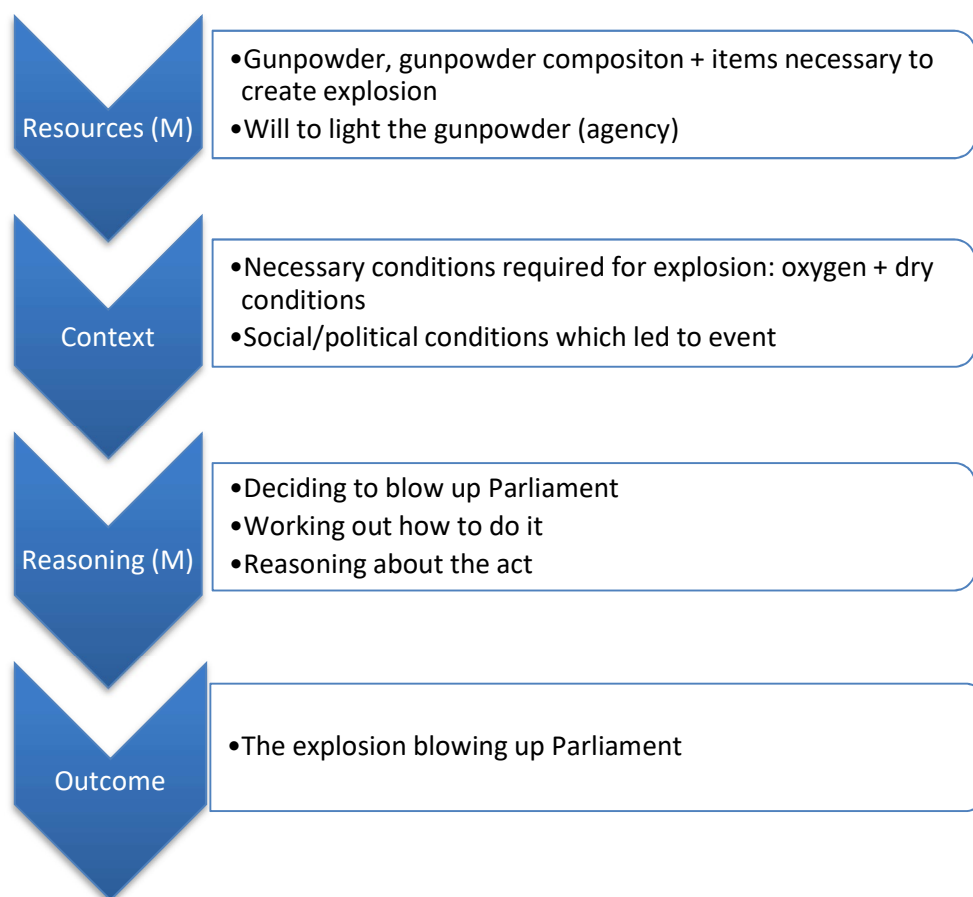
For this study, I found an interpretation of CR by Dalkin *et al* (2015) particularly useful in putting CR into practice by providing a means of viewing and interpreting the data which aided understanding and interpretation. They suggest that Pawson and Tilley's equation  $C+M=O$  could be reductionist leading to a perception that phenomena are 'on/off' events rather than – as they put it – a 'dimmer switch' (Dalkin *et al*, 2015). They see the mechanism element of this equation as a continuum; rather than an intervention that leads to an outcome, they formulated this as the 'workings out', suggesting the 'mechanism is what generates the observed relationship'. Pawson and Tilley (1997) suggest that 'mechanisms are identified at the level of human reasoning' and therefore have 'different meanings'. Dalkin *et al* (2015) incorporated this into the equation as  $M \text{ (resources)} + C \text{ (Context)} \rightarrow M \text{ (Reasoning)} = \text{Outcome}$  (see figure 11).

**Fig 11 – Dalkin *et al* (2015) Interpretation of CR**



Below, I apply this variation of CR to the gunpowder analogy provided by Robson (2002 – see figure 12):

**Fig 12 – Dalkin *et al* (2015) applied to Robson’s (2002) gunpowder analogy:**



(Adapted from Robson, 2002 & Dalkin *et al*, 2015)

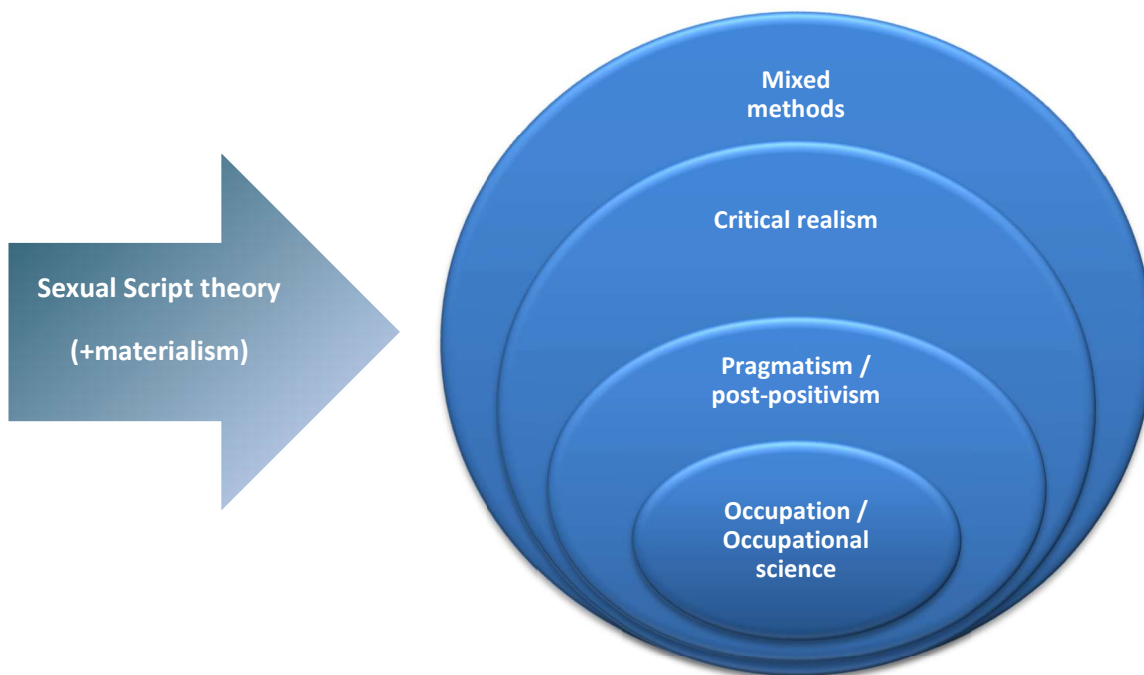
This formulation of CR was useful when incorporated with Template Analysis (TA – a form of data analysis discussed in the next section) during the writing up phase as it helped me link themes and maintain an occupational underpinning consistent with occupational therapy conceptualisations around the person, environment and occupation. The challenge in using Dalkin *et al*’s (2015) interpretation of CR was that although it gave me a firm foundational framework, it could sometimes feel too systems-oriented, which I balanced by maintaining the reflective “hankering” for the lived experience as indicated above, considering the foci of occupational science discussed in chapter 1.2 as an anchoring point, and being mindful of the ‘dimmer switch’ aspects of phenomena.

### **Summary: Conceptual frameworks and theory**

By combining post-positivism, pragmatism and CR and using sexual script theory and materialism as critical lenses, this study took a holistic approach to the phenomena in keeping with occupational

therapy and occupational science. The post-positivist view acknowledges there is a reality as well as constructivist, subjective meanings to experiences, providing a holistic view of practice congruent with the core assumption of occupational therapy whilst encouraging constant reflection on 'what works' and reducing potential dogmatic adhesion to methodolotry. Pragmatism was used to guide the choices in research design and data collection based on a pluralistic conception of what would work as this study developed. Pragmatism is one of the epistemologies from which occupational therapy draws (Hooper and Wood, 2002), which I felt would ensure this study considers the realities of practice and consideration of 'what works'. This allowed me to use a combination of qualitative and quantitative data in order to gain a broad and deep picture of practice and experience finding factual, objective information on practice, and subjective data on attitudes and experiences. Pragmatism helped me integrate the post-positivist position that there is a reality that can be known whilst acknowledging that this reality is subject to interpretation and individual meanings. CR involves methodological 'eclecticism' (Clark *et al*, 2008) in that an array of methods may be used to explore the complex causes of how and why; for example, how context and individual factors interact. This is also congruent with Kinsella (2012), who advocates the use 'pluralistic paradigms' that is, using a variety of relevant theories to underpin and advance the knowledge base of occupational science, whilst Kuhn (1970, cited in Teddlie and Tashakkori, 2009, p.84) suggests that being a relatively recent branch of science, the human sciences may simultaneously allow competing paradigms. I felt that CR was a good fit within this study as it accommodated qualitative and quantitative data and flexibly supported the exploration of experiences and practice by allowing me to consider the context, reasoning and resource mechanisms and outcomes. This provided a structure for considering the participants' attitudes and practice whilst also mirroring occupational therapy approaches, which I felt would help maintain an occupational standpoint. The combination of approaches, epistemology and ontology are illustrated in figure 13 below.

**Fig 13 – Summary of methodological framework to study**



Centring on occupation as central to human experience, this study utilised an array of inter-related methodological theories based on a post-positivist paradigm and using a pragmatic focus on 'what works'. Critical realism was used to operationalise this approach, encompass reflection and the acknowledgement of philosophical theory, and allowing a mixture of quantitative and qualitative approaches. This meant I could draw on sexual script theory and materialism to support my exploration. Based on this foundation, a mixed methods approach was formulated as the best fit for exploring the practice and experiences of occupational therapists broaching sexual concerns, which will be set out in the next section.

## 3.2 Research Methods and design

This section will describe the research method used in this study. Generally, research is categorised around three methodologies; quantitative, qualitative and mixed methods (Bryman, 2016). Mixed or multiple methods is a research approach which either simultaneously or consecutively combines both qualitative and quantitative data with the aim of providing a comprehensive examination of the research question or subject (Creswell *et al*, 2011). Qualitative data is associated with thoughts, feelings and meanings whilst quantitative data is associated with measuring, statistical and numerical data. As such, qualitative and quantitative research methods are often considered to be opposing and incompatible (Creswell, 2009) with differing philosophical foundations. Despite this the combination of these methods has increasingly been accepted in order to explore the 'bigger picture'. Creswell (2003, p.21-2) suggests that when choosing which approach to use the researcher should consider:

- matching problem and approach: quantitative to identify what was happening in practice, qualitative to explore little researched phenomena and experience, mixed methods to do both – in this study the aim was to do both;
- personal experiences – the researchers' training and experience – although I was more familiar with qualitative research I felt that quantitative data would give a fuller picture;
- audience – for this study the audience was most likely to be occupational therapists, HCPs, people who work in RSE<sup>14</sup> and sexual health and disabled people/ clients. Their interest would be primarily in the how and the what.

I therefore utilised a mixed methods approach to 'expand understanding' (Creswell, 2003) utilise the strengths and off-set the weaknesses of both qualitative and quantitative approaches (Creswell, 2003,) in order achieve a broad exploration of the experiences and practice of occupational therapists broaching client sexual concerns. Mixed methods were applicable to this study as they reflect the nature of the data to be collected; a purely quantitative approach would have failed to consider feelings, attitudes and experiences, whilst a purely qualitative approach could not have ascertained the "what" and "how" of actual practice; what occupational therapists do and how they do it, providing valuable insights and practical problem-solving information as well as the context of practice and outcomes.

---

<sup>14</sup> Relationships and Sex Education



## Mixed methods

Using a mixed method is closely associated with pragmatism (Tashakkori and Teddlie, 2003, p.87) and regarded as a third methodological movement (Tashakkori and Teddlie, 2003; 2009, p.87); a synthesis of qualitative and quantitative methods, providing breadth and depth, and using the strengths of both qualitative and quantitative approaches, meaning that this project could incorporate practical, descriptive data with qualitative data on attitudes, feelings, barriers and facilitators. Using mixed methods challenges those who adhere to the 'incompatibility' problem. Greene (2007, cited by Creswell *et al*, 2011) suggests researchers who hold different philosophical positions may find mixed methods research difficult because of the tensions created by differing beliefs, whilst Guba and Lincoln (1994) suggest that mixed methods are not possible due to paradigm incompatibility. However, Creswell *et al* (2011) suggest that mixed methods provide 'an opportunity to transform these tensions into new knowledge through a dialectical discovery'. By being oriented 'towards solving practical problems in the real world' (Feilzer, 2010, p.8), mixed methods ensure that the research question and problem is the primary focus (Morgan, 2007), mitigating problems of dogma and methodology. Mixed methods provide an opportunity to address 'confirmatory and exploratory questions, providing 'stronger inferences' and allowing for diversity of opinions and the re-examination of concepts (Teddlie and Tashakkori, 2009).

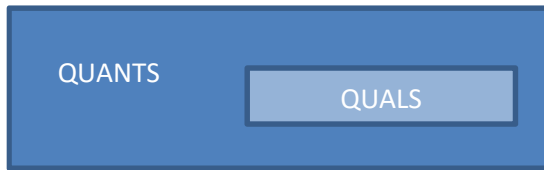
Using mixed methods involves a pragmatic approach, as the 'decision regarding whether the use of either qualitative or quantitative methods (or both) depend on the research question... and the place of the research cycle' (Tashakkori and Teddlie, 1998, p.24), focussing on 'what works'. Mixed methods is flexible and adaptable to answering the research question being 'knowledge claims on pragmatic grounds' (for example consequences, problems and 'pluralistic') (Cresswell, 2003, p.18). In this way I could incorporate pragmatism ('what works'), CR (acknowledging the subjective and objective elements of the research question such as agency, mechanism and context) and the centrality of occupation underpinning this research. Using a purely quantitative method would not have allowed me to explore nuance, thoughts and feelings, whilst purely qualitative data would have curtailed my ability to uncover important "nut and bolts", practice information which the literature indicated is missing from knowledge. Using mixed methods provided flexibility and helped me examine the "big picture" of both feelings and practice. As with CR, mixed methods reflects day-to-day pragmatic occupational therapy professional practice; occupational therapists gather information from assessment, observation, discussion with the client and their carers' and family members, information from other members of their team and other stakeholders, in the context of the client's environment.

Using mixed methods meant it was possible to integrate different types of data at different stages of the study, combining open and closed questions, emerging and pre-determined approaches and qualitative and quantitative data analysis (Cresswell, 2002, p.19). The disadvantages are there is a need to specify the purpose of quantitative as part of the larger qualitative data (and vice versa), it can be difficult to integrate the results, and there is limited literature to refer to. However, mixed methods is advantageous when time and resources are not sufficient to commit to extensive qualitative and quantitative data collection and it becomes logistically manageable for a novice researcher (Creswell and Plano Clark, 2007, p.70).

Implementation of mixed methods can be sequential or concurrent. Decisions on whether, if at all, qualitative or quantitative data are given greater 'weight' or priority is dependent on the aims, audience and researcher. The premise for this decision is based on whether no single data set is sufficient or whether different questions need to be answered, with each question requiring a different type of data (Creswell and Plano Clark, 2007). This means embedding one set of data within the other (Creswell and Plano Clark, 2007, p.67). In an embedded design one set of data 'plays a supplementary role within the overall design' (Creswell and Plano Clark, 2007, p.68). Within my study the supplementary role changed according to the research aim explored. In order to ascertain the scope of practice in the survey, quantitative data was primary, when exploring perceptions in views the quantitative data was secondary but necessary in terms of understanding and supporting the whole picture studied (for example the participants' feelings about aspects of their role required information on the nature of their practice).

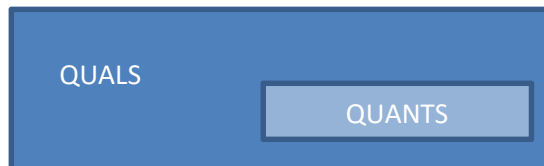
For this study, stage 1 and 2 (the survey and questionnaire) used a concurrent / nested strategy (Figure 15) in order to gain broader perspectives (Creswell, 2003, p.218). This involves simultaneously collecting predominantly quantitative data whilst also gaining some qualitative data (for example, in the survey my aim was to scope practice relating to sexual concerns but I also provided a free text box for participants to comment qualitatively on this aspect of practice). For stage 3, I used a concurrent exploratory strategy (Figure 15) which explored the thoughts, feelings and experiences of the participants focussing predominantly on qualitative data, with some relevant quantitative data relating to practice activities. The strategies involved are illustrated in figures 14 and 15. The data collection process is outlined in more detail under the section on data collection below.

**Fig 14 - Stage 1 and 2 (survey and questionnaire) - Concurrent / nested:**



These stages focussed predominantly on quantitative data on the scope and nature of practice, whilst some qualitative data was collected concurrently as part of the survey and questionnaire. The survey helped identify practitioners who broached sexual concerns whilst the questionnaire collected a mixture of predominantly quantitative data on experience, education and practice and some qualitative data to inform development of the interview guide.

**Fig 15 - Stage 3 (interviews) - Concurrent / exploratory:**



This stage focussed primarily on qualitative data, exploring thoughts, feelings and experiences but also explored some of the “nuts and bolts” of practice.

Using mixed methods provided an opportunity to explore both quantitative and qualitative data, enabling me to look at an area of practice which has been largely unexplored, allowing me to draw a more comprehensive picture than if I had taken either a qualitative or quantitative approach (Tashakkori and Teddlie, 2003). The approaches were used to complement one another rather than being combined in order to achieve the study’s aims.

## Research design

This next section outlines the research design - the means by which the data was sampled, collected and analysed based on the philosophical and methodological framework outlined above. Data collection was split onto three phases ; a scoping survey, a quantitative-oriented questionnaire and qualitative, semi-structured interviews, which will be outlined below. These were piloted before undertaking the fieldwork.

### ***Sampling and demographic information***

Finding participants in research can be challenge, especially when the subject is sensitive and (as discussed in chapter 2.4) not always seen as a priority for practitioners. This study used a non-probability type of sampling which narrows the potential participants within the population to those

which fulfil certain criteria (Lavrakas, 2008). Specifically I used a purposive sampling method as the sample was selected in accordance with the purpose of this study. Purposive sampling is subjective, based on the researchers perception of the target population (Lavrakas, 2008), and can therefore be subject to bias. However, it is a form of sampling which is appropriate for research with a ‘restricted population definition’ (Lavrakas, 2008) and applicable to using a mixed methods approach (Palinkas *et al*, 2015). It incorporates the identification of individuals who are experienced and knowledgeable about the area being researched (Cresswell and Plano Clark, 2007) who are available and willing to take part (Palinkas *et al*, 2015). Finding occupational therapists who broached sexual concerns and were able to make time to take part was a challenge. I used the scoping survey in stage one of the study to find possible participants and gather some general baseline data on the extent to which occupational therapists broached sexual concerns. Initially I embarked on the fieldwork with a narrow set of criteria limited to the UK and practitioners working with clients in physical settings between the ages of 16 and 65 years old. However, the difficulty in finding appropriate participants for stages two and three led me to be more flexible regarding participants and I extended this to include practitioners who had worked in other areas. Details of the data collection process are in the next section.

#### **Number of participants:**

Scoping survey	105	All online
Questionnaire	14 <sup>15</sup>	Both online / Word
Interviews	12	7 face to face / 3 telephone / 2 Skype

Below outlines the demographic information of the participants who took part in the questionnaire and interviews (figures 16 to 23).

<b>Figure 16: Age range</b>	<b>Number of participants</b>
<b>QUESTIONNAIRE age range:</b>	
<b>20-29</b>	<b>2</b>
<b>30-39</b>	<b>7</b>
<b>40-49</b>	<b>3</b>

---

<sup>15</sup> Due to a technical issue with the online questionnaire, there was some duplication where online forms were semi-completed and participants subsequently completed a Word version. Of those who completed questionnaires, 2 were unable or did not wish to undertake interviews.

<b>50-59</b>	<b>2</b>
<b>60 or above</b>	<b>0</b>
<b>Prefer not to say / left blank</b>	<b>0</b>
<b>INTERVIEWS Age range:</b>	<b>Number of participants</b>
<b>20-29</b>	<b>1</b>
<b>30-39</b>	<b>6</b>
<b>40-49</b>	<b>3</b>
<b>50-59</b>	<b>2</b>
<b>60 or above</b>	<b>0</b>
<b>Prefer not to say / left blank</b>	<b>0</b>

**Figure 17: Questionnaire / interview participants by stated gender:**

Questionnaires:

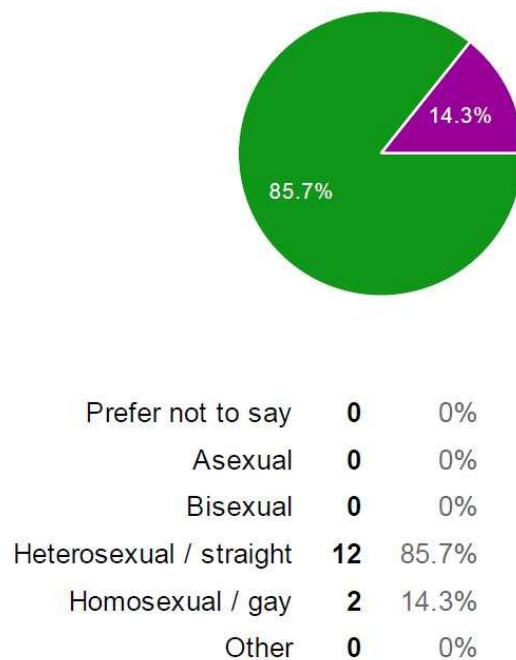
<b>Gender</b>	<b>Number of participants</b>
Female	12
Male	2
Prefer not to say / left blank	0

Interviews:

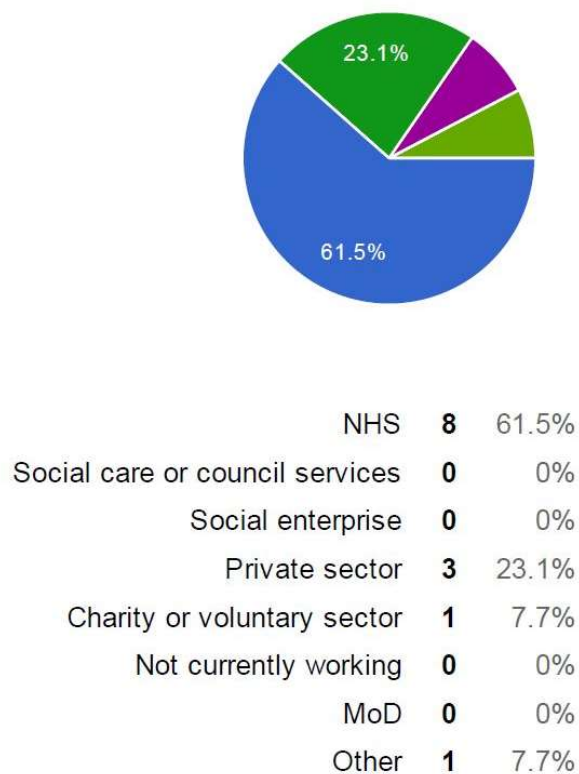
<b>Gender</b>	<b>Number of participants</b>
Female	10
Male	2
Prefer not to say / other	0

**Figure 18: Sexual orientation / preferences of the questionnaire participants only**

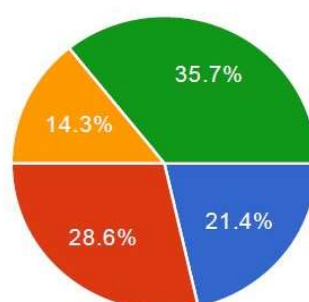
**What is your sexual orientation?**



**Figure 19: Questionnaire participants work sector at time of participation only**



**Fig 20: Questionnaire participants' occupational therapy experience only (years)**



Newly qualified to less than 2 years	3	21.4%
2 years to less than 5 years	4	28.6%
5 years to less than 10 years	2	14.3%
Over 10 years	5	35.7%
Prefer not to say	0	0%

The occupational therapists who participated in the questionnaire and interviews were 'outliers'; unlike the majority of those who took part in the survey and according to the literature within the profession generally, they did broach sexual concerns to the extent that they were willing to talk more about it as part of their work. However the majority did not include it as a regular, daily or even weekly part of their role, most describing it as occasional, that is, once a month or when asked. This flexibility in the sampling criteria became necessary due to the challenge of finding participants.

Below is an outline of the occupational therapists who took part in interviews, information has been kept to a minimum in order to ensure anonymity and I have used pseudonyms:

- Anthony – worked in the independent sector<sup>16</sup>, very experienced from a predominantly Learning Disability (LD) background.
- Carol – worked in the independent sector, very experienced from a predominantly neuro/physical background.
- Cathy – worked in the NHS. Although an experienced occupational therapist, Cathy was the least senior and comparatively newly qualified.
- Diane – worked in the independent sector in a management role, very experienced from a predominantly neurological background.

<sup>16</sup> Independent occupational therapists work in the private sector in a variety of roles. This can be with private companies, as consultants for legal or insurance purposes or in a freelance capacity.

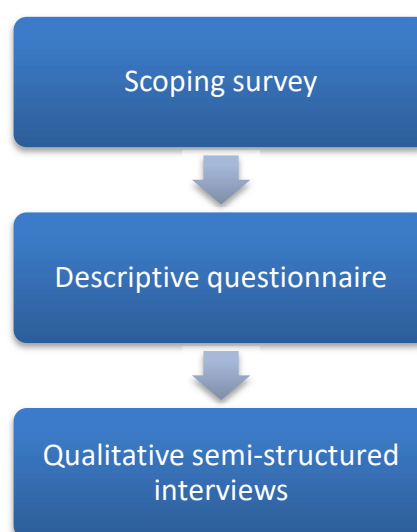
- Emily – worked in the NHS, very experienced.
- Jane – experienced occupational therapist who was working in a more generic role outside of the NHS at the time of interview.
- John – had worked in the NHS predominantly in mental health, working as an educator at the time of interview.
- Kelly – worked for the NHS, working in a neurology role.
- Lisa – worked for the NHS, working in a neurology role.
- Mary – worked in the NHS in a management role, very experienced predominantly in rheumatology.
- Nicola – worked in the independent sector in a management role, very experienced from a predominantly neurological background.
- Sarah – worked in the independent sector and as an educator experienced predominantly in LD.

### ***Data collection***

Potential participants were sent an invitation to take part through COT<sup>17</sup> Specialist Sections and via flyers at the COT conference, Naidex and The OT show which provided a link to information about the research, a consent form and subsequent survey / questionnaire, which can be found in appendix 4. Participants could also request these in Word or in hard copy.

The data was collected in 3 stages (figure 21):

**Fig 21: Data collection stages**



<sup>17</sup> College of Occupational Therapists now known as RCOT – Royal College of occupational Therapists



### *Phase 1 - scoping survey*

The aim of the survey was to scope the extent of practice and to identify eligible participants for the questionnaire and interview stages. Surveys are an effective and cost-efficient means of obtaining a large number of respondents in a short timescale. Scoping surveys are widely used in health related research in order to achieve a greater understanding of the area researched and in order to identify areas requiring further research (Davis *et al* 2009). The survey used a purposive sample (Holloway and Wheeler, 2010) accessed using COT Specialist Sections in HIV, Oncology and Palliative Care, Neurological Practice, Independent Practice and Rheumatology; the professional publication *OT News*, flyers distributed at Naidex, The OT Show and COT Conference 2016, and the Sexual Health and Disability Alliance (SHADA) organisation. The scoping exercise helped gain a snapshot of current practice, and identified participants for the questionnaire and interviews (Polgar and Thomas, 2008).

### *Phase 2 - questionnaire*

From the survey, potential participants were identified for the more in-depth research. The questionnaire was designed to ascertain descriptive, quantitative data on practitioner practice: what participants did, information on the settings they worked in, education and training they may have received, formal and informal assessment and interventions used. This was intended to provide background information and inform the development of the interview guide. Initially my intention was to link the questionnaire and interview data however in order to do this the questionnaire participants would have been required to register on the host site. This was problematic in two ways; I wanted to allow participants to remain anonymous if they wished to remain so, and I felt that needing to register would impact negatively on the number of potential participants. Given the limited time many practitioners have, I wanted to make the process as easy and quick to use as possible.

### *Phase 3 - interviews*

Interviews were conducted face-to-face, over Skype or via the telephone and provided an opportunity to explore qualitative questions on how the participants felt about this aspect of their practice, and their perceptions of challenges, barriers and facilitators (personal, organisational and client). The semi-structured interviews captured rich, detailed and contextual attitudinal data. My technique improved with practice which was reflected in the length and content of the interviews. The interviews were recorded using audio digital recording equipment, accompanied by notes to capture non-verbal communications. These were transcribed using 'Listen and Write' software by the researcher. The audio recordings, notes and subsequent transcriptions were stored securely on password-protected university storage, ensuring confidentiality was maintained. Participants were

then asked to check transcripts to ensure accuracy and quality, most of the participants agreed to the accuracy with one requesting amendments to ensure complete anonymity. The data was organised and coded using 'QDA miner lite' software, an open source equivalent to NVivo. Further information on how I maintained quality and rigour can be found in section 3.3.

I chose to undertake semi-structured interviews rather than focus groups. In semi-structured interviews the agenda is set by the researcher but it is not rigid, therefore probes and prompts can (and were) used to clarify and investigate further, and experiences could be explored further. Semi-structured interviews provide an opportunity to gain 'insider experience' and 'privileged insights' which would be otherwise difficult to explore (Polgar and Thomas, 2008), and acknowledged the sensitivity of subject discussed. For example, a focus group may have caused discomfort regarding attitudes to client sexual concerns or 'groupthink' pressure to say the 'right thing' (Matthews and Ross, 2010). Interviews can be difficult to standardise which impacts on reliability and increases the potential for bias. They can be a challenge for the novice researcher and time-consuming, however they are flexible and adaptable, providing the opportunity to follow up interesting responses and motives, and provide insights into actions and feelings (Robson, 2002).

### ***Piloting the study***

A pilot was undertaken to ensure that the research instruments formulated achieved the aims of the research. This involved testing the survey and questionnaire both in terms of content and as a practical tool, and trialling the interview guide. I tested the survey and questionnaire by enlisting former members of my undergraduate cohort, who are mostly employed as occupational therapists and with whom I was in a private Facebook group. This gave me 15 responses which helped test instruments as well as providing valuable qualitative feedback. Based on these responses I made several changes to the questionnaire, whereas the survey only required minor rephrasing. To pilot the interview, I enlisted two members of my undergraduate cohort – this gave me an opportunity to practice my interview techniques as well as gaining valuable feedback on the content of the interview guide. Copies of the instruments and the interview guide, along with accompanying material sent to the participants to ensure they were supported in line with ethical practice, can be found in appendix 1.

### ***Data analysis***

This section describes how the data was analysed. The qualitative and quantitative data sets were examined for syntheses and disparities. The scoping survey and questionnaire were made up of predominantly descriptive data, which were analysed using descriptive content analysis and

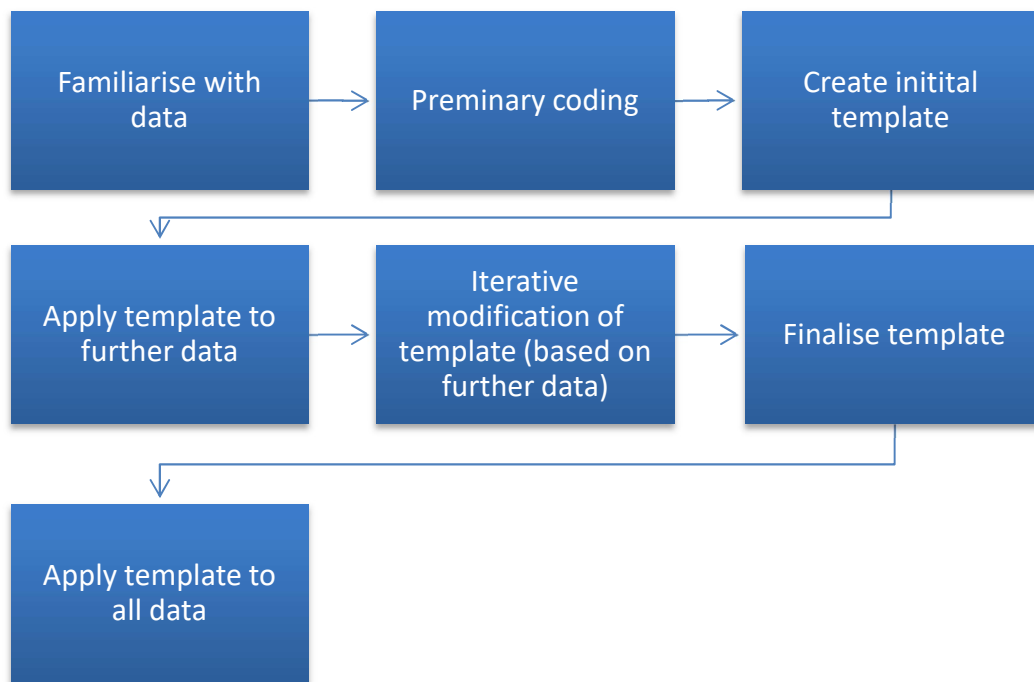
quantitative methods. The qualitative data from the questionnaires and interviews were examined with a conventional / thematic form of analysis (Pope and Mays, 2006; Matthews and Ross, 2010; Hsieh and Shannon, 2006), using Template Analysis (TA) (Brooks and King, 2014) to ascertain how occupational therapists made sense of their experiences and practice, and explained their feelings and attitudes. This meant the study was inductive, exploring the phenomena based on the data. Thematic analyses are rigorous methods of describing and enhancing understanding of the data (Elo and Kyngäs, 2007; Polgar and Thomas, 2008). King (2004) suggests TA works well when the focus is to examine 'the perspectives of groups of staff within a specific context' (p.257), as occurred in this study.

Template Analysis (TA) involves 'thematically organising and analysing data in social science research' (Brooks and King, 2014 p.3), this requires immersion in the process (Pope and Mays, 2006) by repeated listening and reading of the transcript, whilst reflecting (Hansen, 2006) and remaining mindful of the project aims. Central to TA is the development of a 'coding template' of the themes identified *a priori* or derived entirely from the data. In this study, themes were predominantly taken from the data, although the literature review influenced the interview guide and the initial template development. The key features of TA are hierarchical coding, whereby groups of similar codes produce a 'higher order' code, and parallel coding where the same text may be classified under two or more codes (King, 2004).

### *Process and development*

Analysis of the data and development of the template followed a process outlined by King (2004) and Brooks and King (2014), which I have illustrated below (figure 22).

### **Fig 22 – Template analysis process**



First, I immersed myself in the early data, grouping the data into codes (Hsieh and Shannon, 2006), systematically working through the transcripts to identify text which was relevant to the aims and objectives of the study to create an initial template. The template evolved throughout the analysis process as 'the initial template was applied in order to analyse the text through the process of coding, but was itself reviewed in light of ongoing analysis' (King, 2004, p.259) in order to reveal inadequacies in the initial template (King, 2004, p.261). When developing the initial template it was important to take what I saw as a 'Goldilocks' approach; too few codes may 'blinker analysis' overlooking data that conflicts with researcher assumptions, too many can leave the researcher directionless and overwhelmed (King, 2004, p.259). The initial template was then applied to more data, modifying the template according to what was found. The template evolved and was re-applied to earlier data to ensure all the relevant themes were included. King (2004, p.265) suggests there are several ways in which the template can be modified in order to reach the final template:

- Insertion – adding a new code
- Deletion – removing codes due to lack of data or which overlap with other codes
- Changing scope – too narrowly or broadly defined codes
- Changing hierarchy – moving up and down from higher-order classification

All of these types of modification were undertaken throughout the data analysis process. The final template was achieved by multiple readings and coding.

### *Advantages and disadvantages*

King (2004, p.268) suggests there are several advantages and disadvantages to using TA. Advantages include; it is flexible and adaptable, not 'bagged' with 'prescriptive procedures', simple to grasp, has a clear organised structure and process, it can be applied to both descriptive and qualitative data sets, and themes are not rigid but can be changed, discarded and given greater or lesser emphasis according to the data. In this way themes are organised so as to represent the data 'usefully and meaningfully' (Brooks and King, 2014 p.4). For my study, TA was congruent with CR<sup>18</sup> as it is not 'wedded' to a particular epistemological approach or theory and therefore could be tailored to match my requirements (King, 2004, p.257). TA permits the use of *a priori* codes and can involve greater 'balance between, within and across case analysis'.

TA also has several disadvantages, including; the lack of 'substantive literature' - it is still relatively new compared to other methods such as grounded theory or discourse analysis. There is the potential for being too shallow or 'too complex to be manageable' which can lead to the possibility that its simplicity may blind a researcher to the complexity of qualitative analysis. It can result in over-descriptiveness and individual participant voices can be lost in the themes. TA can imply the use of a linear approach and simple structures which aid clarity but may not reflect relationships (King, 2004 p.267). To counteract these disadvantages, I used CR to aid mapping between themes and understandings of interrelationships, and used reflection and occupational science perspectives to counter over-simplification and shallowness, always considering that people and occupations have a complex interrelationship. I used both supervision and a reflective diary to challenge and balance any personal bias and preconceptions during the data analysis period. TA is congruent with the pragmatism and the focus on 'what works', it also allowed for a pluralistic range of post-positivist and interactionist interpretations of the data in keeping with sexual script theory combined with materialism, and was flexible enough to incorporate mixed method data sets.

### **Summary: Research methods and design**

This section set out the practical instruments and decision making processes I used in order to conduct this study. As I developed this research I applied logical steps based on the post-positivist ontology adopted, with a pragmatic focus on 'what works'. I also encompassed an occupational science approach congruent with a "hankering" for considering the lived experience as a means of preventing an overly simplistic, mechanistic or reductionist outlook on the data collected. I attempted to navigate the subject mirroring occupational therapy by having a metaphoric 'foot in

---

<sup>18</sup> Critical Realism

both camps' between art and science. I felt that a mixed methods approach was the best fit with the needs of the study and with occupational perspectives in considering both realism and relativism. It allowed me to utilise both quantitative and qualitative data to uncover the "big picture" regarding occupational therapy practice which broaches sexual concerns, ascertaining information on the "nuts and bolts" of practice as well as the thoughts, feelings and experiences of the practitioners. Template Analysis allowed me to organise and analyse this data flexibly yet with a manageable structure which was supportive for a novice researcher, whilst reflection helped me overcome some of the disadvantages of this method of analysis, balancing out issues around over-description or over-complexity. Throughout I ensured that my research was undertaken ethically with due attention to maintaining the rigour of this study – how I accomplished this is described in the next section.

### 3.3 Ethics and rigour

This section will outline how I undertook this research within ethical frameworks and how I ensured quality and rigour throughout the research process, which are important to protect ‘the dignity, rights and welfare of research participants’ (WHO, 2011) and ensure research is carried out within ethical principles.

#### Ethical considerations

This research received ethical approval from the School Research Ethics Committee and was checked on the UK Integrated Research Application System (IRAS)<sup>19</sup> to ensure no further ethical approval was needed. The research process adhered to ethical principles outlined by the World Medical Association of Helsinki (2008, cited in Holloway and Wheeler, 2010) and guided by the (Royal) College of Occupational Therapists Code of Practice (2016); the Healthcare Professions Council (HCPC) code of practice (2016) and the British Sociological Association Statement of Ethical Practice (2002). The British Sociological Association (BSA - 2002) places the onus on the researcher to weigh the potential benefits of research against the potential for harm. Beauchamp and Childress (2009) distilled the core requirements of ethical practice as ensuring autonomy, non-maleficence, beneficence and justice. Below outlines what these elements are and how they were met in this study:

- **Autonomy** – the right to control of thought, action and intention, un-coerced.  
Participants should have the right to withdraw (Pope and Mays, 2006) and be provided with extensive information to ensure informed consent (Holloway and Wheeler, 2010). Although complete anonymity is difficult in qualitative research (Pope and Mays, 2006), anonymity and confidentiality is maintained by anonymising and securing all data and compliance with the Data Protection Act 1998 (Gov.uk, 2014). In this study, these conditions were adhered to. The data was only accessed by the interviewer (Aveyard and Hawley, 2007) and supervisory team. The participants could withdraw their data within a specified time period.
- **Non-maleficence** – do no harm.  
In order to mitigate and ensure the benefits of this research outweighed the risks, this study used several strategies to ensure no physical or emotional harm occurred (Holloway and Wheeler, 2010). These risks were mitigated by ensuring anonymity and confidentiality, and providing information to support the participants if distress arose. A risk assessment was carried out (see appendix 3). There were several possible risks including the potential

---

<sup>19</sup> Electronic system for gaining ethical approval for health and social care research in the UK - <https://www.myresearchproject.org.uk/>

embarrassment to services/organisations, the risk of triggering negative associations from the participants' past, and the potential for placing participants in a difficult legal or moral position regarding the sexual needs of their clients. At the close of interviews I asked the participants if they had any questions for me and ensured they were comfortable about what we had discussed. It was heartening to find that they had welcomed the opportunity to talk about this subject from an occupational perspective.

- **Beneficence** – the intention to do good.

This research makes a beneficial contribution to both occupational therapy practice and the lives of clients by supporting the inclusion of sex and sexual concerns as normal and legitimate concerns, encouraging holistic practice within the values of the profession. To ensure the beneficence of this study I used reflection, a reflective diary and supervision to ensure the ethical use of self (Tarling, 2002) and a moral, non-judgemental and self-aware approach to participants, the services involved and the data. With permission, study results were shared with participating Specialist Sections to support future practice, with further publications planned to disseminate knowledge.

**Justice** – fairness.

Fair and equal regard was given to the participants and their contributions, confidentiality and anonymity were maintained throughout data recording, management and analysis, and an honest and faithful representation of data given (Beauchamp and Childress, 2009). Data analysis was fair and balanced in order to ensure equality and justice, and interview participants were given the opportunity to check and confirm the authenticity of transcripts.

Ensuring ethical practice involved embedding these principles throughout the research process to ensure all participants were fully informed and supported, and treated with equal positive regard; that any potential for distress was minimised, and that anonymity and confidentiality were maintained. During this research this was particularly salient to avoid revealing the identities of clients or services. As the study involved a sensitive subject I was concerned about the potential discomfort of the interviewees and sought to create a relaxed, conversational atmosphere for the participants whilst maintaining a professional demeanour. In the event, all the participants were comfortable, interested and engaged; keen to share their knowledge and experiences with colleagues. Ethical considerations and anticipated risks were addressed throughout the research process; risks were assessed as part of the ethical approval process to ensure the study adhered to the principles of beneficence and non-maleficence. Risks were also assessed and mitigated throughout the study in keeping with the code of conduct of the occupational therapy profession. I



also considered my own well-being and security by making sure my whereabouts were known when undertaking interviews (details are outlined in the risk assessment in appendix 3). Throughout the research collection and analysis confidentiality and anonymity were maintained; names were anonymised, information which may have identified services was omitted and the data kept securely in password protected files.

In order to ensure informed consent the participants were given key information about the research and a consent form as part of the scoping survey, questionnaire and semi-structured interviews and with regard to recording the interviews. This ensured that participants had been fully informed of the features and aims of the study (Aveyard and Hawley, 2007). Data collected was held securely and will be destroyed within the required time frame after the end of the study. For the participants the study offered an opportunity to share their practice, thoughts and feelings, and an opportunity for reflection on an often overlooked subject. Capturing this information and knowledge provides a basis for reflection and foundation for widening practice in this area, ultimately benefitting both the profession and clients by supporting the inclusion of sexual concerns, an aspect of client's lives which is often omitted and ignored, in occupational therapy practice.

### **Ensuring quality, rigour and validity**

In order to ensure quality and rigour and improve the validity of the study, the study was conducted using an honest, transparent and accountable process. As this study progressed a significant proportion of the data collected involved qualitative methods; Pope and Mays (2006) suggest that qualitative research has had to overcome prejudice and misunderstandings within healthcare as issues of quality have been contested (p.82) due to the perception of being a 'soft option', the usually small numbers and in not seeking statistical representation. In order to counter this I paid attention to ensuring a transparent process. Rigour requires trustworthiness in data collection, analysis and interpretation and includes credibility, transferability, dependability (Lincoln and Guba, 1986):

- Credibility – truthfulness of data and interpretation;
- Transferability – applicability to other populations;
- Dependability – auditable so decision making processes can be followed;
- Conformability / neutrality – either absence of researcher bias / assumptions or bias has been clearly delineated.

(from Prion and Adamson, 2014)

In order to achieve this I used several approaches including member checking, transparency in describing my research methods and reflection in order to identify bias and maintained an honest research process. Below I have outlined how I incorporated several strategies in order to ensure and improve validity into my study:

- **Triangulation** – data from two or more methods of data collection or two or more data sources. Seen as a means of ‘ensuring the comprehensiveness of a set of findings’ (Pope and Mays, 2006, p.87). Triangulation can reveal support for or inadequacies in differing methods or how different data sets can be at odds (Noble and Smith, 2015, p.87). By using a mixed methods approach which incorporated both qualitative and quantitative data I sought ‘patterns of convergences to develop or corroborate an overall interpretation’ (Cleland, 2017, p.68) to provide a multifaceted view of the broaching of sexual concerns by occupational therapists;
- **Respondent validation** (member checking) – the researchers account is checked by the investigated. A means of reducing errors in the data (Noble and Smith, 2015, p.88). I asked the participants to check and correct the interview transcripts;
- **Transparency and clarity** – in the use of methods, data collection and analysis. Setting out the process and evolution of data analysis, as described here and in the previous section;
- **Reflexivity** – An awareness of how the researcher and process have ‘shaped’ the data, and an awareness of assumptions and biases. Usually taking the form of a diary as well as setting out ones position (for example, social class, professional status, ‘distance’ between researcher and researched). In order to counter-balance potential bias and to manage the sensitivity and potential feelings of taint discussed in chapter 2.5, I kept a reflective diary and used an occupational perspective to help me consider the ‘bigger picture’ of the data I collected;
- **Negative cases** – Exploring contradictory data. There was a great deal of agreement within the study data in terms of perspectives, however where there were contradictions or dissonance these were explored in the results;
- **Fair dealing** – incorporating and representing the differing perspectives and ensuring no one viewpoint dominates. I ensured all the data was collected and analysed fairly, considering all the relevant information provided.

(Noble and Smith, 2015; Cleland, 2017;  
Prion and Adamson, 2014)

Due to the sensitivity of the subject it was important to reflect on my own attitudes and the impact

of discussing sexual concerns could have on the comfort and thoughts of the participants. I used a reflective diary to consider my feelings and issues of 'awkwardness' which arose, particularly during the interview data collection phase. Using a reflective diary was particularly important in questioning my biases during interview and the data analysis. For example, here is an excerpt from the early stages of developing the template during the data analysis phase:

I'm going to have to simplify things as I think I'm mashing up my codes. It seems over-complicated. That is, should I re-do it or just jig it about. Stuff like discomfort – is it about meaning or attitude, or can I really separate the two? It's definitely more about attitude whereas meanings are more about values. It's interesting this data process – you think you have a grasp on it and then suddenly it's like wet soap.

The diary gave me an opportunity to question my processes and consider my thoughts and feelings. Using reflection throughout the research process, adhering to ethical principles and by showing my 'workings out' in this methodology section, I have ensured quality and rigour, and the validity of my results.

### **Summary: Ethics and rigour**

This section set out how I ensured this study was undertaken within ethical frameworks and how I ensured quality and rigour throughout the research process. I used a variety of strategies to ensure autonomy, beneficence, non-maleficence and justice, using reflectivity, triangulation, member-checking, fair dealing and transparency to make sure my research was fair, valid and rigorous.

## Chapter 3 Conclusion

This chapter set out the methodological theory and practical design of this study as well as how I ensured rigour, transparency, validity and an ethical process. This study applied pragmatic and post-positivist outlooks, using a critical realist (CR) approach, utilising mixed methods as a means of operationalising CR, congruent with using predominantly qualitative supplemented by quantitative data. Decision-making was based on my view that whilst we experience the world subjectively, there is a material 'real world' (for example, structural barriers, physical illness / impairment) which impact on the practice and lived experiences of the study participants and the clients they worked with. Sex and sexual concerns are complex and contested aspects of human experience and existence, subject to historical, social and cultural settings (Weeks 2003), as well as physical embodiment, and impacting on numerous aspects of life such as inter-relationships, identity, sensuality, decision making, self-awareness, intimacy, private behaviours and public presentation. The essentialist domination of medicine/psychology set against more constructivist approaches within sociology/humanities may limit the understanding of sex, sexuality and health; constructivism can disembodify the person, ignoring the real physical impact of impairment and disease, whereas an overtly essentialist position can focus entirely on the body encouraging an unchallenged focus on function and the individual, omitting social and cultural factors and meanings. The critical realist and occupational science approaches used to underpin this research were intended to unify the social-cultural and the body to avoid the reductionism implicit within this dichotomy.

This study took a pragmatic approach in order to ascertain the data I sought, coupled with a "hankering" to understand the thoughts and feelings of the participants. In order to do this I combined several research instruments to aid rigour and uncover the "bigger picture" in my exploration of broaching sexual concerns. This involved a survey, on-line questionnaire and semi-structured face to face interview. Due to the purposive, self-selecting sample, the results of this study are not generalisable but provide insight into the practice of outlier practitioners and practical information to support future occupational therapy practitioners. Throughout I ensured the research was undertaken transparently and ethically.

## Chapter 4: Results, analysis and discussion

The aims of this research were to investigate and explore occupational therapy practice when broaching the sexual concerns of clients (see box for a reminder of the research question, aims and objectives). This chapter sets out the results of the data template analysis, drawing together the literature and discussion. This was formulated around several themes drawn from the data identifying, exploring and investigating occupational therapists experiences of broaching sexual expression.

This part of the thesis focusses predominantly on the qualitative data from the interviews, supplemented by quantitative data from the survey and questionnaire used where appropriate in the exploration of this subject. This is due to the richness of the qualitative data which I felt would be particularly useful to practitioners. The first chapter (4.1) looks at sex as an occupation and the remit of occupational therapy. The second and third chapters (4.2

and 4.3) focus on practice and the comfort, discomfort and barriers within practice of those occupational therapists who broach sexual concerns. Chapter 4.4 examines how the participants manage and counter some of those challenges and barriers, invoking 'dirty work' countering strategies around professional values and identity. Lastly, chapter 4.5 examines some of the ambiguities and assumptions the participants negotiated when practising in this area.

### Study question, aims and objectives

#### Research question:

Does current occupational therapy practice support clients' sexual concerns and, if so, how?.

#### Aims and objectives:

Aim 1: Identify existing UK occupational therapy practice in sexual expression and intimacy;

- *To identify individuals and organisations which incorporate sexual needs / issues within their practice.*
- *To identify the scope of this practice.*

Aim 2: Explore occupational therapy practice regarding sexual expression and intimacy;

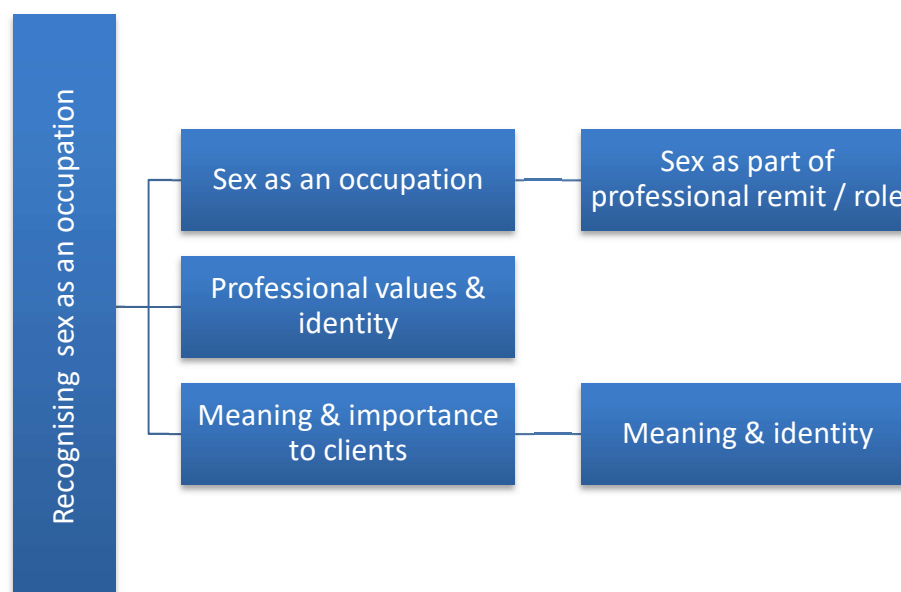
- *To explore this practice within the occupational therapy process.*
- *To investigate sexually related occupational therapy practice and its fit within the organisation / institution and the wider MDT.*
- *To investigate practical aspects, such as assessments and interventions, used in relevant practice.*

Aim 3: Explore occupational therapy practitioner attitudes to and experiences of practice concerning sexual expression and intimacy;

- *To investigate the attitudes and influences on individual occupational therapy practice in this area.*
- *To explore and examine the barriers and facilitators to this practice, as perceived by occupational therapy practitioners.*

## 4.1 Recognising sex as an occupational concern

This section draws on the survey, questionnaire and interview data to explore the study participants' views on sex as an occupational concern. The survey provided a quantitative overview of the participants' activities whilst the interviews provided an opportunity to explore what the participants thought about sex as an occupation in more detail, and provided some of the reasoning and nuance behind the survey statistics. As discussed in chapter 2.1, there has been debate as to whether sex may be regarded as an occupation. This study shows that a majority of the occupational therapists who took part saw sex and sexual expression as occupational, yet the majority did not include it regularly in their practice. This section also looks at the reasoning of those who include sexual concerns to explore why they saw sex as part of the occupational therapy remit. The interview participants indicated that they saw sex as an activity of daily living (ADL) and part of ordinary or 'normal' life, perceiving it as a meaningful and important occupation for their clients, linked to roles, identity, self-esteem and confidence. Due to this recognition they felt that sex was part of their remit as occupational therapists.

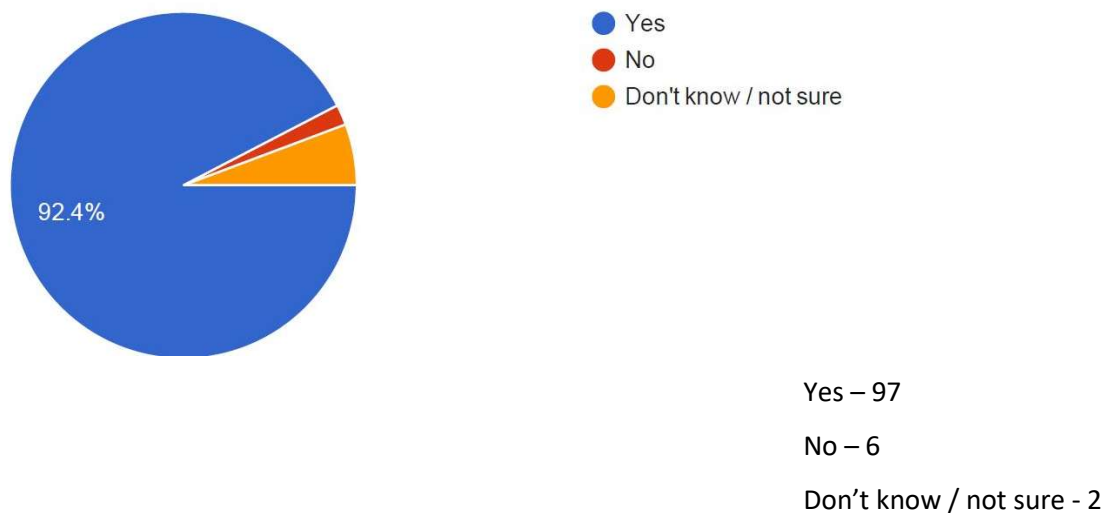


### Sex as an occupation

Out of the 105 participants in the scoping survey, 92% (97) felt that sexual function and intimate relationships were occupations, (see figure 23 below). This suggests a slight increase on the figure found by Parkin (2014) - 87%, Hyland and McGrath (2013) - 88%, and Couldrick (1998) - 90%, indicating a large percentage of UK occupational therapists have consistently felt that sex should be seen as an occupation. However, the low number of respondents couple with ,as with the literature, the possibility of responder bias (being self-selecting, many participants may have had a previous

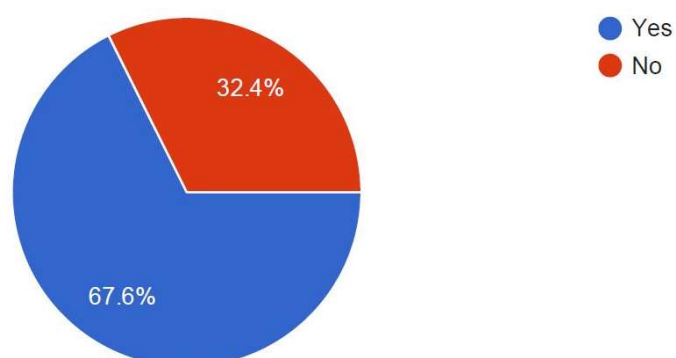
interest in the subject and therefore more likely to both take part in this research and express this opinion) means that this figure cannot be seen as generalisable.

**Fig 23 - Do you feel that sexual function / intimacy are occupations? (survey data)**



Although the survey provided an opportunity to provide qualitative data, none of the respondents who felt that sex was not an occupation took the opportunity to give qualitative comment. For those who replied 'don't know / not sure', one suggested that 'I feel that intimate relationships are more of a role than an occupation' - indicative of some ambiguity around how occupation has been defined within the profession as discussed in chapter 1.2 and 2.1. Of those who completed the survey, 68% said they included sexual concerns as part of their occupational therapy role (figure 24) – although the majority of these (59%) indicated they broached sex occasionally; that is once a month or when asked (figure 25).

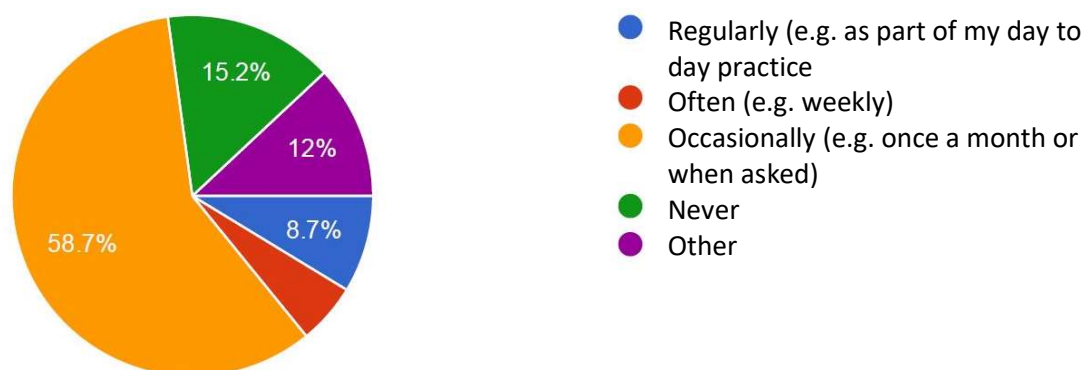
**Fig 24 – Do you include the sexual concerns of the client as part of your role as an OT? (survey data)**



Yes - 71

No - 34

Fig 25 – If so, how often do you address these client concerns? (survey data)



Regularly - 8

Often - 5

Occasionally - 54

Never - 14

Other - 24

Of those who did broach sex, only 11% felt they did so to the extent that they felt they could provide more information via questionnaire and/or interview. This may be due a limitation to the study around misunderstanding the criteria for taking part in the interviews, for example Carol indicated she was unsure whether she should be interviewed as she felt her experience was limited, but during the interview it was clear sex and sexual concerns featured regularly in her work. Aside from potential misinterpretation, this figure may reflect more pragmatic issues around having limited time to take part in an interview. As stated above, the low number of respondents means that this survey can only hint at the situation regarding broaching sexual concerns the time of undertaking the study, the survey's primary role being to identify occupational therapists who did broach sex regularly or often for the main focus of further exploration on practice and experience.

## Defining sex and sexual expression

The interview participants were fairly homogenous in their views of what sex and sexual expression included, despite their broad range of practice and geographical backgrounds. All of the participants felt that sex and sexual expression included a 'wide range of things', as Anthony put it:

...it can be anything can't it? - watching a film, looking at pornographic material, it doesn't even have to be pornographic, really, it could be just something stimulating that turns people on, your own enjoyment, pleasure or arousal, so that's sexual expression in a way,



isn't it? Masturbation, a whole range of things isn't it? Going on a date, holding hands, kissing, having a cuddle - a whole wide range or the most simple, basic touch or connection to - very passionate sex, boring sex, all things in-between really. All things. **Anthony (Non NHS)**

Emily suggested that sex included physical, spiritual and emotional elements: 'the whole spectrum of sexual practice', going on to say:

so the physical side - I mean that could be anything from people, if I'm thinking about a couple, people sitting close together, people holding hands, demonstrating affection to one another, demonstrating attraction to each other, so it could be kissing, it could be sex. It could be masturbation, it could be kind of games people play sexually - all kinds of stuff really, the whole - it's a very broad spectrum. **Emily (NHS)**

Carol also spoke of a spectrum of sexual activities:

So for me it sort of goes all along the spectrum, and whether it actually amounts to - or can physically - amount to sort of intercourse on one end of that scale but on the other end of the scale it's about actually just having a relationship that's different to a friend, that might involve a lot of physical intimacy and personal intimacy on a different level. And I'm not even describing that very eloquently but I suppose; it's that one-to-one, different to a friend. **Carol (Non NHS)**

Throughout the interviews, expressions such as sex and sexuality were sometimes used interchangeably by some participants, and defined broadly to include physical intercourse, emotional aspects of sex and the outward manifestation of feeling attractive, for example a questionnaire respondent in my research stated 'I believe for some people taking pride in their appearance has some relationship to expressing sexuality' (Q4).

### **Sex as an occupational therapy concern**

The study participants based their views that sex and sexual expression were occupations around two central themes; that sex was an ordinary, everyday part of life - an Activity of Daily Living (ADL), and that it is linked to their professional values around holistic and client-centred occupational therapy practice. Several participants felt that sexual activity was an ADL and therefore part of everyday life. Two of the questionnaire respondents commented that 'it is a very important aspect of everyone's life' (Q6) and that 'for many people being sexually active is an activity of daily living and one that plays a big impact on someone's social, emotional and physical wellbeing' (Q5). Several

interviewees concurred; Jane indicated that 'I think it should be because it's part of [...] activities of daily living, isn't it? It's part of normal life', whilst John noted that the reality of practice meant that the subject was likely to come up as a concern in clients' everyday lives, that 'those were day-to-day, everyday occupational things'. When asked why she felt fine about broaching sex, Sarah replied 'I just thought, well, it's normal'. Diane stated 'I would always see part of someone's sexual activity as part of their normal, healthy relationship, part of what we do', going on to say 'it's an ordinary part of life, it's an expectation, and also it's pleasurable, or even functional – whichever'.

The debate regarding whether sex could be considered an occupation discussed in chapter 2.1 was acknowledged by several participants, with two specifically mentioning the views of Gary Kielhofner, the influential occupational therapy theorist who felt that sex was not an occupation. Nicola reflected on this debate and on how she felt that sex should be part of her work because of its occupational focus and due to its meaning to her clients:

There's a lot of controversy, you've probably looked at this, there's a lot of controversy about some occupational therapists - I think it was Kielhofner - didn't believe, did he? that [sex] is an occupation? So we kind of have those debates .... You know, what is an occupation? What isn't? But I, and I think (I realised after doing research myself) that my practice is very occupation-based, we're not in the medical model at all, it's very, very much occupational-focussed, occupationally-based - there's got to be, we've got to be working towards that persons' meaningful occupation, and for me sex, sexuality, having - engaging in a positive relationship - that's all part of your occupations, isn't it? I think so. **Nicola (Non NHS)**

Nicola suggested that being occupationally-focussed meant rejecting the medical model, invoking professional values around a focus on what was meaningful for the client.

John perceived a conflict between discussions of what was considered as the remit of occupational therapy in theory, and what clients were saying to him in their lived experiences:

... there was a discussion on the internet about that we should not be involved with sex, drugs and rock 'n' roll as occupational therapists, or politics for that matter, or religion because [in Kielhofners view] these elements are not part of our remit as occupational therapists, and occupational therapists' business is purely clinical and getting people to function - fair enough. But the discussions I was having with clients [in a mental health setting] was that one of the main things going on was sex... **John (Non NHS)**

For the interviewees, there was little doubt that sex was an occupation and therefore part of their role as occupational therapists. Most saw sex as a 'normal' part of life which had significance and meaning for their clients. None of the study participants indicated they did not perceive sex and sexual concerns in this way, and subsequently they saw it as part of their holistic practice.

### ***Exclusively occupational therapy?***

Although all the interviewees felt that sexual concerns should be part of the occupational therapy role, views varied as to what extent and how exclusive that role should be. Several participants felt that occupational therapy was the ideal profession to deal with sexual concerns, for example Kelly felt occupational therapy attributes such as an holistic approach, a focus on every-day activities and mental and physical health dual-training meant that occupational therapists were 'perfectly placed' to broach sex:

Our training covers the physical aspects - the activity analysis and breaking down the practical problems that people have and finding practical solutions to any difficulties. We're also trained in the cognitive/ behavioural/ emotional side of things, so we can talk to people in quite a pragmatic way about how they feel, feedback around confidence building or appropriate behaviours. And because we're talking with people about all of their life, we're not focussing on anything specific, we talk about all the issues that they're facing in their lives, this is just another part of that. You've got the transferable assessment skills as well, so if you're looking at how people are able to do transfers, then you're looking at movement, tone, that side of things which is going to help you to think 'well, if they're in missionary position are they going to be able to get up from it?' whereas other professions aren't focussed on things in quite that way ... **Kelly (NHS)**

Lisa also suggested that occupational therapy was 'a perfect window' to discuss and address sexual concerns, whilst Mary thought that 'occupational therapy definitely helps', going on to say 'it is about considering occupations in the broadest sense, we as occupational beings in whatever, whatever that is, whether it's at school, home or wherever. And about what is meaningful to the individual, completely'. Some questionnaire respondents indicated that it should be part of the occupational therapy role as 'we assess physical and mental health, with a focus on supporting people to live as independently as possible and to engage in meaningful occupations' (Q1), going on to say 'I do not think that there is another profession that would address these issues'(Q1). Sarah felt that broaching sex was something which could be a fundamental part of the occupational therapy role, unique to occupational therapists:

... there's kind of an untapped thing, and nobody else is talking about it, we haven't really got a USP<sup>20</sup> for occupational therapy. If we linked ourselves into that aspect of it at least it would give us something where we could hang on every single group of people that we work with, because it underpins everyone's lives, every single person. Sex comes into your life or you're exposed to it, it underpins everything. **Sarah (Non NHS)**

These views were not the consensus, however; several participants indicated that although they saw sex as part of their role, they questioned whether clients would be comfortable about an occupational therapist broaching the subject, alluding to a general lack of understanding of the occupational therapy role, whilst other study participants indicated that sexual concerns should be broached by the most appropriate HCP within that context. Emily suggested that 'I don't think people are aware of what we can do' whilst Sarah pointed out the restrictive view of occupational therapists: 'I don't think people recognise that because they're socialised into thinking - this is what occupational therapists do, you know, we're washing, [dressing, etc.]'. Mary and Carol suggested that clients may not see sexual concerns as part of the occupational therapy role; Mary stated:

... part of it is the perception of occupational therapy, isn't it? Because if you go to a sexual health clinic you expect to be asked about your sexual habits, if you go into occupational therapy sometimes they still think they're going to see a physiotherapist. And there's no reason why a physiotherapist shouldn't be talking about sexuality and emotions and that area, either, but I still think there's a perception of people coming through the door who don't really know why they're coming to see me at all, to be honest **Mary (NHS)**

Carol also indicated issues around clients being unclear about the occupational therapist role:

I also don't think that's what they're expecting from me. So I think we just....a lot of the time people don't know what an occupational therapy does anyway. But I suppose when I'm talking to them and I suddenly start asking this, if they're not expecting it, I think it would be a bit ... flustery for people. **Carol (Non NHS)**

These comments reinforce suggestions that there remains a degree of ignorance about the role of the occupational therapy outside the profession, reflecting some of the challenges around professional identity and the struggles the profession has had in communicating its role and value as outlined by Molineux (2004), Mackey (2007) and Turner and Knight (2015).

---

<sup>20</sup> Unique Selling Point

Several participants felt that concerns around sex and sexual expression should be broached by the most appropriate professional and that sex should not exclusively be the remit of occupational therapists, indicating that other HCPs should also be involved. Carol, for example, felt it would be unfair on occupational therapists to be seen as experts in this area and that there should be access to more specialist support, saying; 'I sometimes do think you actually need to have access to experts. And I don't think occupational therapists are experts of that, I think it's a little unfair to expect us to be.' John felt that although occupational therapists had a role to play; 'I think it's possible that you can interpret stuff that you've been trained in, in the course of occupational therapy, in ways that would help' but also suggesting; 'I think that in many other respects a range of professionals should enable us to be able to have a perspective [...] I don't think it's exclusively an occupational therapy preserve'. John indicated that sexual concerns should be viewed as a multi-disciplinary issue, and not exclusively the remit of occupational therapy.

Some participants noted that their colleagues in the wider MDT found sexual concerns problematic. Reflecting the findings of Dyer and Das Nair (2013) and Haboubi and Lincoln (2003), Diane suggested that occupational therapists were not the only HCPs who omitted sex; her experiences indicated that nurses and physiotherapists also omitted sexual concerns, for example:

I don't know any physiotherapists who had gone down this line, and when I've been working with a physio, I'll say: - "Could you work on such and such?" and they reply: - "Yeah, I can do. What's that?" - "Could you just look into this or the spasm<sup>21</sup> for such and such because we're thinking of sexual positions?" - "WHAT?!" [laughs]. **Diane (Non NHS)**

Whilst several participants indicated that they were often the first HCP to broach sexual concerns with a client, for example:

I didn't see very much evidence of it being part of a typical assessment and certainly patients are assessed by doctors, nurses and research therapists before we see them, and I've never seen anything come up in their assessments, although the psychologist does touch on it slightly, but I don't think to the [laughs] nitty-gritty level that perhaps we do in occupational therapy. **Emily (NHS)**

Several participants suggested they dealt with sexual concerns because colleagues had passed clients on to them, with both Carol and Nicola indicating that dealing with sex had 'fallen' to them; Nicola suggesting that it was a 'hot potato' passed on from her non-occupational therapy colleagues whilst Carol noting that no one else was prepared to 'take it on' whilst she was willing to 'give it a

---

<sup>21</sup> Where a muscle may involuntarily contract or become tighter, or convulsive movement that cannot be controlled (Cambridge Dictionary [online], 2018)

go'. This could be seen as what Turner (2011) reflected as a perceived lack of understanding of the occupational therapy role by colleagues, and a tendency towards 'gap-filling' in the profession (Fortune, 2000; Molineux, 2004). However this did not appear problematic; Nicola seemed mused that her colleagues had 'passed the buck' onto her whilst Carol accepted that sexual concerns fell under her remit. Anthony spoke of how colleagues often referred to him as they were aware he 'had an interest' in the subject. Rather than seeing this as a negative reflection of their colleagues' attitudes and understanding of occupational therapy, they appeared to see it as indicative of their colleagues' recognition of the flexibility and strength of occupational therapy, and embraced broaching the issue as a fresh challenge, invoking their professional skills and knowledge to find solutions.

The study participants were largely positive about broaching sexual concerns, and some were critical of their occupational therapy colleagues who omitted these concerns; for example, Carol suggested the omission of sexual concerns was negligent whilst Kelly voiced frustration at colleagues who refused to include sexual concerns, stating that many of her colleagues 'just refuse to talk about it, used to tell people it wasn't part of their role. [pause] I find that quite difficult to cope with really'. Despite suggesting she had become less combative about the inclusion of sex, Sarah also stated she felt that by omitting sexual concerns practitioners were not being client-centred and that therefore:

... if they're not being client-centred they're not being occupational therapists - so take off the uniform, take off the badge and put another one on. If you want to be a nursing assistant or HCP assistant, that's fine, I don't have a problem about that, just be honest about who you are. **Sarah (non NHS)**

The study participants, then, considered sex to be part of the remit of occupational therapy but varied in their views as to whether sex should be the exclusive preserve of occupational therapy.

### **Taking an occupational approach**

In broaching sexual concerns, several participants indicated they adopted an occupational approach. For example, Lisa felt that being an occupational therapist gave her an opportunity to redress the balance towards being person-centred against the prevailing medicalised approach of her service:

Because the consultants in [the department] are so busy, they're only really concerned about medical management and the disease process not much on the impact it has on anyone's life, including their sex life and relationships, so then therefore I think occupational therapy is a perfect window to discuss and for someone to address that really... **Lisa (NHS)**

In contrast, Kelly felt it was important to 'be clinical' and professional to ensure the comfort of the client: 'We're there to talk about clinical things and if you're putting yourself across as a professional and bringing sex across as a professional, it will help people feel more comfortable about disclosing'. Kelly's comment raises one of the difficult challenges for occupational therapists within the organisations they work in; balancing the holistic and client-centred values of occupational therapy with both service demands and the desire to be perceived as professional in a predominantly medical hierarchy and in the eyes of clients, an idea of clinical professionalism which may be at odds with occupational therapy professional values and identity. Caccioni (2015) and Roberts (2006) indicated that the broaching sexual concerns in healthcare has been influenced by medicalised approaches whilst Shakespeare (2014) suggested that the medical model remains prevalent in perceptions of disabled people's sexual lives. Diane suggested that for some occupational therapists the dominance of the medical model had an impact on professional confidence or had created 'silo' thinking which was dissonant with an occupationally-focussed approach: 'I think maybe some of that lack of confidence and conviction in things sometimes outside the medical model and, you know, that "we can do equipment or we can do this, or we can work in physical or we can work in mental health"'. Persson *et al* (2001, p.16) suggests that this exclusive focus on a 'micro perspective' could lead occupational therapy to become 'meaningless and ineffective practice' failing to consider the 'bigger picture occupational issues'. This view was reflected by Sarah who felt that if an occupational therapist failed to work within their professional values then 'don't say you're an occupational therapist, 'cos you're not. If you're not doing occupational therapy philosophy, values, ethics - you could be a nursing assistant, or a physio assistant, what are you? You're not an occupational therapist - what are you doing there?!' She questioned whether 'a lot of occupational therapists in our current system in the NHS are even working as occupational therapists'.

Overall, the participants in this study had managed to create space to broach sexual concerns from an occupational perspective by retaining their professional values, either by working in parallel with the dominant medical model or actively countering it.

## Recognising demand, meaning and importance

A key factor in the participants' reasoning around sex as an occupation was their recognition that it was a meaningful yet unmet need for clients, which therefore demanded occupational therapy input and support. Emily spoke of how she felt that once given the opportunity to talk about sexual concerns, clients were keen to do so, suggesting that 'at the moment, 100% of our patients make reference to this'. Nicola also noted a demand for support from clients who were adapting to new situations, providing the example of younger people becoming adults: 'the people [that] are going through transitions, 18/19 year olds, who like I say have had a brain injury around their mid-teens, because they're kind of wanting to express themselves'. This suggests the study participants recognised sexual concerns as an unfulfilled demand from the clients, reflecting the findings of Shakespeare (2015), McCabe (1999) and Bahner (2012).

Several participants spoke about the meaning and importance of sex for their clients and how sex impacted on client roles and identity, reinforcing perceptions of sex as an occupation. For example, questionnaire participants stated that 'I feel sexuality and intimacy can involve activities which can be meaningful' (Q4), and that 'I do believe that sexual functions/ intimacy are meaningful occupations' (Q1). John stressed how sex was a part of ordinary life:

... it is the reason why people have relationships and live together, it's part of that reasoning, it's the thing that sustains people through longer lives, longer disability-free lives; more activity - they do things together, they go out together they go off and see their kids and grandkids and all that kind of stuff, and cement that relationship through renewed intimacy. It's the thing that's missing when you're on your own because you've had bereavement. These things, it's a really fundamental thing,

### The significance of sex

Emily provided an example of how sex played a significant role in how a client saw herself, speaking of a client who had a Long Term Condition (LTC):

*Nobody had ever asked her that question before and she was really relieved to finally talk about it*

The LTC had impacted on the clients' relationship:

*One of his quotes was 'I'm your carer first and your husband second' and so they were no longer really intimate at all, he felt very much like a staff member to her, but yet they...really missed that level of intimacy. She knew he was scared to touch her in any sort of tender way or at all really because of her pain condition*

Emily spoke of how she worked with her client using graded exposure and motivational interviewing until the client felt confident about raising the subject with her husband:

*Each time I've been in touch with her since she will makes reference to that as something that was a very significant time, and they've just been going from strength to strength.*

Emily's experience illustrates how a condition can impact on client roles and identity, working with the client to build confidence to re-connect with a meaningful and important part of her life.



it's a really fundamental aspect of being human, it is one of the things that underpins human productivity, and all that kind of stuff. **John (Non NHS)**

Throughout the interviews, the participants indicated that sex was a significant aspect of their clients' lives in terms of roles, meaning and identity, impacting on how their clients saw themselves and in relation to other people, as well as affecting their choices and occupations. There were suggestions that sex was a subject which some clients welcomed the opportunity to discuss due to this significance (see box). Sex was seen as part of a bigger picture of how the client saw themselves, for example, Cathy suggested 'it's so important to the patient. And it isn't just sex, so much of it was about being confident with their body and their pain, and communication with their partner. There's actually so much more. It's a really huge topic'. This meaningfulness and significance was reflected in how the study participants acknowledged the impact of sex in relation to client roles, self-esteem and body image and intimacy and closeness with partners.

### ***Roles, self-esteem and body image***

Several participants indicated that impairment and illness had an impact on how clients saw themselves in terms of their roles, self-esteem, confidence and body image, which related to sexual concerns and were meaningful occupational aspects of their clients' lives. For example, Emily spoke of how self-esteem was the 'crux of the matter' for many of her clients, whom she described as having concerns relating to self-respect and self-esteem. Kelly indicated that body image and self-esteem had impacted on client confidence and feelings of being less attractive, which they struggled to adapt to psychologically. Cathy also identified issues of body image and self-esteem as having impacted on her clients:

I think from losing their roles like working or losing independence, so loss of confidence about themselves and body image as well, patients often find that their limb is so swollen or changes colour, it looks so different they don't feel comfortable about their partner seeing them naked or whatever, they feel like they look really different. **Cathy (NHS)**

Several participants linked client feelings of low confidence and self-esteem to their roles, for example, Emily spoke of male clients who 'don't feel like they're in their productivity role anymore, their masculine role, so we work on helping them re-engage with that' and observed the impact of erectile dysfunction on male self-image. Mary, Emily and Cathy spoke of the negative impact on how some female clients saw their roles within relationships with partners and within a family, for example, of 'the partners' fear of being rejected', a client who 'was worried [her partner] was going

to start getting fed up of it even though she knew he loved her'. Mary also observed how a clients' feelings about herself combined with her impairment, manifesting in anxiety about losing her role:

...a lot of her stuff was actually psychosomatic stuff about her role as a wife, and mother, and as a sexual being, and fundamentally she was worried that her husband was going to divorce her really, so unless you can address that then how can you address the pain 'cos it's part and parcel of the same thing. **Mary (NHS)**

These observations on roles, body image and self-esteem reflected how the participants took a holistic approach and saw sex as a meaningful part of their clients' lives and therefore linked to occupational concerns. Recognising sex as a missing aspect of their clients care contributed to its subsequent inclusion as part of practice assessment, reasoning and interventions.

### ***Closeness and intimacy***

Intimacy concerns, particularly in terms of relationships, were less likely to be avoided than more overtly sexual concerns and were often used as a means of 'opening the door' to broaching more sensitive sexual concerns. The assumptions inferred in using this strategy will be discussed further in chapter 4.5. During the interviews the participants indicated that sexual concerns were seen as more potentially challenging than intimacy due to their sensitive, taboo nature. Closeness and intimacy were perceived as meaningful and important to some clients by several study participants:

quite often [disabled] people will ring up [SHADA<sup>22</sup>] saying all they really want to do is go on a date, it's hold someone's hand - they miss that sort of, that sort of contact - and it's not just about sex and orgasm and all that stuff, but it's about more simple, basic things really. That's what they're looking for. **Anthony (Non NHS)**

I had some clients recently, husband and wife, wife had had a stroke, they were quite elderly and he wanted to know, because he was worried about her having another stroke if they got too active, so he brought it up and said "you know, we are quite old but we still like a cuddle, will it affect her if we do?" **Kelly (NHS)**

Diane suggested that it was 'company and touch and cuddles that they wanted, which is a very important part', whilst John felt that 'everybody is a human being and we all want some kind of

---

<sup>22</sup> Sexual Health and Disability Alliance – an organisation to connect and support healthcare professionals and disabled people in broaching sexual concerns.

togetherness with somebody, or many of us do'. The study participants also recognised that intimacy and closeness were linked to how their clients saw themselves:

I've had a lady before who was talking about cuddling and saying that it was really uncomfortable for her to even have her husband put his arms around her and how much she missed that. So then I talked to her about that and went down that path, that route, and I think for her that was the bigger - that was about intimacy really, [...] she just missed having a cuddle, and she did go on to talk about sex as well but it was the whole, just the idea of not being able to have a hug from somebody because you'd feel, because if you're tender and sort of uncomfortable, how that was for her impacting on intimacy, just her perception of who she was completely. It was really tied into her whole sexuality and how she felt about her body image. **Mary (NHS)**

Intimacy and closeness are not necessarily sexual in nature but the participants indicated that closeness, especially with partners and families, was important to their client's meanings, roles and identity. It shows that this was an unmet need and a concern which was important to the client. These comments reflected the findings of Shakespeare *et al* (1996) and Tepper (2000) which indicate that access to dating, intimacy and sexual interaction are important aspects of disabled people's lives.

### **Summary: Recognising sex as an occupational concern**

Reflecting the findings of Couldrick (1998), Hyland and McGrath (2013) and Parkin (2014), this section found that whilst many occupational therapists recognise sex and sexual expression to be occupational concerns, many practitioners omit sex

from their day-to-day practice. Whilst, the survey reflected previous studies such as Couldrick (1998), McGrath and Lynch (2014) and Yallop and Fitzgerald (1999) suggesting that many occupational therapists were unsure about how to broach the issue of sex and felt they lacked the education and competence to confidently raise it, the interviewees had chosen not to distinguish sex from other occupations. Of those participants who broached sex more regularly, all considered sex to be an occupational concern based on reasoning related sex as an ADL, around meaning, roles and

#### **Key points: sex as an occupational concern**

Study participants felt that:

- Sex is an occupation
- Sex is part of the occupational therapy remit

Based on reasoning around:

- Sex as an ordinary occupation / an ADL
- The meaning and importance of sex and sexual expression for clients
- The impact on self-esteem, body image and confidence
- That sex is an unmet need clients would like to have addressed
- The need to adhere to client-centred and holistic practice
- Countering the medical model

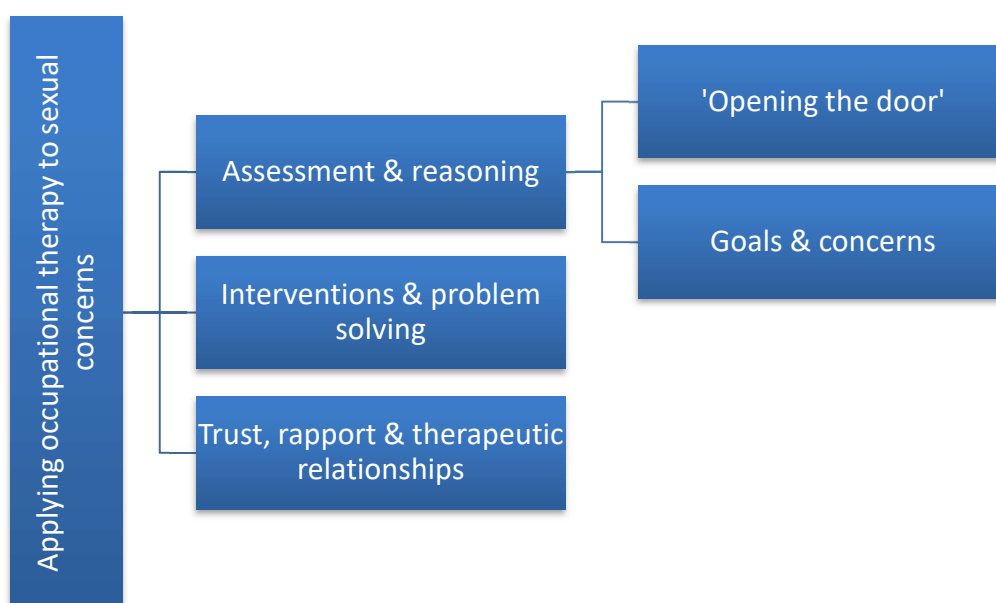
identity and their holistic client-centred occupational therapy practice, leading to the participants perceiving sexual concerns as part of their remit as occupational therapists. The interviewees recognised how these multiple facets of how clients saw themselves were meaningful and important, but were also ordinary parts of their lives which were not always directly verbalised, that they were 'part and parcel' of clients' lives and identity. The sense of meaning and yet ordinariness of sex was reflected in how sex contributed to the participant's recognition of how clients saw themselves. The homogeneity of the interviewees' views around the meaning and importance of sex reflect a consistent view of occupation and its value to individual clients. Despite some of the debated ambiguity around definitions of occupation, it was this professional belief that occupation has meaning and importance, and has a therapeutic value and role in their clients' lives, that contributed to the inclusion of sexual concerns in their practice. This perceived meaning and importance to their clients was manifested around client roles, self-esteem and body image. Recognising the impact of conditions and impairment on these meanings and identities contributed to the interviewees' perceptions that broaching sex was part of their holistic practice as occupational therapists, that if occupational therapy is about meaning and purpose, then this includes sexual concerns.

The participants' perceptions of their role were congruent with Crabtree's (1998, p.205) suggestion that the profession's philosophy should be more about 'the ideal state of the individual' – wholeness, fulfilment, authenticity, going beyond health, that is 'the essential nature of human beings is making and expressing meaning through occupation'. Occupational therapy can be about 'meaning-making' through transformation or development rather than skills building, although building skills can be a part of this. A focus on competency in particular skills could constrain the client and limit their opportunities, and place too much onus on the client fitting-in with an intervention rather than *vice versa*. Despite Clouston and Whitcombe's (2008) suggestion that occupational therapy identity is undermined by being about 'everyday life' and activity based on 'common sense', making it 'taken for granted....habitual and therefore not highly valued' (p.318), the participants indicated that these 'everyday' and 'common sense' aspects of occupational therapy were valuable to their practice, and meaningful and important to their clients; this 'everydayness' helped them put the client at the centre and include sexual concerns as an ordinary part of the whole person, highlighting the professions flexibility and ability to find practical solutions to problems, looking at client needs and bridging the gap between medicalised approaches and what the client wants and needs, bridging science and lived experience, function and 'art'. The

participants, then, recognised sexual concerns as occupational concerns and applied their practice skills and knowledge as part of their holistic and client-centred occupational therapy practice.

## 4.2 Broaching sexual concerns in occupational therapy practice

This section focusses on the practice aspects of the participants, looking at how they used and applied their professional skills and knowledge in relation to sexual concerns. This is an area which has not been studied previously and which the literature (and participants) in this study indicate there is a demand for further information. The participants indicated that they applied an occupational perspective and focus to the sexual concerns of their clients, applying their professional skills and knowledge by using or adapting their day-to-day assessments and interventions, often treating sexual concerns like any other occupation, albeit one which they indicated required rapport, trust and consideration of the sensitivity and taboo around the subject.



### Assessment and reasoning

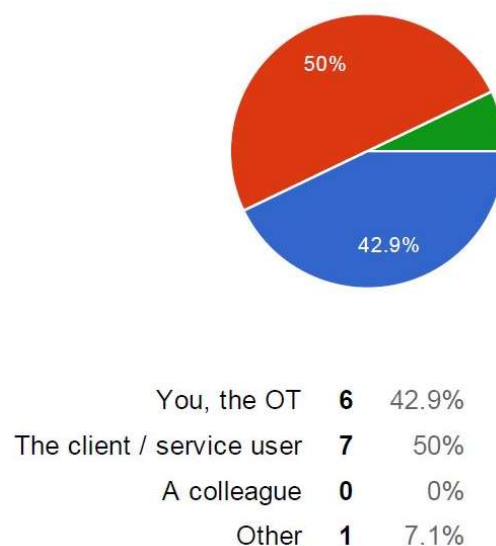
As discussed in chapter 2.4, both anecdotally and in the literature, occupational therapists have indicated difficulty in raising the subject of sex with clients (Couldrick, 1998; Hyland and McGrath, 2013). I asked the participants about the types of assessment they used in the questionnaire, followed by discussion on how they broached or dealt with the subject and their feelings around assessing sex during the interviews. The participants predominantly used non-standardised assessment (see figure 26), often using their professional reasoning to decide whether to directly include sexual concerns.

**Fig 26 – How do you go about assessing client needs? (questionnaire data)**

Non-standardised assessment = 7 – 58.3%  
 Internally designed document / form =1 – 8.3%  
 Standardised assessment =0 – 0%  
 Other =4 – 33.3%

Study participants indicated an almost even split between who usually raised the subject first, the participant or the client (figure 27):

**Fig 27 – Usually, who raises the subject first? (questionnaire data)**



This may reflect the sensitivity of the subject, indicating the participants' consideration in how sexual concerns were approached and raised with the client. This sensitivity was alluded to in the participants' use of language when talking about assessing client needs; they spoke in terms of 'opening the door', 'teasing' it out and 'finding a way in', suggesting they sought ways of giving or gaining permission to raise and discuss issues. For example, when asked about how she might broach the subject, for example, Nicola suggested 'it depends on the client. So it is that perception of "where's my way in?"'. Mary felt that although sex 'doesn't usually come up specifically as a goal [...] although clients might say that they're experiencing pain. And sometimes if you unpick that a little bit more they'll then disclose that'. The language used by the participants suggested they attempted to gently approach the subject with their clients:

We don't have a set question in our initial assessment about intimacy, but we do...we ask about [the condition], we ask about home circumstances, partners, boyfriend, husband, whatever, and then often you can kind of tease it out within that. **Cathy (NHS)**

If you're certainly feeling that people are a little bit worried about it I would say, I think I would ask "are you in a relationship?" and if they say yes, "is it going well?" And if they go, "oh, well...", [I] go "how has it changed? are there some things you're not doing now that you'd like to do again?" and I'd skirt around it that way, they're not going to say "I'm not having sex anymore" and if they do say that then you say "alright..." **Diane (Non NHS)**

The interview participants used a variety of assessment strategies, seeking ways of 'giving permission' to their clients to talk about concerns or finding discrete means of gaining implicit permission from their clients to gain consent to raise the subject. Mary indicated that it was not something she would specifically ask her clients but would base questions around what she had observed, for example 'often if I notice they have restricted movement in their shoulders, and then that might move on to a conversation about anything else that they find difficult'. Lisa suggested that people might feel 'okay to bring it up' discussing other problems such as around relationships, but that she had 'never had anyone bring up anything to do with their sex life at all or the impact of that.' Emily suggested she invited discussion by discretely asking around self-care:

What I'll say is "we're thinking about your self-care and self-care could include learning to relax, it could include things about your sleep, it could touch on levels of intimacy with your partner which many people tell us has become a problem", and then I normally take a breath and then the person will say "oh no I really want to talk about that". **Emily (NHS)**

Cathy spoke of how she had learnt that removing potential barriers between herself and the client by putting aside paperwork and speaking conversationally with the client, helped disclosure of concerns: 'Often, having just put the paperwork away, and then just talk - all kinds of stuff will just come out, whereas if you stick to a script of "and how to manage getting on and off the toilet" that's when you miss stuff'. Sarah stressed the need to keep assessment simple but to make sure it was included as an ordinary part of people's lives and to be receptive to client concerns:



... you can ask quite broad questions; how has that impacted on your relationship? [...] If you say, you know, how is that impacting on them? has anything changed? [...] So make it an ordinary - don't make it something [...]. Just slot it in between so people will hardly notice, okay, sort of open the door for them to talk about it if they want to.

Although none of the interviewees directly referred to the use of models to inform this aspect of their practice, the approaches described reflects documented models for the inclusion of sexual concerns, PLISSIT or Ex-PLISSIT (Davis, 2005; Taylor and Davis, 2006 - see box and the Recognition Model (Couldrick *et al*, 2013; SHADA, 2013 – see box), this appears to be a strategy the participants were employing to broach sexual concerns. Despite this sense of 'giving permission', the degree to how directly sex was raised as a concern varied; Mary suggested that 'it's a social embarrassment for a lot of people to be talking about that'. Both Carol and Jane felt it was not always appropriate due to the clients' condition or concerns about raising expectations:

I think that is actually valid because if I'd had gone in and said "oh how are all these things?" and they say "everything has fallen apart, our lives have fallen apart" and then I ask "and what about your sex life?" That's not appropriate, because - maybe that's another assumption of mine - but I think that comes, sexual intercourse comes at a point in your life when everything else is calmer. **Carol (Non NHS)**

### **Models for including sexual concerns:**

#### **PLISSIT / Ex-PLISSIT**

The PLISSIT model (Annon, 1976) was developed to support HCPS and sex therapists in broaching sexual concerns with clients.

- PERMISSION – giving the client permission;
- LIMITED INFORMATION – providing information or referral to support services;
- SPECIFIC SUGGESTIONS – in-depth support on specific concerns;
- INTENSIVE THERAPY – referral to intensive therapy for underlying issues.

The Ex-PLISSIT model (Davis, 2005; Taylor & Davis, 2006) evolved in response to a tendency of HCPS to providing information without involving the client in discussion or an opportunity for them to disclose concerns. Ex-PLISSIT placed greater emphasis on giving permission, reflection and on-going assessment. The focus on 'opening the door' and creating a relationship in order to discuss sex indicated that the interviewees were using an Ex-PLISSIT model, albeit perhaps unknowingly.

#### **RECOGNITION MODEL**

This model was intended to promote sexual health by physical disability teams follows 5 stages:

- Stage 1 – recognising the client as a sexual being;
- Stage 2 - granting permission to clients to discuss their sexual concerns;
- Stage 3 – exploring and identifying issues
- Stage 4 – addressing issues within team expertise / boundaries
- Stage 5 – referral / advocacy

(Annon, 1976; Davis, 2005; Taylor & Davis, 2006; SHADA. 2013: Couldrick *et al*. 2013: Wikipedia. 2017)

... some people are in so much pain, for example, that it's probably the last thing on their minds, and it's just about getting through, you know, getting through the day or whatever, you know - why raise yet another thing that isn't going to be able to be resolved for them?

**Jane (Non NHS)**

These reflect the assumptions indicated by the literature that if a client is considered too ill or too old sexual concerns are less likely to be broached (Saunamaki and Egstrom, 2013), however there were no indications that the participants had ageist attitudes suggested by a minority of HCPs by Dyer and Das Nair, 2013.

As with other aspects of their practice, the process of assessing when and how to broach sexual concerns, and with whom, was based on the participants' professional reasoning. For example, Mary based this decision on other issues which arose during her assessment:

Sometimes I'll see people and I can see that they've got very restricted shoulder movement and if I'm assessing that I'll say "can you bring your hands to your chin? Can you put them behind your head and behind your back?" [...] but you're not actually assessing - there's nothing that you're assessing in the range of movement that would necessarily lead you to say "do you had any difficulty having sex?" [laughs], and it probably isn't appropriate either, but if clients bring - if you are asking open questions of clients, asking them how they're managing, and if you're asking if there's anything in particular that's causing them any problems, and they feel that they can disclose it or they want to disclose it, or it's an issue then it's about providing the opportunity in the same way as you would for any other functional activity or occupation. **Mary (NHS)**

Diane described how she would base her decision on 'just going by reading what people, how people's body language is, how they were together, and certainly if there's any frustrated behaviours'. Some of the participants spoke of how they would introduce the subject in terms of relationships, for example Lisa stated that 'I kind of ask a little about how it's affecting people's hobbies, work, employment, and I would then ask about relationships as well, I don't necessarily ask them directly about sex but I would always ask about their relationship'. Cathy spoke of how she used her reasoning to ascertain who and how to ask:

I don't think I've ever been taught that [when to ask] but it just feels quite natural in interviews and often I know whether it's right or not to ask. I don't know whether we should

just ask everyone as a blanket question, but it just doesn't seem right sometimes just because of how distressed and how many other issues. You know, sometimes we just have to prioritise what we're getting out of the assessment. **Cathy (NHS)**

Choosing the right time to discuss concerns could be challenging. Like Cathy, Anthony suggested that sometimes his clients were not always ready to discuss the issue:

... sometimes it's just not appropriate, if you work with a client really early on and they've just kind of come out of coma, they're just glad they're alive - you don't really start talking about sex and relationships, at that stage - probably not appropriate. [Maybe] further down the line - it really varies. **Anthony (Non NHS)**

Whether it was always appropriate to broach sex could be down to the client's condition or it could be complicated with concerns around how it might be perceived. Jane and John suggested there was potential for leaving oneself open to accusations of inappropriate behaviour, for example:

if someone asks me to do something I do kind of feel "oh my goodness" not because [pause] that they might be asking me something I don't want to do, it's just, it's just opening up this minefield about what should I do, what shouldn't I do. **Jane (Non NHS)**

She went on to say: 'I think I'd be worried that, erm, it could be thought by someone else that I was [pause] putting an idea in their head kind of thing'. John suggested it was important to think about the context of talking about sexual concerns:

...these are areas where you have to be very, very careful because is what you are suggesting going to be something that might look like an abusive relationship - are you grooming that person? You are in an environment where those sorts of behaviours or even that kind of discussion could lend itself to grooming behaviour. Really think carefully before you ask some of the questions - well okay, is this directed at me? Is this directed at having a relationship? Who is this person having a relationship with? Is this person a child, an adolescent, an older person who may not have a full ability to control things? What is going on? What do I know? Do I know enough about this situation before I start to weigh in with my two'penny' worth of advice? Where have I had the training from, to do this? **John (Non NHS)**

Carol suggested there may also be a concern about causing offence, saying:

I think sometimes people are fearful too that they might get into trouble about it, like they're going to, that whole thing about offending someone. Because everybody is so private, you don't always understand other people's contexts or their sexual world. **Carol (Non NHS)**

These comments reflect the sense that broaching sexual concerns can be a 'can of worms' indicated by the literature (Gott *et al*, 2004; Dyer and Das Nair, 2013), suggesting that sexual concerns are complicated by negative socio-cultural sexual scripts around risk and taboo. Judgment and reasoning around when it is appropriate to assess sexual concerns, and how to go about doing so, involves the complex navigation of sex as both ordinary yet exceptional (Jackson and Scott, 2004). Whilst the literature indicates that occupational therapists are concerned about the potential to cause embarrassment or offence, or the impact on their professional relationships (Couldrick, 1997; Dyer and Das Nair, 2013; Mellor *et al*, 2013), none of the participants in my study expressed unease that broaching sexual concerns could potentially damage their relationships with clients and carers.

Whilst Mary questioned whether directly broaching sex was always appropriate and raised the subject indirectly based on other aspects of her assessment, in contrast, Sarah felt the subject should be raised more directly to ascertain readiness to talk about sexual concerns on the part of the client:

Sometimes it isn't, it's "whoa, I just need to get my body back in line and get home, and then that'll be" because in terms of people's lives they've got their own Maslow's hierarchy of what's important, sometimes that's way off the list, especially when it's people in their 60's, some people in their 60's might be their biggest concern, and so if you don't even ask people you're not addressing even their concerns and people are going away still concerned about it. **Sarah (Non NHS)**

Sarah felt it was important to discuss sex within assessment to ensure client needs were not missed. She noted that sexual dysfunction could be a clue to other health problems and indicative of other problems which may need support and which clients may be unlikely to verbalise directly themselves:

...the first sign of heart problems is erections because that's the smallest artery, so when people start presenting with difficulties of erection you need to be looking at their arteries or are they on the risk list? That's the first clue. GPs know. But we don't know because we don't ask the question. So you could do some preventative work. That's just in cardiology.

Stroke - may be similar things. Depression, anxiety...going back to relationships; maybe I'm gay and I'm trapped in this heterosexual relationship. If we never have those conversations, we never go exploring there. And people don't bring it up because they're don't know they can talk about it. **Sarah (Non NHS)**

This suggestion of sexual concerns as a hidden need or demands was also inferred by other study participants who noted that when the issue was raised, as Emily suggested, 'people just always look very relieved when they realise they can talk about it with somebody who isn't going to look uncomfortable'. Cathy also noted sensing a 'huge weight lifted' in some clients, whilst Kelly stated:

Often it's just a case that people just discuss it or air their concerns or whatever, they just feel much better about it even if you don't necessarily come up with a huge plan or conclusion or anything. Just the fact that they've aired it to someone neutral, who's not in their family or anything then that often just helps.

*Interviewer: It sort of takes that concern away from them?*

Yeah, absolutely. And when they hear that it's very common and it affects a lot of people, I think again that gives them a bit of a relief really. **Kelly (NHS)**

Although the participants in this research broached the sexual concerns of their clients, most were selective about with whom, when and how to assess a client about their needs, seeking ways to give their client permission to raise any concerns rather than always directly or overtly bringing up the issue. The participants used their professional reasoning to ascertain when and how to assess their clients about sexual concerns. This was often based on subtly giving permission to either raise the subject themselves or 'invite' the client to bring up their concerns. The participants often used relationships as a means of opening discussion, although this may be a potentially problematic, as will be discussed further in chapter 4.3.

### **Client goals and concerns: interventions and problem solving**

During the interviews, I asked the participants about the issues they had come across which I have summarised below (see figure 28). Some of these concerns were specifically about sexual performance and function, whereas some were related to other aspects of client's lives such as body image, confidence, self-esteem, fatigue, role loss and adjustment to disability – areas which may have a direct or indirect impact on other parts of their lives such as work, social lives, non-sexual relationships and self-care as well as sex and relationships. As indicated in the WHO (2105) definition of sexual health, sexual concerns are not distinct and separate from other parts of clients' lives but, as Mary put it, 'part and parcel' of their lives and experiences.



**Fig 28 – Concerns arising during the interviews**



I asked the participants about some of the interventions they had used to broach some of the concerns discussed above. The questionnaire indicated they used an array of interventions, broadly categorised in figure 29 below:

**Fig 29 – Types of interventions used (questionnaire data)**

Adaptive equipment provided by service	4	30.8%
Advice on equipment purchase - for the service user to purchase	4	30.8%
Advice on positioning	8	61.5%
Fatigue management	6	46.2%
Referral to other services	4	30.8%
General advice and guidance	7	53.8%
Other	2	15.4%

The predominant interventions were around providing guidance, advice and information. During interviews, I asked about more specific interventions and solutions they had used when broaching sexual concerns. These could involve being creative and resourceful, coming up with new ideas or improvising with the resources they had available. At other times these interventions could be described as ordinary, 'bread-and-butter' occupational therapy interventions which were part of their everyday practice. Several participants spoke of their difficulties in finding appropriate and safe interventions and support, largely due to limitations on what was feasible, available and within the resource constraints of their service. Whilst independent occupational therapists were less resource limited, they also spoke of difficulties in finding services which were appropriate for their clients. Figure 30 below outlines some of the interventions discussed:

**Fig 30 – Examples of interventions used (interviews)**

Graded exposure	Fatigue management	Advice on positioning	Role play	Adaptive equipment to aid masturbation
Finding client-friendly sex toys	Desensitisation, sensory input / sensory memories	Supporting access to social / dating opportunities	Advice on using 'safe words'	Listening, acknowledging and reassurance
Sex & relationship education	Information provision	Referral to other services / charities	Advice on socialising and behaviour	Impact of equipment in home
Motivational interviewing & coaching	Supporting access to sex workers	Liaising with police regarding sex workers	Planning	Sensual bedding / clothing
Confidence & esteem building	Advising on alternatives to penetrative sex	Raising awareness of inappropriate behaviour	Scheduling time with partner	Psycho-educational input
	Supporting self expression	Communication skills	Improving fitness levels	



Some interventions were directly related to sex and sexual activity, for example Diane spoke of an occasion where she supported a client with issues of high tone<sup>23</sup> who had concerns about masturbating due to fears he may not be able to control grip and movement and thus injure himself. Diane used creative problem solving to come up with a potential answer:

I was walking around some exhibition somewhere and I saw a really large, not the small ones, but a large grip – you see, such an occupational therapist! - a larger gross grip water bomb that if you just, if you hold it and just squeeze it gently enough to hold it, it wobbles [...] and I thought ‘what an excellent movement’, because if you squeeze it too hard it shoots up in the air so you know that you’ve gone into spasm, so I said [to the client] “I’m going to lend you this, see what you do, if you can manage to do that for a minute, you can try it, can’t you?” **Diane (non NHS)**

This intervention was successful. Diane had assessed the problem and applied her skills and knowledge to support her client in an occupational goal.

Several participants spoke of the difficulty in finding suitable solutions, and so used their problem-solving skills to creatively improvise interventions, despite a lack of available specifically designed adaptive equipment for broaching sexual concerns. This could involve improvising using existing equipment, such as Diane’s creative use of a ‘water bomb’ described above, or adapting and using available resources. Emily and Cathy spoke of how they used a variety of fabrics and materials to help their clients manage pain by supporting sensory changes, which Cathy described as ‘kind of like re-wiring the nervous system so that rather than focussing on pain we get people to remember pleasant sensations from before they had the condition’. This involved invoking ‘sensory memories [...] getting the patient to focus more on the feel of things other than the pain, so the pain was still there but it’s not the main focus, that’s our aim, so it’s not at the front anymore’ using desensitisation routines and graded exposure to pleasant sensations to change how their clients processed sensory input, building their confidence. Cathy and Emily also accompanied or encouraged clients to visit high street lingerie / ‘sex shop’ Ann Summers to not only help them find clothing and aids which could provide pleasant sensory experiences to help with pain management but also to help them re-connect with their sense of selves as ‘sexy’, to ‘get their imaginations going again’, and provide the opportunity to become comfortable with talking about sexual concerns with partners, and thus support improved body image, self-esteem and confidence.

---

<sup>23</sup> Involuntary increased tension in muscles making them difficult to relax or move.

Other interventions were less directly linked to sex, for example where an activity indirectly supported sexual lives such as access to social opportunities, as John suggested:

There might be things that they do or are interested in which you can tap into [...] okay, let's get people baking, let's get people writing, or let's get people painting pictures or going to adult education classes. Those are actually the vehicles that people traditionally use to base their relationships around, it's not about sex upfront, it's actually about finding out after 6 months of art class you've actually got the eye for somebody and they're got the eye for you - fair enough! So actually it's kind of like, it's a primary thing but also it's the product of a secondary thing, and maybe one of the things that we might teach people is that the way to use occupation is a way to use occupations as a way to navigate their way into relationships.

**John (Non NHS)**

The participants indicated that they used their day-to-day occupational therapy skills and practice to assess and find interventions to broach the sexual concerns of their clients. This could be challenging due to the lack of appropriate resources and other barriers which will be discussed further in chapter 4.3. They often had to draw upon creative problem solving and improvisation to support their clients.

### **Trust, rapport and therapeutic relationships**

A key factor all the participants indicated in this was the therapeutic relationship. All the participants who broached sexual concerns alluded either directly or indirectly to the importance of trust, rapport and the therapeutic relationship as important factors in facilitating the broaching of sexual concerns, with some participants suggested that either failing to build that relationship or conversely getting too close to a client could impact on 'opening the door' to discussion or on whether a client would feel comfortable in disclosing their concerns. This section will look at the participants' thoughts and feelings on this relationship.

Rapport, trust and therapeutic relationships featured highly in the data. Cathy suggested that 'it's so much what it's about, that relationship, 'cos otherwise a person would never feel able to talk about this, so yeah, building a rapport'. Nicola indicated how this developed into a situation where the subject could be broached - 'if I felt that I've got enough rapport and we'd talked and we'd edged onto those subjects then I might talk about it a little bit more at the time'. Mary indicated that this was based on the clients feeling that they could trust the individual therapist and that occupational therapy could do something to help. She felt that 'clients won't disclose that information with you unless they feel secure that you can, first of all, handle the information and help them with it'. For

Diane, the client's ability to trust the therapist was imperative, and this was based on the behaviours displayed by the therapist, suggesting 'you can't trust somebody if they're embarrassed or if they can't talk about it'. Here, Diane indicated how the demeanour of the therapist could impact on this trust. This was also raised by Emily and Carol, who suggested that if a therapist looked embarrassed or awkward it could impact on rapport and the clients' trust. Carol suggested that building the relationship 'probably does take a lot of work to really break that barrier and make them feel comfortable to talk about it'. This emphasis on trust and relationships with the client indicate the participants' recognition of the sensitivity of the subject for clients; although the therapeutic relationship is important for all client-practitioner settings, the focus placed on it throughout the interviews highlights how sex has a 'special' status, a subject which requires consideration regarding approach or handling.

Enhancing feelings of comfort on the part of the client was mentioned as an important aspect in relationship building, Mary indicated this could derive from the client knowing that she was comfortable in talking about sex, indicating the two-way process involved: 'I think clients can tell when you're uncomfortable talking about something, they'll only disclose information if they feel safe, if they feel that they're in a safe environment'. Kelly indicated she tried to facilitate a comfortable 'type of social environment' to 'make sure they're feeling as comfortable as possible, and then bringing up things in quite an honest, non-judgemental way'. Carol also highlighted the need to make the environment 'very safe and comfortable for them to express themselves', indicating that this required 'a lot of work, and certainly requires the therapeutic relationship; it isn't necessarily going to happen on your first visit'. Carol suggested it could take time to be able to broach sex with a client:

... you might find it doesn't happen on the first conversation you have, you might not get half of the information, it might be one of those areas of occupation that takes a long time to really get down to what's going on and where is it going wrong - people probably will withhold information... **Carol (Non NHS)**

Despite the importance attached to the trust and rapport required to build a good therapeutic relationship, conversely, some participants felt that there was also a danger that becoming too close to clients could be a barrier. Lisa told me 'I think sometimes if you see someone too many times I think then I think they feel like missed... I feel like I can't bring it up now because I know them or they know me too well, and it's a bit awkward'. Carol suggested that feelings of comfort around

discussing sex for her personally were complex, speculating that it may be easier to talk to someone she didn't know:

... in my own context, if I went to a doctor and they wanted to ask me, I think I'd feel... I dunno how I'd feel, [...] I think I'd probably prefer to have them know me a little bit more and my life a little bit more. But then I was just thinking maybe that wouldn't be so good actually, maybe that would be better if they knew very little about me and, I spoke about it quite openly and frankly. I've just again disproved my theory on that one [laughs]. Putting it my context I would find it easier to talk to a complete stranger about it. [That] might actually be easier. **Carol (Non NHS)**

Jane suggested that if she were to discuss sexual concerns with an HCP as a client, how much she disclosed would depend on the individual involved, that trust and rapport would be important, suggesting that she would feel uncomfortable with some individuals. These comments reflect the sensitivity around sexual concerns within society. Several practitioners who have acknowledged the significance, meaning and importance of sex find discussing sex difficult depending on the context and the person they may be discussing it with.

The challenge of building and relying on rapport and relationship building to broach sex meant that sometimes practitioners could get the relationship wrong. For example Anthony and Nicola both spoke of how rapport could be broken. Anthony shared what he described as a 'cautionary tale' of a time when he felt the relationship had broken down due to not broaching 'tricky situations' in a 'good way', whereby he had offended the father of an adult client. Anthony suggested that he had sought to 'save time' and 'open a dialogue' by broaching the subject by email 'but thinking about it, it would have been much better to do that face to face, in a different way'. Nicola spoke about times when she felt she had made clients withdraw from the relationship:

I hopefully know how far to push, and sometimes I push too far, and I know I'll have pushed too far because I'll come away and think "oh, I pushed way too far then and they pulled back", so it does tend to be as that relationship grows really, and I test the boundaries a little bit. **Nicola (Non NHS)**

The participants suggested that building a therapeutic relationship was important in 'opening the door' to broach sexual concerns. This could help or facilitate their practice, but occasionally this could go wrong and become a barrier. Building a good therapeutic relationship is considered a core skill in occupational therapy (Creek and Loughter, 2008; Duncan, 2011), but may be intangible and

difficult to quantify, particularly for novice occupational therapists. This may impact on their ability to broach or deal with sensitive subjects such as sex.

### **Summary: Broaching sexual concerns in occupational therapy practice**

In terms of practice, this section found that the study participants adapted and applied their skills, knowledge and experience, using their professional reasoning along with their rationalisation that sex was part of their remit, despite the sensitivity and taboo that surrounds sex derived from dominant socio-cultural sexual scripts. Building rapport, trust and a therapeutic relationship were seen as vital to this but can be affected by cultural sexual scripts around taboo and sensitivity. Basing their assessment on professional reasoning, few of the participants broached sex with all of their clients, instead basing their approach on other information during assessment or based on their client

relationship. The participants indicated that their clients had an array of concerns which impacted on their ability to engage in an ordinary sex life; some had physical changes which impacted on mobility, dexterity or the ability to position themselves, affected their bodily functions or had changed their physical appearance (for example, limb discoloration or changes in muscle tone), some had limited insight or struggled to predict or see the consequences of their actions, others had difficulty in initialising or had issues around coming to terms with changes in their circumstances, leading to low confidence and self-esteem. Interventions included advice on fatigue management and positioning, graded exposure, changing or adapting sensory input, finding adaptive equipment, supporting access to sex workers, role play, education to help adapt to changes and communicate with potential partners, and supporting access to dating and social opportunities. Many of these concerns and interventions are comparable to other areas of occupational therapy practice, albeit subject to socio-cultural concerns and a sense of dissonance with dominant cultural scenarios leading to feelings of taboo, sensitivity and concerns about what is seen as appropriate.

The study participants used problem solving skills and their professional reasoning to 'open the door' to assess their clients' needs, as they would with any other occupation. Although none expressed awareness of models for broaching sexual health concerns such as PLISSIT, Ex-PLISSIT or

#### **Key points: Applying occupational therapy to sexual concerns**

Participants applied their occupational skills and knowledge and the occupational therapy Process (Creek *et al*, 2005) to sex and sexual concerns, treating them like any other occupational concern.

This required professional reasoning, therapeutic relationships/ rapport and problem solving in order to assess and apply appropriate interventions.

Due to the limited support and resources available, the participants at times had to improvise and be creative in broaching unmet needs.

the Recognition model, these strategies were reflected in their practice when exploring and assessing concerns and issues, recognising and giving permission to their clients to discuss the subject. This did not appear to require special skills rather they applied their day-to-day occupational therapy practice resources; their skills and knowledge, problem solving and therapeutic relationships. Their practice reflected the ways in which Hyland and McGrath (2013) suggest that sex could be included as an occupational concern by occupational therapists by:-

- Supporting development of self-concept, self-esteem and body image
- Facilitating roles (mother, father, partner, lover)
- Providing education on problem solving
- Suggesting compensatory strategies
- Adapting activities

(Hyland and McGrath, 2013)

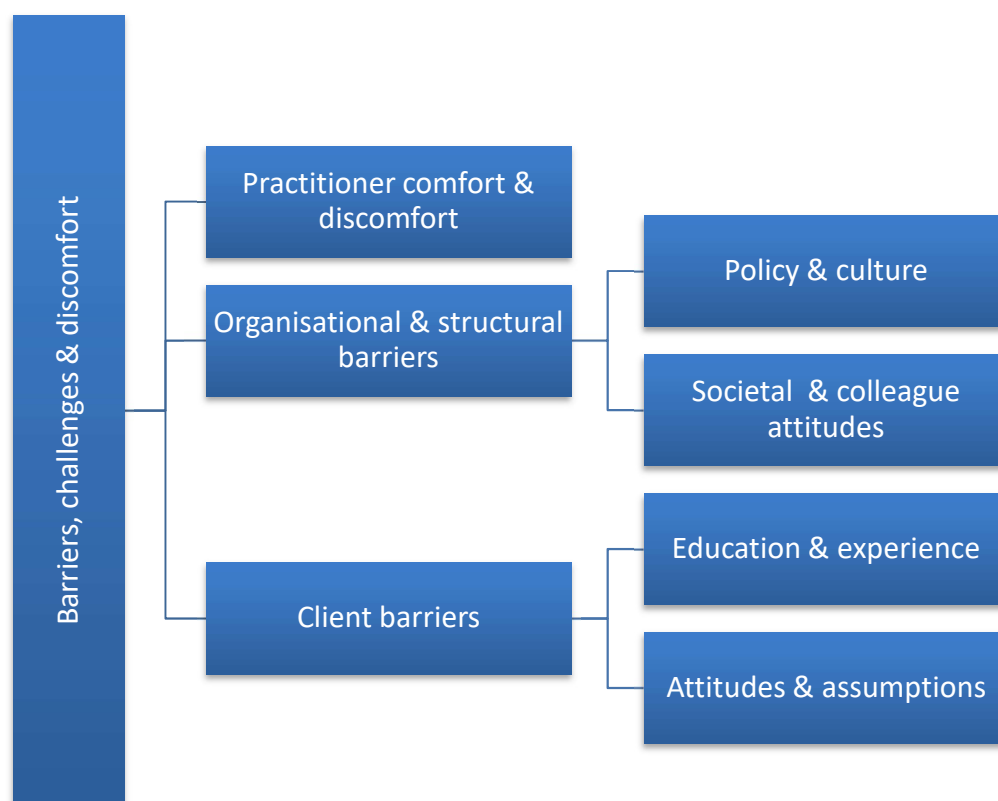
This reflects how sex does not have to be considered as special or exceptional, nor an occupation apart; occupational components used in other aspects of a clients' life are used for sex and sexual expression, and in turn sexual concerns impact on other aspects of clients' lives and therefore should not be considered in isolation. This study indicated that the participants were more likely to work within a social relational model rather than the medical or social models of disability. For example, Nicola spoke of how she was not 'within the medical model, at all', and this was reflected in the work of all the interview participants, with a more medicalised approach alluded to in responses by a minority of survey respondents. This suggests the participants perceived their clients were disabled by social factors such as the attitudes of society, internalised attitudes around sex, the physical and cultural barriers which prevent access to sex and excluding design, as well as the problems associated with their conditions, illness or impairment, reflecting that although society contributed to disablement as indicated by the social model, the material reality of impairment contributed to this as well.

As this research was based on the experiences and thoughts of occupational therapists rather than from directly talking to clients, it could only provide an indirect view of their experiences and perspectives. This study infers that clients were sexual, asexual, private, open, and held a spectrum of attitudes, assumptions, tastes and desires. Therefore they have goals or circumstances in which they wanted or needed occupational therapy input to facilitate their needs and wants, or support in achieving those goals, as with any other occupation. These included sexual intercourse, masturbation, meeting people, being close to partners, breaking up with partners, and a broad range

of sexual activities, expression and experience. There were suggestions that some clients seemed to jump at the opportunity to talk about their concerns whilst others were more private. The study participants used their professional reasoning to assess this on a person-by-person basis, and occasionally this could go wrong (for example, approaching the subject too soon or 'pushing too far'). However, as Sarah indicated, if the question was not asked then the client may find an important and worrying unmet need continued to be unfulfilled. Despite sensitivity around the subject, several participants indicated this was a need / want they considered to be like any other occupation.

### 4.3 Comfort, discomfort and barriers to broaching sex

This section looks at aspects of practice which the participants indicated gave rise to discomfort, and the other barriers and challenges they indicated when broaching sex. Several barriers were indicated such as structural and organisational barriers around resources, policy and cultural and attitudinal barriers. The participants also indicated that clients faced structural, cultural and attitudinal barriers such as lack of education and experience around sex and their own internalised attitudes and assumptions.

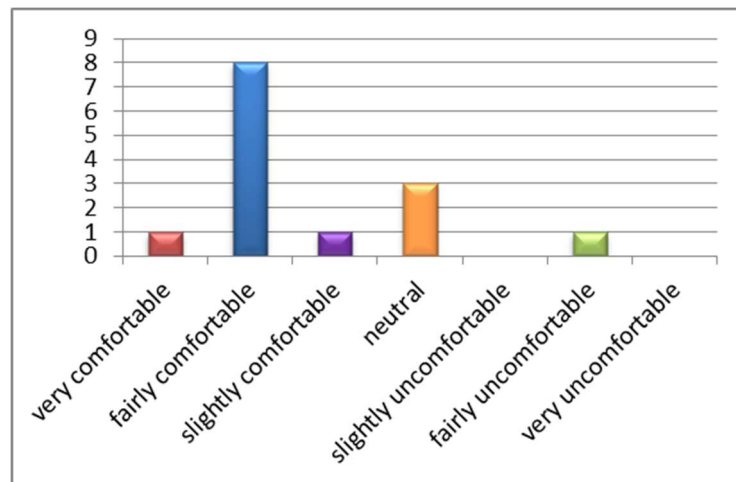


#### Comfort and discomfort

Issues of comfort and discomfort arose extensively in the literature (for example, Yallop and Fitzgerald, 1999; Jones *et al*, 2005; Dyer and Das Nair, 2013). Therefore I asked the participants about their levels of comfort in both the questionnaire and interviews. Given the small sample of respondents to the questionnaire, it was difficult to draw generalisable conclusions regarding levels of comfort, nor could I draw conclusions around the impact of the participants' gender, sexuality, age, and so on. However, contrary to the literature, the quantitative data collected in the questionnaire indicated the participants in my study were largely comfortable about broaching sex (see figure 31).



**Fig 31 - Levels of comfort (questionnaire data)**



None of the questionnaire participants in this study indicated that they were very uncomfortable, the majority feeling very, fairly or slightly comfortable. This reflects how the participants had accepted sex as both an occupation and part of their remit, whereas the findings in the literature (for example Jones *et al* (2005) and Dyer and Das Nair (2013)) found high levels of discomfort. During the interviews, however, issues around comfort and discomfort were more nuanced; levels of comfort were dependent on several factors such as the client, their circumstances, the relationship and rapport with the client and the type of intervention required.

I asked all the participants whether they had felt discomfort regarding any particular client groups - a factor that had been raised in the literature (Dyer and Das Nair, 2013). None of the participants expressed discomfort with issues of ethnicity, culture or religion either directly or through non-verbal communication, only tending to express discomfort with regards to particular individuals or specific experiences with individual clients or circumstances. For example, Carol felt there were no particular groups she felt uncomfortable with stating 'is there a group of people that I would feel less comfortable with? I think the answer now is no'. Emily also indicated that she did not feel that social or cultural differences had an impact on her work:

I mean I think, in those situations I've just used the same kind of way of introducing it which is just like a gentle nudge, so again, talking about self-care which could include these things, and then, you know, I would wait and see what people say, where I'm currently working now we tend to have a fair amount of different cultures [...] I think I just introduce it in the same way. **Emily (NHS)**

Whilst culture, ethnicity and religion were not seen as problematic, several participants did express some feelings of discomfort around the age of their clients. Cathy, for example, stated that she had felt 'awkward' with both younger men-

I think guys that were like closer to my age where if we weren't in a patient / therapist situation it would be quite different. I think that would make me feel awkward, [...] there was one much closer to my age and I remember feeling awkward. **Cathy (NHS)**

And with older clients:

I felt quite awkward because I'm young, I'm really newly qualified and actually lots of the patients, in fact all of the patients, are much, much older than me and I often think it must be weird for them because I could be their child's age and I'm asking them something that's so private. **Cathy (NHS)**

This acknowledgment of potential feelings of discomfort in their clients illustrates how the therapeutic relationship discussed in chapter 4.2 is a two-way process, with the comfort of the client impacting on the practitioner and – as Emily and Mary indicated – the comfort of the practitioner potentially impacting on the trust and inclination to disclose concerns for the client.

Although some discomfort was expressed around age, ageism was not indicated by the participants. Nor were there indications of homo- or bi-phobia, instead there were indications of uncertainty about unintentionally causing offence. For example a questionnaire respondent stated that 'I hope I have the ability to accept people for who they are, not their sexual orientation'. Carol suggested that if working with a lesbian client that 'I don't think that there's anything that I would have difficulty dealing with from a feeling uncomfortable point of view. I think it would be more from a lack of understanding thing'. Harbin, Began and Goldberg (2012, p.152) suggest that HCPs often want to support their LGBT clients but were unsure how or reacted out of ignorance rather than being judgemental. They suggested that this uncertainty led to discomfort and recognition of their power over the client. On the whole the data reflects the findings of the literature; in their systematic review, Dyer and Das Nair (2013) suggests there is some degree of both ageism and homophobia but these are not the majority and there was little to indicate such attitudes in this study.

Several participants indicated that a clients' willingness to talk about the subject aided their comfort, for example, both Cathy and Anthony indicated that when clients were 'open' it made the subject

easier to discuss. Cathy suggested this openness may be due to the prior experiences of the client; that 'they've been used to having to just get everything out, be really kind of exposed with their bodies, I think, so they're the ones who I've found have been more open to just trying anything', whilst Anthony indicated that some clients were generally open about aspects of their lives such as recreational drug use or promiscuity, which helped make potentially uncomfortable conversations easier to negotiate.

The study participants' feelings of comfort could also be affected by the response required from them; some participants expressed more comfort in practical, pragmatic and problem-solving responses whilst others were more comfortable with emotional and psychological ones. Nicola stated that 'about people's sexuality, people expressing themselves, the emotional side I feel much stronger with; the emotional-psychological side, that adjustment to disability', and 'with someone's emotional relationship I feel much more confident than actually the sex'. Jane also felt more comfortable with providing responses relating to emotions:

Either they're asking us to do something, or that they want to talk about someone they fancy, or, you know, they've got a boyfriend or girlfriend or whatever. If it's the conversation I usually feel completely fine about that, [...], so I've been through all that, so nothing embarrasses me really. So if people want to talk about stuff, I'm comfortable about it. **Jane (Non NHS)**

In contrast, some participants indicated they felt more comfortable with practical responses which reflected the findings in literature; Yallop and Fitzgerald (1997) found that occupational therapists were more comfortable with scenarios which required practical or straight-forward responses, admitting to discomfort with scenarios outside a 'normal' range of their perceived experience or based on personal attitudes or societal and cultural norms, whilst Jones *et al* (2005) also found that experiences that fell outside usual client / practitioner activity evoked feelings of discomfort. The participants' feelings of comfort, then, may have been affected by feelings of familiarity with the situation presented.

Several interviewees expressed concern about coming to terms with not always being able to solve a problem. For example, Emily stated: '(I) may have been more panicky that someone was going to ask me a question that I wouldn't be able to answer', whilst Kelly spoke of needing to get comfortable with the idea of not providing solutions:

... from an occupational therapy point of view - often we're keen to kind of problem solve and find solutions, and sometimes with the effects of [impairment] you can make suggestions about alternative options but you're not always finding a solution. I think I had to get comfortable with just listening and not really necessarily having the solution. Sometimes people don't need the solution they just need to talk to you about it. So I think the first time I was a bit uncomfortable with not necessarily knowing how to fix their kind of problems or give the correct solution to try, whereas actually when I understood that people don't always need a particular solution, they just need to be able to discuss it and feel they can discuss it freely, then actually that often helps within itself. **Lisa (NHS)**

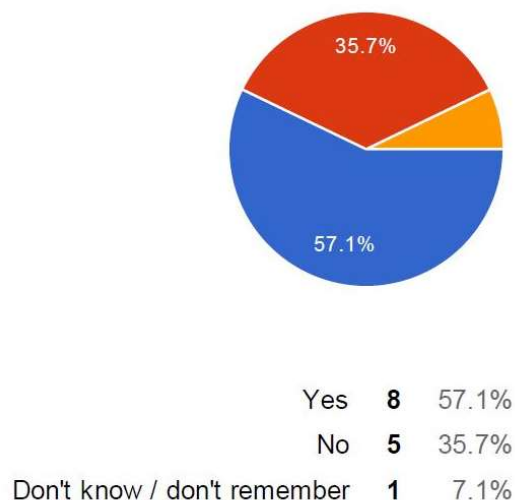
The participants' feelings of comfort and discomfort were complex, impacted by the client, relationships with the client, the situation, feelings of not having answers, and experiences on which they could draw. Whilst the literature (Couldrick, 1998; Yallop and Fitzgerald, 1997; Jones *et al*, 2005; Dyer and Das Nair, 2013; among others - see chapter 2.4) indicated that discomfort was a prevalent barrier for occupational therapists and HCPs generally when broaching sexual concerns, the study participants indicated they were largely comfortable in this area, suggesting this was a discomfort they had learnt to manage, which will be discussed further in relation to sexual concerns as 'dirty work' in chapter 4.4.

In discussing their comfort and discomfort with broaching sex, it was possible there may have been elements of respondent bias in the study participants' answers. As occupational therapists working within profession codes of ethics and conduct, and keen to show they were non-judgmental in their practice, they may not have wished to acknowledge or admit to a discomfort which may be construed as sexist, racist, ageist or heteronormative. However, from observation of non-verbal cues during the interviews, there was no evidence of this potential bias. The participants seemed to be genuine in their wish to support all their clients despite potential discomfort around particular individual clients.

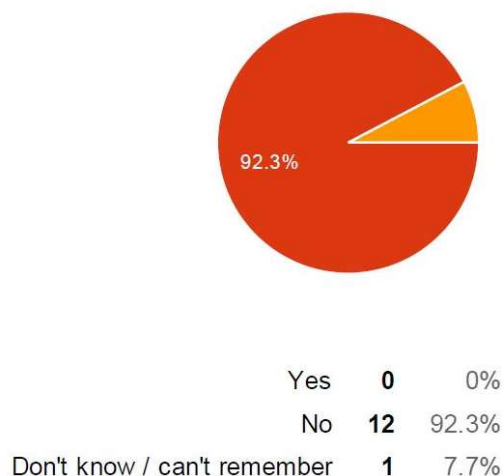
### ***Facilitating factors: Education and experience***

In this study, as in the literature, participants suggested education, training and both life and professional experiences were seen as key factors which aided comfort and helped the interviewees broach sexual concerns. Several interviewees had received some education during their pre-registration training (figure 32) whilst none indicated they had received specific training whilst in practice (figure 33). Some of the interviewees indicated that they had struggled to find training to support them in this aspect of work.

**Fig 32 – Did you receive any training regarding sex and sexual concerns / intimacy during your pre-registration training? (questionnaire data)**



**Fig 33 – Have you undertaken specific training related to sex, sexual expression since you qualified as an occupational therapist? (questionnaire data)**



### *Education and training*

The literature indicated that education and training had encouraged or supported participants in broaching sex. Several participants in the study also stressed the importance of education and training, for example Carol indicated that exposure to discussing sex through education was important to help prepare an occupational therapist in case sexual concerns arose:

... because it's something that people do feel awkward about I think it's more important to bring it up. You are going to be exposed to other aspects of daily living, like toileting and mobilising but it's covered as part of the course so you're sort of more prepared. I imagine if, as an occupational therapist, and someone asked me about sexual concerns, I'd be trying to put the professional face on but I'd be thinking "what do I do about it?" and I think if you're not exposed to it beforehand it does make it more difficult? **Carol (non NHS)**

Both Diane and Emily spoke of receiving training related to sex and disability / impairment, either pre- or post- registration, which had given them a moment of realisation that sex was an occupation and therefore part of their role as occupational therapists. These participants noted that it was difficult to find relevant education and training, and that sex was seldom included in pre-registration training, however when asked all indicated that education and training would be useful.

### *Life and professional experience*

Several participants indicated that experience of sexual-related or other sensitive subjects had helped them feeling more comfortable about broaching sex. Several participants stated they had previously worked in areas which involved dealing with sexual or other sensitive matters, for example, working in palliative care, with people with HIV or women with gynaecological conditions, which they indicated had helped them feel more comfortable. For example, Cathy and Nicola indicated that experience had helped them feel greater comfort:

I did feel really awkward to start with, especially because we'd never touched on this in Uni., never done anything about intimacy, never in my previous role on the acute ward have we ever - we didn't have time really, but we'd never looked at it at all. So it was quite alien to me to talk about it. **Cathy (NHS)**

When I was a basic grade if things came up, you know sort of 21, you'd feel, you're much more embarrassed, but as you get older, you know, and had a child and bared your body to the world! You get to a point where you're not shocked. **Nicola (Non NHS)**

Support and leadership from more experienced senior colleagues were indicated as helpful to several participants; Cathy acknowledged how she would have found broaching sexual concerns difficult without the support of her colleague saying 'I've just learnt from [senior colleague]. So she's really, really experienced and she's really open about everything – nothing was an awkward conversation with her. So because I've been learning from her, it's come naturally. Whereas I think if I were in a job where my senior didn't talk about these things, it wouldn't have come so easily, then

I'd have really struggled'. Colleague support was important as part of the learning process for several participants; Emily spoke of past situations where she learnt and gained support from non – occupational therapist colleagues in a spinal unit, Nicola spoke of using a 'team approach' saying 'I do internalise and go 'what am I going to do?!' but I've got really, really good colleagues and I work in such great teams'. For most of the participants, though, they tended to be isolated from others dealing with the subject and some sought support elsewhere, for example Anthony spoke of finding 'communities of people' to support him, finding SHADA<sup>24</sup> – a network of HCPs interested in supporting sexual concerns – particularly useful.

Experience, either from work or life experience, supported the participants in feeling less discomfort and greater confidence in broaching sexual concerns. These could come from previous experiences of working with sensitive subjects, experience of discussing issues related to sex, life experience which involved making the private more public or talking about sensitive subjects (for example during pregnancy or discussions about sex with children, and peer learning from colleagues, senior staff or supportive communities (for example, SHADA or LGBT professional groups). On the whole, the participants were comfortable about broaching sexual concerns, although this comfort could be influenced by factors such as the age and impairment of the client, these were less important than the individual client in terms of whether the client was comfortable about discussing their concerns, the relationship between client and practitioner, and personal characteristics of the client. Race, religion and sexual orientation were not seen as important factors which affected comfort. Comfort was supported by education and experience which could come from a variety of formal or informal, personal or work environments.

## **Organisational and structural barriers**

Aside from discomfort, the data also indicated several other barriers and challenges to practice, including the attitudes of colleagues, and structural barriers within organisations, and from societal attitudes. Several participants indicated that organisational and institutional factors could be barriers to broaching sex. This was demonstrated in the lack of policy or clarity around policy, resource and time pressures, institutional risk-adversity and a lack of leadership from the professional body, the Royal College of Occupational Therapists. Those who had worked in the NHS indicated that the exclusion of sex reflected a culture where sex was seen as a low priority, out of place and therefore routinely omitted.

---

<sup>24</sup> Sexual Health And Disability Alliance

## ***Policy and culture***

Participants indicated few services had specific policies regarding broaching the sexual and intimacy needs of clients, unless they had reached a position whereby they could write policy themselves. Where policy had been introduced, Jane discussed how its introduction had created 'confusion' in her service as members of staff had interpreted it differently. Jane's experience illustrated the grey areas which participants felt they were entering when sexual concerns arose as staff tried to support their clients but were unclear on where to draw the line in their involvement. Jane suggested 'there was probably confusion [before] but we just didn't know about it because nobody talked about it'.

The lack of clarity around policy and support was reflected in sex rarely being included on assessment documentation with the participants themselves using their discretion to do so. Anthony indicated it was often down to him to decide on the depth and breadth of his assessment of sexual concerns as assessment documentation offered little direction:

Some psychologists will bring it up more frequently than others, but within our assessment process, [...] we've got a template for our initial needs assessment, quite a long, quite a detailed assessment - there is a section on there about relationships but it doesn't give you much prompting in terms of how far you go, it's left down to you in how far you'll go with that. **Anthony (Non NHS)**

The lack of policy and documentation to support the inclusion of sex may be further compounded by what John described as 'a risk adverse environment and you can sort of sense that if you look at, if you talk to people in practice'. Several participants indicated that there was a culture of prioritising risk management over the privacy and wishes of the client which went unchallenged when combined with the attitudes of some occupational therapy colleagues. Diane stated that 'in the NHS it's "ooo, don't go there"', whilst Anthony also suggested that it was 'not part of the culture'. Mary spoke of her attempts early in her career to introduce sexual concerns as part of an internal assessment form, these had not been welcomed by her team who 'weren't keen to go down that route'. Nicola suggested the predominant attitude within the NHS generally was to avoid broaching sexual concerns and that it was something practitioners were discouraged to ask about, going on to say 'the culture was that, don't go there'. These comments underline the perception some of the participants felt that the NHS in particular was dominated by concerns about organisational convenience or priorities, leading to NHS practitioners viewing clients as pathologies to be dealt with and discharged, rather than as whole human beings. Carol stated she found that she felt more supported to include sexual concerns in her practice in the independent sector where she had more freedom to deal with issues and more acceptance that sexual concerns were a 'real goal, a real



something that someone wants to work on'. Anthony also felt he had more scope to include sex as an independent occupational therapist. Despite this openness, those working in the independent sector suggested the inclusion of sex was related litigation calculations, that is, how compensation was worked out after an injury or accident, rather than due to more positive attitudes towards sex.

Diane alluded to experiences that indicated a tendency for colleagues and institutions to view sex as an inconvenience to institutional priorities (such as discharging the client) and to the practice activities of HCP/ support staff, reflecting what she described as a 'disregard for any continuing of family life'. John also wondered if tensions around a predominantly discharge-oriented culture in the NHS had had an impact, saying that 'I think the culture of the NHS has shifted to a more contractual one for example, so asking some of those questions [about sexual concerns] people might feel on less sure ground'. He suggested this culture had 'distorted into a kind of neoliberal marketplace based on an Amazon warehouse, where people were just sort of discharged like they've been dispatched to their buyers'. Nicola suggested there was a concern regarding funding within the organisation, speculating it was seen as a superfluous extra saying 'I suppose they view it as a bit like vocational rehabilitation! [laughs] which the commissioners don't fund this bit', and for this reason was omitted from assessments. John noted a culture that focussed on costs could have an impact as 'in a reductive costs-centred world that we live in, the idea that people might be healthier and happier if they have relationships was something we don't take account of'.

Sarah and Anthony commented on the lack of guidance from the occupational therapy professional body, the Royal College of Occupational Therapy (RCOT); Sarah was particularly frustrated at the lack of support or leadership from the College: '...don't get me started on the COT. Where's the guidelines on it?!' Anthony also mentioned the lack of support from the College, suggesting he had found it more useful to seek guidance and resources to support his practice from elsewhere:

It's not on the agenda is it, unless you've got an interest in it, and then when you've got an interest in it, then you create your own little group, kind of like I do I suppose, going to SHADA, and like-minded people. **Anthony (Non NHS)**

This perceived lack of support from RCOT may well contribute to the omission of sex within occupational therapy generally, adding to ambiguity around whether sexual concerns are occupational concerns, leaving it to individual practitioners to decide.

### ***Lack of time and resources***

Several participants reported it could be difficult finding resources or services, from which they and their clients could draw support, or to which they could refer their clients on occasions where they felt they lacked the knowledge to deal with specific concerns arising. John spoke of the restrictions in resources and the demands created by changes in NHS services:

Some of the frustration of occupational therapy might be that actually we have a limited range of activities and a limited range of resources, and we can't address some of these things, and we can't deliver the follow up; can we follow up our advice? Can we support somebody in the direction they have chosen to take?' **John (Non NHS)**

Finding appropriate adaptive equipment and aids was also reported to be difficult; Diane spoke about becoming a regular visitor to local 'sex shops' in her quest to find appropriate aids and equipment which her clients could operate independently, sometimes accompanying clients or enlisting the help of the sex shop staff. Her experiences highlighted how finding appropriate equipment could be difficult. Carol also found that services or products intended to support clients in accessing sex and relationships were not always inclusive, tending to be aimed at adolescents or sexual pathologies. Carol gave the example of the problems she had had finding appropriate services for one of her clients:

Trying to find a sexual health clinic that would be able to give her advice in a way that she was able to understand it, and one-to-one so that was really difficult actually, I spent a long time navigating NHS services in her area that would give her the advice around sex practice, looking at contraception, all that and there was really nothing - it was all aimed at teenagers.

**Carol (Non NHS)**

Carol told me that 'I would happily try and find those people. And I wouldn't sort of feel worried about having that discussion, but it's difficult to find those people'. Both information materials and services provided by the NHS seemed limited and Carol felt it would be useful for the NHS to consider sex beyond pathology. As part of this study I looked into possible suppliers of equipment and services via the internet: it was difficult to source appropriate equipment and the few companies who did stated these were imported from the US<sup>25</sup>, whilst sexual health services were invariably related to contraception, STIs and genitourinary health.

---

<sup>25</sup> Conversation with supplier, 4<sup>th</sup> April, 2016.

Carol also expressed concerns regarding dating platforms which she perceived to be potentially problematic for her clients due to the lack of adequate vetting procedures and placed her clients at risk of potentially unscrupulous 'dates'. She spoke of how she had considered setting up a dating platform with a client specifically for people with brain injury, on the lines of an existing platform for people with learning disabilities, 'Stars in the sky'<sup>26</sup>.

Space and time were also structural barriers which impacted on several participants' abilities to build the necessary therapeutic relationship to broach sexual concerns. Cathy suggested that '... to have time to build a therapeutic relationship which I know is becoming more and more of a challenge for the vast majority of occupational therapists, [to] actually have time to build up that, because you do have to have a relationship I think to talk about'. For some participants this meant building trust over a period of time with long-standing clients, for example when working with someone with a LTC. Mary discussed how raising issues of sex had taken several years with one client:

I had quite a long-standing relationship with her though, like I've know her since she was 17 and she's like [pause] she's 27 so she was kind of in her early 20's when she came to talk about that.... **Mary (NHS)**

Anthony suggested that even outside the NHS, time could be difficult due to costs saying 'within this work, you're always conscious of cost, because everything is costed, you see, every minute of work you do is costed, and people look at your bills and you're aware of time and how long things are taking'.

Although time was raised by several participants, usually in relation to building relationships, this was mentioned less than indicated by the literature (Dyer and Das Nair, 2013; Couldrick, 1998; Saunamaki and Engström, 2013; Mellor *et al*, 2013), whilst the challenge of finding appropriate resources and support services was raised by several participants.

### ***Colleague / societal attitudes and assumptions***

Aside from organisational barriers, the participants also indicated that the attitudes of occupational therapy colleagues, HCPs generally and wider society could challenge their practice. Diane pointed to how concerns around health and safety issues could be used as barriers to client sexual lives:

---

<sup>26</sup> A friendship and dating platform <https://www.ourway.org.uk/our-way-projects/stars-in-the-sky/> featured in Channel 4 programme *The Undateables*.

I had a couple of occupational therapists who actively tried to discourage people from sleeping together or cuddling, as in, 'cos "it isn't safe" [...] or they were insisting on this person being in a single bed or a hospital bed because of care or it being safer or positioning, etc., and as soon as I would hear something like that it was "the husband is doing this and he refuses to do that and der der der" and I had to then approach it and say:

-“well, why not? If it was you, if you had slept with your husband for the last 15/16 years and your MS was getting bad and he wanted to still hug you, why on earth would you consider taking that away? What are you doing?” -“They would be better in a hospital bed.” -“Better for what?” **Diane (Non NHS)**

Diane’s experiences indicate tensions around balancing institutional and client priorities where the clients’ wants and needs could become secondary, indicating that in some cases occupational therapists were placing organisational demands ahead of client-centred practice.

Whilst Diane alluded to the prevalence of risk-adversity, Nicola found some of her colleagues struggled with sex as a sensitive subject; ‘My occupational therapists that work with me are good. But I would say that some of the occupational therapists [...] are probably not quite as-, because they'll ring me and go “Oh god, this came up!”’, whilst Sarah noted sexual concerns were seldom mentioned when talking to occupational therapists she had supervised; ‘it doesn't come up anywhere - people blank it out of their minds’. Sarah also reflected on her experiences of training occupational therapists: ‘I do activity analysis with condom demonstrators, there's a different...some people are okay with it, some people are not okay’. She went on to say, ‘there's different reactions; some people think we shouldn't be doing it, some that we should’. Diane had also found a mixed response when training fellow occupational therapists, which she felt reflected societal attitudes to sex and impairment, suggesting that the ‘public perception’ and those of her trainees were that disabled people were unable to engage in sexual activities: ‘some people say: “Can they?”’. She found a split in people’s reactions but that the most common reaction was ‘well, I hadn't really thought about it.’

Sarah indicated that broaching sexual concerns was not something all occupational therapists could engage with; that it was ‘not for everyone’ and suggesting that ‘some people you can train them but they are still not going to feel comfortable about it’, whilst Carol felt it was unrealistic to expect all health professionals to feel immediately comfortable about talking about sex and that acknowledging discomfort was important:

...they [trainers on a course] would sort of talk to you; 'you should never feel uncomfortable about talking about sex', but now that's not normal, a lot of people feel uncomfortable talking about sex and just because you're a therapist, doesn't mean you're not going to feel uncomfortable, so I think to make someone feel like they're already failing if they feel slightly squirmy isn't helpful. **Carol (Non NHS)**

Attitudes within wider multi-disciplinary teams could also be barriers; Diane spoke of several occasions where HCP colleagues would report the 'problem behaviours' of clients which she felt were normal, healthy responses to their circumstances. For example, a client had been reported for 'inappropriate behaviour' when a member of staff had refused to leave her alone in the shower and she had 'proceeded to use the sponge to rub her breasts and pleasure herself, etc.....the member of staff had said "don't do that!" grabbed the sponge off her and said "that's out of order, you can't do that"'. Diane went on to describe how she 'felt myself feeling extremely cross' at the attitudes of the member of staff, pointing out that if the client was safe she should be allowed privacy.

Despite finding often negative attitudes to sex and impairment, several participants felt that these attitudes were changing. Both Anthony and Carol pointed to an increase in media and television representations on sex, disability and sex education generally, for example *The Undateables*. Whilst Diane felt that there had been increased acceptance of disabled people as sexual beings due to the increasing visibility of Paralympians and military veterans, and greater exposure to 'flashy limbs, where people are proud of their limb, their false limbs and their flexi-feet, and you've got these big, good looking guys but they happen to be disabled', suggesting it was 'creeping into the public psyche, [...] creeping into the younger generation psyche of "well, yeah"', suggesting disabled people were being more widely accepted as sexual beings.

## **Client barriers**

As noted in the literature, disabled people face hurdles in accessing sex and sexual expression due to societal barriers, a lack of education and experience and internalised attitudes (Shakespeare, 2014). Several of these barriers were noted by the participants in this study, which contributed to the issues they supported their clients in overcoming. The interviewees observed barriers such as their lack of sexual education and experience which excluded them access to ordinary sexual lives. The participants also alluded to the ways in which the clients own attitudes could be barriers which manifested in several ways; internalised attitudes, discomfort and sensitivity around the subject, concerns around privacy and independence and assumptions about their own impairment or illness.

Several participants also observed that clients could have unrealistic expectations about sex and relationships.

### ***Exclusion from education and experience***

McCabe (1999) found that disabled people had lower levels of experience than non-disabled people, particularly around dating/ intimacy and sexual interaction. Several participants in this study also noted that this lack of experience led to difficulties for some of their clients in building and managing the complexity involved in sexual expression and relationships. This was a particular concern for those who worked with clients who had been injured and/ or spent extended periods of time in hospital during adolescence or early adulthood, and had therefore missed out on important peer learning in relation to sex, sexual expression and relationships generally:

...some of my clients will have had their brain injury when they were about 15/16 when there's a lot of peer learning, and you get peer feedback on your behaviour and you're trying things out and meeting members of the opposite sex and you're having those relationships, and they've been in hospital over that time, so that time where that insight grows and develops, they've missed out on. So then when they hit the 20's plus and they're going out, and they've kind of not had that development, plus they've got a neurological injury on top of it, plus they don't feel great about themselves because they've got a massive scar down their head or whatever that might be or some disfigurement, then that has a massive impact on their sexuality. **Nicola (Non NHS)**

John also noted how being in hospital or an institution could have a negative impact on clients:

...people haven't got maybe all the emotional equipment, experience, to know how to handle their own desires or anybody else's they're working with or having a relationship with, and how you might negotiate having a relationship. It's the same for people with a physical disability, many don't have the opportunity to have the experience of a relationship, so therefore you have things like surrogate partners being a kind of service that people turn to in order to experience what a relationship might be like, which is prone to all kinds of issues. **John (Non NHS)**

Several participants also noted that some clients were often denied access to sexual education, for example:

...mom had never dealt with him wanting to sleep in the same bed as someone, you know, just, it just raised a whole load of things that actually a lot of disabled people just don't ever get that same education that other people do. [...] he was sort of left in the dark because he

had never had any sexual education, nobody had ever really spoken about it, and it had then fallen down to me to sort of raise [...]. He...we want to encourage, we don't want to stop him but we need to give him the tools and the knowledge to know what he does and doesn't want. **Carol (Non NHS)**

This lack of experience and education could then continue into adulthood as clients could be excluded from opportunities for sexual experiences. Carol had been frustrated when a client had been excluded by the dating agency featured in Channel 4's *The Undateables* programme, rejecting her client with brain injury as being 'too disabled' despite not knowing anything about the client.

Lack of experience regarding sex was something the participants observed had an impact on their clients' ability to engage and manage sex and relationships as clients had to navigate sex and sexual relationships with limited knowledge and experience. This was something several participants identified as an occupational concern and broached through discussions with their clients, role-play and informal and formal education, with one of the participants setting up a sex education group for LD clients, applying occupational interventions to support their clients.

This exclusion of clients/ disabled people had been observed in both the quantitative and qualitative literature discussed in chapter 2.3; disabled people were not included in the ordinary 'banter' of adolescence and sex was seldom discussed in families and with their non-disabled peers (Shakespeare *et al*, 1996), reinforcing the idea that either disabled people were not interested or able to partake in sexual expression and unlikely to be sexually active (Esmail *et al*, 2010; Howland and Rintala, 2010), they were omitted from opportunities for education (Shakespeare *et al*, 1996; McCabe, 1999). The repercussions of this gap in education and experience meant that the participants who broached sexual concerns in this study had to attempt to find services or undertook interventions to fill these gaps and support their clients.

### ***Client internalised attitudes***

As discussed in chapter 2.3, the literature indicated disabled people often had internalised negative cultural scripts around impairment, illness and sex (McCabe and Taleporos, 2003; Liddiard, 2012; Santos and Santos, 2017), and several of the study participants' observations reinforced this perception that clients saw their impairment or illness as a barrier to sexual activities and relationships. For example, Emily spoke of clients who expressed concerns that their condition might prevent them from seeking sex:

...to the extent of those who say “well I'm single, I'd love a partner but I can't, can I? that's just never going to happen”, and I've had quite a nice quote from one woman – well, it's a horrible quote really - and she's in her 40's and divorced and she's really keen to regain a new relationship but sort of said “Well, I can't, can I?, because what about the sex? and it's my pain, it's not his pain, so in a way why should I put this on a man that he's going to have difficulty having a sexual relationship with me when it's not his problem, it's my problem”.

**Emily (NHS)**

There were also indications that prevailing societal prejudices towards maintaining independence could create barriers to getting support in sexual concerns; Anthony found that some clients had internalised attitudes of independence and privacy which made it difficult for them to accept his input:

...they like to get on with their own lives [pause], and like a lot of clients really, don't really like having support really. They know they need it but they don't really want it. Kind of keep you at arm's length? Yeah? Even having support workers, they have it because they sort of need to, and they don't really want it. **Anthony (Non NHS)**

Internalised ideas of what may be possible and available could constrain the activities and occupations of these clients, limiting their choices. The study participants arguably challenged and countered their internalised attitudes by broaching sexual concerns as an occupational norm.

### **Summary: Comfort, discomfort and barriers to broaching sex**

This section found that the study participants had to negotiate their own, their clients and/or colleagues discomfort around sex, and faced several barriers in doing so. The study participants' experiences of comfort and discomfort varied; whilst the scoping survey findings were congruent with the literature (Couldrick, 1998; Parkin, 2014; McGrath and Lynch, 2015), the interview participants' feelings of comfort and discomfort were more nuanced. On the whole, they expressed greater comfort than suggested in the literature. This was helped or hindered by a variety of factors; their personal attitudes to sex, education and training, previous exposure to sensitive subjects, the nature of the concern raised, institutional support (or the lack of it - for example, time, resources or referral pathways) and the attitudes, education and experiences of their clients. The study findings are consistent with those in the literature indicating that experience, knowledge and education facilitate higher levels of comfort (Yallop and Fitzgerald, 1997; Haboubi and Lincoln, 2003). Couldrick



(1998) and Saunamaki *et al* (2010) suggest that comfort, attitudes and competence in relation to sex and sexual expression seemed to be increased by personal and professional experience.

The barriers to broaching sexual concerns explored here reflected those found in the literature; whilst the participants did not indicate some of the attitudinal barriers found by Couldrick, 1998, Jones *et al*, 2005, and McGrath and Lynch, 2014, they did face practical and institutional barriers indicated by Haboubi and Lincoln, 2003; Dyer and Das Nair, 2013 and Mellor *et al*, 2013, and barriers from both colleagues and their clients. The study participants noted their clients could be affected by internalised attitudes and assumptions (as found by Liddiard, 2012; McCabe and Taleporos, 2003 and Santos and Santos, 2017), as well as structural barriers such as lack of education and exposure to sex (reflecting the findings of McCabe, 1999; Shakespeare *et al*, 1996, Esmail *et al*, 2010, among others).

Whilst some of the barriers discussed in the literature such as education and experience were found in this study, other barriers to disabled people in accessing sexual experiences spoken about in the literature did not arise, for example around physical access to transport and social spaces (Shakespeare, 2014). The focus of the research was on the practitioners' experiences which may explain this omission and may reflect the type of work the participants were undertaking.

Although it could reflect that societal physical barriers to disabled people are so accepted and normalised they pass without comment.

Whilst the literature and the survey indicated that the majority of occupational therapists omit sexual concerns or only broach them occasionally, the interview participants in this research are outliers within the profession in that they broach these concerns and appear to be largely

### **Key points: Discomfort and barriers to practice**

Participants indicated greater comfort in broaching sexual concerns than indicated in the literature, although some expressed some discomfort regarding some individual clients.

Age and high levels of impairment were factors which were more likely to give rise to discomfort.

Comfort was aided by education and training, experience and / or prior exposure to sensitive subjects.

There was greater heterogeneity in participant responses to comfort around solutions – some congruent with the literature in preferring common sense, practical solutions, others preferring emotional and psychological aspects.

Barriers to broaching sexual concerns include:

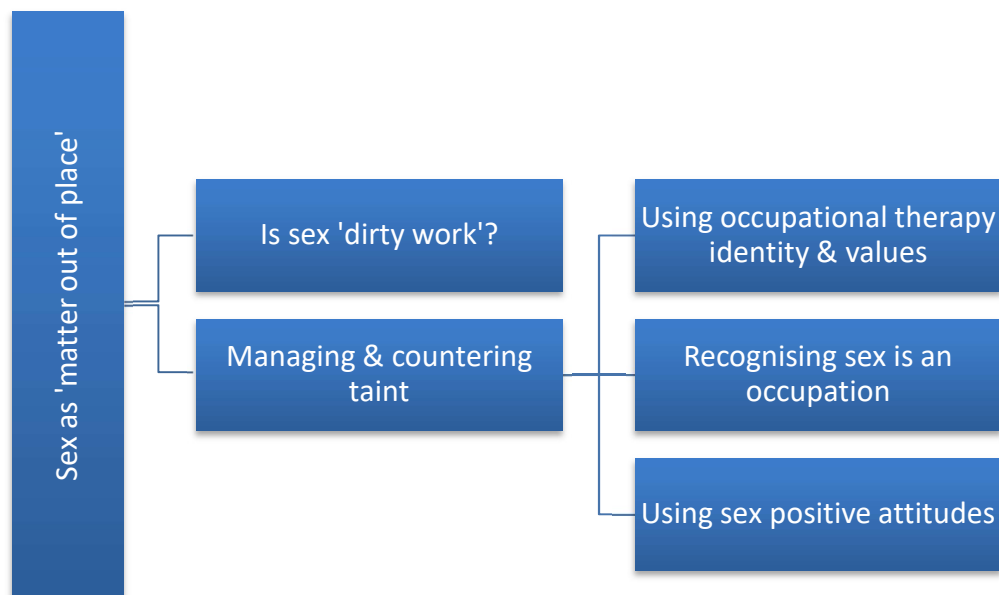
- Lack of policy on local, national or professional levels;
- Institutional negative attitudes to sex
- Lack of support / resources / time /referral pathways
- Colleague negative attitudes;
- Client internalised assumptions and attitudes, due to exclusion from education and experience.

comfortable in doing so. There were several factors which may explain this. As discussed in chapter 4.1, the participants indicated that they saw sexual concerns as being occupational in nature, and therefore under their remit. For Emily and Diane this was derived from training taken either during pre- or post- registration, others like Anthony and Sarah suggested a previous interest in considering sex as an occupation during their pre-registration training, even though it had not been raised formally.

The discomfort and barriers the participants negotiated arguably reflect the idea that sex is 'dirty work' or 'matter out of place' within practice being 'disorder within a system of cultural and moral norms' (Douglas, 1966, in Jensen, 2016, p.3) and therefore may be described as a tainted occupation which requires management in order to broach it. This concept will be examined further in the next section.

## 4.4 Countering occupational taint: Managing sex as 'dirty work'

This section will examine the idea that sex is tainted, 'out of place' or 'dirty work', and look at the countering strategies the participants appeared to use to manage this (Ashforth and Kreiner, 1999). The concept of 'dirty work' can be used to explain the management and negotiation used by the participants, reflecting its 'special' and sensitive status. This section will explore sexual concerns as a tainted aspect of the participant's practice and how they managed the sensitivity and taboo around sexual concerns using taint countering strategies.



### Is sex 'dirty work'?

The previous chapters indicated that although the study participants accepted that sexual concerns were occupations and part of the remit of occupational therapy, these concerns differ from other occupations in that they require negotiation around sensitivity, discomfort, taboo, conflicting needs and wants, and multiple sexual scripts derived from personal, professional and societal cultural scenarios. The tendency for sexual concerns to be omitted shown by the literature (for example Dyer and Das Nair, 2013; Haboubi and Lincoln, 2003) indicate that sexual concerns are seen as 'special' and outside the norms of day-to-day practice, requiring greater consideration and sensitivity than other occupations. They therefore fit with the definition of being 'matter out of place' (Douglas, 1966) or 'dirty work' (Ashforth and Kreiner, 1999). This was reflected in how the participants recognised sensitivity and taboo around sex, and the stigma and discomfort involved.

Although the data provided limited direct evidence to suggest that the participants perceived themselves to be doing 'dirty work' or involved in a tainted occupation, indirectly there was evidence to suggest that they were undertaking 'dirty work' or were using taint managing and

countering strategies described by Ashforth and Kreiner (1999). This sense of 'dirty work' was reflected in a variety of ways in the study findings; the emphasis on sensitivity and the need for the therapeutic relationship discussed in chapter 4.1, the omission of sex from organisational policy, procedure and the lack of guidance discussed in chapter 4.3, the sense that the participants indirectly asked permission to discuss sex, the omission of sex by colleagues, the use of reasoning around who and how to broach sex and sexual expression, concerns around appropriateness alluded to in chapter 4.3 and discomfort around individual clients and circumstances discussed in chapter 4.2.

The participants were exposed to several activities which may be seen as overtly 'out of place' or potentially 'dirty' in the course of broaching sex, such as supporting masturbation, visiting sex shops or the employment of sex workers, as well as less the overt such as the sense of sensitivity indicated by the study participants - for example, Nicola remarked that 'sex is that embarrassing subject we don't really want to talk about. It's the elephant in the room', Jane spoke of a 'minefield', whilst Mary indicated that sex was a subject people did 'not want to talk about'. Carol, on talking about broaching sexual concerns with her clients said: 'I dunno why it is any different to "how do you get washed and dressed?" but it seems far more personal', going on to say that it was generally a 'tricky subject', Lisa suggested that 'for most people it's an uncomfortable topic' whilst Emily spoke of 'breaking the taboos' and wanting to 'demystify it'. Kelly stated that 'if you're treading carefully and they don't want to hear, it can be uncomfortable for everybody, whereas areas or people that you feel more able to talk openly with, then everybody feels more comfortable'. Like the participants in Tyler's (2011) research, the participants were exposed to potentially tainting aspects and seemed to recognise they were 'working across boundaries, including moral boundaries' (p.1489) as part of their broaching this area of practice.

A comparable occupation the participants indicated, which may give rise to similar feelings of sensitivity and taboo, was when dealing with the toileting concerns of their clients. Lisa indicated that she had been surprised during training that occupational therapists would be involved in very personal care:

I think there were certain things that came up during the course that none of us realised was part of occupational therapy, for example I never realised that delivering some aspects of personal care would be part of occupational therapy, going onto the course I never realised that I'd be wiping bottoms on wards, and that was brought up on the course which I found

quite shocking. I think a lot of us did go onto it thinking a particular thing and not realising that we would be asked to be part of every single part of people's lives. **Lisa (NHS)**

Sarah also spoke of how occupational therapists were able to discuss sensitive personal cares such as toileting and yet omitted or avoided sexual concerns, for example:

"How often do you go to the toilet, how often do you open your bowels?" – what kind of question is that?! "How is your stool?" – what the hell?! And people are like; "oh, I'm quite constipated." And it's quite a topic; people are alright to talk about bowels but not about 'has it impacted on you having an erection?' You're just moving a bit further forward. **Sarah (Non NHS)**

Lisa spoke of the 'squeamishness' of occupational therapist colleagues with regards to toileting issues:

We talk to them about their bladder and their bowel, which is even more intimate, and I know some of us are a little bit squeamish about that as well, but we still find a way to bring it up. And just considering sex as, which, you know, you might find a little bit squeamish, but you find a way to bring it up. **Lisa (NHS)**

Both Lisa and Sarah indicated that despite the sensitivity of both subjects, broaching toileting concerns appeared to be more accepted within occupational therapy practice than broaching sexual concerns. This may be due to having greater exposure to toileting concerns in practice whereas sexual concerns are often omitted. This difference may be explained by Ashforth and Kreiners' (1999) typology of 'dirty work' which suggests that the management of certain taints could be affected by the type of taint, for example a physically tainting occupation like toileting may be managed as a 'necessary evil' as it can have a direct impact on physical health and social well-being whereas sexual concerns may be seen as a greater moral or social taint, are not seen as a direct threat to health and well-being and are therefore more difficult to counter, by using ideologies around necessity and need (Ashforth and Kreiner, 2014).

### **Countering occupational taint**

Ashforth and Kreiner (1999) suggest that 'dirty work' may be managed through a variety of strategies to reframe, recalibrate or refocus the taint. The data suggested that participants tended to reframe broaching sexual concerns by embracing or ignoring the taint. For example, Emily embraced broaching sexual concerns as a 'badge of honour' (Ashforth and Kreiner, 1999), as part of her role as an occupational therapist but one few others included:

I've always been interested in how people express themselves in any way so I suppose sexual expression is just one facet of that, and I'm really interested in people, I think that's why I'm an occupational therapist, I'm interested in difference, and kind of what makes us all different from one another so, and I, I don't know, I think I really enjoy working with people on something that perhaps nobody else has felt happy to broach with them. **Emily (NHS)**

Other participants suggested they ignored the taint of broaching sexual concerns, reframing it as just another occupation:

It's not that big a deal! Let's get over ourselves, not one of us would be here.... Not one of us would be here if it wasn't for the sexual act between some people, everybody's doing it so why aren't we talking about it, and it's all in the papers, it's all in the media... **Sarah (Non NHS)**

Diane suggested she 'just slipped it in' to her assessments, Anthony referred to sex as being something 'so basic', whilst Nicola stated that she 'would always see someone's sexual activity as part of their normal, healthy relationship, part of what we do', saying 'it was no big deal'. Lisa spoke of 'just accepting that sex is an everyday activity and changing your attitude towards it'.

Whilst the majority of participants indicated they embraced or ignored the taint, only one participant indicated finding 'dirty work' more problematic, seeming to tolerate dealing with sexual concerns in terms of doing the 'right thing' professionally, and seemed to be more comfortable about conversations around emotional concerns rather than more physical aspects. The participant admitted that in previous roles it had 'never even crossed [their] mind'. This seemed to be due to the lack of clarity about their role in broaching sex within the organisation, rather than negative attitudes towards sex, having spoken of how they felt it was 'sad' that their clients were not given the opportunity for sexual expression should they wish. Other participants indicated colleagues who omitted sex was due to avoidance, for example Sarah suggested that many occupational therapists tended to 'block it out of their minds' and spoke of her experiences where sexual activities were ignored and 'under the radar'.

### ***Countering taint through professional identity and values***

All of the participants appeared to have strong senses of professional identity, and adhered to occupational therapy values, some speaking of their profession with great pride which arguably helped them to counter the potentially tainting or taboo aspects of broaching sexual concerns. These attributes were evident in how they described their work, their occupational focus and their adherence to client-centred and holistic values. The study participants projected strong senses of

professional identity and values which were demonstrated in their use of occupational language and focus, such as referring to and applying occupational models (for example, Emily reflected on her work in relation to the person - environment - occupation (PEO) model, and referred to the Canadian Occupational Performance Model (COPM) as a means of assessing priorities), adherence to professional values such as holism and client-centeredness, and the application of occupational therapy skills including occupational analysis, problem solving and collaborative goal setting.

The professional identities of the study participants appeared counter to those described in chapter 2.1, where Finlay (1998), Molineux (2004), Mackay (2007), and Clouston and Whitcombe (2008) suggested ambiguity, doubts about professional status and expertise, and tensions between professional values/ agency versus systems of 'accountability and assurance' (Mackey, 2014, p.171). In contrast, the study participants appeared to have strong professional identities despite their diversity of practice backgrounds, variety of roles and many having had a broad range of prior work experiences - which was cited in the literature as a cause for ambiguity around professional identity. Their sense of identity as occupational therapists was very strong; for example, Mary (NHS) stated 'I feel like I've got a very strong professional identity. I'm an occupational therapist first and a manager second, and I'll always identify myself as an occupational therapist when I'm introducing myself to somebody'. They were clearly passionate about their profession and about applying the values of occupational therapy within their practice, and this was something I perceived to be both part of their reasoning for including sex as well as being a resource they drew upon.

This strong sense of professional identity contributed to their inclusion of sexual concerns; they believed that sex was an occupation and therefore part of their remit, but also that excluding sex would be a lapse in professional values. For example, Carol suggested that not seeing sexual concerns as occupational might be problematic for occupational therapists when broaching sex and intimacy:

I think if you didn't feel yourself as having a role with this, I don't think you would seek information, I don't think you would try and find out more, I don't think you would force yourself to start being more comfortable .... If you didn't view that as your role, and didn't feel comfortable in that context perhaps, or you wouldn't be able to put yourself in that context professionally to deal with it professionally, which is how you should... **Carol (Non NHS)**

Sarah questioned the practice of occupational therapy colleagues whom she felt were failing to adhere to professional values, making her question whether some occupational therapists were truly practising occupationally and as such were unable to make the most of the profession for their clients:

Occupational therapists are person-centred and should be listening to the persons' goals and values and beliefs, if you're not doing that then it's fine, it's fine that you don't do that, it's fine if you're a discharge person and have the skills and knowledge for that, but you're not doing occupational therapy so just be upfront about it. **Sarah (Non NHS)**

An example of how a participant managed the taint of broaching sexual concerns using professional values and identity can be found in Kelly's description in the box ('Sexual concerns as matter out of place') which suggested discomfort when a client wanted support with her sexual concerns, but the discomfort was tempered by a sense of achievement and satisfaction that the client had achieved a meaningful occupational goal and had been happy with Kelly's input. This reflected Ashforth and Kreiner's (1999) theories around managing taint; the taint was refocussed as necessary and essential for the client; a key goal, and reframed as a source of professional pride for Kelly; redressing the stigma/ taboo through the satisfaction of supporting better quality of life and therefore a job well-done.

Simpson *et al* (2012, p.11) suggest that people undertaking 'dirty work' resist taint by drawing on and mobilising 'privileged frames in these ideological reconstructions' and the data indicated that the participants perceived the uniqueness of the occupational therapy role and a focus on occupation were used to counter and manage taint.

### **Sexual concerns as matter out of place**

Kelly provided an example of 'matter out of place' in terms of both content and context when a client raised sexual concerns in her busy office:

*It felt strange to start off with but because [the client had] raised it ... she very much wanted to talk about it and then we talked about positioning and equipment, and I ended up getting her some equipment for her bed which she could use to help lever herself and take some of the strain off some of her muscles, and she rang me up – I was in quite a crowded office – and she told me quite loudly over the phone that she was using the bed-loop to hang onto while her partner took her from behind, and she was very overt about it! I found that quite shocking but it was also a good thing because she was using some of the equipment and positions we'd talked about to have a natural sex life and she was really pleased, that was a big tick in her goals for life really, giving her better quality of life.*

Kelly expressed mixed feelings of discomfort and professional satisfaction at an early stage in her career, having supported the client in achieving her goal yet discussing it in an open, public environment.



Cathy spoke of how sexual concerns were 'so important for the client' and how she managed broaching sexual concerns by seeing it as part of the occupational whole of the client's life:

...try and see the whole picture of being close to someone, and if it helps to think of it just start smaller like things like having a hug or holding hands and communication and all of that so, ... I think, yeah, try and see the whole picture of how it affects somebody's whole life rather than just talking about sex, which was part of it but also about being close to people and communicating. **Cathy (NHS)**

Lisa perceived sexual concerns as part of the remit of an occupational therapist 'I think in terms of occupational therapy skills – if it's part of people's relationships and roles and important, and it has value to people's lives then that's core occupational therapy skills really'. Mary referred to sex as 'part and parcel' of how people see themselves 'fairly fundamental to your occupational needs and occupational roles', and therefore part of her role. Nicola spoke of how her occupational focus had led her to include sex, sexuality and relationships. Carol suggested that her sense of professionalism and professional values were key, summing up how as an occupational therapist she used her professional identity to include sexual concerns, saying 'I do think there's probably a safe, a little, a sort of protective barrier isn't it? It's not really the right word but you sort of feel comfortable because you are the professional.' Diane spoke of her keenness to find solutions to the unmet needs of her clients exploring 'sex shops' in order to find suitable interventions, whilst Emily suggested that, from her earliest experiences of encountering sex as an occupational therapist, her curiosity outweighed potential discomfort stating 'quite frankly, I would have been really interested! (laughs)'.

Several participants reiterated that sex should be included due to the client-centred and holistic core values of the profession, for example; 'It is part of a fully holistic assessment of the impact of illness or injury on a person'(Q7)<sup>27</sup>, 'It's an important occupation and if we are being holistic it should be included'(Q9)<sup>28</sup>, whilst Jane stated that 'I would think I should include it as part of my role as I would include work and seating and everything else'. Carol questioned whether an occupational therapist who did not believe that sex was part of their role would be able to broach sexual concerns:

...if you understand and believe that the dealing with sexual relationships is part of your role as an occupational therapist, it makes you feel more comfortable talking about it. If you fully believe that is part of your role, you can put up that professional – not a front, because it's

---

<sup>27</sup> Questionnaire data

<sup>28</sup> *ibid*

not trying to stop the interaction between the two of you but you, you deal with it within your professional boundaries. And it gives you some boundaries and some context and some safety, in discussing it. But I do believe that you do have to believe it's part of your role, if you don't believe it's your role you're gonna feel like "uh-oh-oh, am I venturing into waters here that aren't my territory?" that's when you'll probably feel uncomfortable. But if you firmly believe that this is my role, that this is an occupation, this is part of this person's life roles and who they are, and their psychological wellbeing and physical wellbeing I think you are more likely to deal with it. **Carol (Non NHS)**

The participants reinforced Molineux (2004) who suggests the profession needs to go 'back to basics', refocussing professional identity by remembering the history of the profession and the centrality of occupation – the participants displayed this focus on occupation to counter taint, adapting to the sensitivity of this part of their roles by bridging the gap between art and science. In doing so they negotiated between tensions and pressures, reflecting Mackey's (2014) view of occupational therapy professionalism as a dynamic process rather than 'static'. The flexibility of occupational therapy professional identity was an opportunity for the participants not a threat, showing that the profession could both 'redefine' its professional identity (Mackay, 2007) and use identity and values to broach an occupation which is often omitted and ignored.

### ***Using sex positive attitudes***

A further factor underpinning the study participants' management of the tainted aspects of broaching sex was their generally positive attitudes towards sex, indicated by their views of sex as being 'normal' or 'ordinary', discussed in chapter 4.1. For example, Sarah spoke of perceived sex:

I think sexuality is normal; sexual feelings, sexual expression is just normal. So you look at life a lot, I've changed as I've got older but you perceive life, you know your own perspective, and I think that's normal for me why isn't it normal for [clients]? 'Course it's normal, it's normal for everyone [...] that's why I didn't have a problem with it... **Sarah (Non NHS)**

Sex positivity is defined as the belief that 'all consensual expressions of sexuality' are good and healthy, and calls for a deliberate focus on personal meanings of sexuality and its relationship with well-being (Wikipedia, n.d<sup>29</sup>). Kimmes *et al* (2015) suggest that this 'is a mind-set needed to combat the still prevalent unidimensional approach to sex in our culture' and advocates for the acceptance of and attention to sexual experience. For the purposes of this study I accepted the idea of sex

---

<sup>29</sup> [https://en.wikipedia.org/wiki/Sex-positive\\_movement](https://en.wikipedia.org/wiki/Sex-positive_movement)

positivity on face value. Sex positive attitudes were reflected in how several participants spoke of sex beyond the purely functional and about the meaning and importance of sex. For example, Emily and Cathy spoke about helping their clients work towards feeling pleasure and having fun, either with a sex partner or on their own; Emily suggesting that 'we look at having fun again - so that's been very much about trying to spice things up'. Cathy also spoke in terms of taking a sex positive approach to support clients in returning to their sex lives when she spoke of how she worked with clients: 'we talk about the importance of foreplay, that kind of thing, but also we advise about the real nitty gritty, positions and things, but nine times of out ten it's more about getting that spark back again and getting the person excited about re-igniting that'. These sex positive attitudes were reflected in several of the participants' comments recognising that fun, pleasure and closeness, as well as the functional aspects of sex, were important and meaningful occupational goals for their client's health and wellbeing.

These 'sex positive' attributes appeared to be related to beliefs around sex as an occupation discussed in chapter 4.1. This seemed to instil a desire to include sex as part of their occupational therapy remit as part of a sense of professionalism. This was common to all the participants to some extent, although in practice was dependent on their reasoning around the individual client and their circumstances.

I considered whether these sex positive attitudes came from the upbringing of participants, however the two interviewees who displayed the strongest 'sex positive' attitudes, Diane and Emily, seemed to have come from quite different personal backgrounds with regards to sex. Diane stated that she had an upbringing where the body was 'no big thing', her 'family was relaxed about sex' and where sex and bodies were 'normalised':

[my] parents were walking about from the bedroom to the bathroom ... and they were naked then it was no big deal. So I'm, my conclusion is that, I suppose the people that are more comfortable are from a background where actually sex is normalised. **Diane (Non NHS)**

Whereas Emily stated she had 'had quite a strong Christian upbringing'. Emily struggled to explain why she felt comfortable about broaching sex; she speculated that sex was not a taboo subject to her because 'I've probably had quite a rich and varied sex life so that might mean I've just always been very comfortable with it, so it doesn't feel like a taboo to me, it could be just that simple I suppose'. Emily pointed to past experiences working with HCP colleagues who broached sex as an

important factor, along with experiences of working with HIV clients. Upbringing, then, appeared less influential than the experiences and open-mindedness of these participants.

Being sex positive is arguably congruent with the holistic and client-centred values of occupational therapy. For several participants they retained an occupational approach rather than adhering to medicalised approaches based on purely physical function or risk management. In line with occupational thinking and occupational therapy values, they considered what was meaningful to the client and how best to work with the client to achieve their goals.

### **Summary: Countering occupational taint - managing sex as 'dirty work'**

This section found that although none of the participants directly or overtly spoke of sexual concerns as being 'dirty work' or tainted, there was evidence to suggest that it can be described as such, for example the recognition of discomfort and embarrassment, the sensitivity and rapport required to deal with these concerns and the strategies the participants used to manage sexual concerns when they arose. Whilst occupational therapy may be deemed 'good work' offering rewards such as job satisfaction, enjoyment and opportunities (Simpson *et al*, 2012, p.2), occupational therapists can be exposed to 'dirty work' due to exposure through the context of their work, how occupations, impairments or client groups relate to or present a threat to preferred orders, and the practitioners desire to maintain distance from potentially tainting factors (McMurray and Ward, 2014, p.1126).

The managing or countering strategies arguably used by the participants mirrored those described by Ashford and Kreiner in their extensive work on the subject of 'dirty work'. Bolton (2005) suggests in her research on gynaecological nursing that taint arises from association with the 'private realm' (p.170), because 'what should remain private and invisible is made public and rendered visible' (Bolton, 2005, p.176). Tyler (2011) suggests that stigma and therefore taint are derived from connotations of immorality and the transgression of boundaries. These issues of the private and

#### **Key points: Sexual concerns as occupationally tainted**

Sexual concerns are congruent with the concept of 'dirty work' or occupational taint due to the sensitivity, taboo and discomfort associated with it.

The study participants did not indicate they perceived sexual concerns as tainting but did acknowledge the taboo and sensitivity involved.

The study participants invoked several strategies based on 'occupational ideologies' which mirrored those set out by Ashforth and Kreiner (1999) to reframe sexual concerns as part of their practice:

- Reasoning around sex as an occupation and therefore part of their remit;
- Professional values based on holistic and client-centred practice;
- Positive attitudes to sex as an ordinary, normal part of everyday life.

transgression were reflected in the sensitivity and taboo acknowledged by the participants and may therefore be applicable to occupational therapy relating to broaching sexual concerns.

Tainted or 'dirty work' derives from cultural scenarios around the specialness of sex within society which tell us that sexual concerns are taboo, awkward and discomfoting and even potentially immoral, involving bodies (Liddiard, 2012; Jackson and Scott, 2004; Rubin, 1984), the private realm (Bolton, 2005), as well as conflicting cultural scenarios around fun, pleasure and spontaneity (Jackson and Scott, 2004). This taint is compounded by cultural scripts around the stigma of impairment and illness (Green, 2009) and assumptions of disabled peoples' vulnerability or asexuality (Shakespeare, 2014). In order to counter and manage the tainting aspects of broaching sexual concerns, the participants, then, navigated these multiple dominant cultural scenarios. This arguable required them to draw on alternative intrapsychic and interpersonal scripts to reconstruct cultural scenarios. These were based on countering strategies around professional ideologies of occupational therapy values and professional identity such as holism and client-centeredness, and their acceptance of sex as an occupation and part of their roles.

Ashforth and Kreiner (1999; 2007; 2014) suggest that physical and social taints are easier to manage than moral taints; physical and social taints can be managed as 'necessary evils', but moral taints are more likely to be seen as 'evil necessities'. The use of the word 'evil' seems somewhat excessive, however, for me the idea that some occupations are more difficult to manage than others due to their physical, social or moral connotations potentially answers a question which arose from my first consideration of examining sexual concerns from an occupational perspective; why occupational therapists broach some sensitive subjects (such as toileting), whilst sex is often omitted or ignored. The concept of occupational taint explains differences in sensitivity based on how an occupation is perceived by individuals and within society, and that therefore occupations can be managed or countered in varying ways depending on the individual and context. Bodily cares such as toileting may be physically tainted but are also viewed as necessary, whereas sexual concerns have some degree of moral taint which may not be seen as 'evil' but are seldom seen as necessary or needed.

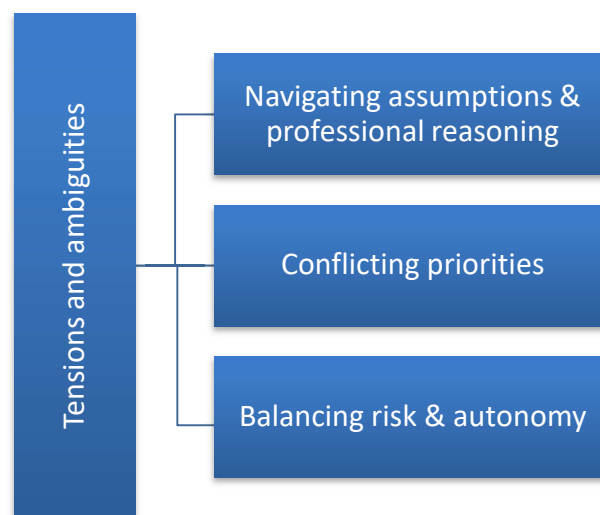
In this study, the participants appeared to use reframing strategies (Ashforth and Kreiner, 1999) to embrace and/or ignore taint focussed around professional values and identity, and on sex positive attitudes founded on perceptions of sex as an occupation and therefore part of their remit. The use of professional values and sex positive attitudes reflected the use of what Ashforth and Kreiner

(1999; 2007) called 'occupational ideologies' as a means of countering taint. Whilst the literature suggests that some occupational therapists have struggled with their professional identities (Molineux, 2004; Turner and Knight, 2015), the participants in this study exuded strong professional identities, values and pride in their profession, which can be equated with an 'occupational ideology'. Managing taint was complex but necessary in order to achieve truly holistic and client-centred occupational therapy practice within the values of the profession ('ideology') and in order to be truly occupational focussed. By not managing taint, a practitioner may unconsciously avoid or omit occupations which are important to the client, or may broach a subject in a way which makes the disrupted occupation difficult to talk about, as Emily stated, 'you don't want a therapist saying all the right words but bright red and shuffling around [laughs], like they really don't want to talk about it'.

In general, occupational therapists are exposed to tainted occupations in their daily lives, both embedded in societal attitudes towards some of the concerns they broach and in aspects of the occupations their clients seek to engage with. Often they recognise the stigma of some tasks and occupations but they may not acknowledge these as tainting, nor might they be aware that they are using a variety of strategies to manage and counter the taint. The concept of 'dirty work' or occupational taint warrants further investigation within occupational science; greater awareness of the concept and techniques to manage it may support reflection around good/ bad or health/ unhealthy occupations, the inclusion of sensitive occupations in practice, consideration around how sensitive and difficult occupations can be managed and how professional identities may coalesce.

## 4.5 Negotiating tensions and ambiguities

This section explores the tensions and ambiguities the study participants negotiated around broaching sex as an occupation. These involved balancing and navigating normative assumptions and multiple sexual scripts with professional reasoning, respect for the autonomy of the client, challenging, risky or inappropriate behaviours, and conflicting priorities.



### Normative assumptions and reasoning

The previous section indicated that the participants had positive attitudes towards sex and sexual expression, and considered broaching sex to be an occupational concern. However, there were also indications that at times the participants could make normative assumptions about some of their clients. Like issues of occupational taint, these assumptions were arguably based on cultural scenarios/ sexual scripts and taboos around what is deemed acceptable or 'normal' in relation to sex, relationships, disability, impairment, age and attractiveness, and given greater complexity due to conflict between the priorities of the participants, their clients and carers/ families and organisations. Tensions could arise from needing to employ assumptions which may be embedded in professional reasoning. This could lead to making normative assumptions about the client, their circumstances and occupations. The data alluded to several ways in which this occurred; around relationships, around essentialist thinking or 'traditional' gender preferences and roles, and around perceived attractiveness, age or the severity of the clients' condition or impairment.

As discussed in chapter 4.1, many of the participants used the discussion of relationships as a means of 'opening the door' to discuss and assess client sexual concerns. This could be potentially

problematic as there was a danger of making heteronormative and/ or mono-normative assumptions around marriage, partners and monogamy as an aspect of this professional reasoning. Several participants suggested or inferred their reasoning about how and who to broach sex was influenced by their clients' relationships. Several participants indicated a tendency to view sexual concerns through the prism of relationships, and spoke of using discussion about relationships as a means of raising the subject, for example Nicola suggested that 'I would certainly ask about the impact just generally on their relationship and I would see how that evolves, because I think it's a very sensitive area', whilst Diane stated:

I would say "do you have a relationship? 'Are you in that relationship now?" And then as the rapport [is built]. [...] I've done couple counselling, through activities and where, I might speak to the girlfriend or the wife if it's a male with a brain injury, say, or MS or a neurological condition to say, "do you have an active sex life?" – "we don't now." – "What's preventing you from doing that?" **Diane (Non NHS)**

As discussed in chapter 4.2 the participants indicated that using relationships was a 'way in' to raising the subject in a way that felt 'natural' and respectful:

Because if you know that they are married or have a partner and, you know, that they have pain to be touched then sometimes it will just come naturally that you can just ask "so how is it with your partner? Are you okay with him touching you, you know, on your arm?" And it just leads on quite naturally. **Cathy (NHS)**

Aside from the participants' direct experiences, there were also indications that when sex was broached by healthcare colleagues it was also couched in terms of relationships. Emily spoke of referral documents she received from colleagues, saying: 'I see things like 'affecting marriage' or 'relationship problems', but never referring to sexual intimacy. That's kind of shocking really!' A minority of participants indicated that sexual concerns were something they broached with all clients, for example Emily:

I mean some people, if they're not in a partnership or if they, as I say, someone who likes multiple partners or they're, the emotional side isn't quite as important, then we would look at things different, but I sort of tend to, I suppose I ease into it in the same way every time. **Emily (NHS)**



Using relationships was seen as a useful tool for 'opening the door' to broaching and exploring sexual concerns, however there may be a danger of overlooking the needs of clients not in relationships or in relationships which may not fit with the experiences of the practitioners.

Several participants indicated they had made assumptions based on reasoning around age and /or perceptions of attractiveness and ability. Some acknowledged these assumptions were based on ideas of what was 'appropriate' or choosing the 'right time' to broach the sexual concerns. For example, Carol acknowledged she made assumptions: 'I absolutely 100% know that I'm supposed to ask about sexual relationships and sexual activity as part of this persons' assessment. I know I'm supposed to do that, but I don't! I absolutely don't'. Diane indicated she had made assumptions around the priorities of older clients saying:

I certainly wouldn't do that if it was, and this is going to sounds ageist, if it's some old lady whose husband had died 10 years ago, it certainly isn't something that I would prioritise and put in there. I would get to know them. **Diane (Non NHS)**

Carol reasoned that clients may have other more pressing priorities, describing the situation of an older client with a spinal injury where 'I might have made some assumptions there'. She felt that there were 'immediate issues that were happening' such as mobility and skin breakdown which should take priority, describing sex as 'the thing that comes very last on that list because you crisis manage a lot of the time'. When faced with clients who felt that "everything has fallen apart, our lives have fallen apart" and then I ask "and what about your sex life?" that's not appropriate'. Carol acknowledged that 'maybe that's another assumption of mine - but I think that comes, sexual intercourse comes at a point in your life when everything else is calmer', indicating that sex was assumed to be a lower priority. Whilst assumptions around age seemed to be recognised those around attractiveness and impairment seemed less so, for example Diane spoke of occasions where the 'attractiveness' of a client had led her to broach their sexual concerns:

There was this gorgeous young lady with a man who had clearly been gorgeous [...] and I said, she said something or other and I said, "so you are an attractive couple and you're still 'together'", and she went "I'd like to be" – so I said "well, you and I can talk about that".  
**Diane (Non NHS)**

Judgements around clients could also be reflected in how several participants spoke in terms of roles (as discussed in chapter 4.1), such as traditional gender roles around men as providers and women as wives and mothers, or in essentialist thinking around sex and familial relationships - for example

Diane spoke of looking for 'frustrated behaviours' in her assessment of clients, indicating a perception of sex as a drive in need of outlet. These examples suggest that occasionally study participants' decisions as to whether to broach sexual concerns may be affected or impacted by conscious or unconscious normative assumptions based on cultural scenarios, societal norms, education and experience. Arguably the predominance of a fairly narrow demographic group within the occupational therapy profession generally may influence assumptions; occupational therapy being dominated by white, middle class, non-disabled women (Clare Taylor, 2007, p.277) and a middle class worldview (Kantarzis and Molineux, 2012) or values (Hocking, 2012). One participant reflected that when she joined the profession there was a prevailing perception that it was a job for a certain set of characteristics - a 'nice profession for nice women' – and that this may impact on whether some occupational therapists might feel comfortable with broaching sexual concerns. Jackson (1995) suggests that occupational therapists can also make heteronormative assumptions around occupational wants and roles due to a lack of knowledge on the impact of sexual orientation on occupation and that the often heterosexual 'background noise' (Jackson, 2000, p.21) within healthcare environments ( that is, the predominance of heterosexual assumptions embedded in daily experiences of healthcare, which may also extend to normative ideas around sex) may influence and overwhelm the practice and values of occupational therapists.

Normative assumptions also derive from societal cultural scenarios around about attractiveness, age and impairment reflected those found in the literature; several articles indicated a tendency in HCPs towards making value judgements on whether a client may be sexually active. Saunamaki and Egstrom (2013) found that nurses were less likely to discuss sexual expression with older people or with people who were bed bound, considering the clients to be 'too ill' or 'too old'. Shakespeare *et al* (1996), Mellor *et al* (2013) and Santos and Santos (2017) found disabled people felt that the HCPs who worked with them made assumptions around their sexual lives.

These assumptions may reflect pervasive societal values and attitudes towards sex derived from the culture the individual occupational therapist has lived in, as well as reflecting the influence of the dominant medical model on occupational therapy practice discussed in chapter 2.2. They also reinforce assessment which unavoidably 'measures' the client in accordance with professional reasoning, incorporating what the practitioner knows and observes about the client, and the client's self-reported perception of concerns and priorities. Arguably, these judgements are embedded in occupational therapy practice as part of assessing client needs is founded on reasoning based on the information presented to the practitioner. This means considering factors including past and current

ability and the resources of the client in order to ensure that therapeutic goals are realistic, to avoid setting a client up to potentially demoralising failure, constrained by the structures / organisations in which the practitioner works in and the resources available. The work of an occupational therapist, then, may be perceived as underpinned by baseline ideas of what was 'normal'; with the aim of returning the client to their 'normal' function or helping them adapt to a new 'normal'. This indicated that to some extent there could be a 'tyranny of the norm' (Davis, 2006, p.29), whereby a 'normalising judgement is always a value judgement' (Hammell, 2009, p.22) against which an individual client is measured and compared, with these normalising assumptions tending to perceive impairment as a 'deviation from socially defined norms' (Hammell, 2009, p.22). Occupational therapists themselves may feel uncomfortable with the word 'normal', for example, Nicola indicated she felt the word 'normal' was problematic, she talked about 'supporting clients to have much more "normal" - not normal sexual relationships but, you know...' indicating her recognition of the assumptions and connotations the word had.

Making subjective judgements and benchmarking what is 'normal', then, is arguably part of the occupational therapy process. This requires practitioners to potentially maintain several conflicting ideas simultaneously; societal concepts and organisational priorities which privilege independence, appropriateness and 'normality', medicalised notions around function, pathology, 'fixing' and discharge, and cultural scripts around disability, sex and sexual expression, alongside professional values around holism and client-centeredness. This could lead to conflict between professional ideologies around holism and client-centeredness against socially accepted norms for appropriate behaviour; the valuing of clients' experience, goals and desires versus supporting the client in behaving in a socially acceptable way perceived as appropriate and correct.

An occupational therapist, then, must balance their core values of being non-judgmental and client-centred against the need to make judgements based on reasoning and often within the constraints of time, resources and the aims of the service. Therefore occupational therapists are required to negotiate several sets of normative standards; their own perceptions and observations, the client's perceptions, expectations and wants based around what they see as 'normal', and those of the colleagues they work with and wider society. For example, the occupational therapy profession describes itself as 'enabling independence' – this could be described as a normative concept with neoliberal connotations which privileges a particular view on how a person should live with an onus on individual responsibility. In this sense, the training and experiences of occupational therapists reinforces conformity to current dominant social ideals or cultural scenarios. It is unsurprising, then,

that the study participants sometimes made normative assumptions as 'shorthand' to aid the assessment and intervention process, particularly when time and resources are pressured. Hammell (2006, p.32) suggests that rehabilitation professionals need to challenge the 'ideology of normality' as a socially constructed and not factual reality, otherwise rehabilitation can reinforce ableism if there is little critical reflection or examination. With regards to sexual concerns and intimacy, navigating these normative ideas and assumptions may be further complicated by concerns around taboo and morality.

This study indicates that occupational therapists can make normative assumptions and recognising this is important; by acknowledging the potential for making assumptions an individual therapist can challenge their thinking in order to ensure non-normative client needs and wants are perceived and accommodated, and can help the therapist in challenging the client's normative thinking which may prevent them from finding alternative means of undertaking activities, roles and occupations and achieving their goals.

### ***Conflicting priorities and occupational assumptions***

A further tension the study participants had to negotiate was between their professional view of a clients' situation and assumptions about client priorities, and the perceptions and priorities of the clients and/ or carers/ family members. Several participants provided several examples of how their assumptions around occupations had conflicted with those of the client or the clients' circumstances. For example, Emily spoke of an occasion where a clients' choice has surprised her with regards to the position of a catheter:

That's [catheter position] something I've spoken about recently with one of my ... patients, she's been offered a supra-pubic catheter because her pain condition has given her problems with her bladder, but she would rather not have the supra-pubic catheter because she thinks her husband will find it less appealing to see her naked then with the normal urethral catheter in, which I found quite interesting because I thought they could both enjoy a much less uncomfortable sex life using the supra-pubic catheter, but she was really clear that's not what she wanted. And that was about her body image and her sex life. **Emily (NHS)**

Diane spoke of one of her earliest experiences of broaching sex where she found her assumptions as an occupational therapist had been challenged when she realised, as she put it; 'that slap of "oh, I hadn't considered that!"', as she had focussed too much on ticking 'boxes' within a rigid conception

of the occupational therapy process. She provides an example of a client who had had a severe stroke and, in her view, was 'doing really well':

He could transfer, all the things we [occupational therapists] get excited about! He could do this, and he was able to dress his top half now, he could do all this stuff, he could get on and off the toilet. And I was like "woo-hoo, let's go on a home visit!"

Diane indicated the client's wife was 'this glamorous lady' whose view of her husband's progress was very different from Diane; his wife wanted her husband to be more independent before returning home. Diane went on to speak of how the case developed and how she perceived the wife of the client as 'cold' until a home visit which made her think about the differing priorities of the client and his wife, and his wife's perception of how she wanted to maintain their relationship, that "I'm his wife. I'm not his carer and I'm not wiping his arse!" Diane realised that his wife wanted 'to preserve husband and wife rather than man and carer, and I respect that', going on to say:

She taught me to make sure that I get the relationship right when I'm starting to get excited about transfers and stuff. I was "hey look, your husband can go home soon he can do this and this and this". But that relationship was another part.

This experience had led Diane to re-think about priorities from her professional standpoint and those of the clients she worked with, reminding her of the occupational 'bigger picture'.

The clients' internalised cultural scenarios could place barriers in terms of expectations and prejudices. For example, Carol observed some clients had unrealistic ideas about finding potential partners that at times she had to manage. She spoke of conversations with clients who when asked about their goals suggested that they wanted a relationship, which she suggested 'was very tough because it's not so easy!' Carol also found negative attitudes from clients towards other disabled people, reflecting a hierarchy of impairment discussed by Deal (2003); of clients who did not want to date other 'disabled' people, having unrealistic expectations about potential boy/girl-friends (wanting a 'playboy / playgirl') and 'end up getting horribly disappointed'.

The study participants had to negotiate several conflicting demands and values; attempting to acknowledge their clients' goals, wants and needs whilst attempting to avoid raising unrealistic expectations or disappointing their client, reflecting a social relational model of disability where barriers arise from culture, society and from impairment.

## Balancing risk and autonomy

A further 'grey area' the study participants negotiated arose around balancing risk with the autonomy of clients. This was illustrated by several practitioners when they discussed how client disinhibition could culminate in inappropriate behaviours, reflecting the comparatively high proportion of interview participants who were working with people who had had brain injury either through accident or stroke. Despite this, none of the occupational therapists reported overt inappropriate behaviour directed towards them by a client, a fear which was indicated in the literature (Mellor *et al*, 2013; Dyer and Das Nair, 2013; Jones *et al*, 2005). Instead concerns were often discussed in terms of protecting the client from potential harm, or the potential for the client's lack of insight causing them to be misunderstood by others, for example, '...they can come across as creepy to people who don't know what's going on with them'.

Inappropriate behaviours could impact on client occupations, needs and wants and lead clients to undertake activities which may be risky to themselves and at best, unacceptable to the people around them. For example, Nicola spoke of how a predominant part of her role was about dealing with behaviour that was inappropriate due to brain injury leading to self-absorbed behaviours:

... it's much more the sort of behavioural, the client who's been in the nightclub and groped a woman, so you know I've kind of had that, inappropriate sexual comments to women, [...], young girls having promiscuous sex, prostitutes, that kind of thing - the self-satisfaction and clients going off to sex shops'. **Nicola (Non NHS)**

Kelly indicated that clients who lacked insight were the most difficult to deal with 'because they don't realise how overt their behaviour is, and they find it quite difficult when they hear that other people have noticed. So it can be quite an embarrassing situation for them.' Faced with disinhibition and the inappropriate behaviour of some clients, several participants expressed difficulty in balancing between minimising the risks to their clients whilst still considering client autonomy, wants and needs. For example, Anthony and Carol talked about the difficulties they had with respecting client's risk-taking behaviours, particularly when they felt those clients may have been inclined to undertake risk-taking behaviours prior to their neurological change. Carol spoke of a 'really fine balance between that and deprivation of liberty...working out what risky behaviour she would have otherwise done', whilst Anthony spoke of the difficulty in giving one of his more reckless and disinhibited clients space to express themselves when their lives had changed and they required the involvement of health services:

...that was the kind of lifestyle he had anyway. So that's a tricky one. [...] It's like balancing his, that was his life and that was how he lived his life whereas you've got to make him

aware of the risks involved. [...] and people don't like that. [...] There's that tension, it does create a tension - bit like paternalism in a way. Isn't it? And it's a bit like "leave me alone, I do things this way". **Anthony (Non NHS)**

Several participants spoke of concerns around negotiating what was appropriate for their clients; Jane expressed concerns about balancing the wants and needs of clients, being seen to 'encourage' clients in activities perceived as morally dubious, and the attitudes of those outside the organisation she worked for 'if they knew' what was going on - indicating an awareness of the potential of transgressing acceptable boundaries. Nicola spoke of an occasion which highlighted the difficulties in balancing risk with the autonomy of the client:

We looked into lots of different options for him, and then we started to look into whether we could get him in [to a sex educational group] - maybe looking at him going to one of those groups as well, to help him to learn how to express himself. Because he was having - he's got a brain injury but was going to some learning disability social groups and kind of having sex in the toilet, I think, we found this out via other people's support workers, so you know we needed to find a way of keeping him safe, because he's mobile, and he's independent, he's going out into town and going into pubs and trying to pick up women. And he's so vulnerable, so trying to actually contain that and help that to be the safest way possible for the client. [...] it's part of his life, you know, he does voluntary work, he's got loads of leisure opportunities, he's got loads of social opportunities, but ... [sex is] a big unmet need. **Nicola (Non NHS)**

Carol spoke of the risks she felt her clients were exposed to when negotiating what she described as opening 'Pandora's box' when her clients used online dating websites saying 'it is quite frightening, and it is very unregulated, and I thought it would be a little more regulated'. Some participants expressed concern about the vulnerability of some clients, for example Nicola spoke of younger clients transitioning into adulthood and wanting to explore and experience sexual relationships:

...they're very vulnerable, as well, to being preyed upon, and because some of our clients may be disinhibited about their, just the fact that they're going through a claim and that they're ...there might be a pot of money, they're preyed upon by the wrong kind of people. And helping people kind of see that, and engage in those positive relationships. **Nicola (Non NHS)**

The study participants spoke of situations where they had to balance the needs and wants of their clients with societal expectations and social norms. In a sense, they were in a position of having to 'police' their clients' behaviours, although none of the participants spoke in such terms. Jane spoke of how it could be a challenge; many of her clients were receiving palliative or end of life care and she felt it was 'sad' for them to be denied the opportunity for sexual experiences, saying:

not that I'd want to do things that are inappropriate at all, but if someone says, you know, "can I have an ice cream?" and they're not allowed ice cream, it's the same kind of thing really. It's like "oh, what a shame that they can't".

The participants took an occupational approach to these more challenging aspects of broaching sex and sexual expression, and applied an occupational focus in their interventions, reiterating the occupational nature of sex.

These experiences of balancing risk and autonomy reflect some of the more challenging scenarios practitioners may face when broaching sexual concerns, or indeed when working with clients generally. This may be particularly difficult when clients lack insight or are engaging in behaviour which challenges social norms and may be deemed inappropriate. On one hand, these may reflect the occupational needs of a client who wishes to find intimacy or closeness, express themselves sexually or have a sexual encounter, or wishes to engage in a fun and pleasurable activity, on the other, the clients lack of education or experience or the effect of their impairment or condition may lead them to engage in activities which are unacceptable to wider society. Practitioners may be required to navigate this balance between risk and autonomy.

### **Summary: Negotiating tensions and ambiguities**

This section found that participants had to negotiate tensions which can be seen to reflect conflicting sexual scripts and priorities, around what is deemed appropriate, acceptable or 'normal'. Using reasoning as part of the occupational therapy process requires making judgements based on the information available, balanced with professional values of holism and client-centeredness, institutional priorities and the needs and wants of the client. This section indicates this can lead to normative assumptions, which could mean occupational needs relating to sex and sexual expression may go unmet, however valid the reasoning underpinning these assumptions may be.

The study participants occasionally had to navigate the conflicting sexual scripts of themselves, their clients, their colleagues and wider society, treading a path between protecting and policing their clients. These issues created dilemmas for the participants who wanted to respect their clients'



wishes but also protect them from harm, exacerbated by the sexual scripts which arise from societal views of disabled people fixated with 'asexuality or dangerous sexuality' (Shakespeare, 2014) reinforced through the omission of disabled people as sexual beings in the media and education (p.218). Shakespeare (2014) perceived a tendency to see sexual expression discussed in terms of vulnerability, protection and abuse, and this was reflected in some of the data. This may have increased as society has become more risk averse and where there has been increased publicity of cases of abuse. As discussed in chapter 2.3, although there has been progress in societal acceptance and attitudes towards bisexuality, homosexuality and alternative sexual lifestyles, for disabled people sexual expression remains controlled, often viewed in terms of asexuality, a

problem to be medicalised or considered as too risky and dangerous (Shakespeare, 2014). Several participants indicated they attempted to counter this, but had to balance this with being mindful of the potential vulnerability of some of their clients.

### **Key points: Negotiating tensions and 'grey areas'**

This study found that participants negotiated 'grey areas' around:

- Assumptions and reasoning
- Risk and autonomy
- Inappropriate behaviour and policing behaviours
- Managing client expectations and realities

At times, participants made normative assumptions around relationships, age, attractiveness and impairment. Awareness of these assumptions varied.

Assumptions were often based on reasoning around the client's circumstances.

These tensions reflect the challenge of negotiating conflicting sexual scripts of themselves, clients and wider society.

For this research, sexual script theory was useful in considering how different identities and ideas might interact – the professional identities of the occupational therapists allied or conflicted with cultural scenarios and the needs and wants of the clients. Based on their experiences, education and professional values, the participants broached and adapted to cultural scenarios outside those of occupational therapists who omitted or ignored sexual concerns. Some cultural scenarios could be problematic which led to several practitioners making normative assumptions about their clients often based on their professional reasoning, others struggled to balance the autonomy and wants of their clients with personal and societal expectations of appropriate behaviour. The participants also had to navigate the cultural scenarios internalised by the clients themselves, particularly if their clients had had limited experience or education around sex and had been excluded from shared cultural sexual scripts, for example representations of disabled people as sexual beings in media / popular culture – see Liddiard (2012) and Shakespeare (2014).

Balancing risk and autonomy may be particularly challenging to professional values focussed on holism and client-centeredness, where the client's occupational priorities are central. On one hand, the participants wanted to support the autonomy and choices of their clients; on the other they recognised some clients could be vulnerable as well as tensions around organisational pressures where risk-reduction may take precedence. The difficulty for the study participants who dealt with these issues was to negotiate them without 'policing' the client and without assuming the vulnerability and paternalistic protection from harm disabled people face noted by Shakespeare (2014). Participants spoke of the sensitivity involved in trying to support clients who may be vulnerable to potentially unscrupulous people, could lack insight on the impact of their actions and as such could be embarrassed by the issue being discussed and possibly harmed as a result. Balancing what clients want, what may be possible with the resources available and minimising risk will always be a difficult area of practitioners to negotiate, particularly when sexual concerns are seen as sensitive and taboo, and difficult conversations are avoided as a result of exceptionalism around these concerns.

## Chapter 4 Conclusion

This chapter explored and discussed the results of the data based around the research question, aims and objectives and Dalkin *et al*'s (2015) interpretation of Critical Realism by considering the context, resources and reasoning (mechanisms) and outcomes. The first section explored what could be described as the context of this research based on sex as an occupation and part of the remit of occupational therapy; the participants indicated they based the inclusion of sex as part of their roles based on this, associating sex and sexual expression to their conceptualisation of occupation around meaning and importance, that sex is an ADL and an ordinary part of their clients' lives. The participants drew on professional values and ideologies around holism and client-centeredness which underpinned the management of sex as sensitive and taboo, and therefore a tainted occupation explored in chapter 4.4.

The outcome of this context and reasoning is the inclusion of sex as part of the study participants' day-to-day practice explored in chapter 4.2. They applied their professional skills and knowledge to sexual concerns as they would with any other occupation, albeit one many participants indicated required sensitivity, rapport and a positive therapeutic relationship. The participants appeared to employ the principles of PLISSIT / Ex-PLISSIT (Annon, 1976; Taylor & Davies, 2006) or the Recognition Model (Couldrick *et al*, 2013) to give or gain permission to discuss and explore their concerns, and provide limited information, and support or refer clients. This section indicated that the participants needed to be resourceful and creative to solve problems and come up with practical and workable solutions. Resources as a mechanism for broaching sexual concerns were explored further in chapter 4.3, which looked at the attitudinal and structural barriers the participants faced. Feelings of comfort or discomfort were impacted by clients and their circumstances. This discomfort and sensitivity around sex as an occupational concern reflected what I perceived to be a degree of 'taint' regarding sex within society, although none of the participants described it as such. This sense of 'dirty work' was reflected in expressions they used such as sexual concerns being sensitive, taboo, 'an embarrassment' and a 'minefield'. This was explored further in chapter 4.4 which looked at some of the reasoning the participants used to manage and counter the tainted aspects of broaching sexual concerns. This found that the participants invoked professional identities and values around holism, client-centeredness, sex-positive attitudes and an occupational focus.

The final section explored the reasoning mechanisms required in negotiating some of the tensions and ambiguities related to broaching sexual concerns. The participants reported challenges around balancing the demands, wants and needs, their clients and their families / carers, the attitudes of wider society, and their own assumptions and professional reasoning around the clients' wants and

needs. The data indicated that several participants made normative assumptions, some of which they indicated they were aware of, in order to accommodate these competing pressures. The participants had to weigh between the risks and potential vulnerability against the autonomy and agency of their clients. The next and final part of the thesis will draw together the key points arising from this research, looking at the implications for practice and presenting recommendations for policy and future research.

## Chapter 5: Conclusion - findings, implications and recommendations

This chapter reviews the findings and implications of the study, providing a summary of the key themes, contribution to knowledge, recommendations, the study limitations and directions for future research. Answering the research question and achieving the aims and objectives of this study, a reminder of which is provided below, required exploring the practice and experiences of occupational therapists who broached sexual concerns, considering their experiences, the sensitivity and taboo around intersections between occupation, occupational therapy practice and values, the lives and experiences of disabled people / clients, and the exceptionalism yet ordinariness of sex and sexual expression. This involved exploring an under-researched area of practice as well as applying a set of methodological tools to an area of study to which they had not been applied before.

### Research question:

**Does current occupational therapy practice support clients' sexual concerns and, if so, how?**

### Aims and objectives:

**Aim 1: Identify existing UK occupational therapy practice relating to in sexual concerns**

#### Objectives:

- To identify individuals who incorporate sexual concerns in their occupational therapy practice.
- To identify the scope of this practice.

**Aim 2: Explore occupational therapy practice regarding sexual concerns;**

- To explore this practice by occupational therapists.
- To investigate practical aspects, such as assessments and interventions, used in relevant practice.

**Aim 3: Explore occupational therapy practitioner attitudes to and experiences of practice broaching sexual concerns;**

- To investigate the attitudes and influences on individual occupational therapy practice in this area.
- To explore and examine the barriers and facilitators to this practice, as perceived by the individual occupational therapy practitioners.

This study was founded on pragmatic and post-positivist outlooks, operationalised by using a critical realist (CR) approach, utilising mixed methods in order to ascertain predominantly qualitative data

supplemented by quantitative data, utilising the strengths of both in order to ascertain information on practice as well as the thoughts and feelings of the occupational therapy practitioners. CR helped me consider the context, resources and reasoning required for occupational therapists to broach the sensitive subject of sex and sexual expression. I drew on sexual script theory and materialism to aid this exploration. Throughout I ensured the quality of the research and an ethical process.

## 5.1 Findings, implications and contribution to knowledge

This section sets out the study findings and implications, as well as showing how this research has contributed to knowledge. Although sex and sexual expression are not embedded throughout UK occupational therapy practice, this study identified practice which did support client sexual concerns, exploring that practice and the attitudes and experiences of those practitioners who did so.

The study findings are summarised around sex as an occupational concern, the practice of the participants, challenges and creativity regarding resources, navigation around assumptions, attitudes and acceptability, tensions and ambiguities around practice, and the management and countering of the taboo and sensitivity associated with sex as a tainted occupation, as well as the use of Critical Realism (CR) as an underpinning methodology.

### Sex as an occupational (and ordinary) concern

This research supports the view that sex is an occupation. The majority of survey respondents accepted sex was an occupation whilst all the questionnaire /interview participants felt this was the case and that therefore sex was part of their

remit as occupational therapists. For participants who broached sex this involved applying their professional values, skills and knowledge;

- considering meaning and importance,
- perceiving occupation beyond potentially limiting concepts of productivity and independence,
- being holistic and client-centred, and

#### Summary of findings

Occupational therapists who broached sexual concerns:-

- Recognised sex as an important occupation for their clients, related to meaning, identity and as an Activity of Daily Living/ part of their lives;
- Had a strong sense of professional values and identity;
- Adapted and applied their occupational therapy skills and knowledge to assess and support clients regarding their sexual concerns.

Occupational therapists acknowledged the meaning and importance of sex to the clients as 'part and parcel' of who they were.

There were tensions around:

- 'Grey areas' of practice such as level of involvement;
- Balancing risk and the autonomy / goals of the client;
- Potentially normative assumptions around what was acceptable for whom.

Occupational therapists navigated taint, taboo and sensitivity by adhering to professional values based on their recognition of sex as part of holistic, client-centred practice.

- using and applying their day-to-day toolkit within the occupational therapy process of assessment, interventions, problem-solving and goal-setting.

This study suggests sex is an occupation because it fits with definitions of occupation; it has meaning, purpose, involves goals and is significant/ important to clients. It is not just a 'tissue need' as suggested by Kielhofner (1993), and involves a host of occupationally relevant factors such as activity, expression, meaning, function, communication and human interaction. Sex and sexual expression are part of how people see themselves as an occupational whole.

The participants had conceptualised sex and occupation in ways which had contributed to them broaching sex in practice; they recognised that the meaning and importance of sex varied but that sex was part of most of their client's lives, at times indicating both essentialist and constructivist ideas had influenced their perceptions – for example Diane spoke of essentialist sexual drives and frustrated behaviours, whilst constructivist views were reflected in her acknowledgement of the impact of impairment on roles, body image and meanings. All of the participants spoke about sex in occupational terms from a variety of perspectives, referring to links to identity, meaning and quality of life, that sex was an ADL, and that it was part of holistic, client-centred practice. Sex and sexual expression involved many of the constituent parts that make up conceptualisations of occupation within practice, including physical function, goal setting and emotional processing, and included many of the performance components used in activity analysis. These perceptions appeared to be based on the study participants' professional values of holism and client-centeredness reflected in views around meaning and importance to their clients, that sex is a 'normal' part of their client's lives, with some suggesting it would be remiss to omit this aspect of their client's occupational lives.

Sex is, as one participant put it, 'not the be all and end all' but for many people sex and sexual expression are significant or important - having meaning for clients, linked to health and wellbeing (for example reduces stress, aids self-esteem), linked to identity and body image and aiding adjustment to changed circumstances. The study participants felt that sex was important to most of their clients, some noting their clients' relief when it was broached, and that it had a significant impact on roles, relationships and how their clients saw themselves. However they also recognised that sex was a sensitive subject, reflecting that attitudes to sex are affected by ideas of taboo and 'dirt'. The participants had predominantly sex-positive attitudes which were reflected in views around sex as an ordinary / 'normal' part of people's lives, with some making reference to the pleasurable and fun aspects of sex. Most participants did not take a medicalised view of sex and when they did it was as part of a holistic approach - they used their professional reasoning but



viewed sexual concerns in occupational terms, linking sex to occupational factors in their client's lives, illustrated in figure 34, focussing on the meaning and importance of sex to their clients.

**Fig 34 – Study participant's perceptions of the meaning and importance of sexual concerns**



Factors which supported the study participants in broaching sexual concerns were previous exposure to sensitive (not necessarily sexual) subjects, specific training or learning experiences as part of pre- or post-registration education (usually classroom rather than practice based) or previous experience where sexual concerns had arisen. These experiences appeared to culminate in reflection on the part of the individual participant that sex was part of their role.

### **Occupational therapy practice skills and sexual concerns**

In terms of practice, this research explored the activities of occupational therapists who broach sex and sexual expression, how they adapted and applied their skills and knowledge, and the bridges and barriers the participants perceived in that practice. Building rapport was vital to broaching sex and was impacted by the individual client and the therapeutic relationship. The occupational therapy process was helped or hindered by a variety of factors; issues of comfort and discomfort, the attitudes, assumptions, education and experiences of the occupational therapists, colleagues and their clients and carers, previous exposure to sensitive subjects, the nature of the concern raised, the lack of structural, organisation or institutional support (for example, lack of time,

resources or referral pathways) confusion and lack of clarity about roles, and their adherence to professional values and identities to bridge challenges. This reinforces the findings in the literature, whilst adding the importance of professional values and identity as a bridge to manage these challenges.

Clients had an array of concerns which impacted on their ability to engage in an ordinary sex life; some having limited insight or struggled to predict or see the consequences of their actions, others had difficulty in initialising or had issues around coming to terms with changes in their circumstances and body image, low confidence and self-esteem as well as the physical impact of impairment. Being a sensitive subject the participants spoke of how they used their therapeutic relationships and rapport to support and work with their clients to broach these concerns. Interventions included advice on fatigue management and positioning, graded exposure, changing or adapting sensory input, finding adaptive equipment, supporting access to sex workers, role play, education, and supporting access to dating and social opportunities.

This thesis explored how the participants used aspects of professional reasoning along with their rationalisation that sex was part of their remit in order to use and apply their occupational therapy skills and knowledge, despite the sensitivity and taboo that surrounds sex derived from dominant socio-cultural sexual scripts. The participants included sex because, as discussed above, they recognised sex as a meaningful occupation, which led to them seeing it as part of their remit and that therefore including it was being true to their professional values and identity. Their responses suggest that even though they recognised it as a sensitive / taboo subject, they manage the taboo through professional values and identity, negotiating 'grey areas' and the conflicting sexual scripts by using their professional values and identity to help them apply their practice skills and knowledge by thinking occupationally and holistically. A professional script focussing on their values of holistic, client-centred practice had helped the participants; through embracing, ignoring or managing the taboo nature of sex.

### **Resources - absence and creativity**

Reflecting the findings in the literature, this study found challenges around the absence of resources (Jones *et al*, 2005; Mellor *et al*, 2013; Dyer and Das Nair, 2013; McGrath and Lynch, 2013); practical, structural and in terms of skills, knowledge and competency. Participants reported difficulty in finding appropriate interventions and referral pathways, and a lack of policy and support, as well as limited opportunities for education and training to support this aspect of their practice. These will be discussed further in the recommendations below. Whilst previous research has indicated problems

with resources, attitudinal and structural barriers to both HCP and occupational therapy practice (Dyer and das Nair, 2013; Couldrick, 1998), and the availability and accessibility of sex and sexual expression for disabled people (Shakespeare *et al*, 1996; Sakellariou and Simo Algado, 2006), this study adds new knowledge by showing how practitioners have used their creative, problem-solving skills, challenged structural barriers and the absence of resources, and have applied sex positive attitudes in overcoming attitudinal barriers. In doing so, they have shown that it is possible for occupational therapists to build a capacity to broach sexual concerns as part of day-to-day practice. The study participants applied their professional skills and knowledge to sexual concerns as they would to any other occupation, drawing on professional resources including improvising and developing interventions, assessment skills, professional reasoning, building therapeutic relationships, occupational analysis and working collaboratively with their clients. Several study participants identified gaps in the occupational needs of clients and had set up services to fill those gaps (for example, education for specific client groups), others used lateral thinking to adapt interventions and equipment to support unmet needs. At times, needs were identified but the absence of services and limited resources meant these needs were acknowledged but unmet. The practice discussed in this study implied that occupational therapists can adapt their skills and knowledge to an occupation which may be outside their 'normal' experiences, highlighting the flexibility of the profession. This reinforces the implication that sex is an ordinary occupation which can be broached using the day-to-day skills and knowledge of occupational therapists, it also suggests that greater incorporation of sex positive concepts could be useful in occupational therapy practice, encouraging practitioners to consider sex in occupational terms.

### **Ambiguity around practice**

This study indicated participants faced ambiguity in broaching sexual concerns due to the lack of structural resources such as relevant policy and procedure, limited formal training and a tendency for sex to be missing from pre-registration practice and class-based learning and from RCOT and occupational therapy literature. This meant that the participants were often creating their roles drawing on their experience and knowledge. This could be liberating as they could create space to include sexual concerns and could be creative and flexible in doing so, and several participants indicated they enjoyed the challenge and the opportunity to support clients in an often overlooked occupational need. However, it also meant that – as indicated above – there were few appropriate resources available to them, they had little support and could face difficult decisions around their level of involvement as well as ambiguity around balancing the risk to and the autonomy of clients.

Although ambiguity around occupational therapy has been extensively explored in the literature (see Molineux, 2004; Mackey, 2007 & 2014; Turner and Knight, 2015), this study contributes to

knowledge by providing an example of how this ambiguity can be both an opportunity and a threat to practice, showing how flexibility can lead to practitioners exploring the broad occupational needs of their clients whilst ambiguity can lead to concerns about risk and inappropriate behaviour, and highlights the impact of ambiguities on practice around a specific occupation. The implications of this is that occupational therapists may err away from practice areas which are opaque, leading to client needs going unaddressed (as is often the case with sexual concerns), whilst those who do engage with ambiguity may feel themselves to be unsupported and exposed to concerns around what is appropriate. More guidance is needed on institutional and professional levels to support practitioners in navigating these grey areas.

### **Navigating assumptions, attitudes and acceptability**

At times the participants made conscious and unconscious assumptions about the needs and wants of clients based on normative ideas around what is expected and accepted around age, relationships and disability, and occupational assumptions around priorities. These arguably reflect the hierarchy of sex outlined by Rubin (1984), suggesting some aspects of broaching sex may be more acceptable and therefore less discomfoting (for example, around relationships) than others (for example, managing disinhibition). They also had to negotiate the attitudes of clients, colleagues and themselves in order to do so, balancing at times conflicting wants, needs and demands.

As noted in the literature, occupational therapists tend to come from comparatively privileged backgrounds (Hammell, 2009), the majority being women from white, middle class backgrounds; Jackson (2008) notes that the more privileged may have greater choice and opportunity to explore their sexual lives. This may influence the assumptions made about clients and impact on the opportunities and support for clients to engage in their sex lives, particularly in an age of budgetary constraints when sexual concerns may be seen as a low priority, compounded by sexual scripts which view sex as taboo and 'special'. Although notions of privilege and occupational assumptions have been explored in the literature, most notably by Hammell (2009; 2011), this is often explored from a philosophical viewpoint rather than highlighting the impact on specific areas of practice. Examining sexual concerns provided an opportunity to explore these assumptions and the impact on practice. By uncovering assumptions around occupation and the possible influence of normative thinking on which occupations are seen as 'normal' or acceptable and for whom, this study explored an aspect of occupational therapy practice which has seldom been examined in the literature. In doing so it has extended the ideas of Twinley (2013) and Kiepek and Magalhaes (2011) regarding what might be considered to be on the 'dark side' of occupation and introduced the concept of occupational taint or 'dirty work' to the work of occupational therapists. This implies that the work

of some occupational therapists involves aspects of 'dirty work'. Although the participants did not directly express feelings of being tainted they did acknowledge that they were dealing with taboo and sensitive occupations. This implies that occupational therapists are influenced by socio-cultural ideas, in this case sexual scripts, around what is acceptable and for whom, which can lead to assumptions about the client, their environment and their occupations.

### **Countering taint through professional identity and values**

All the participants conveyed a strong sense of professional values and identity, whilst several expressed pride in their profession. The participants arguably drew on this sense of professional identity and values as a countering strategy to the potentially tainting and taboo aspects of broaching sex, as suggested by Ashforth and Kreiner (1999). Concepts such as tainted occupation or 'dirty work' and the strategies which may be invoked to manage and counter them have not been explored in occupational therapy literature previously. This study found that participants redressed the taboos around sexual concerns by using taint-countering strategies based around sex positive attitudes, their recognition of sex as an occupation and part of their remit, and adherence to professional values around holistic, client-centred practice. Mills *et al* (2007) note that one of the responses to the stigma of 'dirty work' is to create a 'strong occupational culture' to dispel any impact on their professional esteem (in Ashford and Kreiner, 1999, p.417), whilst Stacey (2005) suggests that people who undertake 'dirty work' can draw pride and satisfaction from it. This was indicated in the comments of some of the participants who were proud of their profession and in some cases proud of broaching sexual concerns. I suggest, then, that it was these strong professional values which led these occupational therapists to include sex as part of their remit and which helped them counter and manage any sense of taboo and sensitivity. This implies that by building strong professional identities and values, practitioners may be able to navigate difficult and sensitive areas of occupational therapy practice.

Despite increased openness around sex in UK society, sex remains a cultural taboo (Jackson and Scott, 2010) and societal attitudes remain impacted by dominant views around heteronormativity, gender, class, ethnicity and ability; this study, however, shows that sex does not have to be an 'elephant in the room' or an intimidating challenge for occupational therapists. Although it requires some degree of sensitivity, management and creativity, these are the result of the special status given to sex rather than sex being very different or exceptional compared to other occupations. The participants did not require a special set of skills and knowledge around sex, instead using occupational skills and knowledge and professional values to 'normalise' sexual concerns, making

‘the extraordinary rendered seemingly ordinary’ (Ashforth *et al*, 2007, p.150), seeing sexual concerns as an occupational ‘part and parcel’ of who some people were and what some people do.

In showing how sex is an occupation this research has contributed to the debate around how occupation is conceptualised. This can be narrow and reductive; as Twinley’s (2013) concept of ‘dark side’ occupations suggested, not all occupations are clearly positive or negative, good or bad, nor fit into the ‘privileged triad’ of self-care, productivity and leisure (Hammell, 2009). The participant’s perception of sex as an occupation suggested their conceptualization of occupation went beyond this narrow view. Using the data to extrapolate what occupation meant to the participants, it was clear they reflected many of the ideas found by Roberts (2012) – occupation for the participants was about what their clients wanted to do and engage with and who they were as holistic beings, what was meaningful and important to them. This was a mixture of the physical, emotional and psychological.

Sexual concerns sit on the fringes of Twinley’s (2013) ‘dark side’ of occupation in that it is generally neither illegal nor immoral but draws feelings of discomfort, or at least a recognition of stepping into a sensitive area of practice, and sits on the borders of conceptualisations of occupation around self-care, productivity and leisure – arguably definable as all three yet not sitting easily in these areas. The literature indicated that it was a discomfiting and sensitive area for many occupational therapists and HCPS generally, and for the participants who did broach it this involved venturing into grey areas around what is appropriate, inappropriate behaviours, social acceptability and challenges around sexual scripts, requiring occupational therapists to process and deal with cultural scenarios outside their day-to-day experiences. Occupations around arranging sex workers or the level of involvement in facilitating masturbation or sexual intercourse were particularly potentially tainted areas of practice, whereas interventions around relationships, intimacy and closeness with partners seemed to be less so – although these at times could be sensitive depending on the circumstances. That so few occupational therapists seem to broach the subject indicated that this was still a taboo subject, despite sex and sexual expression being dissimilar from other ‘dark side’ occupations such as drug use, violence or smoking.

The participants did not indicate they viewed their roles as ‘dirty work’ but some did allude to the comparative low standing of occupational therapy within healthcare – that people ‘don’t know what we do’, that occupational therapy lacks a ‘USP’, that it was associated with what was ‘wishy washy’. They did not express feelings of being tainted but did express acknowledgement that they were

dealing with taboo, sensitive and 'dark side' occupations. They redressed this by using taint countering strategies based around professional values and identity. I suggest that it was these strong professional values which had led these occupational therapists to include sex as part of their remit and which help them counter and manage any sense of taboo.

### **Using Critical Realism in occupational therapy /science research**

There has been limited use of critical realism (CR) as a methodological approach within occupational therapy and this study indicates that it may be congruent with occupational science and useful in supporting occupational therapists in undertaking research. By using the more practical interpretation of CR by Dalkin *et al* (2015) drawing on Maxwell (2012) rather than directly from the works of Roy Bhaskar, I found CR to be a practical tool for supporting an occupational focus in this study. Using Dalkin *et al* (2015) aided my understanding and was also useful in framing the template analysis results in a logical way by helping me step back and consider the inter-relationships and interplay between various aspects of the data. CR was useful in that it helped me perceive how the actions and practice of the occupational therapists, attitudes and contexts linked together, illustrated in figure 35.

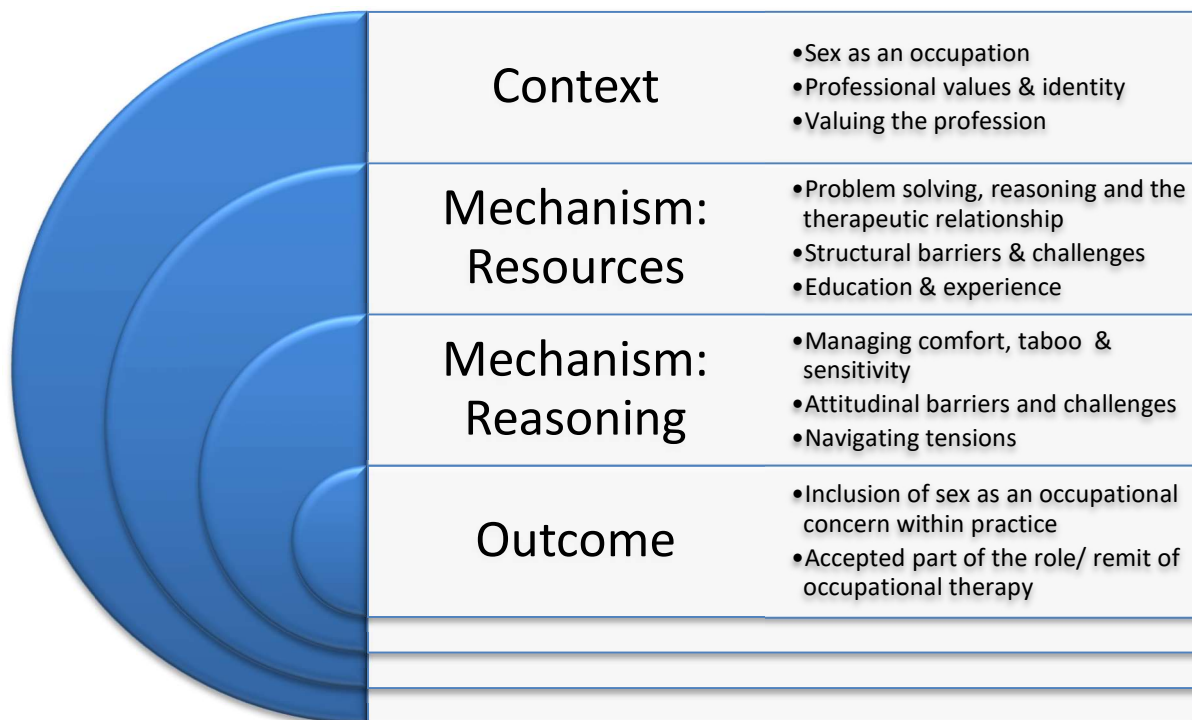
I found the congruence with occupational therapy theory useful; looking at the Context, Mechanism (resources and reasoning) and Outcome were relatable to thinking in terms of the Person, Environment and Occupation which underpins much of occupational therapy theory, and supported me in seeing the whole story from an occupational standpoint. Using CR, I could incorporate sexual scripts and materialism to look at the bigger picture; attitudinal and structural resources, the participants' reasoning, the context of their physical and socio-cultural environment and what they actually did, and how reasoning, activities and the outcome linked together.

In exploring sexual concerns as part of occupational therapy practice, this study contributes to the debate around sex as an occupation and provides extensive new knowledge about practice in this area and around the management of sensitive and 'difficult', discomfoting occupations. It shows how practitioners may be using countering strategies to support more difficult aspects of their work by invoking professional values, identity, skills and knowledge, in this case to reason that sex is part of their remit and broach the unmet needs of clients. These are aspects of occupational therapy practice which have not been explored before and imply that sexual concerns involve 'ordinary' occupations which could be embedded into the day-to-day occupational therapy role.





**Fig 35 – Using Dalkin *et al* (2015) in this study**



This way of operationalising CR has implications for future research as it shows how complex phenomena which involve multiple relationships and interactions between attitudes, ambiguities and ideas of various groups and individuals (for example in my study the occupational therapists, their clients and colleagues), structural and practical resources (for example, time, policies, professional attributes, the availability of equipment) can be unpicked and explored, whilst avoiding becoming too systematic, simplistic and reductionist. CR used in this way may be particularly useful exploring for subjects which have received little attention previously.

### **Using sexual script theory/ materialism in this research**

Following Jackson and Scott (2010b) in combining sexual script theory with materialism supported exploration of the bigger picture, as I could examine both structural issues such as limited resources and attitudinal issues around discomfort and assumptions. For this research, sexual script theory was useful in considering how different identities and ideas might interact – the professional identities of the occupational therapists allied or conflicting with cultural scenarios and the needs and wants of the clients. Based on their experiences, education and professional values, the participants broached and adapted to cultural scenarios outside those of occupational therapists who omitted or ignored sexual concerns. As seen in chapter 4.5, some cultural scenarios could be problematic which led to several practitioners making normative assumptions about their clients often based on their professional reasoning, others attempted to balance the autonomy and wants

of their clients with personal and societal expectations of appropriate behaviour. The participants also had to navigate the cultural scenarios internalised by the clients themselves, particularly if their clients had had limited experience or education around sex and had been excluded from shared cultural sexual scripts (for example representations of disabled people as sexual being in media / popular culture – Dune, 2013). Incorporating materialism with sexual script theory allowed me to consider how structural and organisation issues affected the participants.

## 5.2 Recommendations and limitations

This study indicates that sexual concerns have been seen as occupational concerns by several occupational therapy practitioners, who have applied their professional skills and knowledge to these often omitted and ignored client concerns by addressing, assessing and seeking appropriate interventions to support their clients. These concerns included issues around access to socialising and dating, physical barriers around mobility, pain, fatigue or high tone, fears and worries around pain, body image, changing roles, self-esteem or acceptance by others and inappropriate or risky behaviours. The participants in this study perceived these as falling under the umbrella of an occupational therapy remit as the profession focusses on meaningful and important occupational activities and goals of the client. Those who took part in the study indicated they addressed these needs and concerns, adapting their skills and knowledge, drawing on creative problem solving and professional beliefs around the nature of occupation, despite facing barriers around a lack of education and training, lack of resources and appropriate interventions, negative organisational attitudes and policy around sex, and the attitudes of colleagues and, at times, the clients themselves. Based on this, below are my recommendations for policy and occupational therapy practice, and areas for future research:-

### **Policy and practice:**

#### ***RCOT statement***

In her research in the late 1990s, Couldrick (1998/9) called upon the then College of Occupational Therapy to provide guidance on sex and sexuality, and there have been several subsequent calls at conference (for example, as a result of the presentation by Parkin in 2014), and through the Twitter discussion forum #OTTalk. Despite this, sex remains missing from the discourse of the professional body. This is perhaps understandable given that the focus of the organisation is to increase awareness and encourage greater use of occupational therapy in public, private and third sectors, and when austerity measures have led to a greater focus on sale-able, outcome-friendly measurables such as discharge and independence. However, the lack of any mention of sex in promotional or guidance literature arguably reinforces the view that sex is not an occupation – or at least one not considered as a serious or important occupation – and the stereotype that, as one participant suggested, occupational therapy is a ‘nice profession for nice women’. Several participants suggested a need for a policy change within the RCOT therefore I recommend that the RCOT consider recognising and normalising sex and sexual expression as just ordinary occupations as part of promotional or guidance information. Ideally, the RCOT should consider setting out a position statement similar to that of the AOTA (2013) clarifying the role and remit of the practitioner. For the professional body to recognise sex as an occupation and therefore part of the remit of occupational

therapy would go a long way to encouraging its inclusion in practice, underpinning reflection and opening up dialogue on this missing occupation. At a minimum, sex and sexual expression could be acknowledged and referred to in RCOT literature among occupations such as work and leisure activities.

### ***Embedding sex and sexual expression into day-to-day healthcare***

Sex and sexual expression need to be normalised as ordinary parts of people's lives as omitting them from local, national and condition-specific policies and guidance reinforces a sense of exceptionalism and taboo. This means embedding sexual concerns as part of the bigger picture of client health, wellbeing and quality of life. In relation to the domains of the Department of Health (2012) Outcomes Frameworks (see chapter 1.1), sex and sexual expression can be linked to several domains relating to quality of life, improving health and health promotion, recovery and positive experiences of care. In general, guidance and policy relating to sex and sexual expression from government and NICE<sup>30</sup> in health and social care are largely preoccupied with negative aspects of sex, rather than the positive role it plays in people's health and wellbeing. Sexual concerns are often omitted from guidance on specific conditions or when included lacks information which may help practitioners broach the subject, whereas occupations such as supporting clients in staying in paid work are often included reflecting a tendency to focus on narrow conceptualisations of productivity and independence. Several participants suggested a need for wider social policy changes specifically around widening sexual health services to go beyond pathology and the prevention of unwanted pregnancy / STIs to include more pleasurable and sex positive aspects of sexual lives. I feel that sex and sexual expression should be included as elements of policy or guidance, recognising them as important yet ordinary aspect of people's lives. The inclusion of sex and sexual expression in policy and guidance would encourage the development of support and referral pathways, and the consideration of sexual concerns in day-to-day practice.

This does not necessarily mean constantly focussing on sex and sexual expression in practice but could instead involve, as indicated by several participants, 'opening the door' to discussion, applying professional reasoning or using other aspects of self-care to raise the issue. This does not require huge fanfare or reams of policy devoted to it, but instead means sex and sexual expression should be acknowledged and embedded alongside other aspects of the clients' lives such as ADLs, work, leisure, mobility, toileting, eating; all the occupations which make up the client's life, how they see themselves and what they want / need to do.

---

<sup>30</sup> National Institute for Health and Care Excellence

### ***Links with Sexual Health services / referral pathways***

Leading on from this, both the literature and my research indicate a lack of referral pathways leading to a struggle to find appropriate services to support their clients. Ideally the remit of sexual health services should be widened to include more positive aspects of sex and sexual expression. In order to achieve this, opportunities could be created for occupational therapists to undertake secondments or practice placements within sexual health charities and services in order to 'sell' the usefulness of occupational therapy within these services. As Emily indicated, 'people don't always know what we can do' – this could provide a window to show the value of occupational therapy within sexual health. Embedding occupational therapists could also help widen the remit of sexual health services beyond pathology and prevention. To support an increased role in sexual health, occupational therapists could get involved with organisations such as SHADA or LGBT professional groups to learn more about the wants and needs of a variety of client groups, to challenge normative and heteronormative assumptions, as well as sharing valuable occupational insights and perspectives with colleagues and other HCPs.

### ***Opportunities for development and widening occupational therapy practice***

Creating links to sexual health is one of the ways in which broaching sexual concerns could be an important opportunity for occupational therapists to widen the scope of practice. During the interviews I was struck how the work that the participants were undertaking filled an important gap in the services and support available, and could be beneficial to many clients. Sexual health and relationship and sex education (RSE) would appear to be areas ripe for occupational therapy input, either as part of specific teams or by including discussion of sex as part of day-to-day practice. Clients affected by illness and impairments such as long term conditions or potentially life limiting conditions such as cancer, people with learning disabilities or people who have had a life-changing injury may be more obvious potential beneficiaries, but also people undergoing transitions and change (for example, age-related changes or trans-gender clients), people with mental health concerns impacting on their confidence and self-esteem, or people who are survivors of domestic or sexual abuse could also benefit from occupational therapy input to help them adapt or re-engage with their sexual lives. There is a 'gap in the market', as one participant put it, which could certainly be filled by occupational therapists developing and delivering appropriate interventions, pathways and support.

## ***Education, training and support***

The absence of education and training came up several times in this study as a key barrier to broaching sex both in the literature and noted as an important factor in facilitating the inclusion of sex by the participants. Therefore training around sex and sexual expression should be made available to occupational therapists and HCPS. Several participants indicated that training had been an important springboard to reflecting on and including sex as an occupational concern, with some indicating that they had been required to challenge colleagues and students who held assumptions disabled people could not be sexual beings. Education and training could challenge these assumptions and provide practitioners with an opportunity to learn and reflect, whilst exposure to the subject in a relatively safe environment could help occupational therapists feel more confident. Sex could be embedded and normalised within pre-registration training and practice placements to improve confidence and competence in discussing this and other sensitive aspects of practice so that talking about sex with clients can be made easier when occupational therapists go out into practice. Several participants indicated class-based opportunities where discomfort and embarrassment may be explored safely away from clients would be useful. As with embedding sex and sexual concerns in practice, this inclusion does not necessarily need to involve specific modules or lectures, rather sex and sexual expression could be included within other areas such as occupational analysis or case studies, or in considering the wider importance of occupation in terms of meaning and spirituality. This could be supplemented by post-registration further training providing practical guidance or in

specific areas of practice or specialities which could be made available to increase the confidence of occupational therapists (and HCPs generally).

Education and training could also include raising awareness of models for recognising, including and exploring sexual health concerns such as PLISSIT, Ex-PLISSIT and the Recognition model (see box). These models are congruent with occupational therapy practice and provide a means of aiding practitioners in understanding the holistic needs of clients.

Given the limited resources available in supporting client sexual concerns, it would also be useful for practitioners to have greater awareness of what support is available for them, in particular the Sexual Health and Disability Alliance. Two of the interviewees were aware of this resource, although one had struggled to find time to attend meetings, the other suggested it was an extremely useful source of information and support.

### Further research:

This research has filled several gaps in knowledge in this under-researched area of practice, but there is still much more to learn about sexual concerns in occupational therapy, in healthcare and regarding the needs and wants of clients / disabled people themselves. I have listed some possible avenues for exploration below:

- **The wants and needs of disabled people/clients regarding sex and sexual expression:**  
Although there has been increasing recognition of disabled people and clients as sexual

#### PLISSIT / Ex-PLISSIT

The PLISSIT model (Annon, 1976) was developed to support HCPS and sex therapists in broaching sexual concerns with clients.

- PERMISSION – giving the client permission;
- LIMITED INFORMATION – providing information or referral to support services;
- SPECIFIC SUGGESTIONS – in-depth support on specific concerns;
- INTENSIVE THERAPY – referral to intensive therapy for underlying issues.

The Ex-PLISSIT model (Davis, 2005; Taylor & Davis, 2006) evolved in response to a tendency of HCPS to providing information without involving the client in discussion or an opportunity for them to disclose concerns. Ex-PLISSIT placed greater emphasis on giving permission, reflection and on-going assessment. The focus on 'opening the door' and creating a relationship in order to discuss sex indicated that the interviewees were using an Ex-PLISSIT model, albeit perhaps unknowingly.

#### RECOGNITION MODEL

This model was intended to promote sexual health by physical disability teams follows 5 stages:

- Stage 1 – recognising the client as a sexual being;
- Stage 2 - granting permission to clients to discuss their sexual concerns;
- Stage 3 – exploring and identifying issues
- Stage 4 – addressing issues within team expertise / boundaries
- Stage 5 – referral / advocacy

(Annon, 1976; Davis, 2005; Taylor & Davis, 2006; SHADA, 2013; Couldrick et al, 2013; Wikipedia, 2017)



beings, there needs to be more research on actual needs from healthcare professionals generally, and specifically from Occupational Therapists.

- **Service delivery around sexual concerns:** There has been increasing recognition that disabled people / clients require support from healthcare services and limited research from an occupational perspective (Northcott and Chard, 2000; Taylor, 2011) regarding their sexual concerns, and these are aspects which require further research. I feel there has been very little attention paid to the sexual concerns of disabled people with a view to developing service provision, possibly due to the current resource-constrained healthcare environment. If healthcare services and particularly occupational therapists wish to broach sexual concerns they need to ascertain the wants, needs and perspectives of disabled people / clients themselves. This research should also consider differences around age, sexuality, sexual practices, culture and ethnicity and people who have learning disabilities or mental health concerns. This could be achieved through mixed methods research via surveys, focus groups and interviews. Although the needs of individuals will vary, undertaking this research through representative groups and charities which represent disabled people and client groups, or at service level, could help services direct assessment and interventions towards clients unmet needs.
- **Occupational Therapist attitudes / behaviours in relation to sex in general:** Examining the attitudes and practice of Occupational Therapists who may not feel sex is an occupational concern, had not considered the subject or are ambivalent regarding sex as an occupation.
- **Occupational assumptions:** This study found that occupational therapists may be making assumptions around the occupational needs and wants of clients. More research is needed into the nature of these assumptions and the impact on practice. This would be best achieved as an ethnographic study.
- **Marginalisation, acceptability and 'luxury':** These are ideas I considered in relation to occupation during this research and require further theoretical exploration in occupational science. Can an occupation be marginalised? Are some occupations considered more acceptable than others and, if so, why? Are some occupations considered 'luxuries', particularly during an age of resource austerity? These are philosophical and sociological considerations which require exploration as they impact on service provision and practice.
- **LGBTIQ+ disabled people and clients / asexuality:** Further research is needed into the occupational wants and needs of client groups who are non-heterosexual, asexual, transitioning or have transitioned between genders or are intersex (some of whom may have been subject to intrusive surgery). These groups would have very different

occupational and sexual needs of which practitioners may have limited knowledge and experience. Ideally this research should be undertaken by people who are LGBTIQ+ / asexual but have an understanding of occupation in a therapeutic sense in order to gain insider perspectives. This will help services and occupational therapists gain a greater understanding of needs and improve cultural competence in this area.

- **Discomfort / taint in occupational therapy practice:** There appears to have been little research undertaken regarding occupations which may be potentially tainting and which practitioners may find sensitive and difficult, giving rise to feelings of discomfort and embarrassment. Research is required to identify areas which may be difficult and look at how, if at all, practitioners manage these. These may be aspects of practice which may be more obviously seen as tainted such as toileting and incontinence (Vickerman, 2008) or other aspects of practice. Ascertaining discomfort and / or perceptions of 'dirty work' within practice is important in that they can affect what and how occupational therapists interact with, attitudes and assumptions around clients and the sort of work therapists may avoid or engage with. This could be achieved using a similar approach to that used in this study, combining a survey scoping discomfort, followed by either focus groups or interviews.
- **Tackling notions of occupational taint:** As well as further exploration of dirty work or occupational taint in occupational therapy and healthcare practice, further research is needed on how feelings of taint may be managed and countered in order to reduce its potential impact on practice. This would provide knowledge to aid therapists / HCPs in acknowledging areas of practice which are seen as difficult, and in the development of training and education to counter taint and discomfort.
- **Developing occupational therapy practice around sexual concerns:** As indicated earlier, there is scope for widening occupational therapy practice within sexual health and in relationship and sex education (RSE) services. Based on my interviews, I also feel there is a role for occupational therapy for people who have lost confidence and self-esteem around sex. This would require very sensitive qualitative research to ascertain wants and needs, reviewing possible assessment and interventions which could support client groups in regaining sexual lives.
- **Reproduction and occupation:** Surprisingly, the subject of sex as a means of procreation did not arise in the interviews and seems to have received limited attention in the literature. Slootjes *et al* (2016) suggest that occupational therapy has a role in women transitioning into a maternal role but research is limited. It would be interesting to explore the role, if any, occupational therapy might take in reproductive health, in terms of supporting sexual

concerns as productivity, or regarding adapting to changes in life such as taking on parental roles.

- **Education and training:** More research is needed into the current availability of education and training for occupational therapists related to sex and sexuality, and how this may be developed to fill the gaps in knowledge current and future practitioners have with a view to increasing confidence and competence, supporting them in including sex and sexual expression as part of their practice, and acknowledging the impact of sexuality on occupation (Jackson, 1995). This could involve developing and piloting workshops or action research.

### ***Sharing best practice and creating an evidence base***

As discussed in part one, literature on HCPs and sex is limited and the published research that exists focuses on either qualitative / mixed methods research on the scope and/or occupational therapist/HCP thoughts and feelings (including my own research), or quantitative research measuring attitudes to sex using standardised scales. Occupational therapists and HCPs generally are unsure about how to broach sex and what to do about the many concerns which may arise (REFS). It would therefore be useful for practitioners who do include sexual concerns to audit this aspect of their work, or record their interventions and outcomes to help build a repository of information and knowledge to help support colleagues. Incorporating best practice into NICE guidelines, and the inclusion of sex as part of client quality of life indices would also support and encourage occupational therapists and HCPS generally to consider and include sexual concerns, and embed this into day to day practice.

### **Study limitations**

All research has limitations and this work is no different; there were several problems which arose during this study. A significant problem arose from defining the terms such as sexual expression, sex, sexuality and even occupation. During the interviews, participants often used expressions such as sex and sexuality interchangeably. This had an impact on the data analysis where I had to be cautious about interpreting the participants incorrectly or out of context.

A further limitation related to the data obtained in this study; although mixed methods remained the most appropriate means of exploring this under-researched area of practice, I was only able to obtain limited quantitative data due to the number of respondents. This meant that the quantitative data, although important and useful in the formulation of the interview guide and in scoping for

eligible participants, did not provide results of statistical significance. Therefore the focus of the study shifted to the richer, qualitative data which was obtained.

A limitation within the design of this study was the lack of data from the scoping survey respondents, this was due to the focus on practitioners who did address sexual concerns fairly or more regularly, leading to the focus on the thoughts and experiences who felt they did broach sexual concerns. The study was also focussed on the UK, with most of the questionnaire / interview participants working within England – a study based within other cultures may have led to different findings.

A key difficulty, and one which is fairly common to much research on human experience, was finding participants; I was greatly supported and helped by several RCOT Specialist Sections who broadcast my call, but a significant Specialist Section did not respond. In order to mitigate this limitation I publicised my request for participants at the COT 2016 conference, and The Occupational Therapy Show, and on two closed occupational therapy Facebook groups. Despite this I was unable to find an occupational therapist to interview who currently worked in trauma and orthopaedics, which I feel is a significant gap in my research. Nor are the participants who took part representative of the whole of the profession in terms of demographics and background. I also omitted collecting demographic information around class and sexuality due to my main focus around uncovering the experience and practice of the participants. A further significant limitation was in the formulation of this study. It would have been interesting to see if the participants in this research were in some way different from their occupational therapy peers; a comparative study of occupational therapists who did not broach sexual concerns or felt that sex is not an occupation would have been interesting. However, this might also have faced problems in recruitment.

Regarding the “nuts and bolts” of the research process, the survey was useful in identifying participants, and although it contributed some useful quantitative information, the limited number of responses meant I was unable to make any definitive claims to significance. The questionnaire, despite functioning well in the pilot, was less useful in the field; there was an occasional ‘glitch’ where the questionnaire seemed to lock for some of the participants which I was unable to replicate in order to solve. This was mitigated by using a Word version of the questionnaire but this challenged the anonymity of the study. During data analysis I realised in hindsight there were questions I should have explored in more depth during interviews, or should have asked about more directly. It would have been interesting to ask the participants their views on whether sex is a

tainted occupation, and on normative and heteronormative assumptions around what are acceptable occupations. However, this may have introduced a degree of bias or may have had a negative impact on rapport within the interviews. My primary focus was on their thoughts on practice and experiences, and the issues around assumptions and acceptability of sex arose more during data analysis.

## 5.3 Conclusion

Despite the World Health Organisation [WHO] (2001) stating sex and sexuality are healthcare issues which should be supported for all, and their inclusion as domains in the *International Classification of Functioning, Disability and Health* (ICF), in the UK sexual concerns and expression are often overlooked by occupational therapists and HCPs generally. When broached, they are often perceived through a prism of negativity (for example, unwanted pregnancy, STIs, *et cetera*) or problematized; couched in terms of risk, vulnerability or potential harm. For occupational therapists, this omission appears contradictory to the consideration of the holistic needs, roles and functions of clients and the 'whole-person' approach advocated by RCOT (2018). Sex and sexuality are important aspects of an individuals' identity and well-being (Couldrick, 2007). Research suggests that addressing the sexual concerns supports the general health of clients by reducing stress and improving feelings of wellbeing (NHS Choices, 2014), improving body image and self-esteem, and aiding adjustment to changes in life circumstances (McCabe and Taleporos, 2003). Research also indicated that clients want these issues to be acknowledged and addressed (Shakespeare, Gillespie-Sells and Davis, 1996) but they do not know who to ask (Northcott and Chard, 2000).

This study used a mixed methods approach to explore sexual concerns in relation to the practice of several UK occupational therapists who broached the sexual concerns of their clients. This is an under-researched area of practice. I incorporated critical realism, and considered sexual script theory and materialism to examine attitudinal and structural aspects of the participants practice, using template analysis to draw the data together. The participants who broached sexual concerns were 'outliers' within the profession as the majority of occupational therapists do not routinely include sexual concerns as part of their day-to-day practice. Even these practitioners did not always embed sexual concerns into their practice, tending to use their reasoning and therapeutic relationships in order to decide if, when and how to broach the subject. The literature indicates that one of the barriers to undertaking practice in broaching sexual concerns was the limited information and resources available in doing so, therefore this research fills a gap in the knowledge available by giving an overview of practice currently undertaken, how the participants managed some of the more ambiguous and sensitive aspects of broaching sexual concerns, and providing a foundation for developing future learning and practice.

This research makes an important contribution to the debate around whether sex is an occupation, providing an insight into what occupational therapists who broach sexual concerns do, and how and why some occupational therapists include sex and sexual expression within their practice. Although

this debate is likely to continue, this study indicates that sex is an occupation and therefore, arguably, the remit of occupational therapy. The consideration of sexual concerns has been largely overlooked in recent years but needs to be re-ignited if the UK occupational therapy profession is to be considered holistic, occupationally-focussed and client-centred. This research has shown many of the sexual concerns raised by clients can be described as occupational; involving finding information and reassurance, building confidence and self-esteem or providing practical / problem solving interventions around client goals, needs and wants. Therefore, there is a role for occupational therapists in broaching sex and sexual expression, as demonstrated by the study participants who applied their unique professional skills and knowledge to undertake assessment, goal-setting and interventions, negotiating barriers and creating bridges to practice. The participants who broached sex found resources and used reasoning to do so (figure 36):

**Fig 36 – Mechanisms for broaching sexual concerns**

### Resources

- Occupational Therapy skills and knowledge
- Confidence and competence
- Structural support or ability to overcome structural barriers
- Creativity and problem solving
- Therapeutic relationships and rapport

### Reasoning

- Belief in sex as an occupation and as part of holistic practice
- Inclusive approach to all occupational needs
- Professional values - professional ideologies
- Clients seeking support or relieved when asked
- Use of professional reasoning

For some of the participants sexual concerns had become embedded in their practice, included as a matter of course. For others it was an issue which arose but one that was considered like any other occupation, their main barriers being finding appropriate resources and interventions. This study shows that in order to negotiate potential bridges and barriers the participants used their professional reasoning based on their belief that sex was an occupation, their professional identity and values and personal, sex-positive attitudes. Although the profession has had widely documented issues around its professional identity, this research indicated that occupational therapists working in a wide range of areas of practice, and different aspects of occupational therapy and locations had

strong professional identities, based on their occupational focus, professional values around holism and client-centeredness and pride in their profession. They used those values and their occupational focus as a basis to help them negotiate the tensions and 'grey areas' they found when broaching sexual concerns, and to help manage and counter the taboo and taint around this part of their practice.

When setting out on this research journey, I had strong assumptions around sex and sexual expression as occupations, and felt almost evangelical that they should therefore be part of the remit of occupational therapy. As the study has progressed and, using my reflective diary, I questioned my views which have become more nuanced; I have a better understanding of why sex and sexual expression might be avoided or omitted, and that there are a host of well-reasoned justifications for why they might be left out when working with some clients, especially given the huge pressure on resources particularly in the NHS. At times I speculated whether occupational therapists should be considering sexual concerns when services are squeezed and time and resources so tight. However, what does excluding sexual concerns mean? It means occupational therapists may be making decisions for and about the client rather than with them; it means making value judgements about the client and about what are 'positive' or 'negative' occupations, and what that client should or should not be engaging in. It is, therefore, potentially discriminatory, and removes an option for a client to access a part of their lives which may have deep importance to them, closing an avenue of therapy, rehabilitation or adaptation. For the client it is telling them that part of their life is now closed to them and runs counter to the holistic and client-centred values of the occupational therapy profession. Omitting sex may be justifiable in some circumstances, based on professional reasoning and depending on the client and context, but ignoring sexual concerns should not be acceptable. Practitioners should 'open the door' to acknowledge sexual concerns and omit it only when the client rejects the opportunity.

Sex occupies an unusual position in society; it can appear to be everywhere in the media and it is an important aspect of people's lives, yet it is also a taboo subject, invoking discomfort and stigma - it is simultaneously ordinary and yet special. Within healthcare sex has been described as a 'minefield' or 'a can of worms'. This study shows that broaching sexual concerns is a meaningful and important unmet need for many clients, that - although it can be challenging - the day-to-day skills and knowledge of occupational therapists can be applied and that, even in a climate of austerity, occupational therapists can carve out a role based on their professional values and creative problem



solving, achieving truly holistic and client-centred occupational therapy practice. Ultimately, sex is an ordinary occupation, and therefore it should be a part of day-to-day occupational therapy practice.

# APPENDICES

## Appendix 1 – Research instruments

### 1.1 – Stage 1: Survey

#### Stage 1 - Survey

**Relevant research aim:**

- Identify existing UK OT practice in sexual function and intimate relationships;

**Objectives:**

- To identify individuals which incorporate sexual needs / issues within their practice.
- To identify the scope of this practice.

This is a simple survey using Google Forms to gain an overview of practice and identify potential participants.

---

## **Quick survey: An investigation into Occupational Therapy (OT) practice in relation to supporting service users' sexual concerns in physical settings.**

### **INFORMATION**

Thank you for your interest in this project. I am an Occupational Therapist / Post Graduate Researcher looking at Occupational Therapy practice in relation to client sexual function and intimate relationships.

**This survey aims to find out more about the scope of current practice.**

### **Who should complete this survey?**

Any qualified Occupational Therapists, of any age, gender or experience, working within a predominantly physical health setting. You may be working within the NHS, social services, a social enterprise, charity or private sector.

### **"Sexual concerns" in the context of this research**

This research defines sexual needs using the WHO International classification of functioning, disability and health of sexual function and intimate relationships, this can include the physical and emotional closeness associated with expressions of sexuality and sexual identity. The WHO (2015) defines sexual health as:

"...a state of physical, emotional, mental and social well-being in relation to sexuality; it is not merely the absence of disease, dysfunction or infirmity. Sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence. For sexual health to be attained and maintained, the sexual rights of all persons must be respected, protected and fulfilled." (WHO, 2015)

### **Why?**

There is little research in this area of practice and the previous research available suggests that OTs and other Health Care Professionals (HCPs) rarely broach sexual issues – the aim of this survey is to find out whether OTs include sexual issues in their practice to get a snapshot of practice.

### **How long will the survey take?**

Including the consent page the survey should take less than 5 minutes.

### **Maintaining anonymity & confidentiality**

Your answers will be treated with complete confidentiality - due to the anonymity of this survey I will not be able to withdraw your contribution.

### Consent

At the start of this survey there is a consent page. By consenting to be involved in this research you are agreeing that:

- You understand the aims of the project.
- You are willing to participate in the project.
- You understand that you may withdraw your consent within [time scale tbc].
- You give permission for statements you make to be quoted, if they do not compromise anonymity.

### Further information:

If you would like any further information please feel free to contact me or my supervisor:

Penny Ralph

Email: [Penelope.ralph@hud.ac.uk](mailto:Penelope.ralph@hud.ac.uk)

Prof Surya Monro

Email: [surya.monro@hud.ac.uk](mailto:surya.monro@hud.ac.uk)

Questions marked with \* are required

## Consent form

**It is important that you read, understand and sign the consent form. Your contribution to this research is entirely voluntary and you are not obliged in any way to participate, if you require any further details please contact me.**

Please tick the box below if you agree:

- I have been fully informed of the nature and aims of this research.
- I consent to taking part in it.
- I understand that I cannot withdraw my data due to the anonymity of my contribution.
- I understand that the information collected will be kept in secure conditions for a period of five years at the University of Huddersfield.
- I understand that no person other than the researcher and supervisory team will have access to the information I provide - unless anonymised beforehand.

If you are satisfied that you understand the above information and are happy to take part in this project please tick this box ☐ \*

## Quick survey

Please tick the relevant boxes below or highlight your answer. Thank you.

- 1) Do you include the sexual function and/or intimate relationship needs of the client as part of your role within Occupational Therapy? \*
  - ☐ Yes
  - ☐ No
  
- 2) If Yes, how often do you address client / service user concerns (please click one option):
  - ☐ regularly (e.g. as part of my day to day practice)
  - ☐ often (e.g. weekly)
  - ☐ occasionally (e.g. once a month / when asked)
  - ☐ never
  - ☐ other: (please state).....
  
- 3) Do you feel that sexual function and/or intimate relationship are occupations (optional)?
  - ☐ Yes
  - ☐ No
  - ☐ Don't know / not sure
  
- 4) Please feel free to make any further comments on Occupational Therapy and the sexual function and/or intimate relationship needs of the client (optional).

Optional - the box will expand.

### Interested in telling me more?

If you have answered regularly, often or occasionally and would like to tell me more about your practice in this area, please feel free to fill in the longer questionnaire which is also attached.

If you have any further queries feel free to contact either myself or my supervisor:

Penny Ralph [penelope.ralph@hud.ac.uk](mailto:penelope.ralph@hud.ac.uk)

Prof Surya Monro [surya.monro@hud.ac.uk](mailto:surya.monro@hud.ac.uk)

Please email your survey and/or questionnaire to [Penelope.ralph@hud.ac.uk](mailto:Penelope.ralph@hud.ac.uk). If you would like to post your survey, please email for my address.

## 1.2 – Stage 2: Questionnaire

**Relevant research aims: Aim 2 - Explore OT practice regarding sexual expression and intimacy;**

- To explore and investigate this practice within the OT process;
- To investigate practical aspects, such as assessments and interventions, used in relevant practice.

### **Objectives:**

This is a questionnaire using Google Forms\* in order to gain largely quantitative information on the training and practice of those OTs who broach sexual function and intimate relationship needs of their clients. An option to provide more qualitative information will also be provided.

This questionnaire may be amended in response to piloting.

\*Another questionnaire package may be used, subject to pilot / usability.

---



## **An investigation into Occupational Therapy (OT) practice in relation to supporting service users' sexual concerns in physical settings.**

### **INFORMATION**

Thank you for your interest in this project. I am an Occupational Therapist / Post Graduate Researcher looking at Occupational Therapy practice in relation to client sexual function and intimate relationships.

**This questionnaire aims to find out more about your practice.**

### **Who should complete this questionnaire?**

Any Occupational Therapist who has answered “regularly, often or occasionally” in the scoping survey. You may be working within the NHS, social services, a social enterprise, charity or private sector.

### **“Sexual concerns” in the context of this research - reminder**

This research defines sexual needs using the WHO International classification of functioning, disability and health of sexual function and intimate relationships, this can include the physical and emotional closeness associated with expressions of sexuality and sexual identity. The WHO (2015) defines sexual health as:

“...a state of physical, emotional, mental and social well-being in relation to sexuality; it is not merely the absence of disease, dysfunction or infirmity.

Sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence. For sexual health to be attained and maintained, the sexual rights of all persons must be respected, protected and fulfilled.” (WHO, 2015)

### **Why?**

There is little research in this area of practice and the previous research available suggests that OTs rarely broach sexual issues – the aim of this questionnaire is to find out more about your practice in this area. Please feel free to use the text boxes to tell me more about your practice.

### **How long will the questionnaire take?**

Including the consent page the survey should take approximately 30-45 minutes.

### **Maintaining anonymity & confidentiality**

Your answers will be treated with complete confidentiality, kept securely and will be anonymised for data analysis. Please provide an email address so I may identify your data should you wish to withdraw. Due to the data analysis process, I will be unable to withdraw your data after the 30 September 2016.

### **Withdrawing your data**

If you wish to withdraw from this research please email me before 30 September 2016. I will delete your contribution immediately.

### **Consent**

At the start of this survey there is a consent page. By consenting to be involved in this research you are agreeing that:

- You understand the aims of the project.
- You are willing to participate in the project.
- You understand that you may withdraw your consent within (time scale tbc).
- You give permission for statements you make to be quoted, if they do not compromise anonymity.

### **Further information:**

If you would like any further information please feel free to contact me or my supervisor:

Penny Ralph  
Email: [Penelope.ralph@hud.ac.uk](mailto:Penelope.ralph@hud.ac.uk)

Prof Surya Monro  
Email: [surya.monro@hud.ac.uk](mailto:surya.monro@hud.ac.uk)

### CONSENT FORM

It is important that you read, understand and sign the consent form. Your contribution to this research is entirely voluntary and you are not obliged in any way to participate, if you require any further details please contact me.

Please tick the boxes below:

I have been fully informed of the nature and aims of this research	<input type="checkbox"/>
I consent to taking part in it	<input type="checkbox"/>
I understand that I have the right to withdraw from the research at any time without giving any reason	<input type="checkbox"/>
I give permission for my words to be quoted (by use of pseudonym)	<input type="checkbox"/>
I understand that the information collected will be kept in secure conditions for a period of five years at the University of Huddersfield	<input type="checkbox"/>
I understand that no person other than the researcher and supervisory team will have access to the information I provide - unless anonymised beforehand	<input type="checkbox"/>
I understand that my identity will be protected by the use of a pseudonym in the report and that no written information that could lead to my being identified will be included in any report.	<input type="checkbox"/>

If you are satisfied that you understand the information and are happy to take part in this project please tick this box ☐

---

### QUESTIONNAIRE

#### About you:

##### What is your...:

Gender

Age range

Sexual orientation

#### OT experience:

##### How long have you been working as an OT?

Newly qualified – <2 years

2-<5 years

5 to <10



10+

**Did you have any pre-registration experience in health and social care?**

yes / no

**Current sector?**

NHS / Social care or council services / Social enterprise / Private sector / Charity /  
Other (please describe)

**Please feel free to say more in the box below:**

**Training & education:**

**Did you receive any training regarding sexual function, expression and/or intimacy included in your pre-registration training?**

Yes/ no

**If yes, what form did that training take (tick all that apply)?**

As part of a lecture

Whole lecture (x1)

Series of lectures (2 or more)

Course module

Practice placement experience

Visiting / guest speaker at University

Visit to outside provider (e.g. Disability Living Centre) organised by University

Visit to outside provider (e.g. Disability Living Centre) organised by self / fellow students

Other.....

**Please feel free to say more in the box below:**

**What subject areas did the training include (tick all that apply)?**

Sexual orientation

Sex as an occupation / activity

Personal attitudes to sexuality

Assessment

Interventions

Gender reassignment

Emotional aspects of sexual expression and intimacy

Physical aspects/ function of sex and intimacy

Issues regarding harassment of self by clients

Issues regarding sexual abuse of  
client

Other.....

**Please feel free to say more about the training in the box below:**

**Have you received training related to sexual function and expression post-registration?**

Yes / no

**If yes, what form did that training take (tick all that apply)?**

Internal - mandatory

Internal - voluntary CPD

External training

(please describe)

**Please feel free to say more in the box below:**

**What did the training include (tick all that apply)?**

Sexual orientation

Sex as an occupation / activity

Personal attitudes to sexuality

Assessment

Interventions

Gender reassignment

Emotional aspects of sexual  
expression and intimacy

Physical aspects/function of sex  
and intimacy

Issues regarding harassment of self  
by clients

Issues regarding sexual abuse of  
client

Other.....

**Please feel free to say more in the box below:**

**Your practice – what you do:**

**In which aspects of your OT role do you include sexual concerns (click all that apply)?**

Initial assessment

Assessment

Goal setting

Interventions

Referral to other services

Other...

**Please feel free to say more in the box below:**

**Assessment - how do you assess client sexual concerns (please tick all)?**

Non-standardised assessments

Standardised assessment

Internal form or documentation

Other...

**Please feel free to say more in the box below:**

**Interventions - please tell me more about the interventions you use:**

Adaptive equipment (provided by service)

Advice on equipment purchase (for client to purchase)

Fatigue management

Advice on positioning

Other ....

**Please feel free to say more in the box below:**

**Do you feel that discussing sexual concerns is a legitimate concern for OTs?**

Yes / no

**Please feel free to say more in the box below:**

**Generally, how comfortable / uncomfortable do you feel when discussing sexual issues with a client?**

Very comfortable / fairly comfortable / neither comfortable nor uncomfortable / fairly uncomfortable / Very uncomfortable

**Please feel free to say more in the box below:**

**If there is there anything you would like to talk about regarding your practice and sexual expression and intimacy, feel free to use the box below:**

**Thank you for taking part in this research.**

## **1.3 – Interview guide – pre-pilot**

### **Stage 3 – interview guide**

#### **Relevant research aim - 3: Explore OT practitioner attitudes to and experiences of practice concerning sexual expression and intimacy.**

To investigate the attitudes and influences on individual OT practice.

To explore and examine the barriers to and facilitation of this practice, as perceived by OT practitioners.

The interview also provides an opportunity to clarify information given in stage 2, the questionnaire.

This interview guide may be amended in response to piloting.

---

#### **1) Introduction**

Welcome and introduce myself.

Explain the aims of the interview and provide a brief overview of why I am doing this research. Ask participant to review information sheet and sign consent form if they have not already done so.

Explain what I'm going to do, i.e. that I have some areas I'd like to cover but that they are free to discuss aspects of the subject as they think; that the interview will be recorded so I can transcribe it, that after I will transcribe the interview they will get an opportunity to check, clarify and correct, and add any further thoughts to the transcription.

Establish that the use of vernacular / day-to-day language is fine, and to use language they are most comfortable with.

Reiterate the confidentiality of the interview, that they are free not to answer any questions they feel uncomfortable with and that they may stop at any point.

#### **2) Defining practice in relation to sexual concerns**

How do you define sexual expression and intimacy in relation to your role?

Prompt - refer to WHO definition for comparison.

As part of your role as an OT, which aspects of client sexual concerns have you broached?

Prompts – such as practical advice, emotional support, etc.

#### **3) Client sexual concerns / function as a role for the OT**

What do you think that OTs in the UK generally think, if anything, about sexuality in relation to their professional role?

Do you think that sexual concerns are a legitimate area for OTs to be involved in?

Can you tell me more about that?

#### **4) Attitudes towards practice**

Can you tell me more about when you discuss sexual concerns with clients?

Could you give me a specific example?

How did you feel about this part of your role?

When you first discussed sexual concerns with clients, how did you feel?

Are there aspects of client sexual concerns which you more comfortable with?

Could you tell me more about this?

Could you give me an example?

Are there aspects of sexual concerns which you less comfortable with?

Could you tell me more about this?

Could you give me an example?  
How do you manage this?  
Do you have any strategies for when you feel uncomfortable?

Have there been any clients or occasions where you decided not to broach their sexual concerns?

Could you tell me more about that?

Prompts - for example: people from other cultures, faith or race, non-heterosexual clients, older people, people with complex / multiple disabilities, etc

#### **5) Professional setting and sexuality**

Could you tell me about your attitudes towards sexuality in your professional role?

Have these changed?

Do you discuss client sexual concerns with colleagues?

Do you feel comfortable or uncomfortable in doing so?

Are there aspects that you do or don't discuss with colleagues?

How do you manage boundaries in a professional setting?

#### **6) Influences on practice, barriers & facilitators**

Do you think that there are specific aspects of being an OT which helps you in broaching sexual concerns?

Could you give me an example / tell me more about that?

Do you think that there are specific aspects of being an OT that hinder you with broaching sexual concerns?

Could you give me an example / tell me more about that?

Could you tell me what, if anything, helps you with this part of your role?

Prompts, such as personal attributes/ characteristics, colleagues, support, clear pathways, good resources

Could you give me an example?

Are there things that hinder this part of your role?

Prompts - such as personal attributes/ characteristics, colleagues, support, lack of resources, lack of clear pathways/ time.

Could you give me an example?

Do you feel supported in this part of your role?

Could you tell me more about that?

#### **7) Conclusion – advice for other OTs**

If you spoke to a newly qualified occupational therapist, perhaps a new OT colleague, who had to discuss sexual concerns with a client for the first time, what advice would you give / what do you wish you had known in the early days of your role that you do know now?

Debrief and thank the interviewee, ensuring they are comfortable and informed with the process.

## 1.4 – Interview guide – post-pilot

### Stage 3 – interview guide (POST PILOT VERSION)

**Relevant research aim - 3: Explore OT practitioner attitudes to and experiences of practice concerning sexual expression and intimacy.**

To investigate the attitudes and influences on individual OT practice.

To explore and examine the barriers to and facilitation of this practice, as perceived by OT practitioners.

The interview also provides an opportunity to clarify information given in stage 2, the questionnaire.

This interview guide may be amended in response to piloting.

---

#### 8) Introduction

Welcome and introduce myself.

Explain the aims of the interview and provide a brief overview of why I am doing this research. Ask participant to review information sheet and sign consent form if they have not already done so. Explain what I'm going to do, i.e. that I have some areas I'd like to cover but that they are free to discuss aspects of the subject as they think; that the interview will be recorded so I can transcribe it, that after I will transcribe the interview they will get an opportunity to check, clarify and correct, and add any further thoughts to the transcription.

Establish that the use of vernacular / day-to-day language is fine, and to use language they are most comfortable with.

Reiterate the confidentiality of the interview, that they are free not to answer any questions they feel uncomfortable with and that they may stop at any point.

#### 9) Defining practice in relation to sexual concerns

What do you understand by the term sexual expression and intimacy?

Prompt - refer to WHO definition for comparison – any thoughts?

#### 10) Client sexual concerns / function as a role for the OT

Do you think that sexual expression and intimacy are legitimate areas for OTs to be involved with?

Can you tell me more about that?

#### 11) Attitudes towards practice

Can you tell me more about when you have discussed sexual concerns with clients?

Could you give me any specific examples?

How did you feel about this part of your role?

When you first discussed sexual concerns with clients, how did you feel?

Are there aspects of client sexual concerns which you more comfortable with?

Could you tell me more about this?

Could you give me an example?

Are there aspects of sexual concerns which you less comfortable about?

Could you tell me more about this?

Could you give me an example?

How do you deal with this?

Have there been any clients or occasions where you decided not to broach their sexual concerns?

Could you tell me more about that?

How do you feel about discussing sexual concerns with:

people from other cultures, faith or race,

non-heterosexual clients,

older people & people with complex / multiple disabilities?

How do you manage boundaries in a professional setting?

## **12) Influences on practice, barriers & facilitators**

Do you think being an OT helps or hinders you in broaching sexual concerns?

Could you give me an example / tell me more about that?

Prompts, such as personal attributes/ characteristics, colleagues, support, clear pathways, resources, time, etc

## **13) Conclusion – advice for other OTs**

What advice would you give an OT who is new to broaching client sexual concerns?

Debrief and thank the interviewee, ensuring they are comfortable and informed with the process.

## 1.3 - Stage 3: Interviews

### Interview information sheet for participants



### **An investigation into Occupational Therapy (OT) practice in relation to supporting service users' sexual concerns in physical settings.**

#### **INFORMATION SHEET**

Thank you for taking part in the survey and questionnaire. Below is further information on the research and what will happen to your information.

#### **What is this research about?**

This research is part of my PhD study and focusses on OTs like yourself who include client sexual expression and intimacy in their practice. There is a gap in knowledge regarding OT practice in this area as previous research focusses on the lack of OT practice in this area. This research seeks to find out about how you broach client sexual concerns and how you feel about that practice.

#### **"Sexual concerns" in the context of this research**

This research defines sexual needs using the WHO International classification of functioning, disability and health of sexual function and intimate relationships, this can include the physical and emotional closeness associated with expressions of sexuality and sexual identity. The WHO (2015) defines sexual health as:

"...a state of physical, emotional, mental and social well-being in relation to sexuality; it is not merely the absence of disease, dysfunction or infirmity. Sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence. For sexual health to be attained and maintained, the sexual rights of all persons must be respected, protected and fulfilled." (WHO, 2015)

#### **Why?**

There is limited research in this area of practice and the previous research available suggests that OTs are unsure how to broach sexual concerns – by sharing your thoughts and experiences you may help encourage fellow OTs to include sexual concerns intimacy as part of their holistic practice.

#### **Maintaining anonymity & confidentiality**

The information you give will be anonymised, stored securely and treated with complete confidence, accessible only by myself and my PhD supervision team. The only exception would be if you indicate that you or anyone else is at risk of serious harm, or you disclose examples of professional malpractice, in which case I would be under a duty of care to report these to the relevant safeguarding authority.

#### **Withdrawing your data**

If you wish to withdraw from this research please email me before 30 September 2016. I will delete your contribution immediately.

#### **What will happen to your interview responses?**

I will transcribe our interview and check the transcript with you. If you agree the transcript is correct, I will collate all the responses and analyse them.

#### **Consent**

Prior to the interview I will ask you to sign a consent form. If the interview is undertaken by Skype I will email the consent form and also ask for verbal consent before we begin. By consenting to be involved in this research you are agreeing that:



- You understand the aims of the project.
- You are willing to participate in the project.
- You understand that you may withdraw your consent by 30 September 2016.
- You give permission for statements you make to be quoted, if they do not compromise anonymity.

**Further information:**

If you would like any further information please feel free to contact me or my supervisor:

Penny Ralph

Email: [Penelope.ralph@hud.ac.uk](mailto:Penelope.ralph@hud.ac.uk)

Prof Surya Monro

Email: [surya.monro@hud.ac.uk](mailto:surya.monro@hud.ac.uk)

## 1.4 - Support information provided to all participants

# Sources of support and guidance

---

If you would like further support or guidance, or feel like you have been affected by taking part in this research and would like to talk to someone for support and guidance.

### Internal sources:

**Supervision** - please talk to your **supervisor / line manager** if you feel you are able to - s/he may be provide support and advice.

**Occupational health departments** – can offer counselling and support.

### External sources:

If where you work does not provide internal sources of support, or you would rather use external sources there are several available:

**Your GP** – can offer support, guidance and referral to counselling.

**College of OT Special Section** – can offer advice and support on practice.

**Relate** – can provide training or advice about personal relationships:  
<http://www.relate.org.uk/help-organisations>.

**The College of Sexual and Relationship Counselling** – directory of specialist counsellors. Can also provide further training: <http://www.cosrt.org.uk/information-for-members-of-the-public/find-a-therapist/>.

**Private counselling** – directory of specialist private accredited counsellors searchable in your area: <http://www.counselling-directory.org.uk/sexuality.html>.

**Sexual Health and Disability Alliance (SHADA)** –organisation aiming to support professionals who include the sexual and relationship aspects of their disabled clients in their practice: <http://shada.org.uk/wp2/> .

# Appendix 2 – University of Huddersfield School of Human and Health Sciences Ethical approval form

THE UNIVERSITY OF HUDDERSFIELD

School of Human and Health Sciences – School Research Ethics Panel

## OUTLINE OF PROPOSAL

Please complete and return via email to:

Kirsty Thomson SREP Administrator: [hhs\\_srep@hud.ac.uk](mailto:hhs_srep@hud.ac.uk)

Name of applicant: Penny Ralph

Title of study: An investigation into Occupational Therapy practice in relation to supporting service users' sexual concerns in physical settings.

Department: HHS

Date sent:

Issue	Please provide sufficient detail for SREP to assess strategies used to address ethical issues in the research proposal
Researcher(s) details	Penny Ralph, Research Student
Supervisor details	Surya Monro & Joanne Stead
Aim / objectives	<p>Aims and objectives:</p> <p>Aim 1: Identify existing UK OT practice in sexual expression and intimacy with working age adults with physical impairment / disability;</p> <p>Objectives:</p> <ul style="list-style-type: none"> <li>To identify individuals and organisations which incorporate sexual needs / concerns within their practice;</li> <li>To identify the scope of this practice.</li> </ul> <p>Aim 2: Explore the OT practice regarding sexual expression and intimacy;</p> <ul style="list-style-type: none"> <li>To explore and investigate this practice within the OT process;</li> <li>To investigate practical aspects, such as assessments and interventions, used in relevant practice.</li> </ul> <p>Aim 3: Explore OT practitioner attitudes to and experiences of practice concerning sexual expression and intimacy;</p> <ul style="list-style-type: none"> <li>To investigate the attitudes and influences on individual OT practice.</li> <li>To explore and examine the barriers and facilitators to this practice, as perceived by OT practitioners.</li> </ul>
Brief overview of research methodology	<p>Mixed methods:</p> <p>Data collection:</p> <ol style="list-style-type: none"> <li>E-Survey of members of College of Occupational Therapy (COT) Special Interest groups and Sexual Health and Disability Alliance (SHADA) in order to scope the extent of practice and whether participants regularly address sexuality as part of their practice. This will be an e-survey on order to find out the extent to which sexuality is addressed in practice and to recruit participants for interview, this will include qualitative and quantitative data.</li> <li>E-Questionnaire of survey participants who have agreed to provide further information. This will be largely quantitative focussing on details of training and practice.</li> <li>Interviews with members of COT Special Interest groups and / or SHADA recruited via the scoping survey who regularly address sexuality and willing to share their practice. These will be semi-structured, largely qualitative interviews about practical aspects, attitudes and perceptions of practice.</li> </ol>



## Appendix 3 – Risk assessment

### THE UNIVERSITY OF HUDDERSFIELD: RISK ANALYSIS & MANAGEMENT

ACTIVITY: PhD research project - fieldwork			Name: Penny Ralph	
LOCATION: Various / off-site			Date: 15/1/16	Review Date:
Hazard(s) Identified	Details of Risk(s)	People at Risk	Risk management measures	Other comments
Interviewing participants off-site	Personal safety	Researcher	<p>Log times and date of interviews with responsible friend / administrator;</p> <p>Phone call to the Human and Health Sciences administration on completing visit.</p> <p>If out of office hours or at the weekend I will inform a responsible friend/family member where I am going and arrange to text them on leaving interview.</p>	Administration / responsible friend will be notified of specific interview arrangements and locations in advance of interview.
Loss/ theft of data	Data security.	Interviewees	<p>Electronic data to be stored only on password secured computer equipment and storage devices;</p> <p>After interview, audio files will be immediately uploaded to a secured University drive and deleted from portable devices, any interviews via Skype will be conducted on secure wifi;</p>	Laptops and other electronic data storage devices to be transported in the boot of a car and lockable case.

			Any hard copy data will be kept in secure lockable storage.	
Display screen equipment	Poor posture sat working for prolonged periods resulting in musculoskeletal problems, visual/physical fatigue and eye strain.	Researcher	All workstations subject to DSE assessment process; Regular breaks / eye rest.	
Potential discomfort and embarrassment for interviewees	Interviews may trigger embarrassment or negative associations.	Interviewees	Interviews are voluntary; Debrief of interviewees to ensure their comfort and wellbeing; Provide details of supportive organisations.	

## Appendix 4 – Flyers and advertising research

Thinking of opening the



**CAN OF WORMS?**

**Would you be interested in getting advice / support around sex and intimacy?**

I'm considering setting up a private Facebook group for Occupational Therapists to share ideas, advice and support – if you think that would be helpful please email me, your thoughts would be welcome.

Email: [Penelope.ralph@hud.ac.uk](mailto:Penelope.ralph@hud.ac.uk)

Thank you for your interest!

**Is talking about SEX ....**



**...or a...**



**Why not share your thoughts and experiences!**

You are invited to take part in this PhD study on your thoughts regarding sexual expression and intimacy, and to share any experiences.

**To find out more, email [penelope.ralph@hud.ac.uk](mailto:penelope.ralph@hud.ac.uk), or go to <http://bit.ly/1XJxOzL> to complete a short survey and questionnaire.**

Your emails and responses will be kept anonymous and confidential.



**Email to COT special sections:**

Dear X

Firstly, apologies for the unsolicited email. My name is Penny Ralph and I am a PhD student working under the supervision of Prof Surya Monro and Jo Stead at the University of Huddersfield, undertaking research on Occupational Therapy practice in relation to supporting service users' sexual concerns in physical settings.

I am contacting you to see whether I may have permission to approach members of your Special Section (name). This research is aimed at any qualified Occupational Therapists, of any age, gender or experience, working within a predominantly physical health setting, working in any sector, including within the NHS, social services, a social enterprise, charity or private sector. It involves an initial 5 minute scoping survey to find out the scope of practice related to sexual concerns, with a follow up questionnaire (30-40 minutes) to find out more about practice, and an interview for those who would like to talk further about how they feel about their practice.

The aim of this research is to find out more about practice and experience in this area. Once the research is completed I would be happy to present the findings to your special interest group, to help share practice. All responses will be treated with complete confidentiality.

I have attached an information sheet. If you would like any further information please feel free to contact me or my supervisor:

Penny Ralph  
Email: [Penelope.ralph@hud.ac.uk](mailto:Penelope.ralph@hud.ac.uk)

Prof Surya Monro  
Email: [surya.monro@hud.ac.uk](mailto:surya.monro@hud.ac.uk)

I would like to assure you that the study has been reviewed and received ethics clearance from the University of Huddersfield Health and Human Sciences School Research Ethics Panel.

Thank you for your time. I look forward to hearing from you  
Kind regards



## Appendix 5 – Data analysis

Screenshot of using QDA Data miner (lite) to code / manage the data:

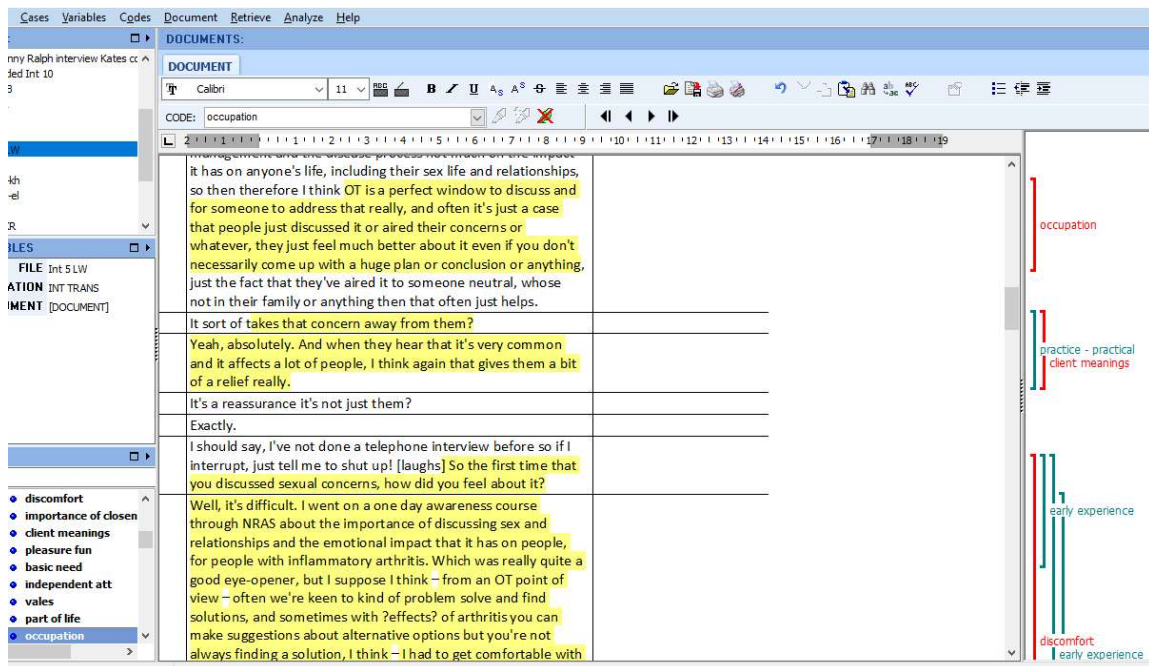


Photo of working on the template, arranging codes around primary themes:



## REFERENCES

- Abbott, K., Ellis, S. and Abbott, R. (2015). 'We don't get into all that': an analysis of how teachers uphold heteronormative sex and relationship education. *Journal of Homosexuality*. 62 (12), 1638-1659. DOI: 10.1080/00918369.2015.1078203.
- Adams, K., Hean, S., Sturgis, P. & Clark, J. (2006). Investigating the factors influencing professional identity of first-year health and social care students. *Learning in Health and Social Care*. 5, 55-68. DOI:10.1111/j.1473-6861.2006.00119.x
- Allen, L. and Carmody, M. (2012). 'Pleasure has no passport': re-visiting the potential of pleasure in sexuality education. *Sex Education*. 12 (4), 455-468. DOI:10.1080/14681811.2012.677208.
- Aveyard, H. & Hawley, G. (2007). How to do ethical health care research. In: G. Hawley. (ed.). *Ethics in Clinical Practice: An Inter-professional Approach*. Harlow: Pearson Education.
- AOTA – American Occupational Therapy Association. (2008). *Occupational therapy framework: domain and process*. Bethesda: AOTA.
- AOTA – American Occupational Therapy Association. (2013). *Sexuality and the role of occupational therapy*. Retrieved from <http://www.aota.org/about-occupational-therapy/professionals/rdp/sexuality.aspx#sthash.LFANF6WS.dpuf>.
- Ashforth, B, Kreiner, G (1999). 'How can you do it?' Dirty work and the challenge of constructing a positive identity. *Academy of Management Review*. 24 (3), 413–34. Retrieved from <https://journals.aom.org/doi/abs/10.5465/amr.1999.2202129>.
- Ashforth, B. & Kreiner, G (2014). Dirty work and dirtier work: differences in countering physical, social and moral taint. *Management and Organization Review*. 10 (1), 81–108. DOI: 10.1111/more.12044.
- Ashforth, B, Kreiner, G, Clark, M, & Fugate, M. (2007). Normalising dirty work: managerial tactics for countering occupational taint. *Academy of Management Journal*. 50 (1), 149–74. Retrieved from <https://journals.aom.org/doi/abs/10.5465/amj.2007.24162092>.
- Bahner, J. (2012). Legal rights or simply wishes? The struggle for sexual recognition of people with physical disabilities using personal assistance in Sweden. *Sexuality and Disability*. 30 (3), 337-356. DOI: 10.1007/s11195-012-9268-2.
- Ballinger, C. (2004). Writing up rigour: representing and evaluating good scholarship in qualitative research. *British Journal of Occupational Therapy*. 67 (12), 540-546. DOI: 10.1177/030802260406701204.
- Barnes, C. & Oliver, M. (1993). *Disability: A sociological phenomenon ignored by sociologists*. Retrieved from <http://disability-studies.leeds.ac.uk/files/library/Barnes-soc-phenomenon.pdf>.

Barnes, C. (1997). A legacy of oppression: a history of disability in western culture. In: Len Barton and Mike Oliver (eds.). *Disability studies: Past present and future*. Leeds: The Disability Press, 3- 24.

BBC (2007). *Thinking allowed*: Interview with Blake Ashforth – normalising dirty work. Retrieved from <https://www.bbc.co.uk/programmes/b00774h6>.

BBC (2016). *Are disabled people's sex lives being ignored?* Retrieved from. <https://www.bbc.co.uk/news/disability-35561347>.

BBC (n.d.). *Ouch: Disability talk*. Retrieved from <https://www.bbc.co.uk/programmes/p02r6yqw>.

Beasley, C. (2005). *Gender & sexuality: critical theories, critical thinkers*. London: SAGE publications.

Beauchamp, T. L. & Childress, J. F. (2009). *Principles of biomedical ethics*. (6th ed.) Oxford: Oxford University Press.

Bergman, M.M. (2010). The politics, fashions and conventions of research methods. *Journal of Mixed Methods Research*. 5 (2) 99-102. DOI: 10.1177/1558689811408318.

Biesta, G. (2010). Pragmatism and the philosophical foundations of mixed methods research. In A. Tashakkori & C. Teddlie. (eds.). *Handbook of mixed methods in social and behavioural research*. (2<sup>nd</sup> ed.). Thousand Oaks: Sage publications.

Blake, C. (n.d.). *Pragmatism and its critics. Intellectual and cultural history of the United States, 1890–1945*. E-Seminar 3. Retrieved from [http://ci.columbia.edu/ci/eseminars/0743\\_detail.html](http://ci.columbia.edu/ci/eseminars/0743_detail.html).

Bolton, S. C. (2005). Women's work, dirty work: The gynaecology nurse as 'other'. *Gender, Work & Organization*. 12, 169-186. DOI: 10.1111/j.1468-0432.2005.00268.x.

Boniface, G. & Seymour, A. (2003). *Using occupational therapy theory in practice*. Chichester: Wiley-Blackwell.

Bowman, J. (2006). Challenges to measuring outcomes in occupational therapy: A qualitative focus group study. *British Journal of Occupational Therapy*. 69 (10), 464 – 472. DOI: 10.1177/030802260606901005.

Bristow, W. (2017). The Enlightenment. *The Stanford encyclopaedia of philosophy* (Fall 2017 Ed.), E.N. Zalta (ed.), Retrieved from <https://plato.stanford.edu/archives/fall2017/entries/enlightenment/>.

British Sociology Association (2002). *Statement of ethical practice*. Retrieved from <http://www.britisoc.co.uk/about/equality/statement-of-ethical-practice.aspx>.

Brooks, J. & King, N. (2014). Doing template analysis: evaluating an end of life care service. *Sage research methods cases*. Retrieved from <http://eprints.hud.ac.uk/19707/>.

Brown, T. M., & Fee, E. (2003). Alfred C. Kinsey: A pioneer of sex research. *American Journal of Public Health*. 93 (6), 896–897. Retrieved from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1447862/>.

- Bryant, W. (2010). Unbelievable. Practice, theory and the work of Jennifer Creek. *British Journal of Occupational Therapy*. 73 (10), 487 – 489. DOI: 10.4276/030802210X12865330218429.
- Bryman, A. (2016). *Social research methods* (5<sup>th</sup> ed.). Oxford: Oxford University Press.
- Bullivant, S. (2016). *The 'no religion' population of the UK*. Retrieved from <https://www.stmarys.ac.uk/research/centres/benedict-xvi/docs/2017-may-no-religion-report.pdf>.
- Bywater, J. & Jones, R. (2007). *Sexuality and social work*. Exeter: Learning Matters Ltd.
- Cacchioni, T. & Wolkowitz, C. (2011). Treating women's sexual difficulties: The body work of sexual therapy. *Sociology of health and illness*. 33 (2), pp.266-279. Doi: 10.1111/j.1467-9566.2010.01288.x
- Cacchioni, T. (2015). The medicalisation of sexual deviances. In: J. Delamater & R. Planke (eds.). *Handbook of the sociology of sexualities*. DOI: 10.1007/978-3-319-17341-2\_24.
- Cameron, C. (2010). *Does anybody like being disabled? A critical exploration of Impairment, identity, media and everyday experience in a disabling society*. Retrieved from <http://etheses.qmu.ac.uk/258/1/258.pdf>.
- Cameron, C. (2015). *Why we are disabled people, not people with disabilities*. Retrieved from <https://www.disabilityartsonline.org.uk/why-we-are-disabled-people-not-people-with-disabilities?stylesheet=default>.
- Caplan, P. (1987). *The cultural construction of sexuality*. London: Routledge.
- Chacala, A., McCormack, C., Collins, B. & Beagan, B. (2014). "My view that disability is okay sometimes clashes": experiences of two disabled occupational therapists. *Scandinavian Journal of Occupational Therapy*. 21 (2), 107-115. DOI: 10.3109/11038128.2013.861016.
- Chalvanagamon, S. (2014). Stigma, taboos, and altered bowel function. *Gastrointestinal Nursing*. 12 (1), 16-22. DOI: 10.12968/gasn.2014.12.1.16.
- Chamberlain, K. (2000). Methodology and qualitative health research. *Journal of Health Psychology*. 5 (3) 285-96. DOI: 10.1177/135910530000500306.
- Christiansen, C. & Townsend, E. (2009). *Introduction to occupation: The art of science and living*. London: Prentice Hall.
- Clare Taylor, M. (2007). The Casson memorial lecture 2007: Diversity amongst occupational therapists — rhetoric or reality? *British Journal of Occupational Therapy*. 70 (7), 276 – 283. DOI: 10.1177/030802260707000702.
- Clark, A. Lissel, S. & Davis, C. (2008). Complex critical realism: Tenets and application in nursing research. *Advances in Nursing Science*. 31(4), E67–E79. DOI: 10.1097/01.ANS.0000341421.34457.2a.

Cleland, J. A. (2017). The qualitative orientation in medical education research. *Korean Journal of Medical Education*, 29(2), 61–71. DOI: 10.3946/kjme.2017.53.

Clouston, T. J., & Whitcombe, S. W. (2008). The professionalization of occupational therapy: a continuing challenge. *British Journal of Occupational Therapy*. 71 (8), 314–320. DOI: 10.1177/030802260807100802.

Collins Dictionary (2017). *Occupation*. Retrieved from : <https://www.collinsdictionary.com/dictionary/english/occupation>.

Connell, R. & Dowsett, G. (1992). *Rethinking sex: social theory and sexuality research*. Melbourne: Melbourne University Press.

College of Occupational Therapists – COT (2010). *Code of ethics and professional practice*. Retrieved from <http://www.cot.co.uk/sites/default/files/publications/public/Code-of-Ethics2010.pdf>.

College of Occupational Therapy. (2015). *Position statement on occupational-focussed practice*. Retrieved from [https://www.cot.co.uk/sites/default/files/position\\_statements/public/Occupation-centred-practice-August2015.pdf](https://www.cot.co.uk/sites/default/files/position_statements/public/Occupation-centred-practice-August2015.pdf).

College of Occupational Therapy - COT. (n.d.). *What is occupational therapy?* Retrieved from <https://www.cot.co.uk/ot-helps-you/what-occupational-therapy>.

Corrigan, P. W., River, L. P., Lundin, R. K., Wasowski, K. U., Campion, J. , Mathisen, J. , Goldstein, H. , Bergman, M. , Gagnon, C. & Kubiak, M. A. (2000). Stigmatizing attributions about mental illness. *Journal of Community Psychology*. 28 (1), 91-102. DOI: 10.1002/(SICI)1520-6629(200001)28:1<91::AID-JCOP9>3.0.CO;2-M.

Couldrick, L. (1998). Sexual Issues within Occupational Therapy, Part 1: Attitudes and Practice. *British Journal of Occupational Therapy*. 61 (12), 538-544. DOI: 10.1177/030802269806101201.

Couldrick, L. (1999). Sexual Issues within Occupational Therapy, Part 2: Implications for Education and Practice. *British Journal of Occupational Therapy*. 62 (1), 26-30. DOI: 10.1177/030802269906200107

Couldrick, L. (2005). Sexual expression and occupational therapy. *British Journal of Occupational Therapy*. *British Journal of Occupational Therapy*. 68 (7), 315-18. DOI: 10.1177/030802260506800705

Couldrick, L. (2007). *Sexual expression, physical disability and professional practice*. Retrieved from [www.shada.org](http://www.shada.org).

Couldrick, L., Sadlo, G. & Cross, V. (2013). Proposing a new sexual health model of practice for disability teams: the Recognition Model. *International Journal of Therapy and Rehabilitation*. 17 (6), DOI: 10.12968/ijtr.2010.17.6.48152.

Crabtree, M. (1998). Images of reasoning: A literature review. *Australian Occupational Therapy Journal*. 45 (4), 113-123. DOI:10.1111/j.1440-1630.1998.tb00792.x.

Creek, J, (2002). *Occupational therapy and mental health*. Edinburgh: Churchill Livingstone.

Creek, J. (2003). *Occupational therapy as a complex Intervention*. London: College of Occupational Therapists.

Creek, J. (2010). *The core concepts of occupational therapy: A dynamic framework for practice*. London: Jessica Kinsley publishers.

Creek, J., Ilott, I., Cook, S. & Munday, C. (2005) Valuing Occupational Therapy as a Complex Intervention. *British Journal of Occupational Therapy*. 68 (6), 281 – 284. DOI: 10.1177/030802260506800607.

Creek, J. & Lougher, L. (eds.) (2008). *Occupational therapy and mental health*. (4<sup>th</sup> ed.). Edinburgh: Churchill Livingstone.

Creswell J., Klassen A., Plano Clark V., & Smith K. (2011). *Best practices for mixed methods research in the health sciences*. Office of Behavioral and Social Sciences Research. National Institutes of Health. Retrieved from [http://obssr.od.nih.gov/mixed\\_methods\\_research](http://obssr.od.nih.gov/mixed_methods_research).

Creswell, J. & Plano Clark, V. (2007). *Designing and conducting mixed methods research*. Thousand Oaks: Sage publications.

Creswell, J. (2003). *Research design: qualitative, quantitative and mixed methods*. 2<sup>nd</sup> ed. Thousand Oaks: Sage publications.

Crotty, M. (1998). *The Foundations of Social Research: Meaning and Perspective in the Research Process*. Thousand Oaks: Sage publications.

Curtin, M., Molineux, M., & Supyk-Mellson, J. (Eds.). (2010). *Occupational therapy and physical dysfunction* (6th ed.). Edinburgh: Churchill Livingstone.

Curtis, M. & Morris, J. (2015). Cross-dressing as a meaningful occupation: A single case study. *British Journal of Occupational Therapy*. 78 (11), 706-712. DOI: 10.1177/0308022615586568.

Dabhiowala, F. (2012). *The origins of sex: A history of the first sexual revolution*. London: Penguin.

Dalkin, S.M., Greenhalgh, J., Jones, D. Cunningham, B. & Lhussier, M. (2015). What's in a mechanism? Development of a key concept in realist evaluation. *Implementation Science*. 10 (49), 1-7. DOI: 10.1186/s13012-015-0237-x.

Davis, K., Drey, N., & Gould, D. (2009). What are scoping studies? A review of the nursing literature. *International Journal of Nursing studies*, 46, 1386-1400. DOI:10.1016/j.ijnurstu.2009.02.010.

Davis, S. (2005). *Rehabilitation: the use of theories and models in practice*. Edinburgh: Elsevier.

Deal, M. (2003). Disabled people's attitudes toward other impairment groups: a hierarchy of impairments. *Disability and Society*. 18(7), 897-910. DOI: 10.1080/0968759032000127317.

Delamater, J. & Hyde, J. (1998). Essentialism vs. social constructionism in the study of human sexuality. *The Journal of Sex Research*. 35 (1), 10-18. DOI: 10.1080/00224499809551913.

Democracy Now (2016). *Interview with Adam Cohen: Buck v. Bell: Inside the SCOTUS Case That Led to Forced Sterilization of 70,000 & Inspired the Nazis*. Retrieved from [https://www.democracynow.org/2016/3/17/buck\\_v\\_bell\\_inside\\_the\\_scotus](https://www.democracynow.org/2016/3/17/buck_v_bell_inside_the_scotus).

Department of Health (2012). *Outcomes framework*. Retrieved from [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/213118/Improving-health-and-care-the-role-of-the-outcomes-frameworks.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213118/Improving-health-and-care-the-role-of-the-outcomes-frameworks.pdf).

Dewsbury, G, Clarke, K., Randall, D. Rouncefield, M. & Sommerville, I. (2004). The anti-social model of disability. *Disability and Society*. 19 (2), 146-158. DOI: 10:1080/0968759042000181776.

Dickie, V. (2013). What is occupation. In: B. Boyt Schell, G. Gillen & M. Scaffa (eds.) *Willard and Spackman's Occupational Therapy* (12th Ed.). Baltimore: Wolters Kluwer Health.

Douglas, M (1966). *Purity and danger: An analysis of concepts of pollution and taboo*. London: Routledge.

Department of Health - DoH (2013). *A framework for sexual health improvement in England*. Retrieved from [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/142592/9287-2900714-TSO-SexualHealthPolicyNW\\_ACCESSIBLE.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/142592/9287-2900714-TSO-SexualHealthPolicyNW_ACCESSIBLE.pdf).

Drummond, A. (2010) The Elizabeth Casson Memorial Lecture 2010: 'Jack of all trades and master of none': the future of occupational therapy. *British Journal of Occupational Therapy*. 73 (7), 292-299. DOI: 10.4276/030802210X12759925544263.

Drummond, J.D. & Brotman, S. (2014). Intersecting and Embodied Identities: A Queer Woman's Experience of Disability and Sexuality. *Sexuality and Disability*. 32, 533-549. DOI: 10.1007/s11195-014-9382-4.

Dukes, E. & McGuire, B. (2009). Enhancing capacity to make sexuality-related decisions in people with an intellectual disability. *Journal of Intellectual Disability Research*. 53 (8), 727-734. DOI: 10.1111/j.1365-2788.2009.01186.x.

Duncan, E. (2006). *Foundations for practice in occupational therapy*. (4th ed.). Edinburgh: Churchill Livingstone.

Duncan, E. (2011). *Foundations for practice in occupational therapy*. (5th ed.). Edinburgh: Churchill Livingstone.

- Dyer, K. & Das Nair, R. (2013). Why don't healthcare professionals talk about sex? A systematic review of recent qualitative studies conducted in the United Kingdom. *Journal of Sexual Medicine*. 10, 2658–2670. DOI: 10.1111/j.1743-6109.2012.02856.x.
- East, L. J., & Orchard, T. R. (2013). Somebody else's job: Experiences of sex education among health professionals, parents and adolescents with physical disabilities in southwestern Ontario. *Sexuality and Disability*, 32, 335–350. DOI: 10.1007/s11195-013-9289-5.
- Elo, S. & Kyngäs, H. (2008). The qualitative content analysis process. *Journal of Advanced Nursing*. 62 (1), 107-115. DOI: 10.1111.j.1365-2648.2007.04569.x.
- Esmail, S., Darry, K., Walter, A., & Knupp, H. (2010). Attitudes and perceptions towards disability and sexuality. *Disability and Rehabilitation*, 32(14), 1148–1155. DOI: 10.3109/09638280903419277.
- Evans, D., (1993). *Sexual citizenship: the material construction of sexualities*. London: Routledge Psychology Press.
- Evans, D. (1998). Making sense of sexuality. In: M. Morrissey (ed.). *Sexuality and healthcare: a human dilemma*. Wiltshire: Quay books.
- Evans, K. (1987). Definition of occupation as the core concept of occupational therapy. *American Journal of Occupational Therapy*. 41, 627-628. DOI:10.5014/ajot.41.10.627.
- Fahs, B. & Swank, E. (2015). Unpacking sexual embodiment and embodied resistance. In: J. Delamater & R. Planke (eds.). *Handbook of the sociology of sexualities*. DOI: 10.1007/978-3-319-17341-2\_24.
- Feilzer, M. Y. (2009). Doing mixed methods research pragmatically: Implications for the rediscovery of pragmatism as a research paradigm. *Journal of Mixed Methods Research*. 4 (1), 6 – 16. DOI: 10.1177/1558689809349691.
- Finlay, L. (1998). *The life world of the occupational therapist: meaning and motive in an uncertain world*. PhD thesis. Retrieved from [www.ethos.bl.uk](http://www.ethos.bl.uk).
- Finlay, L. (2006). Mapping methodology. In: L. Finlay & C. Ballinger. *Qualitative research for allied health professionals: challenging choices*. Chichester: John Wiley & Sons Ltd.
- Flick, U. (2015). *Introducing research methodology*. (2nd ed.) Thousand Oaks: Sage publications.
- Fortune, T. (2000). Occupational therapists: Is our therapy truly occupational or are we merely filling gaps? *British Journal of Occupational Therapy*. 63 (5), 225 – 230. DOI: 10.1177/030802260006300507.
- Fox, N. (2008). Introduction. In: L. Given (ed.) *The SAGE encyclopaedia of qualitative research methods*. Retrieved from [http://www.sagepub.com/chambliss4e/study/chapter/encyc\\_pdfs/9.3\\_Induction.pdf](http://www.sagepub.com/chambliss4e/study/chapter/encyc_pdfs/9.3_Induction.pdf).
- Foucault, M. (1981). *The history of sexuality*. Harmondsworth: Penguin.



Fouché, L. (2014). An occupational therapist's perspective on sexuality and psychosocial sexual rehabilitation. In: R. Crouch & V. Alers (eds.). *Occupational therapy in psychiatry and mental health*. (5<sup>th</sup> ed.). DOI:10.1002/9781118913536.ch14.

Fraher, A. (2017). Invisibilised dirty work: The multiple realities of US airline pilots' work. *Culture and Organization*. 23 (2), 131-148. DOI: 10.1080/14759551.2016.1244825.

Fraley, S.S., Monson, L.R. & Theodore. (2007). The sexual lives of lesbian, gay, and bisexual people with disabilities: Psychological perspectives. *Sexuality Research and Social Policy*. 4 (1), 15-26. DOI:10.1525/srsp.2007.4.1.15.

French S. & Swain, J. (2004). Whose tragedy: Towards a personal non-tragedy view of disability. In: Swain J., French S., Barnes & Thomas (eds.) *Disabling Barriers – Enabling Environments*. (2nd ed.). London: Sage.

Gagnon, J. (2004). *An interpretation of desire: essays in the study of sexuality*. Chicago/London: University of Chicago Press.

Gagnon, J. & Simon, W. (1973). *Sexual conduct: the social sources of human sexuality*. Chicago: Aldine.

Gagnon, J. & Simon, W. (1984). Sexual scripts. In: Parker, R. & Aggleton, P. (2007). *Culture, society and sexuality*. (2<sup>nd</sup> ed.) London: UCL Press. Gagnon, J. & Simon, W. (1986). Sexual scripts: Permanence and change. *Archives of Sexual Behavior*. 15 (2), pp 97–120. DOI: 10.1007/BF01542219.

Gerlach, A. J. (2015). Sharpening our critical edge: Occupational therapy in the context of marginalized populations. *Canadian Journal of Occupational Therapy*. 82 (4), 245 – 253. DOI: 10.1177/0008417415571730.

Giffney, N. (2009). Introduction: The q word. In: N. Giffney, & M. O'Rourke (eds.). *The Ashgate Research Companion to Queer Theory (Queer Interventions)*. Oxon: Routledge.

Goffman, E. (1963). *Stigma: notes on the management of spoiled identity*. London: Penguin Books.

Gott, M., Galena, E., Hinchliff, S. & Elford, J. (2004). "Opening a can of worms": GP and practice nurse barriers to talking about sexual health in primary care. *Family Practice*. 21 (5), 528–536. DOI:10.1093/fampra/cmh509.

Giannotten, W., Bender, J., Post, M. & Höing, M. (2006). Training in sexology for medical and paramedical professionals: a model for the rehabilitation setting. *Sexual and Relationship Therapy*. 21 (3). DOI: 10.1080/14681990600754559.

Goodley, D. & Runswick-Cole, K. (2016). Becoming dishuman: thinking about the human through dis/ability. *Discourse: Studies in the Cultural Politics of Education*, 37 (1), 1-15, DOI: 10.1080/01596306.2014.930021.

Green, G. (2009). *The end of stigma: Changes in the Social Experience of Long-Term Illness*. London: Routledge.

The Guardian. (2016). *Disability and sex are not mutually exclusive*. Retrieved from <https://www.theguardian.com/lifeandstyle/2016/oct/15/disability-and-sex-are-not-mutually-exclusive>.

Guba, E., & Lincoln, Y. (1994). Competing paradigms in qualitative research. In: N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of Qualitative Research* (105-117). Thousand Oaks: Sage publications.

Guba, E. & Lincoln, Y. (2005). Paradigmatic controversies, contradictions and emerging confluences. Chapter 8. In: N. Denzin & Y. Lincoln (eds). *The Sage handbook of qualitative research*. (3<sup>rd</sup> ed.) Thousand Oaks: Sage publications.

Haboubi, N. & Lincoln, N. (2003). Views of health professionals on discussing sexual issues with patients. *Disability and Rehabilitation*. 25 (6), 291-296, DOI: 10.1080/0963828021000031188.

Hagedorn, R. (1995a). *Occupational therapy: Perspectives and processes*. Edinburgh: Churchill Livingstone.

Hagedorn, R. (1995b). The Elizabeth Casson memorial lecture 1995: An emergent profession — A personal perspective. *British Journal of Occupational Therapy*. 58 (8), 324-331. DOI: 10.1177/030802269505800802.

Hall, R. (2012). *Mixed methods: In search of a paradigm*. Conference proceedings: International Conference: Innovative Research in a Changing and Challenging World. Retrieved from [https://www.researchgate.net/profile/David\\_Geelan/publication/273520118\\_While\\_Heisenberg\\_is\\_not\\_looking\\_the\\_strength\\_of\\_'weak\\_measurements'\\_in\\_educational\\_research/links/55e5260408aeb1a7ccb962b.pdf](https://www.researchgate.net/profile/David_Geelan/publication/273520118_While_Heisenberg_is_not_looking_the_strength_of_'weak_measurements'_in_educational_research/links/55e5260408aeb1a7ccb962b.pdf).

Hansen, E. (2006). *Successful qualitative health research: a practical introduction*. Maidenhead: Open University Press.

Hambrook, C. (2009). *Interview with Colin Cameron*. Retrieved from <http://www.disabilityartsonline.org.uk/affirmative-model-of-disability>.

Hammell, K.W. (2004). Deviating from the norm: A sceptical interrogation of the classificatory practices of the ICF. *British Journal of Occupational Therapy*. 67(9), 408-411. DOI: 10.1177/030802260406700906.

Hammell, K.W. (2006). *Perspectives on disability & rehabilitation. Contesting assumptions; challenging practice*. Edinburgh: Churchill Livingstone.

Hammell, K.W. (2009). Self-care, productivity, and leisure, or dimensions of occupational experience? rethinking occupational "categories". *Canadian Journal of Occupational Therapy*. 76 (2). 107-14. DOI:10.1177/000841740907600208.

Hammell, K.W. (2011). Resisting theoretical imperialism in the disciplines of occupational science and occupational therapy. *British Journal of Occupational Therapy* .74 (1) 27 – 33. DOI: 10.4276/030802211X12947686093602.

Hammersley, M. (2009). Why critical realism fails to justify critical social research. *Methodological Innovations Online*. 4 (2), 1-11. Retrieved from <http://oro.open.ac.uk/20394/1/1. Hammersley final August 9 09.pdf>

Hansen, R. & Atchison, B. (2000). *Conditions in occupational therapy: Effect on occupational performance*. Baltimore: Lippincott, Williams & Wilkins.

Haraldsdóttir, F. (2015). *The wheeling of shame: The political action of sexing up disability and crippling up femininity*. Talk given at Interrogating queer, crip and the body: an international symposium. 3<sup>rd</sup> July 2015. Sheffield Hallam University.

Hassouneh-Phillips, D. & McNeff, E. (2005). “I thought I was less worthy”: Low sexual and body esteem and increased vulnerability to intimate partner abuse in women with physical disabilities. *Sexuality and Disability*. 23 (227). DOI: 10.1007/s11195-005-8930-3.

Health & Care Professions Council - HCPC (2008). *Standards of conduct, performance and ethics*. Retrieved from <http://www.hcpc-uk.org/assets/documents/10003B6EStandardsconduct,performanceandethics.pdf>.

Hecimovich, M. & , Volet, S. (2011). Development of professional confidence in health education: Research evidence of the impact of guided practice into the profession. *Health Education*. 111 (3), 177-197. DOI: 10.1108/09654281111123475.

Hill, R-G. (1998). Multiple positions: a philosophical approach to sexual health. In: M. Morrissey (ed.). *Sexuality and healthcare: a human dilemma*. Wiltshire: Quay books.

Hocking, C. (2008). The Way We Were: The Ascendance of Rationalism. *British Journal of Occupational Therapy*. 71 (6), 226 – 233. DOI:10.1177/030802260807100602.

Hocking, C. (2012). Occupations through the Looking Glass: Reflecting on Occupational Scientists' Ontological Assumptions. In: Whiteford & C. Hocking. *Occupational science: society, inclusion, participation*. Oxford: Wiley-Blackwell.

Hocking, C. & Nicholson, E (2007) How far will occupational therapists go? In: Creek, J. & Lawson-Porter, A. (Eds.). *Contemporary issues in occupational therapy: Reasoning and reflection*. John Wiley and Sons Ltd: Chichester.

Holloway, I. & Wheeler, S. (2010). *Qualitative Research in Nursing and Healthcare*. 3<sup>rd</sup> ed. Chichester: Wiley-Blackwell.

Hordern, A. & Street, A. (2007). Communicating about patient sexuality and intimacy after cancer: mismatched expectations and unmet needs. *Medical Journal of Australia*. 186 (5), 224-227.

Retrieved from <https://www.mja.com.au/journal/2007/186/5/communicating-about-patient-sexuality-and-intimacy-after-cancer-mismatched>.

Hooper, B. & Wood, W. (2002). Pragmatism and Structuralism in Occupational Therapy: The Long Conversation. *American Journal of Occupational Therapy*. 56(1), 40-50. DOI: 10.5014/ajot.56.1.40.

Howland, C., & Rintala, D. H. (2001). Dating behaviors of women with physical disabilities. *Sexuality and Disability*. 19 (1), 41–70. DOI: 10.1023/A:1010768804747.

Hsieh, H. & Shannon, S. E. (2005). Three Approaches to Qualitative Content Analysis. *Qualitative Health Research*. 15 (9), 1277-1288. DOI: 10.1177/1049732305276687.

Hyland, A. & McGrath, M. (2013). Sexuality and occupational therapy in Ireland – a case of ambivalence? *Disability and Rehabilitation*, 35 (1). 73-80. DOI: 10.3109/09638288.2012.688920.

Hughes, E. (1962). Good People and Dirty Work. *Social Problems*, 10(1), 3-11. DOI:10.2307/799402.

Hughes, J., Simpson, R., Slutskaya, N., Simpson, A. & Hughes, K. (2016). Beyond the symbolic: a relational approach to dirty work through a study of refuse collectors and street cleaners. *Work, Employment and Society*. 31 (1), 106 – 122. DOI: 10.1177/0950017016658438.

Hunt, J. (2015). *Speech on personal responsibility*. Retrieved from <https://www.gov.uk/government/speeches/personal-responsibility>.

Irvine, J. (1990). From difference to sameness: Gender ideology in sexual science. *Journal of Sex Research*. 27 (1). 7-24. DOI: 10.1080/00224499009551539.

Irvine, J. (2014). Is sexuality research ‘dirty work’? Institutionalized stigma in the production of sexual knowledge. *Sexualities*. 17(5/6), 632–656. DOI: 10.1177/1363460713516338.

Jackson, J. (1995). Sexual orientation: Its relevance to occupational science and the practice of occupational therapy. *American Journal of Occupational Therapy*. 49, 669–679. DOI: 10.5014/ajot.49.7.669.

Jackson, J. (2000). Understanding the experience of non-inclusive occupational therapy clinics: Lesbian perspectives. *American Journal of Occupational Therapy*, 54 (1), 26-35. DOI: 10.5014/ajot.54.1.26.

Jackson, S. & Scott, S. (2004). Sexual Antinomies in Late Modernity. *Sexualities*. 7 (2), 233 – 248. DOI: 10.1177/1363460704042166.

Jackson, S. & Scott, S. (2010a). *Theorizing sexuality*. Open University Press: Maidenhead.

Jackson, S. & Scott, S. (2010b). Rehabilitating Interactionism for a Feminist Sociology of Sexuality. *Sociology*. 44 (5), 811-826. DOI: 10.1177/0038038510375732.

Jensen, T. & Sanstrom, J. (2016). Dirty work as seriality. *Tamara - Journal for Critical Organization Inquiry*. 14 (3), 99-112. Retrieved from <https://tamarajournal.com/index.php/tamara/article/view/417/pdf>.

Jones, D., Blair, S., Hartery, T. & Jones, R.K. (eds.) (1998). *Sociology and Occupational Therapy: an integrated approach*. Edinburgh: Churchill Livingstone.

Jones, M. K., Weerakoon, P., & Pynor, R. (2005). Survey of occupational therapy students' attitudes towards sexual issues in clinical practice. *Occupational Therapy International*. 12(2), 95–106. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/16136867>.

Kantarzis, S. & Molineux, M. (2012). Understanding the discursive development of occupation: Historico-political perspectives. In: G. Whiteford & C. Hocking. *Occupational science: society, inclusion, participation*. Oxford: Wiley-Blackwell.

Kattari, S. K. (2014). Sexual experiences of adults with physical disabilities: negotiating with sexual partners. *Sexuality and Disability*. 32 (4), 499–513. DOI: 10.1007/s11195-014-9379-z.

Kennedy, M. (1987). Occupational Therapists as Sexual Rehabilitation Professionals Using the Rehabilitative Frame of Reference. *Canadian Journal of Occupational Therapy*. 54 (4), 189-193. DOI.org/10.1177/000841748705400409.

Keywood, K. (2003). Supported to be Sexual? Developing Sexual Rights for People with Learning Disabilities. *Tizard Learning Disability Review*. 8 (3), 30-36, DOI.org/10.1108/13595474200300025.

Kielhofner, G. (1993). Occupation as the major activity of humans. In: H. Hopkins, H. Smith (eds.) *Willard and Spackman's occupational therapy*. (8th ed.). Philadelphia: JB Lippincott.

Kiepek, N. & Magalhães, L. (2011). Addictions and Impulse-Control Disorders as Occupation: A Selected Literature Review and Synthesis. *Journal of Occupational Science*, 18 (3), 254-276. DOI: 10.1080/14427591.2011.581628.

Killaspy, H. (2006). From the asylum to community care: learning from experience. *British Medical Bulletin*. 79-80 (1), 245–258. DOI: 10.1093/bmb/ldl017.

Kimmes, J., Mallory, A., Cameron, C. & Köse, Ö. (2015). A treatment model for anxiety-related sexual dysfunctions using mindfulness meditation within a sex-positive framework. *Sexual and Relationship Therapy*. 30(2), 286-296. DOI: 10.1080/14681994.2015.1013023.

King, N. (2004). Using templates in the thematic analysis of texts. In: C. Cassell and G. Symes. *Essential guide to qualitative methods in organisational research*. London: SAGE publications.

King, N. (2015). *Workshop on Qualitative Data Collection*. University of Huddersfield. 25<sup>th</sup> November 2015.

- Kinn, L. G., & Aas, R. W. (2009). Occupational therapists' perception of their practice: A phenomenological study. *Australian Occupational Therapy Journal*. 56(2), 112–121. DOI:10.1111/j.1440-1630.2007.00714.x.
- Kinsella, E.A. (2012). Knowledge paradigms in occupational science: Pluralistic perspectives. In: G. Whiteford & C. Hocking. (eds.) *Occupational science: society, inclusion, participation*. Oxford: Wiley-Blackwell.
- Kinsey, A.C. (1947). Sex behavior in the human male. In: S. Bernard Wortis, *et al.*, *Physiological and psychological factors in sex behavior*. *Annals of the New York Academy of Sciences*.47:603-664.
- Kinsey, A.C., Pomeroy, W.B., Martin, C.E., & Gebhard, P.H. (1953). *Sexual behavior in the human female*. Philadelphia: W.B. Saunders.
- Kirkby, H., Wilson, S., Calvert, M. & Draper, H. (2011) Using e-mail recruitment and an online questionnaire to establish effect size: A worked example. *BMC Medical Research Methodology*. 11 (89). 1-4. DOI: 10.1186/1471-2288-11-89.
- Kreiner, G, Ashforth, B, & Sluss, D (2006). Identity dynamics in occupational dirty work: integrating social identity and system justification perspectives. *Organization Science*. 17 (5): 619–36. DOI: 10.1287/orsc.1060.0208.
- Kristensen, H. & Petersen, K. (2015) Occupational science: An important contributor to occupational therapists' clinical reasoning. *Scandinavian Journal of Occupational Therapy*. 23 (3), 240-243. DOI: 10.3109/11038128.2015.1083054.
- Kronenberg, F., Simo Algado, S. & Pollard, N. (2004). *Occupational therapy without borders - volume 1. Learning from the spirit of survivors*. London: Churchill Livingstone.
- Kvale, S. (2007). *Doing interviews*. Thousand Oaks: Sage publications.
- Kvåle, G. & Rambø, R-G. (2015). Expressing Professional Identity through Blogging - A Case Study of Blogging in the Study of the Subject of Norwegian in Pre-School Teacher Education. *Nordic Journal of Digital Literacy*. 10 (2 / 4) Retrieved from [https://www.idunn.no/dk/2015/01/expressing\\_professional\\_identity\\_through\\_blogging\\_-\\_a\\_case\\_](https://www.idunn.no/dk/2015/01/expressing_professional_identity_through_blogging_-_a_case_).
- Larsson, A. T. & Grassman, E. J. (2012). Bodily changes among people living with physical impairments and chronic illnesses: biographical disruption or normal illness? *Sociology of Health & Illness*, 34, 1156-1169. DOI:10.1111/j.1467-9566.2012.01460.x.
- Lavrakas, P. J. (2008). *Encyclopaedia of survey research methods*. Thousand Oaks, CA: SAGE Publications Ltd. DOI: 10.4135/9781412963947.
- Learmonth, M. (1997). Managerialism and public attitudes towards UK NHS managers. *Journal of Management in Medicine*. 11 (4), 214-221. DOI:10.1108/02689239710177314

- Leclair, L. (2010). Re-Examining Concepts of Occupation and Occupation-Based Models: Occupational Therapy and Community Development. *Canadian Journal of Occupational Therapy*. 77 (1), 15-21. DOI: <https://DOI.org/10.2182/cjot.2010.77.1.3>.
- Liddiard, K. (2012). *(S)Exploring disability: Intimacies, sexualities and disabilities: research summary*. Retrieved from [http://www2.warwick.ac.uk/fac/soc/sociology/staff/current/sypgbj/accessible\\_research\\_summary\\_second\\_draft\\_repaired.pdf](http://www2.warwick.ac.uk/fac/soc/sociology/staff/current/sypgbj/accessible_research_summary_second_draft_repaired.pdf).
- Liddiard, K. (2014). The work of disabled identities in intimate relationships. *Disability and Society*. 29 (1), 115-128. DOI: 10.1080/09687599.2013.776486.
- Lincoln, Y. S. & Guba, E. G. (1986). But is it rigorous? Trustworthiness and authenticity in naturalistic evaluation. *New Directions for Program Evaluation*. 73-84. DOI: 10.1002/ev.1427.
- Link, B.G. & Phelan, J.C. (2001). Conceptualizing stigma. *Annual Review of Sociology*, 27, 363-385. Retrieved from <https://www.scopus.com/inward/record.uri?eid=2-s2.0-0035629556&partnerID=40&md5=4bb83412ef040998c3d2507fd32fb42c>.
- Lipscombe, M. (2008). Mixed method nursing studies: a critical realist critique. *Nursing Philosophy*. 9, 32-45. DOI: 10.1111/j.1466-769X.2007.00325.x.
- Little, W. Fowler, H. & Coulson, J. (1987). *Shorter English dictionary*. Oxford, Oxford University Press.
- Löfgren-Mårtenson, L. (2013). "Hip to be Crip?" About Crip Theory, Sexuality and People with Intellectual Disabilities. *Sexuality and Disability*. 31 (4), 413-424. DOI: 10.1007/s11195-013-9287-7.
- Mackey, H. (2007). 'Do not ask me to remain the same': Foucault and the professional identities of occupational therapists. *Australian Occupational Therapy Journal*. 54 (2), 95–102. DOI: 10.1111/j.1440-1630.2006.00609.x.
- Mackey, H. (2014). Living tensions: Reconstructing notions of professionalism in occupational therapy. *Australian Occupational Therapy Journal*. 61(3), 168–176. DOI:10.1111/1440-1630.12097.
- Malinowski, B. (1929). *The sexual life of savages in north-western Melanesia*. New York: Eugenics Pub. Co.
- Matthews, B. & Ross, L. (2010). *Research methods: a practical guide for the social sciences*. Harlow: Longman.
- Maxwell, J. & Mittapalli, K. (2010). Realism as a Stance for Mixed Method Research. In: A. Tashakkori & C. Teddlie. (eds.). *Handbook of mixed methods in social and behavioural research*. (pp.145-167). Thousand Oaks: Sage publications.
- Maxwell, J. (2012). *A realist approach for qualitative research*. Thousand Oaks: Sage publishing.

- May, T & Powell, J. (2008). *Situating social theory*. (2<sup>nd</sup> ed.). Maidenhead: Open University Press/McGraw-Hill.
- McCabe, M. (1999). Sexual knowledge, experience and feelings among people with disability. *Sexuality and Disability*. 17 (2) 157-170. DOI: 10.1023/A:1021476418440.
- McCabe, J. L., & Holmes, D. (2009). Reflexivity, critical qualitative research and emancipation: A Foucauldian perspective. *Journal of Advanced Nursing*. 65 (7), 1518–1526. DOI: 10.1111/j.1365-2648.2009.04978.x.
- McCabe J. & Holmes D. (2013). Nursing, sexual health and youth with disabilities: a critical ethnography. *Journal of Advanced Nursing*. 70 (1), 77–86. DOI:10.1111/jan.12167.
- McCabe, M. & Taleporos, G. (2003). Sexual esteem, sexual satisfaction, and sexual behaviour among people with physical disability. *Archives of Sexual Behaviour*. 32(4), 359–369. DOI: 10.1023/A:1024047100251.
- McCruer, R. (2012). *Crippling queer politics, or the dangers of neoliberalism*. Retrieved from <http://sfonline.barnard.edu/a-new-queer-agenda/cripping-queer-politics-or-the-dangers-of-neoliberalism/#sthash.ielfSZhm.dpuf>.
- McCruer, R. (2018). *Crip times*. New York: New York University Press.
- McDermid, D. (n.d.). *The internet encyclopedia of philosophy*. Retrieved from <http://www.iep.utm.edu/>.
- McGrath, M. & Lynch, E. (2014). Occupational therapists' perspectives on addressing sexual concerns of older adults in the context of rehabilitation. *Disability and Rehabilitation*. 36 (8), 651-657. DOI: 10.3109/09638288.2013.805823.
- McGrath, M. & Sakellariou, D. (2016). Why Has So Little Progress Been Made in the Practice of Occupational Therapy in Relation to Sexuality? *American Journal of Occupational Therapy*. 70 (1), 1-5. DOI: 10.5014/ajot.2016.017707.
- Mcguire-Snieckus, R., McCabe, R., & Priebe, S. (2003). Patient, client or service user? A survey of patient preferences of dress and address of six mental health professions. *Psychiatric Bulletin*. 27 (8), 305-308. DOI: 10.1192/pb.27.8.305.
- McLaughlin, H. (2009). What's in a Name: 'Client', 'Patient', 'Customer', 'Consumer', 'Expert by Experience', 'Service User'—What's Next? *British Journal of Social Work*. 39 (6), 1101–1117. DOI: 10.1093/bjsw/bcm155.
- McMurray, R. & Ward, J. (2014). 'Why would you want to do that?': Defining emotional dirty work. *Human Relations*. 67 (9), 1123 – 1143. DOI: 10.1177/0018726714525975.
- Mead, M. (1928). *Coming of age in Samoa*. New York: W. Morrow & Company.



Mellor, R. M., Greenfield, S. M., Dowswell, G., Sheppard, J. P., Quinn, T., & McManus, R. J. (2013). Health care professionals' views on discussing sexual wellbeing with patients who have had a stroke: a qualitative study. *PloS One*. 8(10), e78802. DOI:10.1371/journal.pone.0078802.

Mencap (2016). *Relationships and sex – what we think*. Retrieved from <https://www.mencap.org.uk/about-us/what-we-think/relationships-and-sex-what-we-think>

The Metro (2018). *Disability shouldn't limit your sex life*. Retrieved from <https://metro.co.uk/2018/01/03/disability-shouldnt-limit-your-sex-life-here-are-some-of-the-sex-toy-industrys-most-innovative-solutions-7131576/>

Merriam-Webster Dictionary. (2015). *Sexuality*. Retrieved from <https://www.merriam-webster.com/dictionary/sexuality>.

Miller, P., Gillinson, S. & Parker, S, (2004). *Disablism: How to tackle the last prejudice*. Demios, Scope & DAA: London.

MIND (2017). *Stigma and misconceptions*. Retrieved from <https://www.mind.org.uk/information-support/types-of-mental-health-problems/mental-health-problems-introduction/stigma-misconceptions/>.

Mitchell, K. R., Wellings, K. , Nazareth, I. , King, M. , Mercer, C. H. and Johnson, A. M. (2011), Scripting sexual function: a qualitative investigation. *Sociology of Health & Illness*. 33, 540-553. DOI: 10.1111/j.1467-9566.2011.01318.x.

Molineux, M. (2004). Occupation in occupational therapy: A labour in vain? In: M Molineux (Ed.), *Occupation for occupational therapists*. (pp. 1–14). Oxford, UK: Blackwell Publishing.

Molineux, M. (2009). The nature of occupation. In: M. Curtin, M. Molineux & J. Supyk-Mellson (eds.). *Occupational therapy and physical dysfunction: Enabling occupation*. (6th ed.). Edinburgh: Elsevier.

Monro, S. (2015). *Bisexuality: identities, politics, and theories*. (Gender and sexualities in the social sciences). Basingstoke: Palgrave Macmillan UK. DOI: 10.1057/9781137007315.

Monro, S., Hines, S., & Osborne, A. (2017). Is bisexuality invisible? A review of sexualities scholarship 1970-2015. *Sociological Review*. 65(4), 663-681. DOI: 10.1177/0038026117695488.

Morgan, D. (2007). Paradigms lost and pragmatism regained: methodological implications of combining qualitative and quantitative methods. *Journal of Mixed Methods Research*. 1 (1), 48-79. DOI: 10.1177/2345678906292462.

National AIDS Trust (2016). *Tackling HiV stigma*. Retrieved from [https://www.nat.org.uk/sites/default/files/publications/Jun\\_16\\_Tackling\\_HIV\\_Stigma.pdf](https://www.nat.org.uk/sites/default/files/publications/Jun_16_Tackling_HIV_Stigma.pdf).

NHS Choices (2008). *History of the NHS*. Retrieved from <https://www.nhs.uk/Tools/Documents/HistoryNHS.html>

NHS Choices (2017). *Benefits of love and sex*. Retrieved from <https://www.nhs.uk/Livewell/Goodsex/Pages/ValentinesDay.aspx>.

NHS London Deanery. (2012). *Professional identities*. Retrieved from <http://www.faculty.londondeanery.ac.uk/e-learning/interprofessional-education/professional-identities>.

Noble, H. & Smith, J. (2015). Issues of validity and reliability in qualitative research. *Evidence-based Nursing*. 18, 34-35. DOI: 10.1136/eb-2015-102054.

Northcott, R. & Chard, G. (2000). Sexual Aspects of Rehabilitation : the Client's Perspective. *British Journal of Occupational Therapy*. 63 (9), 412–418. DOI: 10.1177/030802260006300902.

Nye, R. (ed.) (1999). *Sexuality*. Oxford: Oxford University Press.

Oliver, M. (2004). If I had a hammer: the social model in action. In: J. Swain, S. French, C. Barnes and C. Thomas (eds.). *Disabling barriers – enabling environments*. (2nd ed.). London: Sage.

Oliver, M. (2013). The Social Model of Disability: 30 years on. *Disability and Society*. 28 (7), 1024-1026. DOI:10.1080/09687599.2013.818773.

OTTalk. (2012). *Discussion on Sexuality in OT Practice*. Retrieved from <https://otalkocchats.wordpress.com/2012/03/07/discussion-on-sexuality-in-ot-practice-21st-february-2012/>.

Oxford Dictionary (2017). *Taboo*. Retrieved from <https://en.oxforddictionaries.com/definition/taboo>.

Oxford Dictionaries (2015). *Sexuality*. Retrieved from <https://en.oxforddictionaries.com/definition/sexuality>.

Padgug, R. (1999). Sexual matters: in conceptualising sexuality in history. In: R. Parker & P. Aggleton. *Culture, society and sexuality*. London: UCL Press.

Palinkas, L. A., Horwitz, S. M., Green, C. A., Wisdom, J. P., Duan, N., & Hoagwood, K. (2015). Purposeful sampling for qualitative data collection and analysis in mixed method implementation research. *Administration and Policy In Mental Health*. 42(5), 533–544. DOI: 10.1007/s10488-013-0528-y.

Parker, R. & Aggleton, P. (2007). *Culture, society and sexuality*. (2<sup>nd</sup> ed.) London: UCL Press.

Parker, R. G., & Gagnon, J. H. (Eds.). (1995). *Conceiving sexuality: Approaches to sex research in a postmodern world*. Abingdon/New York: Taylor & Frances/Routledge.

Parkin, A. (2014). *Approaching issues of sexuality with clients: an online survey of current occupational therapy practice in the UK*. Paper presented at the College of Occupational Therapists Conference, Brighton.

Pattison, M. (2018). Message from the President: Global Health Policy. *World Federation of Occupational Therapists Bulletin*. 74 (1), 3-7, DOI: 10.1080/14473828.2018.1432472.

Pawson, R. & Tilley, N. (1997). *Realistic evaluation*. London: SAGE publications.

Pentland, D., Kantartzis, S., Giatsi Clausen, M. and Witemyre, K. (2018). *Occupational therapy and complexity: defining and describing practice*. London: Royal College of Occupational Therapists.

Pierce, D. (2001). Occupation by design: Dimensions, therapeutic power, and creative process. *American Journal of Occupational Therapy*. 55, 249-259. DOI:10.5014/ajot.55.3.249.

Planned Parenthood. (2007). *The health benefits of sexual expression*. Retrieved from [https://www.plannedparenthood.org/uploads/filer\\_public/a0/ee/a0eed54c-ffda-4f82-b53d-4fb2b4666eee/benefits\\_sex\\_07\\_07.pdf](https://www.plannedparenthood.org/uploads/filer_public/a0/ee/a0eed54c-ffda-4f82-b53d-4fb2b4666eee/benefits_sex_07_07.pdf).

Polatajko, H.J., Townsend, E.A. & Craik, J. (2007). Canadian Model of Occupational Performance and Engagement (CMOP-E). In: E.A. Townsend & H.J. Polatajko, (eds.) *Enabling occupation ii: Advancing an occupational therapy vision of health, well-being, & justice through occupation*. Ottawa: CAOT Publications .

Polgar, S. & Thomas, S. (2008). *Research in the health sciences*. (5th ed.). London: Churchill Livingstone Elsevier.

Pollard, N. & Sakellariou, D. (2007). Sex and occupational therapy: Contradictions or contraindications? *British Journal of Occupational Therapy*. 70 (8), 362 – 365. DOI: 10.1177/030802260707000807.

Pope, C. & Mays, N. (eds.). (2006). *Qualitative research in health care*. (3rd ed.). Oxford: BMJ / Blackwell publishing.

Potts, A. (2002). *The science/ fiction of sex. Feminist deconstruction and the vocabularies of heterosex*. London: Routledge

Priestley, M. (2004). *Disability: a life course approach*. Cambridge: Polity.

Prion, S., & Adamson, K. A. (2014). Making sense of methods and measurement: Rigor in qualitative research. *Clinical Simulation In Nursing*. 10 (2). DOI: 10.1016/j.ecns.2013.05.003.

Public Health England (2017). *Research and analysis - Chapter 1: life expectancy and healthy life expectancy*. Retrieved from <https://www.gov.uk/government/publications/health-profile-for-england/chapter-1-life-expectancy-and-healthy-life-expectancy>.

Punwar, A. (1994), Current trends in international occupational therapy practice. *Occupational Therapy International*. 1: 1-12. DOI:10.1002/oti.6150010103.

Payne, M. J., Greer, D. L., & Corbin, D. E. (1988). Sexual functioning as a topic in occupational therapy training: a survey of programs. *American Journal of Occupational Therapy*. 42 (4), 227–230. DOI: 10.5014/ajot.42.4.227.

Post, M. W. M., Gianotten, W. L., Heijnen, L., Lambers, E. J. H. R., & Willems, M. (2008). Sexological competence of different rehabilitation disciplines and effects of a discipline-specific sexological training. *Sexuality and Disability*. 26, 3–14. DOI: 10.1007/s11195-007-9068-2.

Public Health England (2015). *Health promotion for sexual and reproductive health and HIV*. Retrieved from [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/488090/SRHandHIVStrategicPlan\\_211215.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/488090/SRHandHIVStrategicPlan_211215.pdf).

Reed, K. & Sanderson, S. (1999). *Concepts of occupational therapy*. Maryland: Lippincott Williams and Wilkins.

Reeve, D. (2004). Psycho-emotional dimensions of disability and social model. In: C. Barnes & G. Mercer (eds.). *Implementing the social model of disability: theory and Research*. Leeds: The Disability Press. 83-100. Retrieved from <http://disability-studies.leeds.ac.uk/files/library/Barnes-implementing-the-social-model-chapter-6.pdf>.

Richardson, D. (2000). Constructing sexual citizenship: theorizing sexual rights. *Critical Social Policy*. 20 (1), 105 – 135. DOI: 10.1177/026101830002000105.

Roberts, A. (2011). *Defining occupation*. Retrieved from <http://www6.plymouth.ac.uk/files/extranet/docs/FoH/OT%20Conf%20Sep11%20-%20Defining%20occupation%20A%20Roberts%20paper.pdf>.

Roberts, C. (2006). Medicine and the making of the sexual body. In: S. Seidman, N. Fischer & C. Meeks. (eds.). *Handbook of the new sexuality studies*. Abingdon: Routledge.

Robson, C. (2002). *Real world research*. (2<sup>nd</sup> ed.). Oxford: Blackwell publishing.

Royal College of Occupational Therapy - RCOT. (2017). *What is Occupational therapy?* Retrieved from <https://www.rcot.co.uk/about-occupational-therapy/what-is-occupational-therapy>.

Rubin, G. (1984). Thinking Sex: Notes for a Radical Theory of the Politics of Sexuality. In: R. Parker & P. Aggleton. (eds). (1999). *Culture, society and sexuality*. London: UCL Press.

Rubin, H. & Rubin, I. (2012). *Qualitative interviewing: the art of hearing data*. 3<sup>rd</sup> ed. Sage Publishing: Thousand Oaks. Retrieved from [https://uk.sagepub.com/sites/default/files/upm-binaries/43179\\_2.pdf](https://uk.sagepub.com/sites/default/files/upm-binaries/43179_2.pdf).

Sakellariou, D. & Simó Algado, S. (2006). Sexuality and Disability: A Case of Occupational Injustice. *British Journal of Occupational Therapy*. 69 (2), 69 – 76. DOI: 10.1177/030802260606900204.

Sanders, T. O'Neill, M. & Pitcher, J. (2018). *Prostitution: sex work, policy and politics*. London: Sage publications.

- Sanders-McDonagh, E. (2014). Conducting “Dirty Research” with extreme groups: understanding academia as a dirty work site. *Qualitative Research in Organizations and Management: An International Journal*. 9 (3), 241-253. DOI: 10.1108/QROM-01-2013-1131.
- Santos, A.C. & Santos, A.L. (2017). Yes, we fuck! Challenging the misfit sexual body through disabled women’s narratives. *Sexualities*. 21 (3), 303–318. DOI: 10.1177/1363460716688680.
- Saunamäki, N., & Engström, M. (2014). Registered nurses’ reflections on discussing sexuality with patients: responsibilities, doubts and fears. *Journal of Clinical Nursing*. 23, 531–540. DOI:10.1111/jocn.12155.
- Saunamäki, N., Andersson, M., & Engström, M. (2010). Discussing sexuality with patients: Nurses’ attitudes and beliefs. *Journal of Advanced Nursing*. 66, 1308–1316. DOI:10.1111/j.1365-2648.2010.05260.x.
- Schwartz, K. B. (2009). Reclaiming our heritage: Connecting the founding vision to the centennial vision (Eleanor Clarke Slagle lecture). *American Journal of Occupational Therapy*. 63, 681–690 . Retrieved from <https://www.aota.org/-/media/Corporate/Files/Publications/AJOT/Slagle/2009-Slagle.PDF>.
- Seidman, S. (2011). Theoretical perspectives. In: S. Seidman, N. Fischer & C. Meeks. *Introducing the new sexuality studies*. (2nd Ed.) London: Routledge.
- Seidman, S. (2015). *The Social Construction of Sexuality (Contemporary Societies)*. (3<sup>rd</sup> ed.). London: W.W. Norton co.
- Sengupta, S. & Sakellariou, D. (2009). Sexuality and Health Care: Are We Training Physical Therapy Professionals to Address Their Clients’ Sexuality Needs? *Physical Therapy* . 89 (1) , 101-102. DOI: 10.2522/ptj.2009.89.1.101.
- Shakespeare, T. & Watson, N. (2002). The social model of disability: an outdated ideology? *Research in social science and disability*. 2, 9-28. Retrieved from <http://disability-studies.leeds.ac.uk/files/library/Shakespeare-social-model-of-disability.pdf>.
- Shakespeare, T. (2003). ‘I haven’t seen that in the Kama Sutra’: The sexual stories of disabled people. In: J. Weeks, J. Holland & M. Waites (eds.) *Sexualities and society: a reader*. Cambridge: Polity.
- Shakespeare, T. (2004). Social models of disability and other life strategies. *Scandinavian Journal of Disability Research*. 6 (1) 8-21. DOI: 10.1080/15017410409512636.
- Shakespeare, T. (2014). *Disability rights and wrongs revisited* (2<sup>nd</sup> ed.). London: Routledge.
- Shakespeare, T., Gillespie-Sells, K., & Davies, D. (1996). *Untold desires: the sexual politics of disability*. London: Cassell.
- Shiloh, S. Heruti, I. & Berkovitz, T. (2011). Attitudes toward people with disabilities caused by illness or injury: beyond physical impairment. *International Journal of Rehabilitation research*. 34 (4), 321–329. DOI: 10.1097/MRR.0b013e32834d2048.

- Shuttleworth, R. & Sanders, T. (eds.)(2010). *Sex & disability: politics, identity and access*. Leeds: The Disability Press.
- Simon, W. & Gagnon, J.H. (1984). Sexual scripts. *Society*. 22 (53), 53-60. DOI:10.1007/BF02701260.
- Simon, W. & Gagnon, J.H. (1986). Sexual scripts: Permanence and change. *Archives of Sexual Behavior*. 15 (2), 97–120. DOI:10.1007/BF01542219.
- Simon, W. & Gagnon, J. (2003). Sexual scripts: Origins, influences and changes. *Qualitative Sociology*. 26 (4), 491-497. DOI: 10.1023/B:QUAS.0000005053.99846.e5.
- Simpson, S., Slutskaya, N., Lewis, N. & Höpfl, H. (eds.) (2012). *Dirty work: concepts and identities. identity studies in the social sciences*. London: Palgrave MacMillan.
- Slay, H. & Smith, D. (2011). Professional identity construction: Using narrative to understand the negotiation of professional and stigmatized cultural identities. *Human Relations*. 64 (1), 85-107. DOI: 10.1177/0018726710384290.
- Slootjes, H. , McKinstry, C. and Kenny, A. (2016). Maternal role transition: Why new mothers need occupational therapists. *Australian Occupational Therapy Journal*. 63, 130-133. DOI: 10.1111/1440-1630.12225.
- Southgate, E. & Shying, K. (2014). Researchers as dirty workers: cautionary tales on insider-outsider dynamics. *Qualitative Research in Organizations and Management: An International Journal*. 9 (3), 223-240. DOI: 10.1108/QROM-01-2013-1129.
- Smith, J. & Deemer, D. (2000). The problem of criteria in the age of relativism. In: N.K. Denzin and Y.S. Lincoln (eds.). *The handbook of qualitative research* (2<sup>nd</sup> ed.). Thousand Oaks: Sage Publications.
- Spashett, E.M. (1981). What role O.T. — Luxury or necessity? *British Journal of Occupational Therapy*. 44 (9), 288 – 291. DOI: 10.1177/030802268104400909.
- Stacey, C. L. (2005). Finding dignity in dirty work: the constraints and rewards of low-wage home care labour. *Sociology of Health & Illness*. 27, 831-854. DOI: 10.1111/j.1467-9566.2005.00476.x.
- Starks, H. & Brown Trinidad, S. (2007). Choose your methods: a comparison between phenomenology, discourse analysis and grounded theory. *Qualitative Health Research*. 17 (10), 1372-80. DOI: 10.1177/104973207307031.
- Stead, J. (2016). *Becoming an occupational therapist: an interpretative phenomenological analysis*. Unpublished doctoral thesis retrieved via email correspondence.
- Stead, M. L., Brown, J. M., Fallowfield, L., & Selby, P. (2002). Communication about sexual problems and sexual concerns in ovarian cancer: a qualitative study. *Western Journal of Medicine*, 176 (1), 18–19. Retrieved from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1071644/pdf/wjm17600018.pdf>.

- Susman, J. (1994). Disability, stigma and deviance. *Social Science & Medicine*. 38 (1), 15–22. DOI: 10.1016/0277-9536(94)90295-X/.
- Swain, J. & French, S. (2000) Towards an Affirmation Model of Disability. *Disability & Society*. 15 (4), 569-582, DOI: 10.1080/09687590050058189.
- Swain, J., French, S., Barnes, C. & Thomas, C. (eds.). (2004). *Disabling barriers – enabling environments*. (2nd ed.) London: Sage.
- Tajfel, H., & Turner, J. (2001). An integrative theory of intergroup conflict. In: M. A. Hogg & D. Abrams (Eds.). *Key readings in social psychology. Intergroup relations: Essential readings*. New York: Psychology Press.
- Tarling, M. (2002). Ethical issues. In: Tarling, M. & Crofts, L. (eds.) *The essential researchers handbook for nurses and healthcare professionals*. (2nd ed.) Edinburgh: Bailliere Tindall.
- Taylor, B. (2011). The Impact of Assistive Equipment on Intimacy and Sexual Expression. *British Journal of Occupational Therapy*. 74 (9), 435 – 442. DOI:10.4276/030802211X13153015305637.
- Taylor, B. & Davis, S. (2006). Using the extended PLISSIT model to address sexual healthcare needs. *Nursing Standard*. 21 (11) 35-40. DOI: 10.7748/ns2006.11.21.11.35.c6382.
- Tashakkori, A. & Teddlie, C. (1998). Mixed methodology: Combining qualitative and quantitative approaches. *Applied social research methods series* , 46. Thousand Oaks: Sage publications.
- Tashakkori A, & Teddlie C. (2003). (eds.). *Handbook of mixed methods in social and behavioural research*. Thousand Oaks: Sage publications.
- Teddlie, C. & Tashakkori, A. (2009). *Foundations of mixed methods research: integrating quantitative and qualitative approaches in the social and behavioural sciences*. Thousand Oaks: Sage.
- Tepper, M.S. (2000). Sexuality and disability: the missing discourse of pleasure. *Sexuality and Disability*. 18 (4), 283-290. <https://doi.org/10.1023/A:1005698311392>.
- Terrence Higgins Trust (n.d.). *Stigma*. Retrieved from <https://www.tht.org.uk/hiv-and-sexual-health/living-well-hiv/sex-and-relationships/stigma>.
- Thew, M. (2011). The Way forward?. In: M. Thew, M. Edwards, S. Baptiste & M. Molineux. *Role emerging occupational therapy: maximising occupation-focused practice*. Chichester: Wiley-Blackwell.
- Thomas, C. (2004). Developing the social relational in the social model of disability: A theoretical agenda. In: C. Barnes & G. Mercer. (eds.). *Implementing the social model of disability: Theory and research*. Leeds: The Disability Press, 32-47. Retrieved from <http://disability-studies.leeds.ac.uk/files/library/Barnes-implementing-the-social-model-chapter-3.pdf>.

- Tiefer, L. (2001). A new view of women's sexual problems: Why new? Why now? *The Journal of Sex Research*. 38(2), 89-96. Retrieved from <http://www.jstor.org/stable/3813698>.
- Tiefer, L. (2006). Female sexual dysfunction: A case study of disease mongering and activist resistance. *PLoS Med.* 3 (4), e178, 0436-0440. DOI: 10.1371/journal.pmed.0030178.
- Tipton-Burton (2013). Sexuality and physical dysfunction. In: H. Pendleton & W. Schultz-Kohn (eds.) *Pedretti's occupational therapy: Practice skills for physical dysfunction*. (7th ed.). St Louis: Mosby.
- Tringo, K. (1970). The hierarchy of preference toward disability groups. *The Journal of Special Education*. 4 (3), 295-306. DOI: 10.1177/002246697000400306.
- Turner, A, Forster, M. & Johnson, S. (2002). *Occupational therapy and physical dysfunction: Principles, skills and practice*. Edinburgh: Churchill Livingstone.
- Turner, A. (2011). The Elizabeth Casson Memorial Lecture 2011: Occupational therapy - A profession in adolescence? *British Journal of Occupational Therapy*. 74 (7), 314–322. DOI: 10.4276/030802211X13099513661036.
- Turner, A. & Alsop, A. (2015). Unique core skills: Exploring occupational therapists' hidden assets. *British Journal of Occupational Therapy*. 78 (12), 739 – 749. DOI: 10.1177/0308022615601443.
- Turner, A. & Knight, J. (2015). A debate on the professional identity of occupational therapists. *British Journal of Occupational Therapy*. 78 (11), 664 – 673. DOI: 10.1177/0308022615601439.
- Turpin, M., & Iwama, M. (2011). *Using occupational therapy models in practice: a field guide*. Edinburgh: Churchill Livingstone.
- Twinley, R. (2013). The dark side of occupation: A concept for consideration. *Australian Occupational Therapy Journal*. 60 (4), 301-303. DOI: 10.1111/1440-1630.12026.
- Twinley, R. & Addidle, G. (2012) Considering violence: The dark side of occupation. *British Journal of Occupational Therapy*. 75 (4), 202-204. DOI: 10.4276/030802212X13336366278257.
- Tyler, M. (2011). Tainted love: From dirty work to abject labour in Soho's sex shops. *Human Relations*. 64 (11), 1477 – 1500. DOI: 10.1177/0018726711418849.
- UK Government (2012). *Health and Social Care Act*. Retrieved from <http://www.legislation.gov.uk/ukpga/2012/7/contents/enacted>.
- UKRIO (2009). *Code of Practice for research*. Retrieved from <http://ukrio.org/publications/>. Vaast, E. & Levina, N. (2015). Speaking as one, but not speaking up: dealing with new moral taint in an occupational online community. *Information Systems Research*. 25 (2). 73-98. DOI: 10.1016/j.infoandorg.2015.02.001.
- Vance, C. (1989). *Social construction theory: Problems in the history of sexuality*. Retrieved from <https://pdfs.semanticscholar.org/020c/7b4916f26ebf0ac39457cf36a22adc8f554b.pdf>.



Vansteenwegen, A. Jans, I. & Revell, A. (2003). Sexual experience of women with a physical disability: a comparative study. *Sexuality and Disability*. 21 (4), 283-290. DOI: 10.1023/B:SEDI.0000010070.46481.17.

Verschuren, J. E. Geertzen, J. H. B., Enzlin, P., Dijkstra, P. U., Dekker, R., & Van Der Sluis, C. K. (2013). Addressing sexuality as standard care in people with an upper limb deficiency: Taboo or necessary topic? *Sexuality and Disability*, 31, 167–177. DOI: 10.1007/s11195-013-9298-4.

Vice (2016) *Sexuality with a disability*. Retrieved from [https://www.vice.com/en\\_uk/article/gqk5bb/sexuality-with-a-disability](https://www.vice.com/en_uk/article/gqk5bb/sexuality-with-a-disability).

Vickerman J. (2008). The occupational therapist's approach to the management of incontinence. In: Haslam J., Laycock J. (eds). *Therapeutic management of incontinence and pelvic pain*. London: Springer.

Weeks, J. (1989). *Sexuality*. London: Routledge.

Weeks, J. (1991). *Against nature: Essays on history, sexuality and identity*. London: Rivers Oram Press.

Weeks, J. (1995). *Invented moralities: sexual values in an age of uncertainty*. Cambridge: Polity Press.

Weeks, J. (2003). *Sexuality*. (2<sup>nd</sup> ed.) Routledge: London.

Weiderman, M. (2015). Sexual script theory: Past, present, and future. In: J. DeLamater, R.F. Plante (eds.). *Handbook of the sociology of sexualities*. Cham: Springer.

WFOT (2012). *Definitions of occupational therapy*. Retrieved from <http://www.wfot.org/AboutUs/AboutOccupationalTherapy/DefinitionofOccupationalTherapy.aspx>.

White, G. & Mortensen, A. (2003). Counteracting Stigma in Sexual Health Care Settings. *The Internet Journal of Advanced Nursing Practice*. 6 (1), 1–5. DOI:10.5580/86b.

Whiteford, G. & Hocking, C. (2012). *Occupational science: society, inclusion, participation*. Oxford: Wiley-Blackwell.

Whiteford, G. & Pereira, G. (2012). Occupation, inclusion and participation. In: G. Whiteford & C. Hocking (eds.). *Occupational science: society, inclusion, participation*. Oxford: Wiley-Blackwell.

Wikipedia (n.d.). *Sex positive movement*. Retrieved from [https://en.wikipedia.org/wiki/Sex-positive\\_movement](https://en.wikipedia.org/wiki/Sex-positive_movement).

Wikipedia (2018). *Google's ideological echo chamber aka Google memo by James Damore, 2017*. Retrieved from [https://en.wikipedia.org/wiki/Google%27s\\_Ideological\\_Echo\\_Chamber](https://en.wikipedia.org/wiki/Google%27s_Ideological_Echo_Chamber).

Wilcock, A. A. (2001). *Occupation for health: A journey from self health to prescription*. Vol 1. London: College of Occupational Therapy.

Wilcock, A.A. (2006). *An occupational perspective on health*. (2<sup>nd</sup> ed.). New Jersey: SLACK Inc.

Wilding, (2009). Defining occupational therapy, In: M. Curtin, M. Molineux & J. Supyk-Mellson (eds.). *Occupational therapy and physical dysfunction: Enabling occupation*. (6th ed.). Edinburgh: Elsevier.

Wilding, C. & Whiteford, G. (2008). Language, identity and representation: Occupation and occupational therapy in acute settings. *Australian Occupational Therapy Journal*. 55, 180–187. DOI: 10.1111/j.1440-1630.2007.00678.x.

Wilding, C., Curtin, M. & Whiteford, G. (2012). Enhancing occupational therapists' confidence and professional development through a community of practice scholars. *Australian Occupational Therapy Journal*. 59 (4), 312-318. DOI: 10.1111/j.1440-1630.2012.01031.x.

Wilmoth, M. C. (1998). Sexuality resources for cancer professionals and their patients. *Cancer Practice*. 6, 346-348. DOI: 10.1046/j.1523-5394.1998.006006346.x .

Wisker, G. (2008). *The postgraduate research handbook*. (2<sup>nd</sup> ed.). London: Palgrave Macmillan.

World Health Organisation [WHO]. (2001). *International classification of functioning, disability and health (ICF)*. Retrieved from <http://www.who.int/classifications/icf/en/>.

World Health Organisation [WHO]. (2011). *Ethical standards and procedures for research with human beings*. Retrieved from <https://www.who.int/ethics/research/en/>.

World Health Organisation [WHO]. (2015). *Defining sexual health*. Retrieved from [http://www.who.int/reproductivehealth/topics/sexual\\_health/sh\\_definitions/en/](http://www.who.int/reproductivehealth/topics/sexual_health/sh_definitions/en/).

Wright, C. & Rowe, N. (2005). Protecting professional identities: service user involvement and occupational therapy. *British Journal of Occupational Therapy*. 68 (1), 45-47. DOI: 10.1177/030802260506800108.

Wright St Clair, V. (2012). The case for multiple research methodologies. In: G. Whiteford & C. Hocking. *Occupational science: society, inclusion, participation*. Oxford: Wiley-Blackwell.

Yallop, S., & Fitzgerald, M. H. (1997). Exploration of occupational therapists' comfort with client sexuality issues. *Australian Occupational Therapy Journal*. 44 (2), 53–60. DOI: 10.1111/j.1440-1630.1997.tb00755.x.

Yerxa, E. (1990). An introduction to occupational science, a foundation for occupational therapy in the 21st century. *Occupational Therapy in Health Care*. 6 (4), 1-17. DOI: 10.1080/J003v06n04\_04.