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**“UNLESS THEY HAVE BEEN THROUGH IT THEMSELVES,
THEY HAVE NO CONCEPT OF HOW IT CHANGES
EVERYTHING”:**

**A PHENOMENOLOGICAL INVESTIGATION INTO THE LONG-
TERM CONSEQUENCES CANCER SURVIVORS EXPERIENCE
FOLLOWING CANCER AND ITS TREATMENT**

JADE CASH

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

The University of Huddersfield

May 2019

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Abstract

This research focuses upon the exploration of cancer survivors' lived experiences of long-term consequences following cancer and its treatment. The sample consists of members from the Macmillan 'Cancer Voices' online support group. This was carried out through two studies with the following overall aims being of focus throughout:

Aim 1: To identify any prevalent long-term consequences of cancer and its treatment that are experienced within a diverse sample of cancer survivors.

Aim 2: To investigate in depth, the lived experiences of a diverse sample of cancer survivors in regards to long-term consequences of cancer and its treatment.

Aim 3: To provide healthcare professionals who support cancer survivors with insights for practice.

The preliminary study consisted of an online survey using open-ended and closed questions and was completed by 84 participants. In addition to demographic and cancer history questions the participants completed the Quality of Life in Adult Cancer Survivors Scale and the Health Anxiety Inventory. Four open-ended questions enabled individuals to share anything they wished to, in regards to their experienced long-term consequences that had not already been addressed. Statistical analyses were conducted to identify relationships between selected variables. Template Analysis was used for the open-ended responses. Statistical analysis found in contrast to much previous literature that cancer type was not associated with quality of life. Template Analysis identified a rich variety of themes shedding light on the experience of long-term consequences. These analyses helped inform the selection of participants for the main study.

The main phenomenological study used e-mail interviews with 16 individuals. The data were analysed using Template Analysis, which identified six main themes within the participants' responses; *Changes in Selfhood, Support, Engagement in the Social World, Feeling Understood, Managing of Consequences, Research Impact* and *The Impact of Cancer Voices*. A Narrative analysis was then performed upon the data of three participants, using the Listening Guide. This enabled the research to explore and identify how individuals narrated and structured their lived experiences.

The present research provides a number of key contributions to knowledge. First, it utilises a relatively new data collection method; e-mail interviewing and in doing so, identifies the advantages it holds. The richness of the responses and of the relationships built with the researcher demonstrates that this method can provide in-depth data. Pragmatically, it enables a wider range of participants to be included than would often be possible for face-to-face interviews. The participants also expressed they found their participation to have a therapeutic quality. Secondly, the research gave some detailed

insights, providing alternative ways of looking at both the 'changes in selfhood' and the concept of 'feeling understood', that occur through the long-term consequences of cancer and its treatment. Finally, the use of the online e-interviewing method showed how issues such as incontinence, fatigue and eating/digestive issues might be more prominent in the everyday concerns of cancer survivors than the fear of cancer reoccurrence.

Disseminated Findings

Poster Presentation

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Contents

Acknowledgements.....	3
Abstract.....	4
Disseminated Findings.....	6
List of Figures.....	15
List of Tables.....	16
Chapter One: Introduction to Thesis.....	18
1.1 The Phenomenon of Interest.....	18
1.2 My Interest within the Research Phenomenon.....	20
1.3 The Present Research.....	21
1.4 Thesis Structure.....	22
Chapter Two: Literature Review.....	25
2.1 What is Cancer?.....	25
2.2 Survivorship; what is it?.....	26
2.2.1 The Acceptability of the Term Survivorship.....	27
2.2.2 Advantages and Limitations of Survivorship.....	29
2.2.3 Researcher Stance.....	31
2.3 Long-Term Consequences of Cancer and its Treatment.....	32
2.3.1 Pain.....	35
2.3.2 Cancer-Related Fatigue.....	37
2.3.3 Cancer-Related Incontinence.....	40
2.3.4 Fear of Cancer Reoccurrence.....	43
2.3.5 Issues within the Social World.....	45
2.4 Support Groups.....	48

2.4.1 What are the Benefits of Cancer Support Groups?.....	48
2.4.2 Why do Individuals Seek Out Cancer Support Groups?.....	52
2.4.3 Support Groups and Significant Others.....	53
2.5 Quality of Life.....	56
2.5.1 How is Quality of Life Measured?.....	56
2.5.2 Quality of Life and Wellbeing.....	58
2.5.3 Quality of Life Measurement Instruments.....	59
2.5.4 Health Related Quality of Life.....	62
2.5.5 Health Anxiety and Quality of Life.....	62
2.6 Assessing Health Anxiety.....	63
2.7 Current Research Rationale.....	65
2.7.1 Overall Aims and Objectives of the Current Research.....	67
Chapter Three: Methodology.....	69
3.1 The Preliminary Study.....	70
3.2 The Main Phenomenological Study.....	73
3.2.1 Epistemology.....	73
3.2.2 Ontology.....	74
3.2.3 Perspectives within Epistemology.....	74
3.2.4 Perspectives in Ontology.....	77
3.2.5 Introducing Phenomenology.....	77
3.3 Establishing Trustworthiness.....	88
3.4 Choices of Data Collection Method.....	90
3.4.1 The Preliminary Study.....	91
3.4.2 The Main Phenomenological Study.....	92

Chapter Four: The Preliminary Study: Methods.....	104
4.1 Introduction.....	104
4.2 Methods.....	106
4.2.1 Sample and Recruitment.....	106
4.2.2 Design.....	108
4.2.3 Measures.....	109
4.2.4 Procedure.....	115
4.2.5 Ethical Considerations.....	117
4.2.6 Statistical Analysis.....	119
4.2.7 Qualitative Analysis.....	120
Chapter Five: The Preliminary Study – Statistical Analyses Findings.....	127
5.1 Quantitative Findings.....	127
5.2 Cancer Type and Quality of Life.....	131
5.3 Cancer Type and Age.....	133
5.4 Cancer Status and Quality of Life.....	134
5.5 Quality of Life and Health Anxiety.....	138
5.6 Gender Differences in Quality of Life Scores.....	139
Chapter Six: The Preliminary Study: Template Analysis Findings.....	141
6.1 Selfhood.....	141
6.1.1 New.....	142
6.1.2 No Change.....	161
6.2 Support.....	164
6.2.1 Significant Others.....	165
6.2.2 Healthcare Services.....	168
6.2.3 People.....	173

6.3 Unpreparedness.....	175
6.3.1 Questioning of Decisions.....	176
6.3.2 Health Issues as Unpleasant Surprises.....	178
Chapter Seven: Discussion of Preliminary Study.....	181
7.1 Quantitative Findings.....	181
7.1.1 Summary of Findings from Statistical Analyses.....	181
7.1.2 Discussion of Findings.....	182
7.2 Qualitative Findings.....	186
7.2.1 Summary of Template Analysis Findings.....	187
7.2.2 Issues Presented within the Template Analysis.....	187
7.3 Reflections on the Preliminary Study.....	193
7.4 Strengths and Limitations of the Preliminary Study.....	194
Chapter Eight: The Main Phenomenological Study: Methods.....	196
8.1 Design.....	196
8.2 Participants.....	197
8.3 Procedure.....	202
8.4 Ethical Considerations.....	207
8.5 Data Analysis.....	209
8.5.1 Template Analysis.....	209
8.5.2 Narrative Analysis.....	216
Chapter Nine: The Main Phenomenological Study- Template Analysis	
Findings.....	228
9.1 Changes in Selfhood.....	228
9.1.1 For the Better.....	229
9.1.2 For the Worse.....	233

9.1.3 Complex.....	236
9.2 Engagement within the Social World.....	241
9.2.1 Fatigue.....	242
9.2.2 Incontinence.....	244
9.2.3 Immobility.....	247
9.2.4 Isolated by Others.....	249
9.3 Support.....	254
9.3.1 Dealing with the Early Crises.....	254
9.3.2 Reality Mismatching Expectations.....	258
9.3.3 Support from Healthcare Professionals.....	261
9.3.4 Being Mothered.....	269
9.3.5 Discretion.....	270
9.3.6 Communication.....	272
9.3.7 Power of Support.....	274
9.4 Feeling Understood.....	277
9.4.1 Can Only Understand Through Experience.....	277
9.4.2 Nobody Understands.....	279
9.5 Managing the Consequences.....	283
9.5.1 Shifting Focus.....	283
9.5.2 Routine and Organisation.....	286
9.5.3 Positive Comparison.....	289
9.6 Research Impact.....	290
9.7 The Impact of Cancer Voices.....	293
9.7.1 The Need to Give.....	294
9.7.2 A Sense of Community.....	296

9.7.3 Seeking Personal Enjoyment/Benefits.....	298
9.7.4 Personal Positive Achievement.....	300
Chapter Ten: The Main Phenomenological Study - Narrative Analysis.....	302
10.1 Reading One - Identifying Narrative and Plots within the Participants' Accounts.....	302
10.1.1 Jane.....	302
10.1.2 Mary.....	304
10.1.3 Gerald.....	305
10.1.4 Reflections.....	306
10.2 Reading Two: Identifying Tone and Structure within the Narratives Presented.....	309
10.2.1 Jane.....	310
10.2.2 Mary.....	312
10.2.3 Gerald.....	314
10.3 Reading Three - Creating 'I-Poems' from Presented Narratives.....	317
10.3.1 Jane.....	317
10.3.2 Mary.....	320
10.3.3 Gerald.....	323
10.4 Narrative Synthesis.....	325
10.4.1 Jane.....	326
10.4.2 Mary.....	330
10.4.3 Gerald.....	332
Chapter Eleven: Discussion.....	336
11.1 Summary of Findings.....	336
11.1.1 Preliminary Study; Statistical Analysis Summary.....	336

11.1.2 Preliminary Study; Template Analysis Findings Summary.....	337
11.1.3 Main Phenomenological Study; Template Analysis Findings Summary.....	338
11.1.4 Main Phenomenological Study - Narrative Analysis Findings Summary.....	340
11.2 Discussion of Key Contributions.....	341
11.2.1 The Manner in which Selfhood Changes.....	342
11.2.2 Lack of Emphasis upon Fear of Cancer Reoccurrence.....	343
11.2.3 Feeling Understood.....	344
11.2.4 Benefits of E-mail Interviewing.....	344
11.3 Discussion of Experiences Faced within the Present Research.....	345
11.3.1 Discontinuity.....	346
11.3.2 Healthcare Provision.....	352
11.3.3 Changes in Selfhood.....	354
11.3.4 Fear of Cancer Reoccurrence.....	358
11.3.5 Feeling Understood.....	360
11.3.6 Benefits of E-mail Interviewing.....	361
11.3.7 Cancer Voices Participation and Shaped Experiences.....	362
11.4 Reflections.....	365
11.4.1 Reflections on Methodology; E-mail Interviews.....	366
11.4.2 Reflection on Template Analysis.....	369
11.4.3 Reflection on Narrative Analysis.....	370
11.4.4 Reflection on my Place in the Research.....	371
11.4.5 Reflection on Thesis as a Whole.....	372
11.5 Strengths and Limitations of the Main Phenomenological Study.....	373

11.6 Implications for Future Practice and Research.....	376
11.7 Conclusions.....	380
References.....	383
Appendices.....	425
Appendix 1 – Message to Cancer Voices Members Regarding the Online Survey.....	425
Appendix 2 – The online Survey with the Included Information Sheet and Informed Consent Form.....	426
Appendix 3 – The Initial Template within the Template Analysis for the Preliminary Study.....	456
Appendix 4 – Blanket E-mail Sent to the Selected Participants for E-mail Interview.....	457
Appendix 5 – Information sheet sent to the selected e-mail interview Participants.....	457
Appendix 6 – The Consent Form for E-mail Interview Participants.....	459
Appendix 7 – An Example of a Completed Consent Form.....	460
Appendix 8 – An Example of Data Gained During the E-mail Interview of One Participant [Kirsty].....	461
Appendix 9 – The Initial Template within the Template Analysis for the Main Study.....	483
Appendix 10 – An Example of a Pronoun List created within Reading Three of the Listening Guide.....	484
Appendix 11 – An Example of Notes made on One Participant’s [Mary’s] pronoun list when exploring how the word ‘I’ was used to create the Resultant I-Poem.....	486

List of Figures

Chapter Three

Figure 3.1. A Diagram to show the process of Heidegger's hermeneutic circle

Figure 3.2. Advantages and Limitations of E-mail Interviewing

Chapter Four

Figure 4.1. The Process of Participant Recruitment, Informed Consent and Data Collection for Phase One of the Research Project

Figure 4.2: The Final Developed Template

Chapter Eight

Figure 8.1: Selection and Recruitment of Participants

Figure 8.2: E-mail Interview Process

Figure 8.3: Finalised Template of Findings

Chapter Ten

Figure 10.1: Plots Identified in Jane's Written Accounts

Figure 10.2: Plots Identified in Mary's Written Accounts

Figure 10.3: Plots Identified in Gerald's Written Accounts

List of Tables

Chapter Five

Table 5.1. Descriptive Statistics on the Presented Cancer Types

Table 5.2. Descriptive Statistics on the Collapsed Cancer Type Groups

Table 5.3. Descriptive Statistics for the Relationship between Cancer Type and Quality of Life

Table 5.4. Descriptive Statistics Showing the Collapsed Cancer Type Groups and Age

Table 5.5. Identified Cancer Status Frequencies

Table 5.6. Descriptive Statistics Showing the Relationship between Identified Cancer Status and Quality of Life

Table 5.7. Descriptive Statistics Showing the Relationship between Quality of Life Scores and Health Anxiety Scores

Table 5.8. Descriptive Statistics Showing the Relationship between Gender and Quality of Life Scores

Chapter Six

Table 6.1. Statements Illustrating How a New Perspective on Life Following One's Cancer Experience Demonstrates New, Positive Alterations to Perceived Selfhood

Chapter Eight

Table 8.1. Cancer Types Represented within Study Two of the Research

Table 8.2. Main Questions and Possible Prompts for E-Interview

Table 8.3. Finalised Template of Findings

Chapter Ten

Table 10.1. Reflective Notes for Reading One

Chapter One:

Introduction to Thesis

This thesis investigates the lived experiences of long-term consequences following cancer and its treatment. This topic is of interest to me for a number of reasons, which include how unacknowledged long-term consequences following cancer and its treatment are within society, as well as the extent of their prevalence and the many forms they present themselves in the lives of a cancer survivor. Personal experiences also add to my interest as I have a close family friend who now lives with long-term consequences following his experience of oesophagus cancer and the treatment he had to cure it. The present chapter contains an introduction to the research phenomenon, its importance, and the scientific rationale. This will be followed by an outline of the thesis structure.

1.1 The Phenomenon of Interest

In the past, the established view within society was that once an individual was diagnosed with cancer they were inevitably being given a death sentence (Bell & Ristovski-Slijepcevic, 2013).

However, during recent years, a transformation has taken place within both cancer knowledge and treatment, resulting in a cancer diagnosis not being associated with death but signifying the beginning of a pathway of available

treatments and becoming cancer free (Bell & Ristovski-Slijepcevic, 2013) with survival rates increasing rapidly over the past few decades (Meikle, 2011; Andalo, 2013). Cancer statistics continuously appear to support this remarkable transformation, with it being estimated for there to currently be 2.5 million individuals living with and beyond cancer in the United Kingdom (Marzorati, Riva & Pravettoni, 2017; Macmillan, 2018; Cavers, Habets, Cunningham-Burley, Watson, Banks & Campbell, 2019). This number is also expected to increase by 3% per year (Maddams, Utley & Moller as cited in Macmillan, 2019), with three million cancer survivors expected to be alive within England by 2030 (NCSI, 2013). This is because more individuals are living longer after diagnosis (Adams, 2012). For instance, an ageing population and developments in diagnosis and treatments have meant that mortality rates due to cancer have decreased over the last decade (Boseley, 2016).

This leads us on to the fact that surviving cancer and being identified as cancer free, does not necessarily mean free from any long-term consequences following it alongside, any necessary treatment. It has been reported for 625,000 individuals to experience at least one of the many prevalent long-term consequences following cancer and its treatment (Macmillan, 2017; ASCO, 2018). These consequences can be physical or psychological or acute or chronic with many commonly continuing to have effect long in to an attained cancer free/in remission/survivorship status, with some remaining for life (Denlinger et al., 2014).

Acknowledging this, NCSI (2013) have stated that it is now more than ever, essential for research in this phenomenon to be conducted to ensure that the needs of cancer survivors are met at all stages of their survivorship journey.

1.2 My Interest within the Research Phenomenon

For as long as I can remember, my life whether it be through family or significant others, has been filled with experiences regarding a diversity of health issues and disabilities. For example, deafness, muscular dystrophy, autism, cancer survival and death, blindness, depression, anorexia, COPD, alopecia and severe learning disabilities are some that I can mention off hand. I can always remember being very inquisitive of these as a child and asking numerous questions, particularly starting with why, in regards to them, probably more than my parents wished me to or could answer them selves. This interest has only grown through my years and particularly into my adult life. However, as I have grown older and found myself around family and significant others in which these experiences have become more frequent that I have then found my self shifting from not only wanting to know 'why' but also 'how'. Such as, 'how do they cope?' and 'how do they perceive their experience of them?'

This is what led me to embark on a psychology degree and then focus upon the lived experiences of deafness within my dissertation in the final year of my undergraduate study. It was as my final year of my degree drew to a close that I was speaking to a significant other at the time in regards to their

experience of esophageal cancer. It was in this conversation that I learnt about possible long-term consequences of cancer and its treatment as he disclosed to me the issues he still has, years in to his remission status. These issues related to eating such as swallowing, the amount he can intake before experiencing discomfort/pain and his ability to taste. It was at this point my eyes were opened to how cancer and its treatment can affect individuals' health even though they are deemed as 'cured' in a medical capacity. This experience led to me wanting to know more about this phenomenon and so, when the opportunity arose to choose this as my research topic for my PhD studies, I jumped at the chance to explore how different individuals experience cancer, its treatment and associated long-term consequences and how they attach meaning to them.

1.3 The Present Research

There are two studies within the present research. Study one is the preliminary study and aims to act as a selection process for the main phenomenological study. This will involve identifying what cancer types, sex, age and identified cancer status should be of focus within it. This preliminary study incorporates a mixed method approach through the measures of an online survey. The second study is of most importance and undertakes a qualitative approach. This study uses e-mail interviews as the data collection method on a sample of sixteen participants and then incorporates both template and narrative analysis to analyse the gathered responses. The importance of study one being viewed as solely a preliminary measure is

paramount and so, they will be discussed separately within the presented thesis. However, in order to make the present research more clear, the methodology underpinning the two will be discussed together within one chapter prior to those containing each study. This structure will now be discussed in more detail.

1.4 Thesis Structure

Chapter two presents a review of the readily available literature surrounding the explored phenomenon within the present research. This involves discussing the survivorship concept and the issues that surround it regarding definition and acceptability. The commonly stated long-term consequences identified within available research are then explored which include; pain, fatigue, incontinence, fear of cancer reoccurrence and social issues. The research surrounding available support groups for cancer survivors and close others are then discussed alongside, any advantages or limitations associated to them. This leads on to exploring the concepts; quality of life and health anxiety and the tools currently available to measure them appropriately. To conclude this chapter, the rationale for the present research is presented alongside, identifying any evident gaps within the available literature and how the present research will attempt to fill them.

Chapter three is split in to two sections and discusses the methodology underpinning both the preliminary study and the main phenomenological

investigation. Therefore, its focus will be on both the mixed methods (study one) and qualitative (study two) approaches.

Chapter four introduces the preliminary study, giving a brief outline to what the study entails and presenting its associated aims. This chapter's main focus however, is the methods used within the preliminary study, paying particular focus to the procedure taken and the analyses incorporated.

Chapter five is dedicated to presenting the results of the quantitative analyses outlined in chapter four from the online survey.

Chapter six focuses upon presenting the findings from the Template Analysis, performed upon the qualitative data from the online survey outlined in chapter four.

Chapter seven is split in to two sections in order to discuss the findings from both the quantitative and qualitative analyses from the online survey outlined in chapter four. A discussion of the results from the statistical analyses will be presented first and a discussion of the Template Analysis findings will subsequently follow.

Chapter eight introduces the main phenomenological study within the present research. This includes presenting a brief outline to the study, before moving on to the methods used to perform it.

Chapter nine's focus is to present the findings of the Template Analysis. This is done by, presenting each of the seven major themes separately with their associated sub themes and identifying when relevant, cases in which they interlink with one another.

Chapter ten follows by presenting the findings of the Narrative Analysis' listening guide. The findings from each of the three readings are presented separately with the chapter concluding with a narrative synthesis, which pulls the findings from each reading together.

Chapter eleven draws the thesis to a close. This chapter will place most emphasis on presenting a discussion of the main phenomenological study's findings. However, the findings of the preliminary study are also drawn upon within this for comparison purposes. Following the discussion of findings, my reflections will be drawn upon and the strengths and limitations identified within this research will be presented. This chapter then concludes by providing suggestions for future practice within this phenomenon before presenting the conclusions drawn from the present research.

Chapter Two:

Literature Review

2.1 What is Cancer?

Cancer is an umbrella term that is given to the collection of connected diseases (NCI, n.d.). It is normal for the body to divide and create new cells when necessary for repair or growth. However, sometimes this process breaks down and cells begin to become more and more abnormal or damaged, and continue to survive when they should have died. It is these cells that then come together and form a mass of tissue, also referred to as a tumour, which can occur anywhere in the body (NCI, n.d.; Macmillan, 2014).

Cancerous tumours are malignant as the cells they are made up of are abnormal and can continue to uncontrollably grow and spread in to neighboring tissue around the body or can travel through the bloodstream and affect parts of the body further away (Fayed & Paul, 2018). Sometimes an error can occur within the cell process and healthy cells can begin to divide and overgrow, also forming a mass/tumour. However, this type of tumour is referred to as being benign; non-cancerous as the cells are healthy and cannot reach out and spread in to nearby tissue. The tumour will still need surgically removing as it will continue to grow which could become dangerous, particularly in certain areas of the body, however, this type of tumour is a lot less severe opposed to a malignant one (Fayed & Paul, 2018).

There are numerous ways that healthcare professionals treat cancer in the current day. Typically, the type of treatment you receive will be dependent upon the cancer type you are experiencing and how aggressive it is, it is common for individuals to need more than one treatment for instance, usually surgery would be performed first to eliminate the tumour and then a follow on treatment such as radiotherapy, chemotherapy, hormone therapy, immunotherapy or targeted therapy would be undertaken (NCI, n.d.).

2.2 Survivorship; what is it?

Survivorship is a concept that focuses upon the health and wellbeing of an individual post cancer treatment until end of life (NCI, n.d.). The American physician Fitzhugh Mullan developed the concept of cancer survivorship. Mullan was personally diagnosed with cancer and believed that the undemanding concept 'cure' failed to capture the long-term cancer experience (Khan, Harrison, Rose, Ward and Evans, 2012). Mullan defined cancer survivorship as referring to all cancer patients from the time of diagnosis up until the end of life (King, Brooks, Featherstone & Topping, 2014) and survivorship organisations existing today carry on this definition. For instance, the National Coalition for Cancer Survivors (NCCS) in which, Mullan is a founder for in the U.S alongside, the National Cancer Survivorship Initiative (NCSI) developed in the U.K, both use this broad definition within their work (King et al., 2014; NCCS, 2015). However, the stated definition of cancer survivorship is somewhat complex as the clinical profession refer it to only

focus upon those cancer patients who are in the remission period, meaning they are living beyond cancer (Bell & Ristovski-Slijepcevic, 2013).

2.2.1 The Acceptability of the Term Survivorship

The acceptability of survivorship is also extensively debatable. A plethora of research conducted within the field of cancer survivorship does indicate that the concept itself is accepted by a number of individuals who have survived cancer (Morris, Lepore, Wilson, Lieberman, Dunn & Chambers, 2014; Cheung & Delfabbro, 2016; Davis, Myers, Nyamathi, Lewis & Brecht, 2016; Smith, Klassen, Coa & Hannum, 2016). For instance, a quantitative study with a sample consisting of long-term breast, colorectal and prostate cancer survivors at least five years into their survivorship journey conducted by Deimling, Bowman and Wagner (2007), found that the majority of the participating individuals did in fact refer to themselves as being a cancer survivor rather than a patient or victim and identified survivorship as an importance part of their being. This is supported by the more recent work of Davis et al. (2016) who focus on the meaning of survivorship by exploring qualitative methods through the use of open-ended questionnaires on a sample of 155 breast cancer survivors. The results suggest respondents to not only identify themselves as cancer survivors, but to also embrace the concept.

However, critics of the cancer survivorship concept argue that the majority of individuals do not endorse the term 'cancer survivor' and so, would not use

the term to identify themselves (Khan et al., 2013; Surbone, Annunziata, Santoro, Tirelli & Tralongo, 2013; Rees, 2018). For instance, Khan et al (2012) argue that the term 'cancer survivor' should be avoided by researchers and policy makers and replaced with alternative adjectives. This was concluded following a detailed qualitative investigation upon 40 individuals of whom were at least five years post cancer diagnosis of the breast, colorectal or prostate. It was found that a minority did accept the term with these individuals holding an understanding that the term was factual and referred to those who had experienced cancer and survived. However, the majority rejected being labelled as a 'cancer survivor' as they expressed their feelings that the term does not portray their identity or that an advocacy role was implied within the term. Of which, was not wished to be taken on by the participants. In addition, some participants refuted the term 'cancer survivor' as they believed it to imply that surviving cancer is due to personal characteristics (Khan et al, 2013).

This was supported by the slightly later work of Surbone et al. (2013) who found from a sample of 40 cancer survivors, that the majority of the participants did not endorse the term 'survivor'. This was stated by some of the participants, similarly to those in Khan et al's. (2013) study, to be because they did not believe it to portray their experience accurately. Most recently, Rees (2018) interviewed twenty females who have survived breast cancer. In line with Khan et al. (2013) and Surbone et al. (2013), Rees (2018) also found that the majority of individuals reject the term 'cancer survivor'. This was shown, like in the previously discussed literature to be due to participants not

feeling their experience to warrant a survivor status. This suggests that, if the sample studied by Khan et al. (2013) and the other scholars spoken about in this section (Surbone et al., 2013; Rees, 2018), included participants with more life threatening cancers rather than those that hold a good prognosis, then the participants would be more likely to accept the term 'cancer survivor'. However, when comparing these studies to those which do find participants to endorse the concept 'cancer survivor', the same cancer types (breast and prostate) are used, meaning that rather than the acceptance of the term 'cancer survivor' being dependent upon cancer type, other factors could be at play, such as personality traits.

2.2.2 Advantages and Limitations of Survivorship

In contrast to literature highlighting survivorship to hold negative connotations, it has been found by some research within this phenomenon that the concept of survivorship does hold great advantages to one's lifestyle (Bellizzi & Blank, 2007). For example, Bellizzi and Blank (2007) conducted a quantitative study upon 490 prostate cancer survivors post diagnosis who ranged between their first to eighth year of survivorship. The findings show that scores on positive effect in regards to perceived wellbeing, were significantly higher for individuals who identify themselves as 'cancer survivors' than those who identify themselves to be 'patients' (Bellizzi & Blank, 2007). This implies that the concept of survivorship can be advantageous towards the health of individuals who have experienced cancer.

On the other hand, research conducted within the phenomenon of survivorship has also identified that the concept also holds some limitations, such as the common effect of survivor guilt (Perloff, King, Rigney, Ostroff & Shen, 2019). This issue however, does not affect the lives of every cancer survivor but it can have damaging consequences for those it does.

Survivorship guilt in relation to cancer appears to be a very well-known concept as evidence of its existence appears in numerous materials (Quinn, Huang, Murphy, Zidonik-Eddelton & Krull, 2013; Marker, 2015; Perloff et al., 2019). For example, Quinn et al. (2013) qualitatively explored how accurate health-related quality of life instruments are in regards to the young adult population of childhood cancer survivors. The content analysis identified survivor guilt as being a major theme with participants implying to feel guilty for surviving their cancer experience when individuals they formed friendships with sharing their experience did not. This involved the participants often questioning themselves; why was it them who survived and why their friends could not.

Similarly, Perloff et al. (2019) used a sample of lung cancer survivors to explore survivorship with them also finding survivor guilt to be experienced by the majority of the participants. In line with Quinn et al. (2013) this also involved questioning as to why they survived when others had not. Survivor guilt has also been displayed in national newspapers. For instance Nicholson (2013) wrote an article published by the Daily Mail, which focused on her experiences of survivor guilt after surviving breast cancer, when she had lost

both her husband and eldest daughter to Leukemia in previous years.

Unfortunately, there appears to be a dearth of empirical research on this topic.

On the whole, it seems to be apparent from the literature within the field of cancer survivorship that the concept itself is very diverse with different meanings being attached by different individuals. This is most likely to be due to the fact that cancer is experienced differently by differing individuals, whether they are those who have been personally diagnosed or clinicians and health care providers. Therefore, one's cancer experience is subjective with differing experiences resulting in differing meanings being attached by the individual to the concept of survivorship. As, each meaning will reflect one's personal experience and interpretation. This in turn, could explain the controversy surrounding its definition and acceptability.

This diversity does not change the fact that the phenomenon of survivorship is an essentially important field to research but adds to the importance of it. The diversity of the concept of survivorship indicates that in order for the needs of individuals living beyond cancer to be met, much research is needed to be gained on the different personal experiences as a one size fits all approach is insufficient.

2.2.3 Researcher Stance

From researching the concept of survivorship it is clear that there are issues with its definition due to the lack of one definitive universal one however, I

cannot ignore how wide spread its usage is by researchers and organisations like Macmillan. Therefore, I am going to use the concept of survivorship in my public facing material as it is recruiting participants through the Macmillan cancer voices group however, I acknowledge that the concept as a whole, does not work.

Furthermore, because the current research is proposing to explore the long-term consequences of cancer and its treatment it will focus upon people in the remission stage of their cancer experience as a specific group within survivorship. I do realise that there are also arguments on how to define remission but in my research it will be defined as being cancer free following treatment.

2.3 Long-Term Consequences of Cancer and its Treatment

As mentioned previously in this chapter, being medically classified as cancer free does not necessarily mean free from the consequences of the experienced cancer and its treatment (Harrington, Hanson, Moskowitz, Todd & Feurstein, 2010). There is a plethora of both physical and psychological long-term consequences of cancer and its treatment being experienced daily by cancer survivors (Harrington et al., 2010; Denlinger et al., 2014; Treanor & Donnelly, 2016). This demonstrates that for a number of individuals, rather than their cancer journey concluding with the finishing of treatment, their journey as a survivor is in fact, just beginning. Some scholars have

researched the concept of long-term consequences from the perspective of the cancer survivor in great depth.

However, a systematic review on late effects of cancer and its treatment found that cancer survivors can still experience long-term consequences ten years post their treatment (Harrington et al., 2010). The study of Harrington et al. (2010) also indicates fatigue to be one of the most common and paramount long-term consequences experienced alongside, pain and mental health issues (depression and anxiety). However, cognitive limitations and incontinence issues were also presented.

More recently, Ntinga and Maree (2015) attempted to qualitatively explore this phenomenon by interviewing sixteen women who had experienced cervical cancer and performed a thematic analysis on the data. The analysis identified a number of themes surrounding the experience of long-term consequences; health care challenges, socio-economic issues such as financial worries, physical issues such as fatigue and incontinence, spiritual concerns, sexual consequences and unattended healthcare needs. Moreover, they identified that individuals were detrimentally restricted from returning to their pre-cancer self because of experienced long-term consequences, this appears to have significant effects upon the individuals' quality of life. Furthermore, in contrast to their negative long-term consequences the participants still appeared to remain positive in regards to their future. However, this research was conducted in South Africa and so, its validity in regards to experiences within

the UK is questionable as life styles, treatment options and healthcare facilities could be viewed as considerably different.

Similarly, Treanor and Donnelly (2016) qualitatively explored long-term consequences of cancer and its treatment in cancer survivors by conducting interviews on sixteen individuals and then performing a narrative analysis on the data gained. The analysis identified long-term consequences to cause issues in a number of areas such as, fear of cancer reoccurrence, relationships, work and finances, ability to perform daily activities and provided healthcare services. Treanor and Donnelly (2016) also state how cancer survivors struggled to make sense of their situation but found that making 'downward comparisons' had a positive effect, making them feel 'lucky' and 'thankful'. This research demonstrates a good example of research attempting to explore the long-term consequences of cancer and its treatment in a qualitative manner. However, the sample used within Treanor and Donnelly's (2016) research focuses upon cancer patients as well as those now classed as 'cancer free', with some participants dying or receiving palliative care at the time of research. Therefore, it could be suggested for research exploring the long-term consequences of survivors deemed 'cancer free' to be advantageous as the experiences of those free of cancer may differ to those still classed as patients.

As suggested above, there are a number of varying psychological and physical long-term consequences of cancer and its treatment experienced by cancer survivors. Due to the large volume of experienced consequences, it

would be unmanageable to discuss them all in depth within this thesis.

Therefore, identified chronic consequences appearing most important and common in readily available literature will now be discussed in this section.

2.3.1 Pain

Pain is a common chronic consequence of cancer and its treatment (Harrington et al., 2010; Pachman, Barton, Swetz & Loprinzi, 2012; Brown, Ramirez & Farquhar-Smith, 2014) with it being reported that over 200,000 cancer survivors have to live with it affecting them daily (Macmillan, 2013). However, it has been said within research that there is no significant difference between cancer type and level of experienced pain as a cancer survivor (Zucca, Boyes, Linden & Girgis, 2012). Glare et al (2014) agree it is a common issue and state within their research that 5% - 10% of long-term cancer survivors still suffer with severe and chronic pain. The causes of such pain however, can and does seem to differ across research, cancer types and treatments. For instance, some research identifies nerve damage and radiotherapy needed to treat breast cancer as causes of chronic pain experienced by cancer survivors (Anderson and Kehlet, 2011; Miller et al., 2016). Glare et al. (2014) support this, but add that the onset of this pain can be anything from months to decades following treatment. In addition, they also state chemotherapy to be a contributing factor to cancer survivors' pain as the endurance of it can cause Chemotherapy Induced Peripheral Neuropathy (CIPN), which often presents itself as numbness, tingling or burning (Miller et al., 2016). Pachman et al's. (2012) earlier work does support the work of

Glare et al (2014) in regards to Chemotherapy Induced Peripheral Neuropathy (CIPN) being a contributing factor however; they also suggest it to not be a permanent contributor.

In addition to this, Levy, Chwistek and Metah (2008) and Fayed (2018) identify there to be three different types of pain associated to cancer of which, are; somatic, neuropathic and visceral. Somatic pain according to Fayed (2018) refers to pain receptor activity either on the surface of the body or in the deep tissues, pain located within deep tissue is known to be experienced from a cancer that has in turn, spread to the bones of the individual whereas, surface pain can be due to an incision site from treatment. Neuropathic pain is the result of damage to the nervous system and is said to be the most severe of the three various pain types. As previously mentioned chemotherapy or radiation can cause this pain to be experienced but it could also arise from the pressure of a tumour on a nerve or the spinal cord (Fayed, 2018). Finally, visceral pain can be felt in any of the different cavities of the human body, which hold an internal organs and the pain is caused by either tumour pressure on said organ/s, the spreading of cancer in this area or the stretching of an organ due to cancer within it. This type of pain is said to be anything from acute to chronic depending on each individual (Fayed, 2018).

Researchers have noticed the importance of efficient pain management for cancer survivors. For instance, Paice, Lacchetti and Bruera (2016) identified the sparseness of guidelines on persistent chronic cancer related pain for individuals in the identified survivorship status compared to the mass

available for individuals with advanced disease/cancer or in need of acute pain relief. Therefore, they conducted a study with a sole focus of identifying suitable interventions for pain management in cancer survivors through the method of a systematic review. The results from this enabled them to develop a number of recommendations in order to aid the support in improvement of cancer pain in cancer survivors. These recommendations include, the screening and documentation of any experienced pain at each encounter using a relevant tool, an in-depth interview to assess the experienced pain, the monitoring and evaluation of recurrent disease or any late effects of cancer or treatment alongside who to include within the management program, what drugs may be appropriate such as opioids and what may not be appropriate such as corticosteroids (Paice et al., 2016).

2.3.2 Cancer-Related Fatigue

Fatigue is one of the most common chronic consequence of cancer and its treatment (Bower et al., 2000; Harrington et al., 2010; Berger, Gerber & Mayer, 2012; Hornerber, Fischer, Dimeo, Rüffer & Weis, 2012; Romito, Cormio, Giotto, Colucci & Mattioli, 2012; Meneses-Echavez, Gonzalez-Jimenez & Ramirez-Velez, 2015; Ntinga & Maree, 2015) with it being estimated by Macmillan (2017) that there are at least 350,000 individuals experiencing chronic fatigue who are either living with or beyond cancer. Fatigue represents its self through extreme tiredness and exhaustion leaving individuals feeling extremely weak, lacking in energy and does not relieve its self once sleep or rest has occurred (Hofman, Ryan, Figueroa-Moseley, Jean-

Pierre & Morrow, 2007; Hornerber et al., 2012).

The experience of fatigue can have detrimental effects upon the experiencing individual (Brown & Kroenke, 2009; Schmidt, Chang-Claude, Vrieling, Heinz, Flesch-Janys & Steindorf, 2012). For instance, Schmidt et al. (2012) explored the psychological effect of cancer related fatigue using validated questionnaires upon a sample encompassing long-term breast cancer survivors. They found within this research that the endurance of long-term fatigue had a damaging effect on all quality of life aspects with cancer survivors six years post diagnosis reporting the lowest levels of quality of life. Within this research it was also reported that chemotherapy appeared to cause more severe fatigue than radiotherapy. It was concluded that if fatigue was only an acute consequence then the individuals would have a quality of life score that is comparable to the general population however, the long-term effect of it causes reported quality of life to lower.

The earlier work of Brown and Kroenke (2009) used a systematic review of previous studies to assess the psychological effects cancer related fatigue can have on cancer survivors. They found that in almost all of the 59 studies incorporated, a rather consistent correlation was found between fatigue and both depression and anxiety. This shows that the long-term consequence; fatigue, not only affects the enduring individual through its own carrying symptoms but that it can also become a catalyst to create psychological concerns, which need to be addressed in order for the experiencing individuals' needs to be met. This was supported by the earlier work of Bower

et al. (2000) but more recently, by Horneber et al. (2012) who conducted a review on literature surrounding cancer related fatigue and identified that both depression and anxiety are psychological issues associated to cancer related fatigue.

There currently is no cure for all cancer related fatigue but there is research that suggests that there are a number of interventions that can aid to minimise its effects (Cramp & Byron-Daniel, 2012; Meneses-Echavez et al., 2015). For instance, both Cramp and Byron-Daniel (2012) and Meneses-Echavez et al. (2015) conducted systematic reviews in order to explore the relationship/if any between exercise and cancer related fatigue. Cramp and Byron-Daniel (2012) concluded that exercise programs caused the experienced fatigue to significantly improve with statistically significant improvements specifically in those who had experienced breast and prostate cancers. More recently, Meneses-Echavez et al. (2015) also concluded that controlled exercises not only reduce cancer related fatigue but they also improve individuals' reported quality of life and so, should be implemented within interventions. However, the accessibility to interventions that incorporate these exercises is limited. It must also be noted here that Meneses-Echavez et al's. (2015) sample only focused upon individuals with an experience of breast cancer. This means that their gathered data may not reflect the experiences of individuals who have had alternative cancer types. Therefore, it is important for more qualitative research to be performed in order to ensure the needs of the individual experiencing this long-term consequence is met.

2.3.3 Cancer-Related Incontinence

Incontinence is another common long-term consequence following cancer and its treatment (Lange & de Velde, 2011; Ntinga & Maree, 2015) with it being estimated that around 150,000 cancer survivors suffer with such urinary problems (Macmillan, 2013). This issue tends to arise following radiotherapy focused upon the pelvic region as the treatment can alter the functioning of the bladder and bowel causing leakage or incontinence (Macmillan, 2013).

The impact of incontinence upon the experiencing individual following cancer and its treatment can be highlighted through the research of Dunberger et al. (2010) who not only identified that incontinence lowered the cancer survivors' quality of life scores but that the issue itself restricted the experiencing individuals from going about their lives as planned. For example, they found that it stopped the participants from going to parties and travelling, that it affected individuals' ability to go to work and caused issues within their sexual life and changing them as individuals. They therefore concluded that incontinence following cancer and its treatment holds associations to psychological issues but also social and sexual too. The earlier work of Skjeldestad and Rannestad (2009) alongside, the more recent research of Adams et al. (2014) and Lindgren, Dunberger and Enblom (2017) support the findings of Dunberger et al. (2010) as all three found the experience of incontinence following cancer and its treatment to have damaging effects upon reported quality of life scores. For example, the most recent work of Lindgren, Dunberger and Enblom (2017) incorporated a sample of

gynecological cancer survivors to explore the affect cancer-related incontinence has upon one's quality of life using content analysis on the gathered interview data. Their findings show that incontinence detrimentally affects cancer survivors' quality of life through the restriction of physical activity and the feeling of being excluded.

Unfortunately, permanent treatment for cancer related incontinence is complex. Surgical intervention is available to some candidates (Shamliyan, Wyam, Ping, Wilt & Kane, 2009; Mirza, Griebing & Kazer, 2011; Huang, Jenny, Chesney, Schembri & Subak, 2014) however; with cancer related incontinence there can be restrictions. There are also a number of currently achievable interventions that can aid the improvement of experienced incontinence in individuals (Shamliyan et al., 2009; Mirza et al., 2011; Baumann, Zopf & Bloch, 2012; Huang et al., 2014). For instance, Huang et al. (2014) investigated the effects of yoga on incontinence in middle-aged women through a six-week therapy program and pamphlets on strategies of self-management for incontinence. Results were analysed through diaries kept by the participants of which, showed the number of total incontinence episodes significantly decrease (66%) in comparison to a slight decrease in the control group (13%). This was shadowed by a decrease of 85% in stress incontinence episodes by the study group compared to a minor 25% decrease within the control group however; no change was identified in urgency incontinence. It was concluded from these findings that a yoga therapy class that is group based would be advantageous for the improvement of incontinence in women. It must be taken into consideration that this study was

based on a sample of women recruited via newspaper advertisements and flyers presented in a variety of community centres, businesses and offices and therefore, not focused upon cancer survivors and so, it is not certain that these results would remain the same if only cancer survivors participated.

In contrast to this, the previous work of both Mirza et al. (2011) and Baumann et al. (2012) whose sample does focus on individuals who had experienced cancer does support the work of Huang et al. (2014), which suggests exercise to aid the improvement of incontinence. For example, in the work of Baumann et al. (2012) a systematic review including twenty-five previous studies found that clinical exercise performed by individuals during and after prostate cancer improves experienced incontinence. Additionally, the work of Mirza et al. (2011) also incorporated a systematic review method on a sample of individuals who had experienced prostate cancer treatment. Due to the fact that the two studies incorporating cancer survivors, supports the work of Huang et al. (2014), it is reasonable to assume that the results are valid.

This is most recently supported by a study focusing on how behavioural interventions for cancer-related incontinence impact mood. Although the focus was not directly aimed upon exercise and incontinence, the findings did indicate that exercise reduces experienced incontinence in prostate cancer survivors, as the researchers relate this to the participants' reporting lower anxiety levels (Zhang et al. 2019).

2.3.4 Fear of Cancer Reoccurrence

As previously mentioned, long-term consequences can also be psychological as opposed to physical, with one of the most common being, fear of cancer reoccurrence (Skaali et al., 2009; Koch, Janson, Brenner & Arndt, 2013; Lebel, Beattie, Ares & Bielajew, 2013; Simard et al., 2013; Treanor & Donnelly, 2016; Simonelli, Siegal & Duffy, 2017). For instance, Simard et al. (2013) conducted a systematic review and found that fear of cancer reoccurrence in cancer survivors is of great concern and frequently, the needs of the individual experiencing it are unmet by healthcare professionals. This is also supported by the work of Lebel et al. (2013). They discovered that high levels of fear of cancer reoccurrence were associated to lower quality of life levels and psychological distress. This was also found in the previous work of Skaali et al. (2009) and Koch et al. (2013). For example, Koch et al. (2013) conducted a systematic review using 17 previous research articles encompassing a sample of cancer survivors. During this review they identified that the level of fear of cancer reoccurrence does not seem to alter no matter the time period since diagnosis and so, remains a constant worry. It was also highlighted that a significantly negative relationship lies between high levels of fear of cancer reoccurrence and low quality of life levels alongside psychological distress, mirroring the results of the later study by Simard et al. (2013).

Most recently, Simonelli et al. (2017) conducted a comprehensive literature review upon research focusing upon fear of cancer reoccurrence within

cancer survivors. Their results support previous literature suggesting the long-term consequence to be significantly prevalent within cancer survivors, identifying them to considerably impact the individuals' perceived quality of life.

Although there is a general consensus amongst the available literature that fear of cancer reoccurrence is a major concern to cancer survivors the triggering of this psychological issue appears to vary amongst different individuals (Ghazali et al., 2012; Lebel et al., 2013). For instance, Ghazali et al. (2012) conducted a study upon 189 individuals who had experienced head and neck cancer using a quantitative approach of questionnaires. Their results showed that the individuals' personal characteristics were the most attributing factor to their experienced level of fear of cancer reoccurrence. They also found age to be a contributing factor, stating that young age was associated to higher levels of fear of cancer reoccurrence. This is supported by the later work of Lebel et al. (2013) who also used a quantitative approach to the research area, which involved 3239 breast cancer survivors completing questionnaires. As they also identified that those younger in age appeared to experience the worst levels of fear of cancer reoccurrence. Ghazali et al. (2012) also support the work of Koch et al. (2012) as they also stated that the level of fear of cancer reoccurrence experienced appears to remain consistent over time.

There are some interventions that have been carefully developed purposely to combat the psychological issues that can come from fear of cancer

reoccurrence whilst teaching the individuals experiencing the consequence, how to cope/manage their fears (Butow et al., 2018). For instance, Van de Wal, Gielissen, Speckens and Prins (2017) investigated the effects of blended cognitive behavioural therapy upon 88 cancer survivors experiencing fear of cancer reoccurrence who had previously been treated for breast, prostate or colorectal cancers. They concluded that blended cognitive behavioural therapy was a successful approach to treating fear of cancer reoccurrence within cancer survivors as a significant improvement was found in individuals' severity of fear of cancer reoccurrence levels following the treatment.

2.3.5 Issues within the Social World

Social Isolation and /or withdrawal are also known through research to be a prominent experienced long-term consequence of cancer and its treatment (Danker et al., 2010; Arunachalam, Thirumoorthy, Devi & Thennarasu 2011; Howard et al., 2014; Kim, Lee & Koh, 2018; Spindelov, Joubert, Lee & Fairhurst, 2018; Zheng et al., 2018). A lot of research in this area tends to focus upon adult survivors of childhood cancers this may be as this is the time period in which social relationships and bonds tend to develop (Howard et al., 2014; Zheng et al., 2018). Social isolation/withdrawal as a long-term consequence can be due to many different factors for instance, it could be due to change in appearance making individuals shy away from social encounters due to lowered self-esteem (Preston, 2010). This is evidenced by the work of Danker et al. (2010) who conducted semi structured interviews on a sample of 218 individuals who had received a laryngectomy in order to treat

their experienced cancer. It was found through a multivariate analysis that two patterns of socialisation withdrawal were present. Conversational withdrawal was the first presenting factor, which was accompanied by speech difficulty and depression and reduced social activity was the second emerging factor of which, was accompanied by perceived/experienced stigmatisation and increased anxiety. Danker et al. (2010) also found that the majority of their participants refused to attend any situation in which speaking was necessary and hardly spoke to their relatives in comparison to before the surgery, with this leading to their experience of social isolation. This is supported by the more recent work of Howard et al. (2014) who undertook a qualitative approach to investigate social isolation on cancer survivors of childhood cancer types. For instance, through comparative methods on interview data collected from 30 participants, they found that over half the individuals experienced one of three forms of social isolation. The identified three forms of social isolation presented by Howard et al. (2014) are; improvement time; the feeling of social isolation lessens as time passes, no change in severity; no matter how much time passes individuals still experience the same severity of social isolation and delayed experience of social isolation; individuals did not feel to be socially isolated at the beginning of their survivorship journey but felt it to hit them later in time.

However, socialisation issues could also be due to other long-term consequences gained from cancer and its treatment such as fatigue (Horneber, 2012), cancer related incontinence (Dunberger et al., 2010) or treatment based psychological impairment (Zheng, 2018).

The above all show factual evidence that cancer and its treatment can cause social issues. However, the majority of research is quantitatively measured and so, lacks in explanation as to why the discussed factors following cancer and its treatment cause such isolation and/or withdrawal. Danker et al. (2010) and Howard et al. (2014) do differ in that they attempt a qualitative approach to the phenomenon however; each only focuses on one consequence of cancer and its treatment with both not being common cancer types. Therefore, it seems appropriate for the current research to incorporate a qualitative approach in order to delve further in to the phenomenon surrounding social withdrawal and/or isolation in cancer survivors.

The above are just a small selection of long-term consequences associated to cancer and its treatment with there being a plethora of alternatives such as sexual dysfunction (Harrington et al., 2010; Lange & de Velde, 2011; Ntinga & Maree, 2015), lymphedema, swallowing/talking issues, hair loss, nausea/vomiting, cognitive issues, heart disease, financial burdens and a variety of mental health problems (Harrington et al., 2010; Macmillan, 2013; Fauske, Bondevik, Bruland & Ozakinci, 2015; Ntinga & Maree, 2015; Treanor & Donnelly, 2016).

However, it must not be forgotten that these consequences do not apply to every individual who has experienced cancer as some are fortunate enough to live free or relatively close to free, from any negative consequences associated with the type of cancer experienced and return to their way of life before their diagnosis (Livestrong, n.d.).

2.4 Support Groups

A support group is a cluster of individuals who share certain concerns or interests, who come together to share their experiences and to give/receive advice (Mayo Clinic, n.d.). The engagement of support groups can be referred to as the self-help concept. This concept is centered on the claim that collective wisdom can be gained by individuals sharing their experiences of particularly challenging circumstances with one another. This collective wisdom is said to measure on a much greater level compared to that capable of professional training (Davison, Pennebaker & Dickerson, 2000). In the past, such support groups have generally been held face to face in a public meeting place; however; due to developments in technology from the 1990s, internet support groups have been introduced and are on the rise, including for individuals with specific health issues or medical conditions. Members of such groups may interact via message boards and forums (Ferguson, 1997; Turner, 2017).

2.4.1 What are the Benefits of Cancer Support Groups?

A plethora of research has been conducted in relation to support groups for cancer survivors with Owen, Goldstein, Lee, Breen and Rowland (2007) finding that almost one in four participants (23.7%) within their Californian cancer survivor sample group engage in such support groups. Given the growth of internet use since Owen's research in 2007, it is plausible that this proportion may now be even higher. It has also been found by researchers

that support groups are very effective (Winzelburg et al., 2003; Rodgers & Chen, 2005; Ussher, Kirsten, Butow & Sandoval, 2006; Seale, Ziebland & Charteris-Black, 2006; Leg et al., as cited in Yopp and Rosenstein, 2012; Medeiros et al., 2015). Whether it be improving psychosocial functioning/wellbeing (Leg et al., as cited in Yopp & Rosenstein 2012; Batenburg & Das, 2014), managing emotions and relationships or providing a feeling of mutual understanding with similar others (Ussher et al., 2006).

For instance, Ussher et al. (2006) explore the relationship between emotional responses and online cancer support groups and conclude that the engagement of such support groups enable individuals to release their heightened emotions. This in turn, enables a stronger relationship between individuals and their family and friends. This is because they have an alternative source of support to release feelings of anger and/or upset and are able to do this in an appropriate manner. Ussher et al. (2006) also identified that participation in support groups helps alleviate feelings of isolation and rejection alongside facilitating feelings of acceptance and better knowledge on their experienced cancer type. Unfortunately, this research only focused on individuals who currently suffer from cancer and does not consider those who have received treatment and are now cancer free and so, the results found may alter if the sample had incorporated individuals in remission status. More recently, Shannonhouse et al. (2014) explored the effects of support groups upon the holistic wellness of breast cancer survivors through a mixed method design. They state from their research for a cancer survivor's participation in a support group to significantly improve their wellness whilst providing a sense

of solidarity, in showing the participants that they were not alone in their cancer experience.

Online cancer support groups have also been shown to be effective in minimising psychological consequences. For instance, research by Winzelburg et al. (2003) explored the effectiveness of internet support groups on breast cancer patients and concluded that the online support group facilitated a reduction in depression, stress and cancer trauma. Participants within Winzelburg et al's. (2003) research, also reported high satisfaction levels from the support group which is important as it shows that they are not only effective but that participating in them is an enjoyable experience for the individual. However, as with Ussher et al's. (2006) study, this research was conducted on cancer patients and fails to explore the effect of online support groups on cancer survivors, which means that it is possible for cancer survivors to experience the support groups differently. In addition, Winzelburg et al. (2003) only explored the participation of breast cancer patients and breast cancer generally holds for many sufferers a relatively good prognosis. The results may have been different if other cancer types had been explored.

Further to minimising psychological consequences of cancer and its treatment, online support groups are also said to hold numerous psychosocial benefits (Rodgers & Chen, 2005; Hong, Pena-Purcell & Ory, 2012; Batenburg & Das, 2014). Such identified benefits from Rodgers and Chen's (2005) research are: receiving and giving information about the experienced cancer type, receiving and giving social support, increased coping ability,

improvement in experienced mood, lowering of psychological distress and the improvement of strategies for stress management. In addition to this, a strong positive correlation was found between participation times and social wellbeing (Rodgers & Chen, 2005). Hong, Peña-Purcell and Ory (2011; 2012), through a review of readily available literature, also attempted to explore the psychosocial benefits associated to cancer survivors' participation in online support groups. They state for the majority of their incorporated studies to report online support groups as being advantageous to one's psychosocial health.

This is further supported by the more recent work of Batenburg and Das (2014) who conducted questionnaires on a sample of 163 individuals and found that there was a positive correlation between active online support and psychological wellbeing. However, this was only the case when individuals wanted to actively deal with their experienced emotions as a negative correlation was found between the two for those who avoided dealing with their issues.

The above research again shows online cancer support groups to potentially be extremely advantageous to those who have experienced cancer and its treatment as it has great psychosocial benefits for those who are willing to receive help from them. Given the good evidence for potential benefits of cancer support groups, it is important to explore people's reasons for joining or not joining them. However, the mentioned research does not explain the reasons why individuals chose to participate in them.

2.4.2 Why do Individuals Seek Out Cancer Support Groups?

Some research has attempted to explore this area of study. For instance, Seale et al. (2006) used comparative keyword analysis to explore the differences in language between male and female cancer patients in ninety seven research interviews and two seemingly popular online support groups, also for individuals experiencing cancer. They found that men and women participate in online cancer support groups for different reasons. For instance, men's concerns tended to focus round information on treatment and relevant medical procedures. However, women tended to use support groups for emotional support purposes. This demonstrates that online cancer support groups appeal to a wide range of individuals as the benefits they provide differ amongst the individuals participating in them.

A year later, Meier, Lyons, Frydman, Forlenza and Rimer (2007) also explored the reasons why individuals use support groups. The sample consisted of survivors within a range of cancer types however, in contrast to Seale et al. (2006), Meier et al. (2007) did not explore the different reasons behind male and female participation separately but focused on them as one sample. Their thematic analysis led to the conclusion that informational support was the communication style mostly used however; emotional support was also sought by many of the participating individuals, indicating that cancer survivors use support groups for both informational and emotional help. However, the sample used for this research was taken from only one support group and so; it is possible that individuals use different groups for

different reasons. In addition, although the researchers collected e-mail messages written on the group over a five-month period, they only analysed 9% of this sample, which means that the validity of the results could be questioned.

2.4.3 Support Groups and Significant Others

It is widely recognised that the experience of cancer does not only affect the individual diagnosed but also those close to them (Bultz, Speca, Brasher, Geggie & Page, 2000; Mellon, Northouse & Weiss, 2006; Northouse et al., 2007; Kim & Given, 2008; Northouse, Katapodi, Song, Zhang & Mood, 2010). For instance, Mellon et al. (2006) explored the quality of life of both cancer survivors and their family caregivers with their results indicating that the family caregivers surprisingly reported lower quality of life and higher fear of cancer reoccurrence than the cancer survivor. The strongest predictors for quality of life did differ between family caregiver and cancer survivor however, social support appeared a consistent predictor for both which highlights that support groups are most likely just as advantageous for these individuals as they are for the cancer survivor themselves.

A full review on the literature of the effects on close others is beyond the scope of the present research. However, previous researchers have explored the phenomenon and identified the importance of support groups being available for cancer patients'/survivors' significant others in addition to themselves. For instance, Northouse et al. (2007) explored the psychological

impact cancer had on individual sufferer's spouses and state in their findings that not only does it emotionally strain the undiagnosed spouse but also their quality of life deteriorates along with the health of their diagnosed significant other.

A little while later, Northouse et al. (2010) conducted a meta-analysis investigating the importance of support intervention groups for family caregivers of people who have experienced cancer. First and foremost, they identified that the patient and significant other (be it partner, close family member or friend) come as one unit in regards to reactions of the cancer. Therefore, support must be made available to and focus upon the well being/quality of life of both because if ones psychological needs are not met then this will negatively impact those of the other. In addition, it was also found that in regards to the caregiver/loved one/friend, support groups improved their; ability to cope, confidence, relationships and some aspects of their quality of life in addition to, reducing anxiety and caregiver burden. In conclusion, they state that support groups for those close to individuals experiencing cancer significantly decrease distress, which in turn has a positive impact on the diagnosed individual.

The above research supports that previously conducted by Bultz et al. (2000) who explored the psychological impact cancer has on the partners of those diagnosed. For instance, they found that three months after the intervention, partners reported higher relationship satisfaction and mood levels alongside being a better support to their partner. Therefore, evidence highlights the

importance of support groups for the loved ones of those who have experienced and or are experiencing cancer and although not as readily available as for those who have been diagnosed, this type of support intervention is accessible and can be found via popular organisations such as Macmillan in the UK (Macmillan.org.uk). Yopp and Rosenstein (2012) also support the use of support groups for cancer patients'/survivors' close others. This support comes from the results of their research exploring widowed fathers as they identify the importance of available interventions providing psychological support for the close others of individuals who are experiencing or have experienced cancer.

Numerous studies have been conducted in order to compare and contrast online and face-to-face support groups (Owen, Bantum & Golant, 2008; Huber et al., 2018). For instance, Huber et al. (2018) conducted a cross sectional comparison study on face-to-face support groups in comparison to those accessible online. They concluded that both do hold strong advantages and significantly impact decision-making in regards to cancer treatments.

However, the younger participants seem to benefit more than the older from online support groups whereas the older individuals preferred face-to-face support.

In line with the work of Huber et al. (2018), Setoyama, Yamakazi and Nakayama (2011) also found through a cross sectional survey on one thousand and thirty nine breast cancer patients, that both online and face to face support groups held strong advantages and conclude that they have the

highest positive impact when used alongside one another. However, they found that different support aspects were strongest for each type of group. For instance, they highlight 'advice' and 'emotional expression' as holding the highest support scores in online support groups whereas, 'insight' and 'emotional support' scored the highest support scores in face-to-face groups.

2.5 Quality of Life

Quality of life (QoL) is a complex phenomenon with a plethora of models and definitions attached to it (Hamming and De Vries, 2007; Costanza et al., 2008; Andereck and Nyaupane; 2011; Theofilou, 2013), which refer to not only the adult population but also some specifically for disability and/or illness (Cummins, 1997). Theofilou (2013) explores the different definition attempts present in readily available literature and from it, defines the general meaning of quality of life in his research as the perceived levels of 'goodness' in numerous aspects of one's life. Examples of these numerous aspects include physical functioning, mental status, relationships and the ability for one to engage socially. It is this definition that will be used for the remainder of the present research when referring to 'quality of life'.

2.5.1 How is Quality of Life Measured?

Costanza et al. (2008) suggest there to be two methodologies within assessing quality of life. The first being the objective, this examines the extent to which human needs are met through the utilisation of economic or social

indicators with income, education and life expectancy being an example. The second being the subjective, this uses an individual's own reported levels of self, whether it be happiness, fulfillment, pleasure or so on. The notion of quality of life being objective is accepted and utilised in a number of research studies. One example of this is the recent work of Bishop-Fitzpatrick, Hong, Smith, Makuch, Greenburg and Mailick (2016), where they took an objective approach to examining quality of life in adults with autism in an attempt to develop a definition encompassing them both together.

However, the concept of quality of life being a subjective experience is predominantly taken and incorporated in to the work of health researchers. Andereck and Nyaupane (2011) are an example of health researchers who demonstrate this through their exploration of how tourism impacts individuals' perceived quality of life. They identify quality of life to be a subjective experience that is predominantly influenced by the feelings and perceptions of the individual.

Also, in previous research, Hamming and De Vries (2007) passionately state in their research that the measurement of quality of life is subjective as each individual thinks, reflects and copes uniquely from another. This indicates that questionnaires alone may not suffice in capturing the level of an individual's quality of life. Therefore, suggesting it is important that a conversation can also take place allowing the individual to freely speak about their perception of their quality of life. This suggested qualitative approach to the phenomena will

be explored within the present research.

2.5.2 Quality of Life and Wellbeing

In line with quality of life, wellbeing is also perceived differently between individuals and so, it has been proven difficult by scholars to provide one solid definition for it (White, 2008; Gillet-Swan & Sargeant, 2015) alongside, accurately differentiating the difference between quality of life and wellbeing (Dodge, Daley, Huyton & Sanders, 2012; Karimi & Brazier, 2016). However, following a multi-disciplinary review focusing upon the previous attempts of scholars to define wellbeing, Dodge et al. (2012, p.230) define wellbeing as being “the balance point between an individual’s resource pool and challenges faced”. Within this, they suggest, stable wellbeing to be acquired by an individual when they hold the physical, psychological and/or social resources necessary to face a specific physical, psychological and/or social challenge. Within their definition, Dodge et al. (2012) also provide examples of unstable wellbeing. For instance they state that when an individual’s challenges outweigh their held resources, then the experiencing individual’s wellbeing will lower. However, if an individual’s resources outweigh the challenges they face then their perceived wellbeing will heighten.

There are researchers that argue the subjective methodology of measuring quality of life is in sense a reflection of subjective wellbeing (Haas, 1999; Easterlin, as cited in Costanza et al., 2008), causing scholars to interchangeably use the two concepts (Dodge et al., 2012). However, other scholars state definite differences between the two with Pinto, Fumincelli,

Mazzo, Caldeira and Martins (2017) stating that psycho-spiritual dimensions are the structural basis of wellbeing whereas quality of life is reflected through the participating individual's personal awareness of their satisfaction of life. They also identify that this distinction between the two is more obviously presented within nursing research, knowledge and theories.

However, Pinto et al. (2017) also explore the reasons why some researchers intertwine the two concepts within their work and validate this by explaining that they are semantically close in regards to their terms of definition and so, it can be understood as to why some research identifies them as being synonymous with one another. This is also supported by the previous work of Theofilou (2013) who highlights the belief by certain researchers that the concept of wellbeing and quality of life both have objective and subjective aspects within it and is not based solely on one or the other. Theofilou (2013) uses this evidence to come to the decision to use the terms quality of life and wellbeing interchangeably with one another within her work of which, will be shadowed by the present research.

2.5.3 Quality of Life Measurement Instruments

There are a number of instruments available to assess one's perceived quality of life for instance, Flanagan (1978) developed the quality of life scale (QOLS), which is one of the most popular scales used amongst researchers. The original scale is comprised of 15 items with the importance of each item to quality of life and the perceived satisfaction of each item being the

components being measured and evaluated. There are five varying domains being measured within these 15 items of which are; recreation, personal fulfillment and development, relationships, wellbeing and civic, community and social activities.

This scale has since been developed and adapted to suit its further application to a number of sub groups and in particular, those experiencing chronic illnesses and because of this a newer version of the scale with a 16th item; independence has been developed and is available to researchers (Burckhardt and Anderson, 2003; Dantas and Ciol, 2014). Burckhardt and Anderson (2003) also examined the quality of life scale and found it to be a valid tool for measuring quality of life across varying subgroups and cultures.

However, this thesis' sole focus is upon cancer survivors and although it has been said for the above to appropriately measure quality of life in those with chronic illness it has not been created/developed to purposely measure quality of life in this research's particular sample set. This brings us on to the most well known established tool in the researcher's phenomenon of interest, of which was developed specifically to measure the long-term problems caused by cancer and its treatment in adult survivors (Jacobsen & Jim, 2011); the Quality of life in adult cancer survivors scale, also referred to as the QLACS scale (Avis, Smith, McGraw, Smith, Petronis & Carver, 2005). This is a scale encompassing 47 items split in to 13 sub scales. Participants then respond to each item through a presented five-point scale with 1 representing; 'Never' and 7; 'always'.

A plethora of research has identified the QLACS scale as being an adequate tool to use within research; for instance, Pearce, Sanson-Fisher and Campbell (2008) reviewed 42 instruments used to examine quality of life in cancer survivors with their findings indicating that the only instrument to demonstrate adequate test-retest reliability to be the QLACS scale.

This has also been supported by other researchers (Avis, Ip & Foley, 2006; Sohl, Levine & Avis, 2015). For instance, Avis et al. (2006) reviewed the scale and concluded that it does hold proven test-retest reliability alongside high internal consistency. More recently, Sohl et al. (2015) whilst conducting research involving breast cancer survivors, also concluded the quality of life in adult survivors scale to hold high internal consistency alongside promising divergent and convergent validity. Whilst conducting their research they also stated that alongside being consistent with alternative methods of capturing quality of life, the QLACS scale is a more inclusive measure of identifying particular issues associated to cancer survivors.

By researching this area it is clear that the QLACS scale is a very efficient and appropriate tool to use within this research in particular, the preliminary study and so, decided by the researcher this to be the investigative quality of life tool incorporated within the present research. The construction of the QLACS scale focused upon Gotay et al's (as cited in Avis et al, 2005) definition of cancer related quality of life, which intertwines both wellbeing, and quality of life within it and so, both concepts comprise its structure (Avis et al., 2005).

Therefore, in regards to the concept of both quality of life and wellbeing, this research will take the stance of Gotay et al (as cited in Avis et al, 2005) and capture them as if synonymous with one another.

2.5.4 Health Related Quality of Life

In recent decades, researchers and healthcare professionals have recognised a growing importance of measuring health related quality of life in individuals (Guyatt, Feeny & Patrick, 1993). This concept still incorporates the measurement of some general quality of life aspects but is specifically concerned with particular health aspects and their importance upon perceived quality of life. However, as with the concept of quality of life, health related quality of life (HRQOL) also has no one standing definition (Theofilou, 2013). This is said to be because the readily available literature fails to differentiate between health and health-related quality of life alongside, quality of life and health-related quality of life (Karimi & Brazier, 2016). Due to this, Karimi and Brazier (2016) state the two terms 'health-related quality of life' and 'quality of life' to often be interchangeably used by scholars. Therefore, this research will use the term 'quality of life' to refer to both.

2.5.5 Health Anxiety and Quality of Life

Veale and Willson (2009) suggest health anxiety to be present in individual's who, despite reassurances from medical professionals, have a pre-occupation with the thought of having a serious illness or a fear of them developing one.

There are a number of factors that can contribute to how a cancer survivor perceives their own quality of life (Dunn et al., 2013). However, as previously mentioned, the experience of cancer and its treatment can result in a number of varying health factors that can and do affect perceived quality of life, with one of the most expected being health anxiety. There is a plethora of research that indicates an impact of anxiety upon quality of life (Olatunji, Cisler & Tolin, 2007; Barrera & Norton, 2009; Sarma & Byrne, 2014), with the general consensus amongst existing literature being that the experience of anxiety lowers perceived quality of life. Therefore, it can be suggested that if an individual is anxious about their health because of their cancer experience, for example, worrying that it may deteriorate again at any given point, then it is likely that this will negatively effect how they perceive the quality of their life. This type of health anxiety is referred to by researchers as 'fear of cancer reoccurrence (FCR)' with the work of Lebel et al. (2013) supporting this theory as they found in their research amongst a sample of cancer survivors suffering from fear of cancer reoccurrence, that the higher their anxiety, the more trips they took to the accident and emergency department within a six month period.

2.6 Assessing Health Anxiety

Due to the mass of research identifying the extent to how severe health anxiety can become, Salkovskis, Rimes, Warwick and Clark (2002) developed an instrument using a cognitive behavioural approach to assess experienced health anxiety; the Health Anxiety Inventory (HAI). The health anxiety

inventory is a scale that consists of forty-seven items in the main section of the scale and seventeen items of negative consequences in the smaller serious illness focused section. In each of these items there are four different statements attached and the participant has to identify which of the four statements in every item accounts the most for how they feel. This instrument has since been developed with the permission of Salkovskis and the remaining researchers of the original scale and a shorter version has been created in which, now only has fourteen items in the main section and four in the serious illness scenario section (Abramowitz, Deacon & Valentiner, 2007). The Health Anxiety Inventory has been reviewed by researchers and has been found to be an appropriate tool to use within research. For instance, Abramowitz et al. (2007) found it to hold validity and reliability alongside positive psychometric properties. In addition, Salkovskis et al. (2002) previously conducted similar testing when developing the scale and found it to be a very reliable tool to measure health anxiety alongside holding validity. Furthermore, they added that their performed data analysis suggests that the short version of the scale and the long (original) version highly correlate with one another, making both suitable investigative tools when measuring experienced health anxiety. This is supported by the more recent work of Alberts, Hadjistavropoulos, Jones and Sharpe (2013), who conducted a systematic review alongside a meta-analysis on clinical, non-clinical and medical samples in order to assess the Health Anxiety Inventory. They found the tool to hold strong construct validity as well as sound scores of Cronbach's alpha. Therefore, concluding the Health Anxiety Inventory to be an acceptable instrument to use across varying sample types.

There are other instruments available to measure varying types of anxiety that are not health anxiety focused. For instance, one well-known tool that is accessible is the Beck Anxiety Inventory developed by Beck, Epstein, Brown and Steer (1988), which they found to be valid and hold good reliability. Additionally, another is the Social Interaction and Anxiety Scale created by Mattick and Clarke (1998), which the developers also found to hold sound validity alongside acceptable psychometric properties. However, these will not be discussed further in the present paper as this research focuses upon health and so, it is clear for the Health Anxiety Inventory of Salkovskis et al. (2002) to be the instrument of choice for this investigation.

2.7 Current Research Rationale

This thesis aims to conduct an investigation building upon the literature surrounding cancer survivors' experiences of long-term consequences following cancer and its treatment, who are in remission status. For instance, more people are living beyond cancer treatment but the majority of the available research detailed above focuses upon the experience of consequences following diagnosis or treatment. Therefore, long-term consequences from cancer and its treatment tend not to be discussed. Therefore, the present research will attempt to understand this.

Additionally, the research that does attempt to explore such long-term consequences tends to favour quantitative methodology, such as

questionnaires or systematic reviews with only the minority using qualitative measures. The limitations of quantitative methodology is that it does not allow for an in depth understanding of the complexity of the experience to be gained by the researcher.

Due to this, the present research will alternatively take a qualitative approach for the main phenomenological study within it. Although quantitative methods enable research to identify long-term consequences of cancer and its treatment, the consequences themselves are rarely explored in any depth. This means that how they affect the individuals' daily life or the meanings the individuals attach to these long-term consequences do not seem to be thoroughly investigated. This research will attempt to fill this gap, as it believes that the exploration of long-term consequences will aid the development of successful means and interventions, which will help cancer survivors, manage them.

The present research will use the e-mail interviewing data collection method. Readily available research on e-mail interviewing as a qualitative method is relatively sparse in comparison to alternative interviewing methods and does not seem to explore the present research's phenomenon of interest. Therefore, more research incorporating e-mail interviews in different research areas would be beneficial to establishing it as a valid data collection method.

Furthermore, from researching the area of online support groups in relation to individuals who have experienced cancer, it is clear that online support groups

are no less worthy than those carried out face to face. It is also evident that, although they both hold differing advantages and limitations they both complement one another as an appropriate form of support. However, much of the available research is on support groups that focus on post-diagnosis to immediate post-treatment phases. Therefore, showing a lack of attention to late effects. Due to this, it feels appropriate to recruit individuals from the widely accessible and used online support group, Macmillan Cancer Voices for the present research focusing upon experienced long-term consequences. The Cancer Voices online support group holds a very large membership group, which means the research will be able to have a wider reach of participants and capture diverse experiences. Additionally, using the Cancer Voices support group also means that the research is able to avoid exclusion through accessibility issues. Alongside, holding a benefit to the participating individuals, as it is said for some individuals to feel a sense of security through the anonymity that comes with online participation (Bouchard, 2016).

2.7.1 Overall Aims and Objectives of the Current Research

The entirety of the current research will focus upon meeting the aims and objectives that are presented below.

Aim 1: To identify any prevalent long-term consequences of cancer and its treatment that are experienced within a diverse sample of cancer survivors.

Objective: To conduct a survey exploring the experiences of long-term effects of cancer and its treatment amongst members of a broadly-based online cancer survivor support group.

Aim 2: To investigate in depth, the lived experiences of a diverse sample of cancer survivors in regards to long-term consequences of cancer and its treatment.

Objective (i) To use the method of online interviewing as a platform to explore survivors' experiences of how long-term consequences of cancer and its treatment impact their everyday lives.

Objective (ii) To investigate ideographically and in-depth cancer survivors' stories of their long-term consequences of cancer and its treatment.

Aim 3: To provide healthcare professionals who support cancer survivors with insights for practice.

Objective: To critically consider the findings of the empirical studies for their implications for the provision of support for cancer survivors.

Chapter Three:

Methodology

The present research comprises of two individual studies. The first uses a survey design with mixed quantitative and qualitative elements to examine the association between factors such as cancer type and identified status, and experiences of long-term consequences of cancer that impact upon one's quality of life alongside, providing some preliminary insights into the experiential accounts of such long-term consequences that have arisen in individuals' daily lives. Furthermore, the link between quality of life and health anxiety was also explored. The online survey's primary purpose however, was to guide the selection process for the main study, which follows it, alongside informing the design and analysis. The second study's methodology is solely qualitatively focused, with the philosophical underpinning being phenomenology, supplemented by a narrative case study approach. The purpose of this second study was to extend on that of the first and gain a wide range of in-depth cross sectional experiential accounts of individuals' personal journey of cancer, its treatment and the long-term consequences that have arisen as a result of them.

This chapter will present the methodology attached to the preliminary study first and then will follow with that of the main phenomenological study.

3.1 The Preliminary Study

In order to meet the first overall aim and associated objective of the current research, a mixed method survey design incorporating both quantitative and qualitative elements (Creswell, 2014) is used in this study. Qualitative methodology is known for being subjective and asking 'why' and 'how' things occur in regards to the explored topic of research (Malina, Nørreklit & Selto, 2011). Whereas, quantitative methodology takes a more objective approach, focusing upon numerical data to identify relationships, seeking the answers to, 'how many and often' things occur (Melina et al., 2011). The application of this methodological approach involves encompassing the qualitative and quantitative aspects synchronously or iteratively. Taking this approach is said to enable the exploration of complex facets within social science and health research phenomena (Malina et al., 2011), particularly in cases where either quantitative or qualitative methods are incapable of answering the applied research question/s alone (Doyle, Brady & Byrne, 2009).

The philosophy behind mixed methodology is most commonly that of pragmatism (Doyle et al., 2009). A pragmatist philosophical position is argued to be one that has a central focus on problem solving rather than finding truth or reality (Powell, 2001). Therefore, rather than imposing a specific ontological and epistemological paradigm, the main concern of pragmatism is finding out 'what works' in finding solutions to identified problems (Patton, as cited in Parvaiz, Mufti & Wahab, 2016; Creswell, as cited in Parvaiz et al., 2016).

This approach has been acknowledged by scholars to be extremely beneficial for social science and health research in particular (Doyle et al., 2009).

Although quite new, there has been a rise in mixed methods research within the last decade with more researchers beginning to integrate the qualitative and quantitative approaches together (Clark, Creswell, Green & Shope, 2008). The advantages of doing this have been acknowledged by researchers as they refer to mixed methodological practice as being its own individual research paradigm alongside the two well-identified major research approaches, Qualitative and Quantitative (Johnson, Onwuegbuzie & Turner, 2007; Doyle et al., 2009). This arguably demonstrates the continuing evolution of research methodology as finding a research paradigm that can combine and utilize the advantages of both quantitative and qualitative methodology can be envisaged as being a progressive leap forward in research methodological development (Creswell, 2014).

In addition to this, the concept of mixed methodology within research has also become recognised under the term 'triangulation' which is based on the viewpoint that rather than opposing one another, the strengths of one should be used to compliment the other (Jick, 1979). Jick (1979) states that the scholars first evidenced to use this 'triangulation' concept were Campbell and Fiske (1959) through their 'Multiple Operationism' theory, stating that the validation process of research requires more than one method to be employed in order to determine validity. Furthermore, although not recognised as a mixed methods approach for several decades (Johnson et al., 2007), this form of research can be evidenced as being incorporated in the work of

numerous researchers (Hollingshead, 1949; Campbell & Fiske, 1959). More recently, Doyle et al. (2009) support Campbell and Fiske's (1959) theory, as they also state triangulation to enable a greater level of validity to be achieved.

However, the view of mixed methods being advantageous to the research field is not one that is shared by everybody. For instance, Guba (1987) claims that because quantitative and qualitative methodology rely on separate paradigms, mixing them together proves rather inadequate, as quantitative and qualitative researchers do not focus on the same phenomenon. This is because quantitative methods are seen as encompassing a positivist paradigm (Doyle et al., 2009) whereas, the qualitative approach cannot be described as one single paradigm as it includes approaches with very differing philosophical bases (Madill, 2015). Therefore, some researchers support Guba's (1987) claim, questioning how it can be scientifically possible to appropriately combine the two contrasting approaches (Sandelowski, 2000).

The perspective of Guba (1987) is not one shared by the present research, as this thesis believes mixed methods can be advantageous. One reason behind this belief is highlighted in the research of Malina et al. (2011), as they point out how mixing both quantitative and qualitative methods can ensure greater validity because qualitative data can be used in order to provide context to unexpected, inconsistent or otherwise inexplicable quantitative results, helping to explain 'why' they are present. This point of Malina et al., (2011) is one that was particularly pertinent to my planned research aims, playing a key

role in the decision to use this methodology for the preliminary study. My preliminary study aims to identify how different cancer types affect quality of life therefore, I believe statistical analysis would be beneficial in order to explore quality of life levels in regards to different cancer types but, qualitative analysis will enable the study to identify 'how' and 'why' participants believe it to be affected.

3.2 The Main Phenomenological Study

In order for researchers to select the appropriate methodology for their research, they must first deeply consider what it is they are hoping to identify and achieve from their work as it is the answers to these questions alongside already retained assumptions that shape the researcher's chosen methodology (Creswell, 2014; Taylor, Dogden and DeVault, 2015).

3.2.1 Epistemology

Epistemology refers to the knowledge of the phenomenon we wish to study, how we can acquire and then communicate this knowledge (Scotland, 2012) and how we can make justifiable claims for the value of the kind of knowledge we produce (Johnston, 2017). In addition, Guba and Lincoln (1994) state that epistemology centres itself upon identifying the relationship between the explorer of information and the knowledge that can be gained. In short, epistemology focuses upon exploring how we know particular phenomena (Renaud, 2018).

3.2.2 Ontology

Ontology is an additional key element of the philosophy of social scientific research; it differs from epistemology in that it centres upon exploring what things are rather than how we know them. For instance, a researcher focusing on their ontological stance may state 'this is so and so' but a scholar with an epistemological emphasis would question how they would know such a thing to be true (Renaud, 2018). Therefore, it could be seen for ontology to actually be a thought process that should come prior to and lead on to epistemology.

3.2.3 Perspectives within Epistemology

It is argued for there to be two distinct polar opposite theoretical perspectives associated with the epistemology of research in the social sciences; positivism and interpretivism, and the researcher must choose their stand point within these two perspectives to shape the structure of their work (Taylor et al., 2015). However, the concept of interpretivism used to contrast with positivism, covers a wide range of positions that also contrast with one another in varying important manners. For instance, King and Brooks (2017), when speaking about the theoretical perspectives within epistemology, suggest interpretivism to have three constituting positions; limited realism, contextualism and radical constructionism. Therefore, the present research takes into consideration the variations within the concept of interpretivism, but will now discuss interpretivism as a broad contrast to positivism for the

purpose of demonstrating common elements in its distinction from positivism (Brown, 2017).

Although it is common for qualitative research to employ an interpretivist approach, in order to understand why most qualitative research rejects positivism in favour of some form of interpretivism, it is important to recognise what a positivist approach claims. Positivism has an objective approach to research and would for example, conduct a study in order to test and in turn prove or disprove set hypotheses (Ryan, 2018) and so, is most often than not incorporated into quantitative led research. It also views reality as a concrete structure that is unconnected to the researcher and can be parceled in to independent and dependent variables as a means of explaining relationships (Major, 2017; King, Horrocks & Brooks, 2019). Positivism as a theoretical perspective has received some critiques with it being argued by scholars that the approach attempts to minimise the exploration of relationships by restricting the limits to what they can be investigated alongside simplifying the complexity of reality. In addition, scholars have stated that although positivism does identify and describe relationships within the phenomena of interest it unfortunately restricts any possibility of gaining understanding or explanation behind the found results and so it is impossible to identify why or how a result has been found (Major, 2017).

In contrast to this, interpretivism, which was developed from the critiques of positivism, has a subjective approach and does focus upon the lived experiences of certain phenomena of interest alongside the individuals'

understanding of said experience and so, can be referred to as being idiographic (Kroeze, 2012; Ryan, 2018; King et al., 2019). This approach also identifies that as a researcher it is effectively impossible to completely separate one's own beliefs and thoughts from the research being undertaken and so acknowledge that it is these factors that will help determine the method by which data will be collected, interpreted and analysed (Ryan, 2018). It must be noted here that many recent scholars argue that it is unhelpful to class quantitative and qualitative researchers as necessarily in opposition and conflict with each other, because they seek to answer different types of questions and can inform each other. Instead, we should work with the premise that different approaches are needed for the two research methods as the theory held by the researchers in what is achievable to study and what is interesting to study varies between them (King & Brooks, 2017).

Therefore, because the present research is interested in exploring the lived experiences of long-term consequences of cancer and its treatment it is justifiable for an interpretivist approach to be the underpinning theoretical perspective behind it. This is supported by the work of King and Brooks (2017) who claim that interpretivism is an approach in which human experience is the focus of the research underway and that how the individuals experiencing them understand particular experiences is what the approach is founded upon.

3.2.4 Perspectives in Ontology

There are two branches within ontology; the realist and the relativist. A realist ontological approach comprises of believing in the presence of a single reality and that its existence is not shaped or influenced by human experience.

Therefore, it can be explored, understood and referred to as a single truth. A relativist approach however, opposes this and centres itself upon the premise that there is no one single truth about reality and that any identified truth can alter depending upon how an individual experiences it at that present time and/or place. Therefore, relativist ontology believes the world is comprised of experiences and how they are understood at the time, meaning the reality is always capable of changing at any moment (Moon & Blackman, 2014). Taking the above into account, it is clear that the present research will adopt a relativist ontological stance throughout as it concerns itself with exploring how individuals have experienced long-term consequences of cancer and its treatment and the meanings those involved have attached to them.

3.2.5 Introducing Phenomenology

There are a number of methodological traditions within interpretivism (Cal & Tehmarn, 2016), as noted above, however, in attempting to meet the current research's overall second and third aim alongside their associated objectives, as presented in Chapter Two, this study will focus upon that of phenomenology. Although phenomenology cannot be defined as being one specific form of methodology due to the development of differing variations

and changed emphases of it over time (Hardy, 2012), each differing extension does tend to be recognized by its developer as being rooted in the work of the original founder, Edmund Husserl (Rodriguez, 2009). This section of the thesis will discuss the origins of phenomenology alongside explaining the use of particular concepts within it for underpinning of this research.

As King and Brooks (2017) point out, phenomenological research concerns itself with describing and understanding individuals' personal lived experiences of particular phenomena, with the researcher making no attempt to refute what the experiencing individual claims to have occurred. In comparison, this thesis aims to explore the lived experiences of long-term consequences following cancer and its treatment alongside, the impact these have upon the experiencing individuals. Therefore, it is clear for phenomenology to be an appropriate underpinning methodology as the aims of phenomenology and the present research align with one another.

Langdridge (2007) argues that phenomenology originates from the work of the late Husserl, who refuted the idea that empirical science can solely provide a complete understanding of the world we live in, and so developed the epistemological theory that we can learn and understand more about the world through describing individuals' personal lived experiences and he named this theory; descriptive (or "transcendental") phenomenology. Within this, he stated that, if something brought itself to one's consciousness, then an understanding of it could be gained via phenomenological research processes, in particular, the phenomenological reduction (Hardy, 2012).

Landridge (2007) suggests there to be confusion amongst scholars in regards to the literature focusing upon phenomenological reduction. However, Husserl believed it to be a method focusing upon retrieving the pre-reflective experience - exploring lived experiences before the individual has interpreted them. This process is then said to enable the exploration and identification of the phenomenon's essence to commence, which focuses upon identifying the reality of the subject of exploration, rather than the appearance it portrays (Hardy, 2012).

However, a number of years later, Heidegger, one of Husserl's students, although agreeing human experience to be temporal and perspectival (Rodriguez, 2009), disagreed with much of Husserl's theory and so developed it using the ontological approach of hermeneutics (Moran, 2000). This meant that instead of merely describing the lived experiences, Heidegger's interpretative phenomenology theory concerns itself with finding the meanings and interpretations attached to such lived experiences. Heidegger's theory is said to refute Husserl's idea of phenomenological reduction and instead, favours an exploration in to how the form of human experience uncovers that of 'being'. It also stresses researchers' reflexivity, considering how they themselves inevitably influence the analysis due to it not being possible to interpret human experience neutrally – in effect to stand outside one's own place in the world (Moran, 2000).

The current research will encompass Heidegger's interpretive approach to phenomenology and will accept his stated importance of applying

hermeneutics. Hermeneutics within interpretive phenomenology is a process in which there is a continuous acknowledgment of the researcher's expectations, experiences, projections and values whilst the investigation is in progress. This is referred to as the 'hermeneutic circle,' which can be evidenced in figure 3.1. Within this metaphorical circle, there is one arc mirroring projection, which enables understanding, alongside a returning arc reflecting the interpretation/evaluation aspect (Rodriguez, 2009).

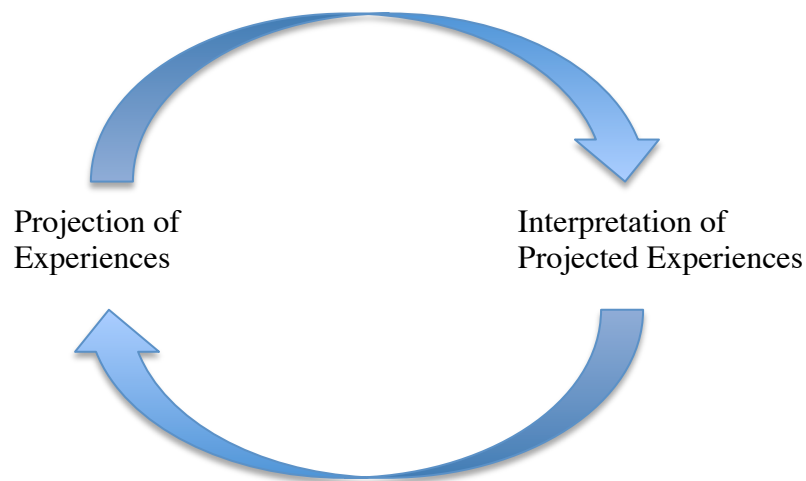


Figure 3.1: A Diagram to show the process of Heidegger's hermeneutic circle

A key concept within hermeneutic phenomenology is 'lifeworld', which is identified as being of central focus to the phenomenology (Ashworth, 2003; Brooks, 2015). Rodriguez (2009), points out that lifeworld is characterised by some as something that an individual has lived experiences of and, is pre-reflective. Brooks (2015) suggests the pre-reflectivity of lifeworld to mean that

rather than exploring our perceptions with a focus on 'how' they are being perceived; the focus is upon 'what' is being perceived.

Ashworth (2003; 2006), amongst other scholars, identifies there to be seven 'fractions' inter-related within the lifeworld concept, these being:

1. Selfhood – The manner in which a particular situation impacts upon one's social identity, one's sense of who one is within one's social world;
2. Embodiment – The manner in which one is physically present in the world, as an embodied being;
3. Temporality – The manner in which a said situation affects an individual's sense of time, biography and duration. For example, a twenty minute wait for toileting services to become available when out with friends, in the eyes of a cancer survivor suffering from the long-term consequence of incontinence, may seem significantly longer than a twenty minute wait for food service.
4. Spatiality – How a particular situation impacts an individual's perceived sense of their immediate geography in regards to the places they attend and perform within

5. Sociality – The impact an experienced situation has upon the relations between the individual and other people
6. Discourse – The manner in an individual uses language to narrate their lived experiences of a given situation
7. Project – How the lived experience of a phenomenon affects individuals' ability to participate in activities that are perceived as central to the experiencing individuals' daily lives.

Not all fractions will be substantially present within all phenomena (Rodriguez, 2009) however, it is suggested that they must be considered when exploring how individuals experience the lifeworld.

There are a number of variants within the overall approach of phenomenology due to how wide-ranging the philosophy is behind it. The approaches to researching descriptive phenomenology do differ from those of interpretative. Since the present thesis focuses upon interpretative phenomenology, I will outline the two main interpretive approaches below and then describe the approached to be used in this thesis.

Interpretative Phenomenological Analysis

The first variant of interpretative phenomenology that will be discussed is Smith's (1996) Interpretative Phenomenological Analysis (IPA), which is an

approach focusing upon the perceptions individuals have of particular events or objects (Griffiths, 2009). Exploring how individuals attached meaning to, and make sense of their experiences is the drive behind Smith's (1996) approach. IPA acknowledges there to be no direct route to exploring lived experience but does identify a form of in-depth interviewing as being an effective data collection method as it enables participants to provide in-depth personally reflective accounts of their experiences (Smith, 2011). Smith and Osborn (2004) demonstrate how the so-called "double hermeneutic" is at play within the IPA approach; the participants are attempting to understand their lived experiences and the researcher is attempting to make sense of their attempts to understand their lived world.

Thematic Analysis is the recommended analysis of IPA, with it suggesting a step-by-step approach to be taken with the left-hand margin being used for the annotation of interesting data, and the right-hand margin being used to make a note of any emergent themes within said data (Smith & Osborn, 2004). These notes are then used to develop themes, initially for individual cases and then encompassing the whole data set with connections and patterns identified between them (Charlick, Fielder, Pincombe & Mckellar, 2017). However, IPA is suggested to be a data-driven approach (Griffiths, 2009), in that it does not necessitate strict rules that must be adhered to within its use, but merely provides considered guidelines for the approach to research (Pietkiewicz & Smith, 2014).

Van Manen – Human Science Research

Van Manen (1990) introduces an approach formed within hermeneutic phenomenology and acknowledges lived experiences as being both the start and end point of research within phenomenology. However, he does also draw upon particular aspects developed within Husserl's descriptive phenomenology (Dowling, 2007). Four existentials necessary to understanding lived experiences are presented by van Manen; these also align with the hermeneutic circle outline previously presented and are - lived body, lived time, lived space and lived human relations (Rich, Graham, Taket & Shelley, 2013).

Van Manen (1990), also describes the methodological structure behind hermeneutic phenomenology as comprising of "a dynamic interplay among six research activities",

1. Turning to a phenomenon which seriously interests us and commits us to the world
2. Investigating experience as we live it rather than as we conceptualize it
3. Reflecting on the essential themes that characterize the phenomenon

4. Describing the phenomenon through the art of writing and rewriting
5. Maintaining a strong and orientated pedagogical to the phenomenon
6. Balancing the research context by considering parts and whole

(van Manen, 1990, pp. 30-31)

It is suggested by Rodriguez and King (2009), the drive behind the interplay of the above stated activities is to achieve a greater in-depth insight of the meanings attached to lived experiences. Although Template Analysis is the analysis focused upon within this thesis, the six activities of van Manen (1990) are also drawn on within the process of the current research, as my overall orientation to analysis is fundamentally hermeneutic. In addition, the different variants within this type of phenomenology do suggest the possibility of overlap between them (Rodriguez, 2009). The manner in which this thesis aligns with van Manen's (1990) necessary identified activities will now be discussed.

The Phenomenological Approach in this Study

The thesis draws upon the six previously stated principles of Van Manen in regards to the methodology of hermeneutic phenomenology and the manner in which they align, will now be discussed.

In regards to van Manen's advice of turning to a phenomenon of interest, I approached my interest of the long-term consequences of cancer and its treatment. I was interested to explore how cancer survivors, in the remission status of their cancer journey, experience the long-term consequences of cancer and its treatments. As previously discussed in chapter one, this interest was particularly enhanced through my experience of seeing such consequences being experienced by a close family-friend.

Van Manen's (1990) suggestion of investigating experiences that are lived is also followed within the present thesis. I decided to use the e-mail interviewing method for data collection as it enables the engaging of a conversation between me and the participants over a period of time allowing me to explore cancer survivors' lived experiences of the phenomenon, long-term consequences following cancer and its treatment (see Chapter Six for more discussion of this).

The reflection of themes is easily applicable to both the collection of the data and the two sequential analyses that followed. I used the findings of the preliminary study to construct *a priori* themes for the main phenomenological study, which contributed to the shaping of the performed interview. When performing the incorporated analysis the responses gained from the participants, were repeatedly re-read and reflected upon according to the previously discussed, hermeneutic circle. Furthermore, the chosen Template Analysis requires the development of themes, in line with the guidelines of

King (2004), these themes were then re-evaluated throughout the analysis process, ensuring an appropriate and effective template was produced.

The recommended art of writing and re-writing (van Manen, 1990) was also achieved as, every draft I wrote in regards to the performed analysis and presented finding was subsequently sent to my two supervisors. They then corresponded by providing me with feedback on how possible improvements that could be made, which led to me re-writing the draft and sending them the updated version, with this process then being repeated until a final draft was achieved.

Van Manen's instruction to maintain a strong relation to the explored phenomenon was demonstrated through me repeatedly reminding myself of the aims of the present research to ensure I stay focused and committed throughout. Having regular contact with my supervisors was also extremely beneficial in regards to this fraction as communicating with them about my research helped me stay in focus. Furthermore, throughout the e-mail interview process, I repeatedly read each response before replying with another question and sent probing questions in instances where I felt more was needed from participants for the aims of the research to be met.

Finally, van Manen's suggested balance to research through the consideration of both 'parts' and the 'whole' of this research was achieved by me exploring specific details from the analysis such as the support retrieved by individuals and using this to look at the bigger picture, for instance, the

manner in which this received support or lack of it, impacts upon the participants' experiences in regards to their long-term consequences and how it affects their quality of life/wellbeing. Therefore demonstrating that the parts and whole inform each other in a cyclical way.

However, in regards to thematising the e-mail data, King's (2004) developed Template Analysis is incorporated, this approach rests upon phenomenology and is a form of Thematic Analysis. Template Analysis is suggested to be an extremely flexible approach as it can be adapted to various epistemological positions rather than being bound to only one like many other thematic approaches, such as, IPA and Grounded Theory (Brooks, Mccluskey, Turley & King, 2015). Template Analysis presents seven steps, which must be taken in order to effectively carry out the process, these are; familiarization with the data, preliminary coding, clustering, producing an initial template, developing the template, applying the final template and writing up (King and Brooks, 2017). These 7 steps of the Template Analysis approach alongside, a more in-depth overview of the analysis will be explored in more detail in the following chapter, as this is the approach incorporated by the present research.

3.3 Establishing Trustworthiness

Critics of phenomenological qualitative research, such as positivists, show reluctance to acknowledging it as a trustworthy approach therefore, a number of scholars have presented frameworks to silence these critics and ensure

trustworthiness is established (Shenton, 2004). Shenton (2004) argues that one of the most favourable frameworks for establishing trustworthiness is that of Guba', who, in 1981, presented the argument for their to be 4 varying factors that all scholars must adhere to address when performing phenomenological research, in order to establish trustworthiness. These 4 factors are:

1. Dependability – This means that researchers should ensure steps are taken so that the study can be repeated in the future by other scholars;
2. Credibility – This refers to scholars ensuring that the phenomenon being explored is presented in a true light;
3. Transferability – This encompasses scholars making sure the context of the phenomenon is presented in adequate detail so that the findings can be applied to alternative, similar situations;
4. Confirmability - This refers to researchers ensuring that their study's findings reflect the gathered data rather than their own ideas.

Dependability is addressed by the present research through seeking to capture the lived experiences of a diverse sample of participants in remission from cancer. This therefore means that future scholars can easily replicate the used sample as the inclusion criteria is not too restrictive in who can participate. Furthermore, is easily replicable as very precise and clear details

are provided in regards to the incorporated methodology and followed procedure. Credibility is addressed as the flexibility of the e-mail interviewing method enables me as the researcher to adjust the included questions as and where needed. Due to lived experiences being subjective, transferability could be seen as somewhat difficult to ensure. This is because it is unlikely for the phenomenon to be experienced the same by various individuals as each person could perceive the same situations differently. However, it is enabled to a great extent because the detailed descriptions of rich accounts, enables readers to draw comparisons with their own situation (Shenton, 2004). Finally, confirmability is adhered to as I performed a reflexivity technique, which involved me continuously making notes of my reflections in regards to both the data collection and analysis phases of the research. These notes were then used in to ensure that my focus remained on using the narratives of the participants to shape the research's findings and not allowing my predispositions to creep in.

3.4 Choices of Data Collection Method

Whilst the detail of the incorporated methods within the present research will be discussed in subsequent chapters (chapter four and chapter six), this section will justify the overall design approach of this research in the light of the philosophical position taken.

3.4.1 Preliminary Study

In order to meet the first overall aim of the current research, the preliminary study's design comprised an online survey. The justification for the survey being predominantly quantitative is that it seeks to assess the prevalence of different cancer types and their associated long-term consequences and establish if there is any relationship between them and the participants' perceived quality of life. Therefore, it seemed wise to include the quality of life in cancer survivor's scale (Avis et al., 2005), which is based on quantitative methods, involving participants responding to questions through a five-point likert scale, also developed by Avis et al. (2005). Quantitative questioning also enabled demographic information to be gained from the participants enabling, further relationships to be explored, such as cancer status and quality of life.

The use of qualitative aspects, through the incorporated open-ended questions, which conclude the online survey are also justified as the current research's first overall aim and associated objective involves exploring lived experiences of long-term consequences following cancer and its treatment of the participants alongside, how these experiences are portrayed by the participants to impact their daily lives. Therefore, allowing participants to freely type their answers enables me to gain a greater insight in to their experiences of long-term consequences alongside, identifying 'how' and 'why' certain relationships were/were not identified within the statistical analysis.

3.4.2 The Main Phenomenological Study

In meeting the second overall aim of the current research as presented in Chapter Two and objective (i) within it, the relatively new method of e-mail interviewing is the data collection method of choice for this part of the research. This section of the thesis will discuss the e-mail interviewing technique whilst providing an explanation as to why I made the decision of incorporating it within the present research. This section is substantially longer than the previous one regarding the preliminary study; this is due to e-mail interviewing still being viewed as a new and seemingly unusual data collection method. Therefore, I believed it necessary to provide context around it.

E-mail Interviewing

Qualitative research provides insight into phenomena through exploratory methods and generally enables researchers to gain a sound understanding of the meaning and opinions attached by those who have experienced them (Hammarberg et al., 2016). Although there is a wide range of data collection methods used within qualitative research, individual and group interviews still remain the most common (King et al., 2019). However, e-mail interviews are increasingly becoming more popular with the advancement of technology and access to the internet (Bowden and Galindo-Gonzalez, 2015; O'Connor and Madge, 2016) and although they are not as common as face-to-face interviews, e-mail interviewing can be very beneficial (Opdenakker, 2006; Redlich-Amirav and Higginbottom, 2014; James, 2015; O'Connor and Madge,

2016). For instance, Burns (2010) states that online interviews via e-mail enable the enhancement of investigatory tools available for the conduct of research studies and so, enrich the range of methods by which data can be gathered.

In order to meet the second overall aim and associated objectives of the current research, it was important in this study to not only gain in-depth rich data via qualitative interviewing methodology but also to be able to communicate with individuals in different areas to promote the collection of different experiences. In addition, with the sample being recruited from an online highly recognised and widely used support group; Macmillan, it was obvious that potential participants were likely to live in different areas of the United Kingdom, if not further a field. Therefore, after researching the topic, asynchronous e-mail interviewing appeared to be a very logical and appropriate method for data collection.

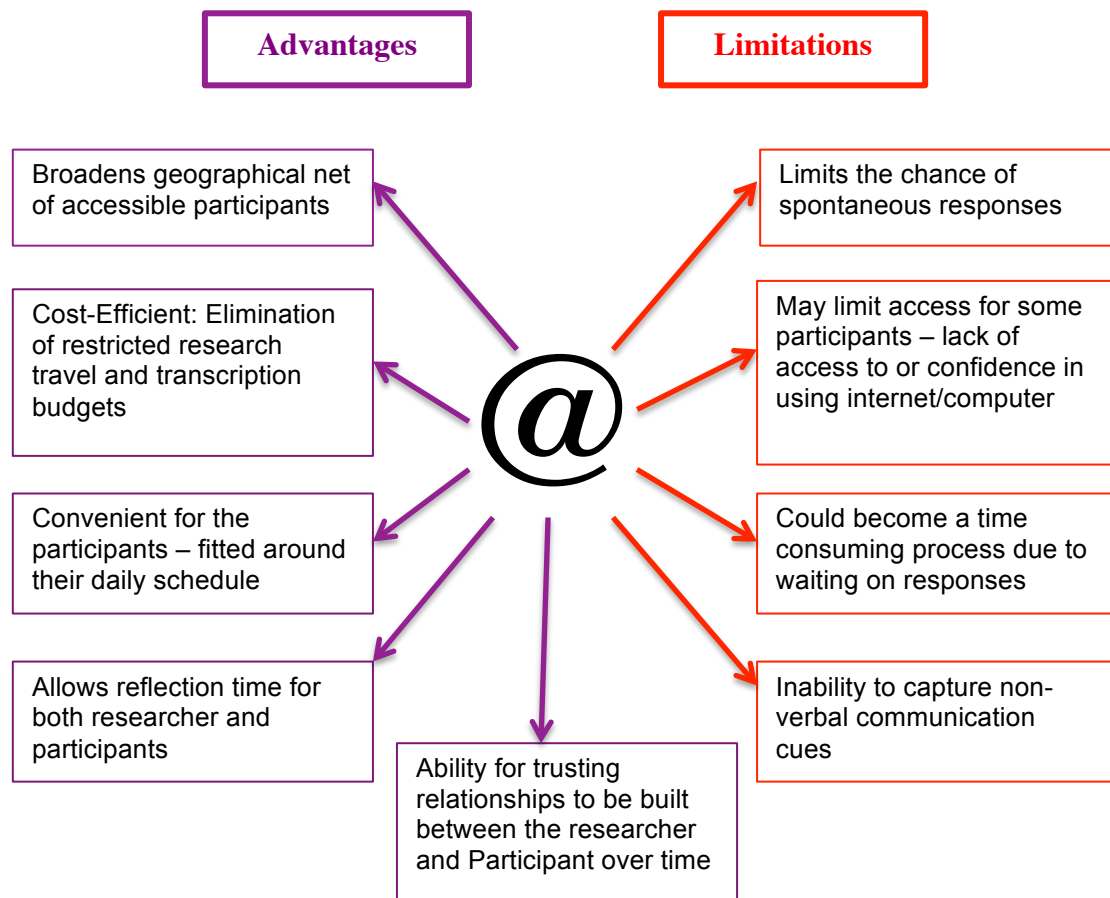
What is E-mail Interviewing?

King and Horrocks (2012) state that an e-mail interview has many similar properties of typical asynchronous e-mail correspondence. This being where one individual/the researcher composes and sends a message then awaits a reply with the recipients/interviewee's response to said message within a set time frame (Ratislavova and Ratislav, 2014). Burns (2010) highlights this form of communication (e-mailing) to be the new norm in the present day.

There are no set guidelines on how to conduct an e-mail interview however; there tends to be two distinct forms for the researchers to choose between (O'Connor et al., 2008; Henn et al., 2009; Wai Man Lo, 2016). The first form is where the participant agrees for the researcher to send a series of e-mails containing interview questions with an interval between each of them (O'Connor et al., 2008; Henn et al., 2009). The second form focuses on the participant agreeing for the researcher to send the interview questions all at once in one e-mail (Cook, 2012). Both of the above e-mail interview forms may have follow up questions incorporated however, the key distinction is the sequence versus all-at-once approach taken. The problem however with the latter approach is that there is less interaction, making it extremely difficult for a trusting relationship to be formed between the researcher and participant. Due to this, the present research will take the sequential approach to e-mail interviewing, giving the time for a relationship to be formed.

The duration of an e-mail interview varies between research studies and is dependent upon which of the above approaches was taken. Rather than simply lasting a number of hours in line with a face-to-face interview, that of an e-mail interview can take days, weeks, months or even years depending on the nature of the phenomenon being studied (Opdenakker, 2006) as discussed further below.

However, as with any type of research methodology, advantages and disadvantages come alongside e-mail interviewing as shown in figure 3.2 and further discussed in the following paragraphs.



Based on: Wai Man Lo (2016)

Figure 3.2: Advantages and Limitations of E-mail Interviewing

Advantages and Limitations of E-mail Interview

As illustrated in figure 3.2, there are a number of previously identified advantages and disadvantages of e-mail interviewing. These will now be discussed with the advantages being presented first and the disadvantages subsequently following.

Broadens Geographical Net of Accessible Participants

A major advantage of using e-mail interviews within qualitative research is that the method broadens the geographical net of accessible participants as researchers are no longer bound to the time or cost of travel (Gibson, 2010; Hawkins, 2018), meaning that researchers can seek participants from different towns, cities or even countries if they wish to do so in order to recruit the most suitable individuals to participate. This is advantageous as it means a more diverse sample can be achieved as it enables participants with very rare characteristics for example, different rare forms of cancer, to be included (James & Busher, 2012; Bowden & Galindo-Gonzalez, 2015)

Cost-Efficient

This leads us on to the advantage that e-mail interviewing is also more cost efficient (Ratislavova & Ratislav, 2014; Hawkins, 2018). Even where travelling to interview is practically possible, travel costs may quickly become unreasonable. Therefore, the availability of e-mail interviewing creates a cost efficient route, which enables participants from areas remote to the interviewer to participate in the same research study (Gibson, 2010; Hawkins, 2018).

In addition, it has been identified that e-mail interviewing is extremely efficient in the transcription process of the investigation, saving the researcher the cost of paying for transcription or the time it would take to do it themselves.

Transcription is a lengthy process and the resources saved through e-mail interviews can be directed to other aspects of the study as all the communication is already written with no verbal speech needing to be transcribed (Meho, 2006; McCoyd & Kerson, 2006; King, Horrocks & Brooks, 2019). Researchers need to be aware, though, of the time required to manage the e-mail data- for instance, anonymising and copy/pasting into word processing files.

Convenient for the Participants

The e-mailing interview method is also advantageous in that, as O'Connor and Madge (2016) and James (2016) point out, it can be carried out in timing convenient to the participating individuals. Participants can respond to the sent questions when their schedules allow them to do so without them worrying about when they are able to fit the interview into their busy daily lives.

Allows Reflection Time for Both Researcher and Participants

The fact that participants do not have to reply instantly to each question sent by the researcher means that there is a strong possibility for richer results to be obtained and in turn, enhance the validity of the research. This is because e-mail interviewing allows the participant to read the question being asked and then reflect on the answer they wish to reply with before actually e-mailing the researcher back (Hawkins, 2018). Not only can the participant

take time to reflect in depth on their experiences before communicating them, the researcher also has time to reflect upon the answers provided and tailor follow-up questions accordingly (Opdenakker, 2006; Bowden & Galindo-Gonzalez, 2015; O'Connor & Madge, 2016).

Ability for Trusting Relationships to be Built Between the Researcher and Participant Over Time

Ratislavova and Ratislav (2014) state that a formed relationship between the researcher and participant is essential when partaking in qualitative research as it encourages more openness within the responses allowing the researcher to receive a more in depth account of the experiences being explored. Due to the fact that e-mail interviewing does not take place in a face-to-face environment, it has been argued by some researchers that it could become difficult for a relationship to be built between the researcher and participant (James, 2016). However, Ratislavova and Ratislav (2014) argue that personal contact is not essential for this type of relationship to develop. In line with this, James and Busher (2012) whilst raising challenges existent within e-mail interviewing, do suggest that the long-term interaction in e-mail interviews can enable relationship and trust building between the researcher and participant. For instance, they provide reasons such as the repeated communication building rapport and that the participants' sense of anonymity that comes with online settings, even though they are no more anonymous than in a face-to-face setting, may enable them to be more open and honest in their responses

in regards to sensitive issues and unpopular opinions, which creates a sense of trust.

Furthermore, it is suggested that the researcher showing commitment through means of answering replies as promptly as possible can also aid the development of a researcher/participant relationship during the e-mail interview process (Ograd, cited in James & Busher; 2012). Alongside, the researcher opening up to the participant a little and sharing pieces of personal information about themselves when necessary so it is not only the participant who is sharing information (Kivitis, cited in Bowden & Galindo-Gonzalez, 2015).

May Limit Access for Some Participants

In contrast to the earlier point of increased access, e-mail interviewing could also restrict some individuals from being able to participate as the process would require common knowledge/skills of computing and the internet alongside the participant holding a valid e-mail address (Ratislavova and Ratislav, 2014). Therefore, it has been stated that groups such as the older generation, younger children or individuals with specific types of disability may be restricted from recruitment to this type of data collection method (Hunt & McHale, 2007). In addition, those who are more confident speaking in comparison to reading and writing may also be hesitant in participating and if they do take part they may misinterpret the question asked which could cause invalid responses (Ratislavova & Ratislav, 2014). However, although this is

the case for some, a number of researchers argue that e-mail interviewing can in fact be a more appropriate method for interviewing individuals with disabilities than that of face-to-face (Ison, 2009), depending of course on the type of disability. This can be evidenced in the research of Egan, Chenoweth and McAuliffe (2006) who explored the method of e-mail interviewing with individuals suffering from Traumatic Brain Injury (TBI). This is because it was found that e-mail interviewing was very advantageous in comparison to other methods for a number of reasons. It allowed participants increased time to reflect on what was being asked of them and grasp a greater insight alongside the ability to control their setting and be more humorous in responses compared to previous research. It was concluded in this study that the relatively new technology allowing e-mail interviewing to break down barriers that are in place for individuals suffering from Traumatic Brain Injury (TBI) in the common face-to-face method of interviewing.

Inability to Capture Non-Verbal Communication Cues

In line with the above point, e-mail interviewing also restricts all visual cues that are otherwise present in a face to face interview such as body language for example, alongside non-verbal cues commonly associated with telephone interviews such as tone and volume of voice (James & Busher, 2012; Ratislavova & Ratislav, 2014). It is because of this, Ratislavova and Ratislav (2014) argue that the richness of data gathered through e-mail interviewing is lacking in comparison to both face to face and telephone. However, they claim that although not parallel, the use of emoticons and acronyms can act as a

substitute to non-verbal cues, and so, researchers should be encouraged to incorporate them into the e-mail interview if able to do so (Meho, 2006).

Could Become Time Consuming

Due to the fact that the interview is via e-mail, this means that although researchers do normally set some time limits to their e-mail interviewing schedule, there is a risk of the total duration of the interview period becoming hard to manage. This therefore could be a very time consuming process as each question asked could take days, even weeks to be answered (Opdenakker, 2006; Bowden & Galindo-Gonzalez, 2015). Therefore, it is possible that a participant could grow tired of the interview and so, withdraw and stop replying or begin to answer the questions half heartedly, damaging the validity and richness of the data gathered.

However, whilst you can set a time limit for each interview, it is not guaranteed that individuals will abide by it. Therefore, the issue is that the process can become time consuming if people do not work to the deadline that is set between them and the researcher. For instance, there needs to be clear protocol regarding the use of set reminders and in turn, the problematic dilemma of deciding how much extra time to allow them to respond before needing to withdraw them from the research (Meho, 2006).

Limits the Chance of Spontaneous Answers

Opdenakker (2006) and O' Connor and Madge (2016) state that a key disadvantage to e-mail interviewing is that it almost eliminates the chance of a spontaneous answer, although this is certainly not always a bad thing, especially if the type of response required for the research needs to be a thoughtfully reflected one. For instance, if the researcher wishes to obtain the type of spontaneous reactions associated with face-to-face interviews then synchronous forms of interview are best. In contrast, where the research topic requires a more considered response then asynchronous methods are arguably the best. However, O' Connor and Madge (2016) suggest the ability to reflect, compose and edit a response as a possible limitation to e-mail interviewing as the drafting of answers to a question before sending it back to the researcher not only loses spontaneity but also leads to the possibility of unconsciously or indeed consciously providing a socially desirable response.

It is clear that as with any other data collection method there are some limitations to using this method in research and although these cannot be ignored there are also some significant benefits and it is because of these benefits that e-mail interviewing will be used within the current research. This research is ideally suited for this data collection method for a number of reasons, but the three most striking are that it enables the researcher to widen the sample range of participants of interest of whom, would have been lost if face to face interviews were used. The second is the fact that the participants involved in this research are users of an online forum so I, the researcher, can

be sure that they are confident in using online methods to engage in conversation in regards to this topic. Finally, the third is that there is no financial funding in the present research and so, the ability to conduct the interviews over the internet is greatly advantageous in cutting travel costs and with the rise in internet and e-mail use for research methods and for everyday use it makes sense to capture this benefit.

Chapter Four:

The Preliminary Study: Methods

This chapter will focus upon the preliminary study, incorporated to guide the main phenomenological study. This study was an online survey using standardised measures and open-ended questions, which yielded textual data for analysis. This chapter will begin by presenting a short introduction to the online survey, and will conclude with the methods used within it. The quantitative and qualitative findings of the analyses will be presented in the following two chapters; they will be split due to their difference in methodology.

4.1 Introduction

The preliminary study revolves around meeting the first overall aim and associated objective of the current research, as stated below:

“Aim 1: To identify any prevalent long-term consequences of cancer and its treatment that are experienced within a diverse sample of cancer survivors.

Objective: To conduct a survey exploring the experiences of long-term effects of cancer and its treatment amongst members of a broadly-based online cancer survivor support group”.

In order to meet these, five more specific objectives were developed for the preliminary study. These are presented below:

- Specific Objective One – To identify the relationship between cancer type and experiences of long-term consequences of cancer that impact upon one's quality of life (as measured by QLACS);
- Specific Objective Two - To explore through qualitative analysis of free text comments, the experiential accounts of how these long-term consequences of cancer and its treatment impact individuals' daily lives;
- Specific Objective Three – To identify whether a relationship exists between health anxiety (measured by the Health Anxiety Inventory) and reported quality of life (measured by the QLACS scale);
- Specific Objective Four – To identify the cancer status adopted by the participants and the relationship, if any, between it and quality of life;
- Specific Objective Five – To guide the selection process for the main phenomenological study within this research; the e-interviews.

Therefore, as mentioned in chapter three, the preliminary study is split into two parts, having a mixed methods approach, the majority of the survey

encompasses quantitative methodology (QLACS and HAI) and the remainder adapts a qualitative approach (open-ended questions).

4.2 Methods

This section of the chapter will explore the sample and recruitment techniques used, the materials employed and the overall design of the preliminary study.

It will conclude by presenting the procedure of this study including the analyses carried out.

4.2.1 Sample and Recruitment

Purposive sampling was used in the current research to enable the selection of participants based upon their personal knowledge of a particular phenomenon (Teddlie & Yu, 2007). In the case of the present research, this involved people who had personally experienced cancer whether this being once or on multiple occasions, but who were now in remission status.

In order to meet the first overall aim and associated objective of the current research, as originally presented in Chapter Two and incorporate a diverse sample to identify any prevalent long-term consequences of cancer and its treatment, participants were recruited with permission of Macmillan Cancer Support, via an advertisement within the Macmillan 'Cancer Voices' online support group (see Appendix 1). A power calculation on an approximate membership of the Cancer Voices group of around two thousand revealed

that a sample size of three hundred and twenty three participants would allow a 5% margin of error and a 95% confidence level, alongside ensuring representativeness of the population in the survey. However, this figure was not reflected in the response rates (n=89). Although this sample size was disappointing and in some areas problematic, because of the study's main aim being to inform the selection for the major study it was still acceptable to proceed with the research.

The inclusion criteria included English speaking and self-defined as being in remission from cancer. Participants also had to be competent to give informed consent. Those who did not meet these criteria or felt that they may find participation too upsetting were asked via the information sheet not to take part in the investigation. In addition to this, all participants were at least eighteen years of age as the focus of the study was on adult survivors. The experiences of child survivors of cancer and its treatment would require a separate study that is beyond the scope of the current research.

It was ethically essential to have informed consent from each participant before they participated in the online survey. In addition to this, a reminder of the research aims and the individuals' rights as a participant to withdraw themselves or their data from the research at any time was enclosed within an information sheet sent to all participants before the research began. A summarised breakdown of this phase of the research can be evidenced in figure 4.1.

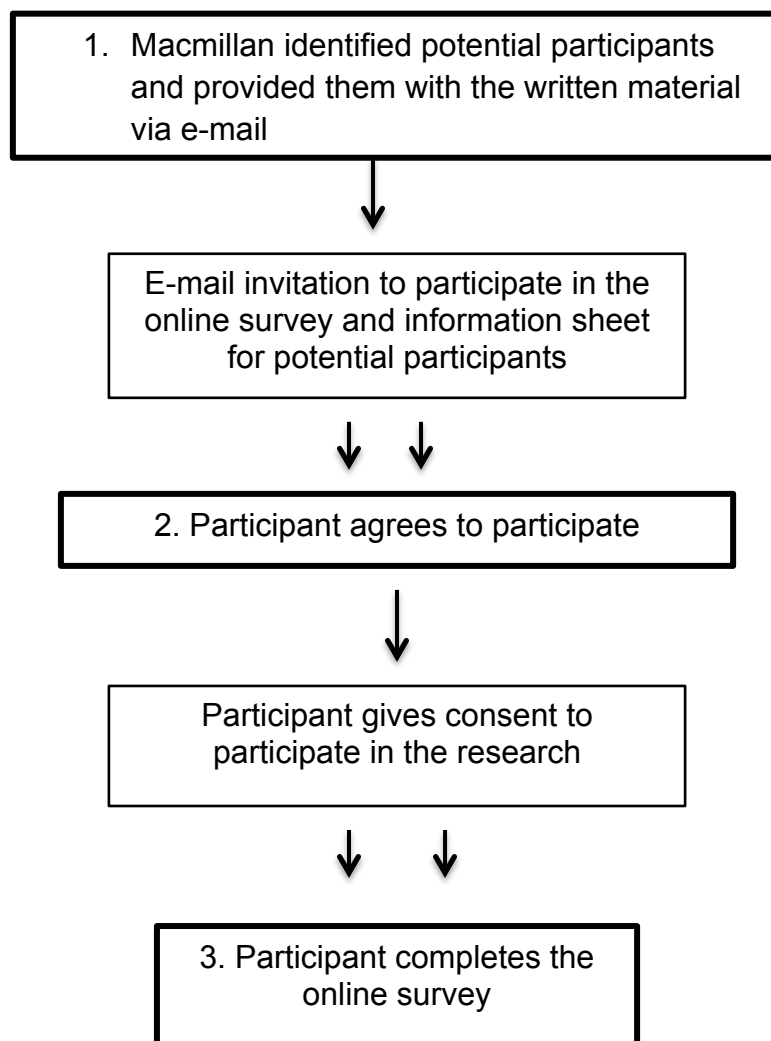


Figure 4.1: The Process of Participant Recruitment, Informed Consent and Data Collection for Phase One of the Research Project

4.2.2 Design

In order to meet the objective stated within the first overall aim of the current research, this study used a cross-sectional survey design, through an online survey (utilizing the Qualtrics online survey system) to assess the frequency

of different cancer types alongside any experienced long-term consequences following cancer and how these affected individuals' quality of life. The participants completed the survey in self-selected locations (see Appendix 2 for the full survey).

4.2.3 Measures

Demographics

Questions regarding the participants' demographics were asked in order to assess whether these had any effect upon facets within their cancer history (discussed in the following section) or upon their quality of life or health anxiety levels (also discussed in the following sections). These consisted of predominantly forced response questions with participants being asked about their gender (male or female) and marital status (single, married/civil partnership, separated/divorced, living with partner, widowed). They were also asked if they held responsibility for any other adults or children. A forced response box was presented with this question (yes or no) however, if the participant selected yes, then they were provided with a free text response box to provide information in regards to what their carer responsibilities were. Additionally a free text response box was presented with a demographic question asking for the participants' age.

Cancer History

The second half of the demographic section within the online survey consisted of questions particularly focusing upon the participants' cancer history. These were also predominantly forced response questions and were asked for both context purposes and for assessing the effects they had upon the answers gained from the demographic questions previously discussed and reported quality of life levels (which will be introduced later in this section). The participants were first asked about the type of cancer(s) they had experienced and forced response boxes (Breast, Lung, Bowel, Prostate, Skin, Blood, Bladder, Pancreatic, Oesophagus, unknown primary and other) were provided to answer this question. However, if the participant selected 'other' then they were asked to use a free text response box to state their cancer(s). This was followed with the participants being questioned about their current identified cancer status and provided with forced response boxes (a cancer survivor, cancer free, in remission, other). Similarly to cancer type, if the participants selected 'other' then they were asked to state their chosen status in the presented free text response box.

Questions regarding the stage of their cancer(s) at diagnosis and their current length of remission from that cancer were also asked. The former included forced response boxes (stage 0, stage 1, stage 2, stage 3, stage 4 and 'do not know'). The latter was first accompanied by a forced response box (years or months), and then followed with an open response box which allowed the participants to type how many months or years they had been in remission,

depending upon the answer box they clicked. Participants were also asked open questions regarding any other experienced primary or secondary cancer types, which were then followed by the same two questions as discussed above regarding cancer stage and length of remission.

Quality of Life in Adults Survivors Scale (QLACS; Avis et al., 2005)

To meet the current research's first overall aim and associated objective, the QLACS scale was used to assess reported quality of life and identify whether this was associated with the type of long-term consequences and/or cancer types experienced. The measure comprises of 47 items within 12 domains, five of these are considered to be cancer-specific (financial issues, distress regarding family, distress regarding reoccurrence, concerns regarding appearance, benefits of cancer) and the remainder, (physical pain, cognitive issues, social avoidance, fatigue, positive feelings, negative feelings, sexual issues) generic.

Participants answer each of these items via a rating scale in which, 1= Never, 2= Seldom, 3= Sometimes, 4= About as often as not, 5= Frequently, 6= Very Often and 7= Always. For instance, one question is, 'In the past four weeks you had the energy to do the things you wanted to do' and in order to answer this the participant would need to choose the one number using the rating scale in order to identify how true the statement is to them.

As stated by Avis et al (2006), the score for each of the cancer-specific domains range from 4-28 and are calculated by adding together the scores of each item within them. The scores from these domains are then added together barring that from Benefits of Cancer, to calculate the cancer-specific summary score. The score for Benefits of Cancer is reported separately.

The process of scoring in regards to each of the generic domains closely coincides with those cancer-specific, in that they consist of adding the scores of each item within the domains together. Also in line with the process for cancer-specific domains, a generic summary score is calculated by adding together the scores of each item within the generic domains however; unlike the rest, Positive Feelings needs to be reversely coded prior to this. A breakdown of the domains is presented below.

Generic:

- Cognitive Issues = the sum of items 2,3,4 and 23
- Fatigue = the sum of items 1 (reversely scored), 5, 11 and 14
- Positive Feelings = the sum of items 6, 8, 22 and 28
- Negative Feelings = the sum of items 7, 9, 19 and 24
- Sexual Issues = the sum of items 10, 12, 16 and 26
- Physical Pain = the sum of items 13, 17, 21 and 27
- Social Avoidance = the sum of items 15, 18, 20 and 25

Cancer-specific:

- Financial Issues = the sum of items 30, 37, 43 and 45
- Distress Regarding Family = the sum of items 31, 34 and 42 multiplied by 1.33
- Concerns Regarding Appearance = the sum of items 33, 35, 38 and 44
- Distress Regarding Reoccurrence = the sum of items 36, 39, 46 and 47
- Benefits of Cancer= the sum of items 29, 32, 40 and 41

QLACS is a well-known established tool and was highly suitable for this piece of research as it was developed specifically to measure the long-term issues caused by cancer and its treatment (Jacobsen & Jim, 2011). In addition to this, a plethora of research has identified the HAI as being a reliable and valid tool - Pearce et al. (2008) reviewed 42 instruments used to examine quality of life in cancer survivors and found QLACS to be the only instrument demonstrating adequate test-retest reliability. Avis et al. (2006) similarly concluded the tool to have proven test-retest reliability alongside high internal consistency. The Cronbach's alpha for the current sample was .93.

Health Anxiety Inventory (HAI; Salkovkis et al., 2002)

This measure was used to assess experienced health anxiety and reported quality of life in relation to specific aspects of experienced cancer types. It contains 18-items assessing worry about health, awareness of bodily sensations and fear of illness related consequences. Each item contains 4

statements relating to the topic of focus within it. For instance, item one contains the statements 'I do not worry about my health', 'I occasionally worry about my health', 'I spend much of my time worrying about my health' and 'I spend most of my time worrying about my health'. In order to complete the questionnaire, the participant must circle one statement out of the 4 presented, which most truly reflects their actions. Each of the 4 statements within each of the 18 items, unbeknown to the participant has a value of 0,1, 2 or 3 attached to it. Once the questionnaire has been completed the values of the selected statements are added together to create the participants' health anxiety score, the higher it is the greater the health anxiety. The HAI is also a very well known established measure with high internal consistency and reliability (Salkovskis et al., 2002) alongside, being found by Abramowitz et al. (2007) to hold good psychometric properties and construct validity. The Cronbach's alpha for the current sample was .87.

Lived Experience of Long-term Consequences Following Cancer and its Treatment

The final step towards ensuring the current research's first overall aim and associated objective was met, was bringing the online survey to a close through asking the participants four open-ended questions regarding their experienced long-term consequences of cancer and its treatment, before presenting them with a final free text response box enabling them to share anything they wish, that had not been addressed. The four open-ended questions are:

- “Please briefly describe the three consequences of cancer and its treatment that cause you the most concern”
- “Please explain your experience of these three consequences and how they impact your daily life”
- “What, if anything, has surprised you in your journey of living with cancer? Please explain your answer.”
- “What, if anything, has surprised you in your experience of living with long-term consequences from cancer and its treatment? Please explain your answer.”

These questions were included in the survey in order for the lived experience of the participants’ long-term consequences to be explored.

4.2.4 Procedure

A paper version of the survey was piloted first, with an opportunistic sample of five individuals in the remission phase of their cancer experience. The purpose of this was not to test the QLACS (Avis et al, 2005) but rather to identify and address any issues that arose regarding comprehensibility and acceptability in relation to the survey as a whole. It must be noted, that at this point, the HAI (Salkovskis et al., 2002) was not part of the survey and the reason as to why it was decided to incorporate it will now be discussed.

The data I received from these pilots showed that my open questioning technique was successful and that the QLACS measure was perfect for what I wished to explore. However, it did come to my attention that some individuals, even after many years of being in remission from their experienced cancer, still felt and experienced much negativity in relation to the long-term consequences of cancer and its treatment.

It was due to this, that I felt that the survey was missing something and so, I then focused on finding an established tool to measure health anxiety. This was because the survey as it stood, had no way of identifying whether participants felt and experienced such negative consequences because they had high health anxiety levels and vice versa. The addition of this was not a necessity to the research as my aim is to explore individuals' experiences of cancer and its treatment. However, I believed it would be interesting to investigate the association between health anxiety and the lived experiences of the explored long-term consequences. After researching appropriate tools I decided upon incorporating the Health Anxiety Inventory (HAI, Salkovskis et al., 2002) into my survey.

The survey was then piloted online using the Qualtrics program, using three individuals currently in remission from their cancer experience. Two of these were participants who had participated in the paper pilot, but were used to gain identified comparisons between the paper and online format. As well as similarly addressing any potential issues not identified in the initial paper version pilot, this was additionally undertaken to test the comprehensibility

and acceptability of the online format. The pilots showed that the Qualtrics program was the right software to use for my research as the participants found it very easy to access and use, similarly to the paper version of the survey.

An information sheet and consent form were built into the survey and participants were instructed to read the information displayed in both before clicking 'I Consent' to provide their consent to participate before beginning the survey itself (see Appendix 2 for the used information sheet and consent form). Originally, it was planned for the survey to be 'live' and available to complete online for one month. However, recruitment showed to be slow as it began to reach the Christmas period. Therefore, the timeframe was extended a further month. Macmillan sent out a blanket message to all the members of the Cancer Voices online support group, reminding them about the survey every two weeks during the period of it being live. At the end of the survey, participants were asked whether they would be willing to take part in an e-mail interview to explore issues in more depth. Those willing to be considered were asked to provide a contact e-mail address.

4.2.5 Ethical Considerations

The preliminary study follows the British Psychological Society's (BPS) ethical guidelines in line with their code of conduct: informed consent, confidentiality, protection from harm, right to withdraw from the study, right to withdraw data, and the right for them to remain anonymous.

Informed consent was addressed as participants were presented with a consent form, which they had to read and sign, by clicking on a consent button, before they were given access to the online survey.

Confidentiality was ensured by the preliminary study in a number of ways. For instance, the survey responses were saved within the Qualtrics software with only me knowing the password to attain them. Furthermore, when the qualitative data within it was transferred to a word document, they were saved on my personal computer at home to the e-mails containing the interview data were all sent to my student e-mail address and there was and will be, only me who knows the password needed to access the e-mail account.

Due to the research exploring a particularly sensitive research topic, more so, through the qualitative aspects of the survey, protection from harm was paramount during the preliminary study. Due to the range of emotions that could arise from this participation, no one support service was presented to the participants in case they felt affected by the survey. Instead, the participants were asked to simply contact my main supervisor or me if they had any issues or queries, which we could then address.

Right to withdraw was addressed within the information sheet that was provided to the participants, prior to their participation within the online survey. It was stated that participants could withdraw at any time throughout their participation, if they so wished, without any need for explanation.

The participants' right to withdraw their survey data was also addressed within the information sheet which they were presented with, before they were given access to the online survey. Within this, they were given a specific date by which this needed to be done by.

Finally, the right to remain anonymous was ensured as each participant was given a pseudonym in the saved word documents containing their data (which, as previously stated, were all saved on my personal computer that is password protected). The consent and information sheets were all online, meaning no paper ones were needed and are all saved to my e-mail account and personal computer.

4.2.6 Statistical Analysis

SPSS version 20 was used to analyse the data. One-way ANOVA's were carried out to assess a number of factors. The first was to assess the effect of cancer type upon reported quality of life levels. A one-way ANOVA was performed to assess whether there were any differences in age between the different cancer types. A one-way between-subjects ANOVA to assess the effect of identified cancer status upon reported quality of life levels using the IV; cancer status, was carried out next. In order to provide context to the data, a Pearson's product moment co-efficient was used to assess if any relationship lay between reported quality of life levels and reported health anxiety levels. Finally, an independent samples t-test was carried out to compare the differences, if any, in reported quality of life scores between male

and female participants.

4.2.7 Qualitative Analysis

The qualitative data was retrieved from the two previously mentioned, open-ended questions concluding the online survey. No transcription was needed because each response was submitted electronically using the Qualtrics computer software program. However, in order to manage and organise the data in an appropriate and efficient manner, each individual response was copied, saved and stored on to a password protected word document assessable only to those involved in the research.

Template analysis (King, 2004) is a thematic method that centres itself upon analysing qualitative textual data that has been conducted within real-world settings (King & Brooks, 2017) and focuses upon the use of hierarchical coding. As mentioned in the previous chapter, Template Analysis (King, 2004) is not bound to any one particular theory of knowledge but can be tied to a variety of epistemological positions, this is advantageous as it enables researchers to adapt the technique to fit the needs of their study (Brooks, McCluskey, Turley & King, 2015). Template analysis does share some similarities with alternative thematic methods such as Grounded Theory (Glaser & Strauss, 1967), Interpretative phenomenological Analysis (IPA) (Smith, 1996) and Content Analysis (Weber, 1985).

This method of analysis is very flexible and involves using a subset of data to

produce a coding template which is then, in turn, applied to the remainder of the dataset and revised until appropriately fitting (Brooks et al, 2015).

Template Analysis (King, 2004) in comparison to alternative thematic analysis methods also encourages the researcher to delve into greater depths within the coding process and can lead to one or more main theme(s) within the data to consist of numerous further sub themes with each elaborating on a distinctively different factor within the identified main theme (King & Brooks, 2017). The method also relies strongly on the continuous re-reading of gathered data in order to ensure the developed template is accurate.

Therefore, it is important for accurate and precise transcripts of the gathered data to be held by the researcher. King and Brooks (2017) present seven clear set steps that must be followed accurately to conduct the analysis, these are as follows:

- 1) Familiarisation with the gathered data - Prior to beginning any coding, King (2004) expresses the importance of undertaking multiple readings of the transcribed data in order to become fully immersed in it.
- 2) Preliminary Coding - Transcripts are read line-by-line and material of relevance to the research question(s) is coded with a word or short phrase capturing what is of interest. Template Analysis allows the use of tentative *a priori* themes, based on the researchers knowledge of the literature, their own previous research and/or real-world concerns of the study (e.g. evaluation criteria). Where data 'fits' with *a priori* themes, it is noted at this stage.

- 3) Clustering - At this phase, the preliminary coding - including both emerging and a priori themes – is reviewed, and initial versions of the themes defined. These are grouped together in ways that appear meaningful with the data and possible hierarchical relationships between themes are highlighted.
- 4) Producing a Draft Template – It is normal in Template Analysis for the above two steps to be carried out on a subset of the data. At this stage, the clusters of themes and sub themes are used to develop an initial version of the coding template, which may be represented in diagrammatic form. This will show both hierarchical relationships within clusters and (where identified) lateral relationships across clusters.
- 5) Template Development – At this point, the template is then applied to the remaining data and amended as appropriate in order to ensure that all of the relevant and important data is captured within it. There may be several iterations of the template as it is tried out on a further subset of data, modified, then tried out again.
- 6) Applying the Final Template – This stage is reached when no further amendments are required to the template and all data relevant in order to answer the research question(s) is highlighted within it. At this point, the final version of the template has been formed and it can be used to make sense of, and interpret the data.

7) Writing Process – This phase is reached once all interpretation has taken place and involves the final template being used to aid the organisation of the presented analysis/results.

In this preliminary study, as previously mentioned, no transcription was needed because each response was submitted electronically using the Qualtrics computer software program. However, in order to manage and organise the data in an appropriate and efficient manner, each individual response was copied, saved and stored on to a password protected word document assessable only to those involved in the research. This is advantageous as all responses gained throughout are typed, meaning that it is impossible for any data to be lost in the transcription process, as one was not needed.

Each individual's submitted responses were read and reread until I felt highly familiar with the data. I began the analysis process with preliminary coding of the data from the first 20 participants; no *a priori* codes were used in the preliminary study. Following van Manen's (1990) suggested line by line approach I began to search for any specific clusters of text which appeared to reveal any significance or potential in enabling me to gain a sound understanding of the meanings each individual had attached to their experiences of the phenomenon. This enabled me to gain an insight into the explored phenomenon alongside identifying the different meanings attached by each individual to the experience. This process of preliminary coding resulted in highlighting particular sentences, phrases or paragraphs that, I

thought signified a form of meaning of the phenomenon and could contribute to the analysis. At this stage, I delved further into the data and began to cluster the coding segments together, transforming emerging themes into more clearly definitive ones, which resulted in the development of an initial coding template. These codes were then compared and contrasted to previous available literature focusing on the explored phenomenon; this in turn helped inform template development as I was able to identify which codes supported what had been previously found and which provided a new insight into the phenomenon.

The template developed from this, was then utilised on the remaining data. This involved examining each text response individually for the first twenty data sets before considering whether any of the existing themes on the developed template failed to represent the text in a meaningful manner. Whilst progressing through the data, notes on possible revisions of the template were made, particularly in instances where it appeared that new themes needed to be added or that particular existing themes proved to be redundant. This resulted in modification of the template occurring throughout its application to the remaining data on numerous occasions, as the sample was quite large in size. The eventual success in applying the modified template to the whole data set signified that the coding process was complete as a finalised template had been produced and further modifications were no longer needed. During the development of this final template, a number of changes occurred. For instance, thirteen major themes were identified in the initial template (please see Appendix 3), these, through numerous template

drafts in which different major and sub themes were explored, were condensed down to three for the final template, but encompass further sub themes within them, that allow for a wider range of exploration. Some of these sub themes were broken down to create further themes, with this process continuing until all the interesting areas of the phenomenon had been addressed. The finalised template can be seen in figure 4.2 however, this did not mark the end of the analysis, as it was at this point that I needed to use the finalised template in order to begin to make sense of the data presented to me and interpret the meaning attached by the participants to the different themes within it in order to be able to understand the results I had gained.

Chapter Five:

The Preliminary Study – Statistical Analyses Findings

There were a total of 90 respondents for the “Long-term Consequences of Cancer and its Treatment” survey. However, six participants had to be disregarded due to insufficient responses within the survey, resulting in 84 participants available for analysis. Within the 84 responses, some questions still remained unanswered which, may be reflected in some of the analyses, particularly the statistical ones. However, these were kept as they still held rich responses within them.

5.1 Quantitative Findings

The most common cancer type identified in the responses was breast cancer (n=23). Table 5.1 illustrates the demographic information of all the cancer types presented within the survey.

Table 5.1

Descriptive Statistics on the Presented Cancer Types

Cancer Type	Number of Participants (%)	Gender	Mean Age	Age Range	Months in Remission
Breast	23 (27.4%)	22 Female 1 Male	55.1	36-85	47.4
Lung	2 (2.4%)	2 Male	65.5	62-69	65.5
Bowel	10 (11.9%)	6 Female 4 Male	57.8	31-76	62.5
Prostate	4 (4.8%)	4 Male	63.3	59-69	48
Skin	2 (2.4%)	2 Female	50.0	44-56	128
Blood	6 (7.1%)	5 Female 1 Male	52.7	26-68	116.7
Bladder	1 (1.2%)	1 Female	54	54	36
Pancreatic	1 (1.2%)	1 Female	40	40	19
Oesophagus	1 (1.2%)	1 Male	68	68	60
Renal Cell Carcinoma	4 (4.8%)	4 Male	58.8	52-79	1.5
Squamous Cell Carcinoma	1 (1.2%)	1 Male	59	59	67
Testicular	4 (4.8%)	4 Male	52.5	38-64	97

Non-Hodgkins	5 (6%)	3 Female	56	50-63	45
Lymphoma		2 Male			
Acnic Cell	1 (1.2%)	1 Male	46	46	84
Carcinoma					
Womb	2 (2.4%)	2 Female	53	51-55	41
Ovarian	5 (6%)	5 Female	52	39-67	28.2
Head and Neck	2 (2.4%)	2 Male	47.5	44-51	59
Rectal	1 (1.2%)	1 Male	59	59	40
Adenoid Cystic	1 (1.2%)	1 Female	36	36	_N
Carcinoma					
Giloblasta	1 (1.2%)	1 Male	57	57	99
Multiframe					
Cervical	2 (2.4%)	2 Female	37	27-47	169.5
Bone	2 (2.4%)	2 Female	23.5	21-26	77.5
Lymphatic	1 (1.2%)	1 Female	42	42	59
Endometrial	1 (1.2%)	1 Female	45	45	62
Acute Myeloid	1 (1.2%)	1 Female	63	63	118
Leukaemia					

_N = months in remission not specified

In order to facilitate statistical analysis, it was decided to collapse the cancer types into groups in order for accurate and efficient analysis to be conducted. Therefore, by thoroughly exploring the 25 original varying cancer types presented it was decided that these could be collapsed into 5 groups; Breast (Remained the same as previously presented), Male Reproductive Cancers (Prostate and Testicular), Blood (Non-Hodgkins and AML), Gynecological (Womb, Ovarian, Cervical and Endometrial) and Other (Lung, Bowel, Skin, Bladder, Bone, Pancreatic, Oesophagus, Renal Cell Carcinoma, Squamous Cell Carcinoma, Head and Neck, Rectal, Adenoid Cystic Carcinoma, Acinic Cell Carcinoma, Glioblasta Multiforme and Lymphatic Cancers). Table 5.2 presents the demographic information for the collapsed cancer types.

Table 5.2

Descriptive Statistics on the Collapsed Cancer Type Groups

Cancer Type	Number of Participants (%)	Gender	Mean Age	Age Range	Months in Remission
Breast	23 (27.4%)	22 Female 1 Male	55.1	36-85	47.4
Male	8 (9.6%)	8 Male	57.9	38-69	76
Reproductive Cancers					
Blood	12 (14.3%)	9 Female 3 Male	54.9	26-68	86.9
Gynecological	10 (11.9%)	10 Female	48.6	27-67	62.4
Other	31 (36.9%)	14 Female 17 Male	53.1	21-79	58.5

5.2 Cancer Type and Quality of Life

A one-way between-subjects ANOVA was conducted on the collapsed cancer types to evaluate the effect of identified cancer type on levels of quality of life assessed via the QLACS data. The independent variable was cancer type, which consisted of five levels; breast, male reproductive cancers, blood,

Gynecological and other. Levenes test for homogeneity of variance was not significant ($P = .977$) ensuring homogeneity of variance and meaning that a one-way ANOVA was a practical choice of test as all assumptions were met. Table 5.3 illustrates the identified relationship between the collapsed cancer types and perceived quality of life.

Table 5.3

Descriptive Statistics for the Relationship between Cancer Type and Quality of Life

Cancer Type	Quality of life score	
	Mean	SD
Male Reproductive Cancers	155.71	44.67
Breast	170.14	37.49
Blood	180.20	38.82
Gynaecological	174.22	42.29
Other	181.65	43.85

There was no statistically significant differences in quality of life depending on cancer type, $F(4, 65) = .644$, $P = .63$.

5.3 Cancer Type and Age

A one-way ANOVA was conducted to assess whether there were any differences in age between the cancer types. This exhibited a non significant levenes ($P = .57$), ensuring homogeneity of variance and again identifying a one-way ANOVA the practical choice of test as all assumptions were met.

Table 5.4 illustrates the mean age for each cancer type group.

Table 5.4

Descriptive Statistics Showing the Collapsed Cancer Type Groups and Age

Cancer Type	Age	
	Mean	SD

Male Reproductive	57.88	9.72
Cancers		
Breast	55.13	11.71
Blood	54.92	11.70
Gynecological	48.60	11.35
Other	53.13	14.25

There was no statistically significant differences in cancer type depending on age, $F(4, 79) = .751$, $P = .56$.

5.4 Cancer Status and Quality of Life

The most used identification was "cancer survivor", this was followed by "in remission", "cancer free" and finally, "other". It was found that the most common reasons behind identifying as "other" are because individuals preferred the term "No Evidence of Disease" or because they "did not understand how to define each term" presented. Table 5.5 demonstrates the frequencies of each identified cancer status within this data on identified cancer status was based on the responses of 83 participants as one individual did not disclose their perceived status.

Table 5.5

Identified Cancer Status Frequencies

Identified Status	Number of Participants (%)
Cancer Survivor	N=46; 54.8%
Cancer Free	N=8; 9.5%
In Remission	N= 20; 23.8%
Other:	N=9; 10.8%
<i>Still Living with Cancer</i>	N=1; 1.2%
<i>Breast Cancer Treated</i>	N=1; 1.2%
<i>Confusion Over Definition</i>	N=2; 2.4%
<i>Living with Long-term Consequences</i>	N=1; 1.2%
<i>No Evidence of Disease</i>	N=2; 2.4%
<i>Had Treatment for Cancer</i>	N=1; 1.2%
<i>Cancer Patient</i>	N=1; 1.2%

Following this, a one-way between-subjects ANOVA was conducted to evaluate the effect of identified cancer status on levels of quality of life. The independent variable (IV) was cancer status and had ten levels: cancer survivor, cancer free, in remission, still living with cancer, breast cancer treated, confusion over definition, living with long-term consequences, no evidence of disease, had treatment for cancer and cancer patient. Levenes test for homogeneity of variance was not significant ($P = .945$) ensuring homogeneity of variance and meaning that a one-way ANOVA was a practical choice of test as all assumptions were met. Table 5.6 demonstrates the relationship between each identified cancer status and perceived quality of life.

Table 5.6

Descriptive Statistics Showing the Relationship between Identified Cancer Status and Quality of Life

Identified Status	Quality of Life Score	
	Mean	SD
Cancer Survivor	177.77	41.79
Cancer Free	175.13	47.33
In Remission	159.00	40.99
Other: Still Living with Cancer	159.00	_A
Other: Breast Cancer Treated	214.00	_A
Other: Confusion Over Definition	178.50	36.06
Other: No Evidence of Disease	195.00	53.74
Other: Had Treatment for Cancer	172.00	_A
Other: Cancer Patient	177.00	_A

A = N is 1

'Other: Living with Long-term Consequences' is missing, as the individual within it did not complete the QLACS scale

There was no statistically significant differences in quality of life depending upon identified cancer status, $F(8, 60) = .449$, $P = .887$.

5.5 Quality of Life and Health Anxiety

In order to fully understand all the collected data, the relationship between quality of life scores and health anxiety scores was explored through a Pearson product-moment correlation coefficient. Preliminary analyses were performed to ensure no violation of the assumptions of normality, linearity and homoscedasticity. Table 5.7 demonstrates the relationship between quality of life and health anxiety scores.

Table 5.7

Descriptive Statistics Showing the Relationship between Quality of Life Scores and Health Anxiety Score

Scores	Mean	SD
Quality of Life	174.44	40.76
Health Anxiety	19.42	7.54

The results indicate a large, positive correlational relationship between the two variables, $r = .62$, $n = 70/84$, $P = <.001$ with high health anxiety scores being associated to high quality of life scores (lowered quality of life).

5.6 Gender Differences in Quality of Life Scores

An independent samples T-test was conducted in order to compare the quality of life scores for male and female participants. The levene's test of homogeneity produced a non-significant result ($P = .145$) ensuring homogeneity of variance and Identifying an independent samples t-test the

practical choice of test as all assumptions were met. Table 5.8 demonstrates the relationship between Gender and quality of life scores.

Table 5.8

Descriptive Statistics Showing the Relationship between Gender and Quality of Life Scores

Gender	Quality of life score	
	Mean	SD
Male	164.41	46.66
Female	179.04	37.38

Although female participants' quality of life scores were higher than males, there was no statistically significant differences between the scores of the male and female groups, $t(68) = -1.40$, $P = .165$.

Chapter Six:

The Preliminary Study – Template Analysis Findings

The qualitative aspect of the survey is comprised of four open-ended questions accompanied by free text response boxes. A further free text response box was also presented enabling individuals to write anything they wish to share about their long-term consequences experience, that had not already been covered. Template Analysis was used to analyse the gathered responses and the findings from it will now be presented,

The three major themes identified are *Selfhood*, *Support* and *Unpreparedness*. Each of the identified themes will now be presented and discussed in depth.

6.1 Selfhood

In popular understanding it may be expected for the experience of cancer and its treatment to alter one's perceived sense of self and this can be evidenced throughout the answers to the open-ended questions. This change appears to be positive or mixed for the majority of cancer survivors with only a minority stating it to have an extremely negative effect. Furthermore, the remaining small number of individuals, report that the experience of cancer and its treatment did not change their perceived selfhood at all. Therefore, *Selfhood* is comprised of two sub themes; *New* and *No Change* with three further sub

themes under *New: Positive, Negative and Mixed*. The further sub themes, *Positive* and *Negative* both hold numerous further sub themes within them. However, due to the mass of further sub themes, the decision was made to encompass them all under first mentioned further sub themes; *Positive* and *Negative*, in order to avoid any confusion. Therefore, meaning all the factors showing to cause a positive change in one's selfhood will be discussed as one under *Positive* and all the factors that highlight a negative alteration in selfhood will be encompassed under *Negative*. Please refer to the previously presented figure 4.2 for a full breakdown of the entire list of further sub themes encompassed with *Positive* and *Negative*.

6.1.1 New

As previously mentioned, the majority of participants expressed themselves to feel their perceived selfhood to alter, creating new aspects to their sense of self, following their cancer experience. The ways in which this new experienced sense of self show to be positive amongst participants will be explored first, with the ways in which it demonstrates negative aspects to be created, following.

Positive

Many cancer survivors express for their sense of self to become more admirable following their cancer experience. There were numerous reasons

behind this transformation and these will be now be discussed within this section.

A number of participants imply for the experience of cancer and its long-term consequences to make them in to more worthy individuals and so, have a heightened sense of self worth following cancer and its treatment. This can be directly evidenced when Sasha (Bowel Cancer) states,

I would never have said that I am a good person or an inspiration but because of cancer, this apparently is what I have become and it's quite overwhelming and I'm proud of what I have achieved

The above suggests Sasha to describe the feeling of a 'more worthy' sense of self, following her cancer experience. By using the phrase, 'what I have become', Sasha indicates that she did not feel this sense of self-worth prior to cancer. This suggests that her perceived selfhood altering in to one more positive is due to her cancer experience. However, the manner in which the word 'apparently' is used in Sasha's statement implies that 'being a good person' and an 'inspiration', are things that other people have led her to believe she has become. Therefore, Sasha appears to be judging herself on the perception of what others believe, rather than what is personally felt to be the case.

A second example of a statement supporting a more worthy sense of self is by Barry (Blood Cancer), who states,

My outlook on life has radically changed. I am far more optimistic and laid back about minor problems now. I am also more sympathetic to the needs of others. For instance, I do voluntary work with a local community group that supports adults with learning disabilities; I can't even imagine me even considering that before I was diagnosed with cancer

This echoes Sasha's described new 'more worthy' sense of self, following the experience of long-term consequences of cancer and its treatment. However, it also describes a more positive orientated sense of self as contributing to the reason behind his perceived selfhood appearing more positive. This view also appears to be shared by a number of participants as Bonny (Breast Cancer) states that she is,

Surprised at how positive it [cancer] has made me. I have changed for the better; much more relaxed about life and can absolutely take the positive out of a fairly negative experience

This suggests that she did not hold this relaxed outlook on life prior to cancer and because she does now, her new sense of selfhood appears to be more positive.

Similarly to this, Sophie (Breast and Bowel Cancer) also says that she has "mellowed a lot and don't stress the small things as much", showing that like

Bonny, she has also experienced new positive aspects within her sense of self as she is more optimistic in potentially challenging situations.

Additionally, the statements of Barry, Bonny and Sophie, suggest a new perspective on life being gained following their cancer experience, which is perceived as a new positive aspect to their selfhood.

There are additional statements provided by different participants that support an experienced positive change in perceived selfhood to be due to individuals gaining a new perspective on life from their cancer experience. These statements can be evidenced in table 6.1.

Table 6.1

Statements Illustrating How a New Perspective on Life Following One's Cancer Experience Demonstrates New, Positive Alterations to Perceived Selfhood

Name	Cancer Type/s Experienced	Quote
Katie	Bone and Non Hodgkin Lymphoma	You feel grateful for every day and that despite having other serious health issues you can still be part of the world
Edith	Bowel	I can see the bigger picture and try not to let things get me down
Leila	Breast	I am more positive in the main and appreciate every day
Danielle	Ovarian and Womb	It makes you grateful for every day and more aware of living in the present

Trevor	Lung	Perspective on what's important in life, relationships and friends, enjoy and live for the moment. So many good and beautiful people out there you just have to look
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Moving forward, a couple of individuals express one reason their perceived selfhood has changed into one more positive is because they have gained more confidence in themselves following their experience of cancer. This is shown in the response of Edward (Non Hodgkins Lymphoma), as he states that he has turned from “introvert to extrovert and no longer suffers fools gladly”.

Similarly to this, Annabelle (Breast Cancer), continues the theme of heightened confidence being the reason behind a positive change in self. For instance, she states,

I am willing to put myself in the public eye- to be a voice for cancer. I used to be very shy!

The above suggests both Edward and Annabelle to describe a new ‘action-orientated’ sense of sense with them both demonstrating this to have altered their perceived selfhood for the better.

Annabelle's mention of being a voice for cancer brings us on to next factor associated to a new positive sense of selfhood following cancer; career change. The present research will refer to the term career using the definition:

A job undertaken by an individual for a significant period of time within their life, which also has opportunities for progression (English Oxford Dictionary, n.d.)

Many individuals within the survey suggest new career involvement within cancer organisations during their survivorship to result in their sense of self becoming more positive. For instance, Natalie (Womb Cancer) states she is surprised at,

How passionate I have become about getting involved in cancer related activities... Macmillan buddy, Cancer voices, reviewing books, online chat and joined my local gynae support group and planning retirement activities around voluntary work with Macmillan etc. Thought I would not want to be involved once I was cancer free but so many are affected by it that it seems a whole new world to get involved in- in a very positive way and not depressing at all.

This shows Natalie's sense of self, appearing to change to one more positive through her experience of cancer. This is because her cancer journey has introduced her to the voluntary opportunities available throughout the different cancer organisations. These opportunities, in turn, appear to show Natalie's

cancer experience to alter to sense of self to one more focused upon helping other individuals compared to her pre cancer self.

The final factor evidenced within the survey data contributing to a positively altered sense of self is healthy lifestyle changes. Although this section is relatively short as only one individual has stated this experience, it is still an arguably interesting factor as Julia (Breast Cancer), states that she,

Adopted a healthier diet and lifestyle, including yoga and meditate on groups, which have gradually become more accepted by my family and friends. Most recently, I have been on a silent retreat and I would never have imagined I would do that. Cancer transformed my life for the better. I take better care of myself. I can honestly say I feel fitter and healthier than before!

The above quote of Julia's can be suggested to be extremely interesting as it demonstrates how an individual can face such a traumatic illness; cancer, but use the experience of it to draw out the positives in life rather than focusing on what could have been. Therefore, highlighting a future-orientated sense of self to have developed and her to hold a glass half full persona. The above statement also describes a new appreciation of life sense of self as Julia's cancer experience has caused her to adopt a much more healthy lifestyle suggesting her to value her life more due to her cancer experience.

The data presented within this section highlights a focus more upon existential change within one's selfhood rather than physical change. It also suggests a new sense of mindfulness alongside, present moment awareness to be experienced.

Negative

In contrast to positive alterations to selfhood, some participants suggest their cancer experience to change their sense of self into one less desirable.

One manner, in which this is evidenced, is through the description of a new 'loss of masculinity' sense of self. The most direct comment supporting this is by Harvey (Rectal Cancer), who when speaking about his experience of the long-term consequence; sexual difficulties, says that because of them, "I am no longer the man I was".

This suggests Harvey to feel his experienced long-term consequence has stripped him of his masculinity and highlights a significant negative alteration to his perceived selfhood.

More indirectly, a couple of participants suggest lowered confidence levels to be the reason behind their negatively altered selfhood. For instance, Kirsty (Ovarian Cancer) states,

I was hardworking, confident and loving life before, now it all seems such a big effort and my confidence has nose dived to the point that I

can't cope with the basics. My tolerance level has dropped to zero too
which has surprised me

This suggests that the experience of long-term consequences of cancer and its treatment has caused Kirsty to experience lowered confidence, which in turn has changed her from a confident, hardworking and happy individual to one that cannot cope with basic daily tasks. Expressing that she is now much more easily frustrated than usual is also interesting because it could be a result of the inability to "cope with the basics" however, in order to investigate this, further research would be needed. Additionally, it is of interest as it is a view shared by other participants.

For instance, a new sense of 'ill temperedness' and 'lowered confidence' within one's self can also be evidenced when Mark (Head and Neck Cancer) says that the experience of long-term consequences of cancer and its treatment,

Has reduced my confidence in being able to do a full time job- I am self employed. Infrequent periods of extreme mental low, depression? Very grumpy, irritable, unsociable, withdrawn

This shows that Mark's post cancer self has new mental health and emotional issues that were not present prior to cancer which cause him to withdraw himself from others. Similarly to Kirsty, Mark also demonstrates his emotional issues to involve being less tolerant of things. These highlighted changes to

Mark's perceived sense of self, are therefore, suggested to be negatively perceived.

In line with this, Ryan (Bowel Cancer) also shows withdrawal to be a factor contributing to his negatively altered sense of self. For instance, in regards to his long-term consequences he says,

I enjoy the countryside, keen fly fisherman and golfer, but I am quite anxious to venture too far off the beaten track these days

This suggests that before cancer, Ryan was very active and adventurous however, due to his cancer experience his sense of adventure appears to have been lost due to psychological issues caused by his experienced long-term consequences. This suggests him to have a more cautious sense of self due to a loss of confidence in his abilities, resulting in him withdrawing from certain activities that, prior to cancer would not have been an issue.

Continuing this, Faye (Non Hodgkins Lymphoma) also suggests lowered confidence in her abilities, due to her experienced long-term consequences to result in a negatively altered sense of self. For example, she states,

I was on a fixed term contract when I was diagnosed and my contract ended soon after I moved into remission ... I've been trying to get a job and each interview is another blow to my self- confidence ... I

sometimes wonder whether I'll fall apart when I do get a job and have to deal with those stresses

This, in line with the previous comments, suggests long-term consequences to have lowered Faye's self-confidence. Directly in line with Mark, this damaged self-confidence sense of self is suggested by Faye to have negatively influenced her career as she doubts her abilities to perform her role with each attempt to get back in to work, further damaging her shattered confidence. Therefore, creating a vicious cycle.

More directly, Tim (Glioblastoma Multiframe) states outright that cancer "has wrecked my career". He does not provide any reason behind this and so no associations can be made like for Faye and Mark, as these would be pure speculations. However, he does also state that,

To avoid embarrassment a journey has to be planned. Go to the loo before a journey/meeting, where is the nearest loo? And if all else fails...

Therefore it is possible that may be Tim's toilet issues as a result of cancer and its treatment may be a reason behind the feeling of his career being 'wrecked' however, more research would need to be conducted upon Tim in order to accurately identify if this is the case.

Fear of cancer reoccurrence is another long-term consequence of cancer and its treatment associated to negative changes of one's sense of self. This is because, many participants express their fear of cancer returning and the impact this will have upon their future. This is interlinked in some aspects with the previous 'career change' factor as both can signify future anticipations. Therefore, the career change factor will intertwine within this sections focus upon how new anticipations for the future arising from one's cancer experience, negatively altering their sense of self.

The most direct statements evidencing fear of cancer reoccurrence is by Annabelle, who states,

I sometimes lay awake at night worrying about the future... I question every ache or pain in case it's a symptom of the return of the disease

And, by Janice (Breast Cancer), who states,

I still think about cancer nearly every day just small dripping thoughts and so I feel I have developed a habit of wondering if and when it will return

This shows that the experience of cancer and its treatment has caused Annabelle and Janice's sense of self to change to one that is severely anxious about their health, fearing in particular the return of cancer. This perceived

health anxiety is strongly associated to the experience of cancer and so, demonstrates how it has negatively altered their sense of self.

A statement showing that both fear of cancer reoccurrence and career change interlink with one another can be evidenced in the speech of Harriet (Breast and Melanoma) who says,

I lost full time work when on a phased return from the second cancer- now self employed with plenty of freelance work but worried what will happen if I get ill again because I'm the only breadwinner and we have large debts

This highlights that cancer and its treatment has negatively affected Harriet's career in the past, thus making her worry about her finance and career situation if she was to develop cancer a third time as she is scared that her family would struggle if she could not work. This therefore, highlights a new health anxious sense of self like suggested by Annabelle and Janice alongside, the fact that 'career change' and 'fear of cancer reoccurrence' are interlinking factors in regards to causing a negative change to one's perceived selfhood following the experience of cancer.

On going symptoms following cancer and its treatment also appear to be a reason for one's sense of self to be negatively altered. For instance, a number of participants appear to experience on going digestive issues following

cancer treatment. An instance where this is evidenced is in the response of Tom (Squamous Cell Carcinoma), who states,

There are certain foods I cannot eat and this affected my social life. I do not get invited out for a meal, as people don't know what I can or cannot eat

This highlights a negative change in selfhood as Tom's long-term consequences have restricted his diet and social life and therefore caused Tom to withdraw from the social group alongside being socially isolated by others. Therefore, highlighting a new withdrawn sense of self.

Similarly, the following statements from Corrine (Breast Cancer) and Kadey (Breast Cancer) refer to weight gain as a result of cancer and its treatment; both present this as causing their sense of self to negatively alter.

Corrine: Weight gain is causing aches and pains and I hate the way I look

Kadey: The weight gain makes me feel less confident and not as energetic as previously felt

The above statements highlight the fact that the long-term consequence; consequential weight gain has created a new 'self conscious' sense of self

which is demonstrated to have negatively altered their perceived selfhood as they relate it to body image and confidence issues.

Similarly to Corrine, the on going symptom of pain seems to be evidenced by Jean (Breast Cancer), who states,

I am in chronic pain at all times and that has saddened me greatly as I struggle to do most things now

However, Jean also appears to experience some depression symptoms due to her on going pain issues following cancer and its treatment, showing how long-term consequences can be physical but cause psychological concerns. From this, it is suggested by Jean, for the experience of cancer to have negatively altered her perceived selfhood through describing a new 'restricted' sense of self.

The final on going symptom of cancer to be discussed is on going emotional issues. For instance, Mandy (Cervical Cancer) suggests her perceived selfhood has changed in a negative manner, as she can no longer control her emotions. This is shown when she is speaking about how her long-term consequences have affected her and identifies a

Struggle with getting upset, something I had no trouble with before cancer

This suggests a new negative ‘emotionally unstable’ sense of self to have been formed due to her experience of cancer and its long-term consequences.

Overall, the above statements suggest that the experience of cancer and its treatment has changed some people’s identity for the worse as it has caused them to experience lowered confidence levels, negative anticipations for the future, especially regarding career change and fear of cancer reoccurrence and on going symptoms of cancer; digestive issues, weight gain, pain and emotional instability.

Mixed

Many individuals during the survey data expressed how their sense of self had changed following their cancer journey but that it was neither solely positive nor negative and instead, was a mixture of the two, with some aspects of their new self, being positive and others, negative. A minority of these cases will be discussed below.

The first example is Demi (Endometrial Cancer), who suggests to suffer from “a lack of intimacy” with her husband as a result of her long-term consequence; sexual difficulties. This being, as she states,

radiotherapy left a lot of internal scarring which I was not warned about and which makes me nervous about sex, as well as not being able to enjoy it as I used to

This shows negative alterations to her daily life alongside, highlighting her unpreparedness of them due to a suspected lack of care provided to her. However, this experience does not appear to have any impact upon her sense of selfhood as when speaking about the difference between her pre and post cancer self she states,

I have also become a bit more adventurous with my holidays and spending; making sure that I do everything I want to and being a bit less concerned about the cost, probably because I am more aware that life is short and that 'later' or 'another time' doesn't always come

Alongside,

I have more confidence in a lot of things – for instance I give talks to other cancer patients or healthcare professionals about my experience of cancer

The above statements indicate that the general experience of the cancer diagnosis to survivorship process has changed Demi's perceived selfhood in a positive manner as it has enabled her to become more confident and adventurous than her pre cancer self allowed.

However, Demi then contradicts this by stating that she, “can’t have a family as we were planning for” and that she is “more depressed about not being able to have children than the actual cancer itself”. Alongside this, she also identifies “struggles with anger” and “insomnia due to hormonal changes and can’t manage more than 4 days work each week” now compared to her pre cancer self.

This shows that although Demi’s perceived selfhood in some aspects has changed positively following her cancer experience, it also has new negative aspects such as infertility, emotional and mental health issues and insomnia alongside, being less active than she was prior to cancer. This suggests that her sense of selfhood has altered due to her experience of cancer but that this change comprises of both positive and negative attributes. This also shows how Demi is able to draw positives from negative situations alongside, not dwelling too much on what she cannot do but focusing more on what she has and can do in her life.

In addition to this, Thomas (Squamous Cell Carcinoma) says,

There are certain foods I cannot eat and this has affected my social life. I do not get invited out for a meal, as many people don’t know what I can or cannot eat. Lack of saliva gives a dry mouth and tooth decay can be a problem... I take antidepressants, which are very good, but would prefer not to take meds

Here, Thomas suggests that he is no longer as sociable as he was previous to his cancer experience. The reason behind this however, appears to be the fault of his 'friends' as he suggests to feel isolated by due to a lack of knowledge on his long-term consequences. Therefore, suggesting a new socially isolated sense of self. In addition, he also suggests for this isolation to cause psychological concerns as he implies the need for medication to combat his associated depressive feelings.

In contrast to this however, Thomas also states within his response,

my confidence has grown; I often stand in front of an audience of strangers and tell them my story, something I wouldn't have done pre diagnosis.

This comment suggests a new 'extrovert' sense of self. Therefore, implying that his cancer experience has caused his sense of self to alter, but again, similarly to Demi, this change is comprised of both new positive and negative attributes.

6.1.2 No Change

The small population remaining within the survey data do not feel their sense of self to have altered at all following their cancer experience. This population size is perhaps unsurprising as these are participants who are using a cancer support group that is generally used by those seeking help and/or support

from others with personal cancer related issues. Therefore, it could be expected for the majority of individuals within the support group to have experienced a change within their sense of self in which they need support for.

The participants within the present research attribute the lack of impact on their perceived selfhood to be based on two potential reasons, with both encompassing focusing upon relationships with others. For example, some participants suggest their selfhood to remain unaltered due to the feeling of needing to be strong for others. A statement evidencing this is by Liz (Bowel Cancer), who says,

In the past I imagined I would go to pieces if anything like this happened to me, but I haven't as I have my family to consider so it has never pulled me down

This implies that because the individual is so committed to appearing strong to her family, thoughts about her cancer experience and associated consequences have not been greatly focused upon. Therefore, restricting their ability to manifest and in turn, alter her sense of self. This demonstrates how advantageous a shift in focus can be towards an individual's perceived selfhood.

In relation to the presence of others restricting a change in perceived selfhood, Kim (Breast Cancer) says,

I have been surprised to learn however sick I get my sense of humour never deserts me. Even in my darkest days last year, my husband and I still found much that made us howl with laughter and that would always lift our spirits... I was surprised that I have emerged from the other side of the cancer process much the same person as I was going in. I thought when we started that life would never be the same again but here I am, two boobs lighter and still feeling like much the same old me

It could be suggested from Kim's comment for relationships with significant others during one's cancer experience to be of extreme importance in restricting change within their perceived selfhood. Kim implies her unaltered sense of humour to be dependent upon the positive relationship she has with her husband. However, with Kim stating to be surprised at her unaltered sense of self, it is implied that she is uncertain as to the reasons behind it.

However, in contrast to this, Kim also states,

I get quite anxious even when we're only going out of a meal with friends and I've avoided taken on any new challenges or starting anything 'difficult'

This therefore contradicts her previous statement suggesting her sense of self to have emerged from her cancer experience, unaltered and suggests for her new selfhood to be complex. For instance, it is suggested that for Kim, her

sense of self is based upon who she is as a whole. Therefore, she can appear to feel to be the 'same' person, even though some aspects of her daily life now differ, with it being suggested for the positives within her life to outweigh the negatives of her cancer experience. In addition, both Liz and Kim expressing a sense of surprise in regards to their perceived unchanged selfhood is of interest, as they both suggest they expected their experience to change them. However, both Kim and Liz speak about their relationships with significant others in regards to their perceived sense of self, remaining unaltered; it is possible that in other circumstances this may not be the case. This is hinted through the response of Kim when she addresses how she still avoids new challenges and suffers from anxiety when socialising with particular friends.

There may be many alternative reasons not touched upon in this piece of work as to why some individuals do not feel their identity to have altered however; these were not presented in the survey data and so, more research in the area may be needed to identify these.

6.2 Support

The final major theme identified within the survey data was Support. This being because, many individuals imply for their experienced level of support during their cancer experience and the impact it has upon their lives, to be dependent upon the source it originates from. Three significant sources of support were suggested throughout the responses of the participants and so,

this major theme *Support*, is comprised of three sub themes, these being: *Significant Others*, *Healthcare Services* and *People*. All three of the identified sub themes will now be discussed and considered in terms of *positive* and *negative* experiences alongside, what factors within them are crucial to providing adequate support to the participants.

The Cambridge Dictionary (n.d.) states that to be supportive to an individual, you must provide encouragement and agree with someone because you want him or her to succeed (Cambridge Dictionary, n.d.) therefore, this thesis will define support in the same manner.

6.2.1 Significant Others

The support from significant others appeared to be mixed in the responses of the participants and so, the repercussions also vary. Some individuals highlight their experience to be solely positive in regards to support from close others. For instance, Jenny (Breast Cancer) says,

Support from friends and family and the treatment I've had from BUPA and NHS has been incredible- wonderful experience across the board

In addition, Sandra (Lung Cancer) states,

Support I have received from family and friends has helped me to motivate myself and get back out there

The above quotes illustrate the positive impact receiving high levels of support from significant others can have upon one's quality of life/wellbeing alongside, the shaping of their perceived cancer experience.

However, the majority of individuals illustrate that the received support from significant others was not all positive. One of the most direct quotes evidencing this, can be seen by Polly (Breast Cancer), when she makes the comment,

Cancer showed me how deeply I was loved. I knew I was loved but the number of people who stood by me was mind boggling. Some people who I thought would stay with me, didn't. So, cancer showed me who my real friends are

However, this point is also suggested in the following statements,

friends mainly very supportive, some just melted away without a backward glance! – Harriet (Breast and Melanoma)

Surprising who will stand by you and who will use you as a means of getting attention themselves – Candice (Bone Cancer)

The reaction of some of my friends and family, some have been supportive and others not which has been surprising – Leila (Breast Cancer)

A sense of surprise is demonstrated within the above quotes in regards to the experience of negative support from the participants significant others. This therefore implies an expectation for high levels of support to be provided by all those significant to them. However, the reasons as to why some individuals appeared to be unsupportive does not seem to be considered within the provided statements of Polly, Harriett, Candice and Leila. This could be suggested to imply that either no explanation was given by the 'significant others' in question or that the reason behind their poor support was not important.

All the above statements also illustrate how the experience of support following cancer and its treatment is not always so clear-cut in regards to identifying it as solely positive or negative. The statements strongly suggest experienced support, or the lack of, leads to the re evaluation of sustained relationships. For example, it is suggested, particularly in the response of Polly, for supportive significant others being identified as true friends, causing a strengthening in their relationship. However, when unsupportive friends come to light, a breakdown of relationships occurs.

The suggestion of negative support causing a breakdown in relationships is also identified in the response of Demi (Endometrial Cancer) as she states,

Some friends and family stopped contacting me. I had to force myself to join support groups and local community activities and have made some lovely new friends

This statement continues the suggested re-evaluation of sustained relationships point with Demi also demonstrating the consequences that negative support can have upon an individual's quality of life. This is because Demi suggests she reluctantly joined a support group in order to restrict feelings of isolation caused by poor support from her significant others, through the hope of gaining new supportive friendships.

6.2.2 Healthcare Services

Similarly to the relation of significant others, some individuals also had solely positive experiences of support from healthcare services, with this experience appearing to be significantly associated to positive wellbeing. For instance, Mark (Head and Neck Cancer) states,

The benefits of psychological counselling have been extraordinary. It came from Macmillan, and was one to one for both me and my wife. It helped dramatically and brought us back together at a time when we were falling apart

Additionally, Sabrina (Breast Cancer) also holds a positive experience of support from healthcare professionals as she comments,

Had to see a psychologist which was a great help. The other part is what a brilliant team there is in hospitals, first class treatment and continued support

The above quotes from Mark and Sabrina reflect the fact that good psychological support from healthcare services is seen to be of extreme importance to the rebuilding of close relationships and personal wellbeing after the trauma of experiencing cancer and its treatment and, is highly valued by those receiving it.

However, the majority of individuals express their experience of support within this sector to be solely negative, with one example being by Sara (Breast Cancer), when she says,

I am astounded by the lack of any kind joined up care and as a result the lack of help for people to get the answers they need when the symptoms they are struggling with may be to late effects of treatment

Additionally, Julie (Womb Cancer) says,

There is very little support available if you live in a rural or remote setting and you are just left to get on with it. I have had no oncology follow-ups since my treatment ended over four years ago. I just seem to have been forgotten about

These quotes reflect the individuals to feel a sense of being 'left high and dry' once treatment ends and the 'acute' stage progresses to the 'chronic'. This, alongside the quote of Sabrina slightly further above, indicates the importance of continuity in support from healthcare services in the long-term. It is also

suggested here that the way in which support is perceived to be given, is dependent upon not only the experience of healthcare services but also the design and provision of them.

However, it is also possible that those who said they had a positive experience of support by healthcare services may have done so at the beginning of their survivorship journey rather than when they become accustomed to their long-term consequences following cancer and its treatment. This point is further suggested within the following statements,

There is a lot of support for people at diagnosis and those at end of life but there is very little support for those in the middle ie, long-term survivors. I have mentioned this to hospitals and charities but get little response

And,

I find it very frustrating that if I go to a clinic at hospital that is not my usual one, the doctor has little if any knowledge of LT side effects for survivors of cancer – Hannah (Blood Cancer)

I feel I was not well monitored after the first couple of years and certainly was not warned of the consequences. I have survived all these but there may be another problem around the corner – Paulina (AML Cancer)

Everyone forgets about you after treatment – Susie (Ovarian Cancer)

No-one tells you about the long-term survival and other health issues it may cause-surprising – Katie (Bone and Non Hodgkin Lymphoma Cancers)

The above statements identify that participants report it to be possible for high levels of support to be readily available and beneficial for those recently treated for cancer, but then suggest it is sparse or non-existent for long-term survivors. It is suggested in the above quotes for this lack of support in regards to long-term survivorship to lead to the individuals feeling a sense of abandonment and unprepared in regards to what to expect in the long-term.

However, Bart (Bladder and Testicular Cancer) does reflect the opposite within his responses as he states,

How little doctors know about different cancers, how difficult it is to find a doctor with expertise appropriate for one's particular condition. My personal experience is that GP's know very little and it took me three years to find a consultant who could help with my form of TCC

This does deter away from the previous suggestion of participants that positive support from healthcare services is available at the beginning of the survivorship journey to all cancer survivors. However, Bart's quote focuses more upon the professionals within the provided service and reflects them to

lack in the knowledge essential to enable them to provide adequate support and care. In line with Bart, Sandra (Lung Cancer) also suggests particular professionals to fail in providing adequate support. For instance, she states,

Medical team and GP could have been more understanding and done more to help me

The above statements highlight a direct lack of understanding by GP's at both diagnosis and long-term status, which negatively affects one's cancer experience. This could be due to lack of training and availability of specialist doctors however, because research in survivorship is still sparse it is more than likely that it is due to the reason that knowledge on different cancers and their consequences is still being formed and so, lacking at present.

It is also evident from them that the type and timing of positive support are of extreme importance to the participants. This is evidenced in the response of Janice (Bowel Cancer), who states,

I wish that the oncology nurse gave me a set of vaginal dilators and told me to use them while I was having radiotherapy that she told me to use them after the treatment finished. She didn't so I didn't and consequently have life without sex

This quote of Janice's highlights the importance of the different types of support received from healthcare services at different points along the illness

trajectory alongside, demonstrating the subsequent negative long-term consequences individuals have to experience when they fail to do so.

Through examining the responses within this section, it is clear that the participants are not describing them to experience a 'joined up' journey in terms of healthcare service provision. It appears very disjointed and according to the accounts of the respondents, reflects to be a 'luck of the draw' situation.

Therefore, on the whole, it could be argued for this section to highlight the extreme importance of the development of services available for cancer survivors suffering from long-term consequences of their cancer and its treatment.

6.2.3 People

It is a human response to expect different levels of support from general individuals compared to significant others and healthcare services. Within the gathered responses, individuals appear to describe received support from people in general to be non-existent.

This is evidenced by Julie (Womb Cancer), as she makes the comment,

How little people know or understand about cancer is surprising. It is the forgotten cancer. People think having a hysterectomy cures everything, People only seem to care about breast cancer

This shows the importance of a generalised understanding being held by individuals on the outside world in order for subsequent levels of support to be provided. This could appear interesting as the quotes within the previous two sub sections tend to refer just to 'cancer' in regards to their received support whereas here, Julie focuses on her specific cancer type. Therefore, suggesting it to play a crucial role in this lack of received support. This being because she implies some cancers to be perceived by individuals as more important than others and in turn identifies hers as being forgotten.

The importance of a generalised understanding in regards to support is also supported by the following statements:

anxiety- both about others perception of how i should be- (expectations that cancer survivors are 'super heroes' or that i should be back to normal as soon as treatment is finished) – Jackie (Ovarian Cancer)

As soon as treatment stops everyone assumes you are 'well' again. In fact, end of treatment signals the start of a long journey to recovery and to redefining yourself as a person – Kirsty (Ovarian Cancer)

People see you and think that you are better, they do not understand that although you might be looking quite well you are often tired and feeling dreadful – Sheila (Bowel Cancer)

People think that once the chemo is over and you're in remission, everything is fine for you. People don't tend to acknowledge the mental effects that cancer has – Candice (Bone Cancer)

At one stage I preferred to socialise with people with cancer as I felt they were the only people who could understand what was going on inside my head - Annette (Breast Cancer)

The first two quotes clearly overlap with the previously explored major theme; *Selfhood* as they associate the lack of held understanding to not only the restriction of support but also to issues within selfhood. The last statement also overlaps with the previously mentioned re-evaluation of sustained relationships as Annette suggests that the lack of support because of restricted understanding, some relationships broke down and her friendship circle changed. However, all of the above statements could be seen to reflect temporality as they insinuate to be about individuals moving from the 'acute' phase of illness to the 'chronic'. It is also strongly implied from the mentioned statements that shared lived experience is crucial to the participants.

6.3 Unpreparedness

A major theme throughout the survey data appears to be *Unpreparedness* as many individuals express how they felt unprepared for certain aspects relating to their experience of cancer and its treatment. This perceived *Unpreparedness* takes two forms and so is comprised of the two sub themes:

Questioning of Decisions and Health Issues as Unpleasant Surprises. The two sub themes encapsulated within the major theme *Unpreparedness*, do intertwine with one another as they both suggest a lack of information from health professionals as being the reason behind their feeling of being unprepared; however, one focuses upon how the participants relate this lack of information to questioning their decisions whereas the second sub theme focuses on the surprising health issues themselves. Both sub themes will now be discussed.

6.3.1 Questioning of Decisions

A number of participants express a sense of being unprepared during their cancer diagnosis and treatment process to the extent that now, as they look back on that particular time period, they question the decisions they made. One example demonstrating this is in the comments from Bonny (Breast Cancer), who says,

Results of the breast reconstruction were not as I had hoped. I feel I made the wrong decision as the surgery has ruined my body shape. Had to undergo further surgery to try and correct but have been left with a swollen stomach which I never had before. I have since had further feedback and the plastic surgeon at the hospital did not have a very good reputation

This implies Bonny's unpreparedness to be a result of poor care and advice, provided by her healthcare professionals, in particular, her surgeon. This is implied to be due to the incompetence of her associated plastic surgeon and is suggested to be the root cause of Bonny's experienced questioning of decisions.

In support of this, Julie (Womb Cancer), says,

Having cancer treatment (chemo and radio) has ruined my life. Had I known what I know now I would not have had the treatment-nothing was explained to me about the side effects. I am angry and frustrated that my life has been ruined

This shows that similarly to Bonny, a lack of care/advice from healthcare professionals is associated with Julie's questioning of her decisions. However, unlike Bonny, Julie appears to regret her decision of having her cancer treatments. This is also seen in the comments of Kirsty (Womb Cancer), who lists her experienced consequences following cancer and its treatment before making the comment,

My quality of life is significantly impaired because of these problems, feeling so determined during treatment but then so flat afterwards. I thought I would be full of the joy of living but in fact often wonder if the hard fight was worth it

Although this statement does not directly aim fault towards the failure of health professionals, it is implied that Kirsty's questioning of whether her reward of living was worth the treatment she endured reflects her unpreparedness for the damaging long-term consequences. Arguably, her comments imply that if she had known about the consequences of her treatments, she may not have deemed the fight to live worthwhile.

The above statements strongly imply a lack of knowledge being the root cause within this issue of unpreparedness. Participants suggest that they were misinformed or uninformed during their treatment phase, which then caused them to be unprepared for their experienced long-term consequences of it and in turn, made them question their made decisions regarding their cancer treatment.

6.3.2 Health Issues as Unpleasant Surprises

Furthermore, a number of individuals express the belief of being unprepared for the health issues that follow cancer and its treatment due to a lack of information from relevant healthcare professionals. As previously mentioned this section strongly intertwines with the previously discussed sub theme *Questioning of Decisions* as individuals in that section also suggest being unprepared in regards to their experienced long-term consequences. However, this sub theme has a general focus on the health issues that the participants felt unprepared for.

For instance, an example in which individuals express a feeling of being unprepared in regards to their subsequent health issues can be evidenced in the responses of Leila (Breast Cancer) as she states,

The serious side effects of the cancer drugs are also surprising, I now have osteoporosis which I have to take further drugs for and these also have knock on effects which has changed my life somewhat

Similarly to this, Sara (Breast Cancer) says she is surprised that,

The treatment has had other long-term consequences, I now have IBS which I did not have before, I had allergies before but have gained a couple more

Here, Leila and Sara highlight being unprepared for the further health issues they have developed due to cancer and its treatment, with these appearing to have a somewhat negative impact upon their daily lives. Although it is not suggested directly, the fact that both Leila and Sara identify their consequential health issues as a surprise, suggests that they were not advised by their health care professionals, during the treatment process, of the chances they had of developing their attained health concerns.

In addition to the development of further health issues, some participants also suggest a feeling of being unprepared for the length of time their experienced long-term consequences following cancer and its treatment would remain for.

This can be evidenced in the responses of Jenny (Breast Cancer), who states,

I'm surprised I haven't got my strength and fitness back as expected- was advised would take 6 months but its far longer and more difficult than originally anticipated

Adding further to this point, Bonny (Breast Cancer) says,

I did think that once treatment was over I would just get on with my life. This did not happen, effects were much longer lasting and I am only just recovering from further surgery, had hoped it would have all been over in 1 year, Wrong!!!

The statements provided by both Jenny and Bonny highlight being unprepared for the time period of their experienced long-term consequences to lead to added unexpected struggles to their daily lives. Therefore, causing them a delayed recovery time, which appears to negatively affect their state of mind due to its unexpectedness.

Chapter Seven:

Discussion of Preliminary Study

This part of the chapter will explore the findings of the quantitative and qualitative aspects of the preliminary study and discuss how they relate and/or contrasts to literature readily available. In order to do this, the quantitative and qualitative findings will be separately discussed. The quantitative aspects will be explored first, this will include firstly presenting a summary of the findings from the statistical analyses and then move on to discussing how these findings compare and contrast to previous literature. The qualitative findings will then explored and, similarly to the quantitative section, this will begin with a summary of the findings gained from the Template Analysis and then continue by discussing how the stated findings also compare and contrast to previous literature. This chapter will conclude by presenting the strengths and weaknesses attached to the performed preliminary study.

7.1 Quantitative Findings

7.1.1 Summary of Findings from Statistical Analyses

As previously mentioned, there are 84 responses/participants within this preliminary study, with breast cancer the most common cancer type identified. This is unsurprising as it is a common cancer that holds a strong prognosis rate.

The incorporation of quantitative features within the survey enabled the identification of numerous major findings. For instance, firstly, the statistical analysis identified the perceived quality of life determined by the participants, to not be associated any specific cancer type/s alongside, there being no suggested difference between experienced cancer type and age. Following this, it was found that the majority of individuals identify themselves as 'cancer survivors'. However, when statistical analysis was performed it appeared that none of the different identified cancer statuses were associated to perceived quality of life levels. Thirdly, when comparing quality of life levels to health anxiety scores, a Pearson product-moment correlation coefficient identified there to be a large negative correlational relationship between them. This therefore highlighting, high health anxiety levels being associated to lower experienced quality of life (high quality of life scores). Finally when exploring gender differences within the quality of life in adult survivors scale scores, there were no statistically significant differences in quality of life scores between men and women.

7.1.2 Discussion of Findings

A discussion of how the presented findings compare and contrast to literature readily available will now be presented. This will be done through addressing the factors explored separately. For instance, findings relating to cancer type will be discussed first and will encompass the explored relationships with quality of life and age. Findings surrounding identified cancer status will subsequently follow and will also encompass both the acceptance of the

survivorship concept alongside, findings exploring cancer status to quality of life. The discussion of findings will conclude by exploring the relationship, if existent, between health anxiety and quality of life.

Cancer Type

The results identifying that an individual's quality of life is not dependent upon their experienced cancer type gives me the confidence to include varying cancer types in the following main phenomenological study. This is because these findings indicate that it is not necessarily the case for particular cancer types to cause certain issues and/or particular levels in quality of life.

However, it could be suggested to be the case for the experience of cancer and it's treatment in itself that affects one's quality of life. This adds to previous research as the majority of that readily available tends to focus upon the exploration of only one or a small number of cancer types and/or one or a small number of facets within the quality of life concept (Dunberger et al., 2010; Schmidt et al., 2012; Meneses-Echavez et al., 2015; Lindgren, Dunberger & Enblom, 2017; Simonelli et al., 2017). Whereas, the present research focuses on a wide range of cancer types and explores quality of life as a whole rather than specific factors within it.

In addition, statistical analysis also proved there to be no relationship between experienced cancer type and age however, this in turn does indicate that it is suitable for a wide range of ages to be incorporated and explored in the main

phenomenological study as there is no association between particular cancer types and experienced age.

Identified Cancer Status

It is suggested within previous literature that individuals who have survived cancer and are now cancer free within the UK deter from identifying themselves as being a 'cancer survivor'. However, the data from the present study contrasts this statement with the majority of participants identifying themselves as 'cancer survivors'. This therefore contradicts the findings from the previously mentioned work of Khan et al. (2012) but supports the findings from the research of Deimling et al. (2007). The reason for this discrepancy in results could be due to the fact that Khan et al (2012) only incorporate a sample of 40 participants whereas, the present study, that of Deimling et al. (2007) and Davis et al (2016) have a sample size considerably larger. Saying this, it is known for qualitative methodology (which Khan et al. (2012) utilizes in their study) to not focus on generalisability but more on gaining in depth data. However, it is still possible for the results to have differed if more respondents were incorporated in Khan et al's. (2012) sample, like in the work of Davis et al. (2016) who also use qualitative methodology.

This result adds to what is already known by previous research readily available, which, as discussed in the extensive literature review in chapter two predominantly focuses on either one type of cancer or a select few when exploring identified cancer status. Whereas, this preliminary study, as

previously demonstrated in the results chapter encompasses a wide range of varying cancer types and so, suggests the results to hold more generalisability. In addition, as participants were given the opportunity to provide their own description of their identified cancer status, it is likely that I have captured the breadth of possible identities.

In line with this point, when using the presented box to explain their chosen identified cancer status, the most common reasons behind participants classifying themselves as “other” was due to them preferring the term “No Evidence of Disease” or because they “did not understand how to define each term” they were presented with. This therefore supports previous literature stating that the definition for ‘cancer survivor’ is not comprehensible due to there being no one set definition in place (Khan et al., 2012; Smith et al., 2016). These findings suggest an importance of developing a concrete definition so that people are able to use and understand the concept appropriately. They also highlight the importance of further research in to the long-term consequences of cancer and it’s treatment. This is because it is clear from the gained results that these experienced consequences play a big role in the participating individuals’ lives. Therefore, these need to be addressed in order to enable the development of interventions to improve such individuals’ living.

Furthermore, the results highlighting identified cancer status to have no association to perceived quality of life levels demonstrates the suitability of incorporating varying identified cancer status’ in the main study. This being

because, as in line with the analyses conducted on cancer type, it indicates that how one identifies themselves in terms of their cancer status does not determine their experienced quality of life. These non-significant findings contrast with those of Bellizzi and Blank (2007) as they found that significantly higher wellbeing scores were held by individuals who identified with the cancer survivor label as apposed to the 'cancer patient' identity.

Health Anxiety and Quality of Life

The results indicating a large negative correlational relationship between health anxiety scores and perceived experienced quality of life levels can be suggested to be unsurprising. This is because as previous discussed in the literature review in chapter two, a number of research studies suggest there to be a link between anxiety and quality of life levels (Olatunji, Cisler & Tolin, 2007; Barrera & Norton, 2009; Sarma & Byrne, 2014). These results are very useful as not only are they in line with previous literature that also suggest this but they also enable me to consciously be aware of this association when exploring my data and using it to prepare for, and conduct the main study.

7.2 Qualitative Findings

This section will now discuss the findings derived from the Template Analysis performed upon the data of the preliminary study. This will begin with a summary of the key findings that are presented in depth earlier in this chapter and then will discuss how they compare or contrast to previous literature.

7.2.1 Summary of Template Analysis Findings

Through performing Template Analysis upon the written data gathered from the 84 respondents within the qualitative component of the survey, a complex template of major themes and further sub themes was identified. The identified major themes are: *Selfhood*, *Support* and *Unpreparedness*. All three of the major themes are comprised of multiple sub themes and in a number of cases, further sub themes. Please refer back to figure 4.2 in chapter four to see a full breakdown of these identified major and sub themes.

A main aim of incorporating this preliminary study was to gain data rich enough to inform the design of the main phenomenological study. With only four free text items, it might be thought that the ability to gain a large quantity of rich data would be extremely restricted. However, the data retrieved from the free text responses was extremely detailed and lengthy, providing rich data for analysis. The identified themes from the Template Analysis provide a basis of what appears to be most important to cancer survivors regarding their lived experiences of long-term consequences following cancer and its treatment and their experiences of cancer as a whole.

7.2.2 Issues Presented within the Template Analysis

Due to a summary of the findings from the Template Analysis having now been presented, the remainder of this section will now focus upon discussing the issues identified within the participants' lived experiences and how they

compare and/or contrast to previous research. Looking at the themes and sub themes as a whole, an overarching issue of discontinuity was apparent.

I will consider below what these qualitative findings contribute, through the lens of discontinuity.

The issue of discontinuity appears to be present in a number of aspects within the participants' daily lives. This thesis will refer to discontinuity, as something that evidences a break with their past, pre cancer life. Therefore, any aspect of a participant's life showing to stop its normal pattern and alter following, and due to, cancer and its treatment, will demonstrate discontinuity and will be referred to as such, in this section. The different aspects by which discontinuity can be seen within the findings of the Template Analysis, will be explored below.

Selfhood

It is strongly suggested within the identified themes for the experience of cancer and its treatment to lead to the long-term issue: fear of cancer reoccurrence. The participants suggest the experience of the long-term consequence; fear of cancer reoccurrence, to cause discontinuity within their perceived selfhood, they suggest their sense of selfhood changed in a largely negative manner. For instance, one participant [Poppy] says this fear keeps her up at night and causes her extreme health anxiety and another participant [Jane], refers to it being a constant concern. This therefore, highlights that both participants appear to strongly suggest the experience of fear of cancer

reoccurrence to have a negative impact upon their quality of life, causing the participants to be much more anxious about their health. The identification of this experienced consequence correlates with the readily available research (Skaali et al., 2009; Koch, 2013; Lebel et al., 2013; Simard et al., 2013) discussed in the literature review in chapter two. All of the discussed previous research identifies fear of cancer reoccurrence to be a concerning and prevalent psychological long-term issue of cancer and its treatment. The research of Skaali et al. (2009), Koch (2012), Lebel et al. (2013) and Simard et al. (2013) were all used quantitative methodology and find that the experience of fear of cancer reoccurrence was negatively correlated to quality of life levels.

Additionally, it is suggested within the responses for participants' selfhood to show discontinuity due to experienced long-term consequences regarding emotional issues. One participant in particular [Mandy], states how she lost all control of her emotions due to cancer and its treatment suggesting this to have caused her perceived sense of self to alter in a significantly negative way. This shows discontinuity as it is implied for Mandy to have had control over her emotions in the past but that her experience of cancer has caused her to lose this control.

Some scholars may argue that the blame for loss in emotional control being placed upon cancer and its treatment could be due to the participants subconsciously over attributing. This can be supported through the Attribution Theory, which focuses upon explaining the behaviour of individuals and then

exploring how these explanations impact upon such individuals' perceptions (Boysen & Vogel, 2008). The concept 'external attribution', within the Attribution Theory, suggests that individuals tend to create cause and effect relationships when they do not exist in order for an individual to explain their behaviour as being the result of an event beyond their control (such as developing cancer), rather than an internal cause (personality trait) (Boysen & Vogel, 2008). This is possible in regards to the participants, especially the one previously mentioned [Mandy], as she cannot give a specific explanation behind her experienced emotional issues and just assumes them to be due to cancer and its treatment. Furthermore, some researchers have found that in regards to stigmatisation, peers are more positively accepting of uncontrollable behaviours than they are controllable ones (Dijker & Kooman, 2003) and that biological causes of certain behaviours were associated to greater understanding alongside being liked, pitied and aided more by others than behavioural causes (Weiner, cited in Dijker & Kooman, 2003). Therefore, it is possible that the participant/s may feel to receive more support by others when facing their emotional issues if they believe them to be cancer based rather than personality based.

Healthcare Provision

Support provided by healthcare professionals is also an apparent aspect of an individual's life that appears to become discontinuous due to their cancer experience. The Template Analysis does suggest that some individuals had positive experiences in regards to healthcare. However, it is predominantly

suggested by participants for their support and care from healthcare professionals to have become turbulent and often negative, following their cancer experience. These negative experiences tend to revolve around the needs of the cancer survivor not being met. The participants suggest this to either be through a lack of available joined-up care once in remission status or, due to healthcare professionals lacking in knowledge relating to the participants' experienced cancer type or associated long-term consequences. This demonstrates discontinuity within the individual's experience of healthcare as participants suggest within their responses, for negative experiences with associated professionals to begin once they reach remission status and are experiencing long-term consequences. Therefore, suggesting that prior to cancer their experienced healthcare provision was stable and positive.

The findings of experienced support from healthcare professionals varying amongst participants are in line with the research of Treanor and Donnolly (2016). Through their Narrative Analysis upon interview data from cancer survivors, Treanor and Donnolly (2016) find experiences regarding healthcare from the appropriate professionals, to vary amongst the participants. Additionally, the finding of healthcare professionals failing to meet the needs of cancer survivors is in line with the previous research of Ntinga and Maree (2015), who found in thematic analysis of interviews with cancer survivors, that a major issue in their lived experience was that healthcare professionals, such as GPs failed to meet their needs. Ntinga and Maree (2015) further support the preliminary study findings as they, like the present preliminary

study, identify individuals as believing that healthcare professionals lack knowledge relating to the cancer they have experienced, making the GPs unable to understand their situation.

Relationships with Others

Through the major theme *Support*, it is also evident that participants' relationships with others can become turbulent following their cancer experience, in turn leading to discontinuity within them. A number of participants suggest some people they deem significant, had not appeared supportive with regards to their experienced cancer and long-term consequences, to their surprise. The participants then suggest this to lead to re-evaluating their relationship, identifying whether or not they can be classed as a 'true friend'. In some cases, individuals express this lack of support is what causes them to participate in organised groups for support, suggesting their quality of life to be affected. The above points demonstrate how negative support from others can lead to the relationship between them becoming unstable.

This finding is in line with the previous research of Meier et al. (2007), who performed both Content and Thematic Analyses upon data provided by cancer survivors demonstrating a range of experienced cancer types to explore participation within support groups. They found that one reason individuals join online support groups is to receive emotional support that they are not currently experiencing from those around them. Therefore, suggesting

that a number of participants, similarly to those in the preliminary study, did not receive positive support from those around them. However, the preliminary study expands on this by identifying the suggestion by participants for this negative support to cause the re-evaluation of sustained relationships with them in some cases, becoming unstable.

7.3 Reflections on the Preliminary Study

During the preliminary study a couple of thoughts came in to mind in regards to the process of it. These will be discussed below.

The development of the survey was rather straightforward and found to be very time efficient, which I believe is due to two things. First and foremost, the extensive research that was undertaken within the area prior to its development and second, the chosen software (Qualtrics) to create it, as the instructions were very clear, enabling me to create the survey with ease.

However, I felt a loss of control in regards to seeking individuals to participate in the survey and so, found the recruitment of participants harder than expected. This is because, with it being decided for the sample to come solely from the Cancer Voices support group, I had to rely on Macmillan to post the advert and subsequent reminders for the members to see and respond to. This meant that there was no way I could attempt to intervene and was unable to use other avenues alongside the Cancer Voices support group to recruit

participants. Having said that, although the sample size was not as high as hoped for, the one gained was still adequate for the purpose of the study.

7.4 Strengths and Limitations of the Preliminary Study

A main strength to this preliminary study is that it has provided me with essential guidelines on how to approach the main phenomenological investigation. These guidelines will aid my ability in gaining the richest data possible alongside, producing more valid results.

For instance, the quantitative aspects of the preliminary study enabled me to identify that a range of cancer types would be advantageous to incorporate within the main phenomenological study as no relationship between cancer type and perceived quality of life was found. Additionally, the quantitative part of the survey enabled the finding of participating individuals identifying themselves as cancer survivors. This finding can therefore add to the existing debate within available research regarding the acceptance of the cancer survivor concept. Alongside this, the survivor concepts appeared acceptance by the participants can be taken in to consideration when structuring the approach of data collection within the main phenomenological study.

However, a possible limitation to this section of the preliminary study may be identified within the above quantitative results highlighting cancer type to not be associated to perceived quality of life levels. For instance, it is possible for these results to have been due to the sample size being smaller than

anticipated however, the process itself gave me significant grounds to rationalise how to continue in the following main study.

The qualitative aspects to the preliminary study also show to be extremely advantageous to the present research. For instance, the provided free text box to conclude the survey enabled participants to provide explanation and description to accompany their quantitative responses. This is beneficial, as not only does it enable a deeper insight in to their lived experiences but it also enables me, as the researcher, to identify suitable aspects of the provided text to later incorporate as a-priori themes for the main phenomenological study.

However, a possible limitation to this could be the lack of structure within the free text box. This is because there are no specific topics covered as the participants are solely asked to provide anything they wish to, in regards to their lived experience within the explored phenomenon. Therefore, it is possible that richer data would be gathered if a particular set of questions were to be incorporated.

Chapter Eight:

The Main Phenomenological Study: Methods

The main focus of this study is to meet the present research's overall second aim and associated second objective (ii), in regards to exploring in depth, cancer survivors' lived experiences of long-term consequences following cancer and its treatment. A solely qualitative approach is taken to do this, which involves both Template and Narrative Analysis being performed upon data gathered from e-mail interviews with 16 participants. As mentioned in the previous chapter, the results from the preliminary study act as a guide on how to approach this phenomenon. This chapter will focus upon the methods used within this main phenomenological study.

8.1 Design

This main phenomenological study used qualitative methodology and utilised semi-structured e-interviews with a sub sample of the respondents who completed the survey in the previous preliminary study. Data were analysed using a phenomenological form of Template Analysis (King, 2012) and a set of narrative case studies informed by The Listening Guide (Mauthner & Doucet, 1998).

8.2 Participants

A purposive sample was sought for the e-interviews, it was important to balance depth and breadth, if too large a sample was chosen then the depth of analysis would suffer and if too small a sample then breadth would be restricted therefore, a sample of 15 individuals seemed appropriate. Each participant was identified from their participation in the previous online survey and their expression of willingness to be approached for interview and was invited to participate via email (see Appendix 4). Figure 8.1 further illustrates how the sample for the e-mail interviews was selected and recruited.

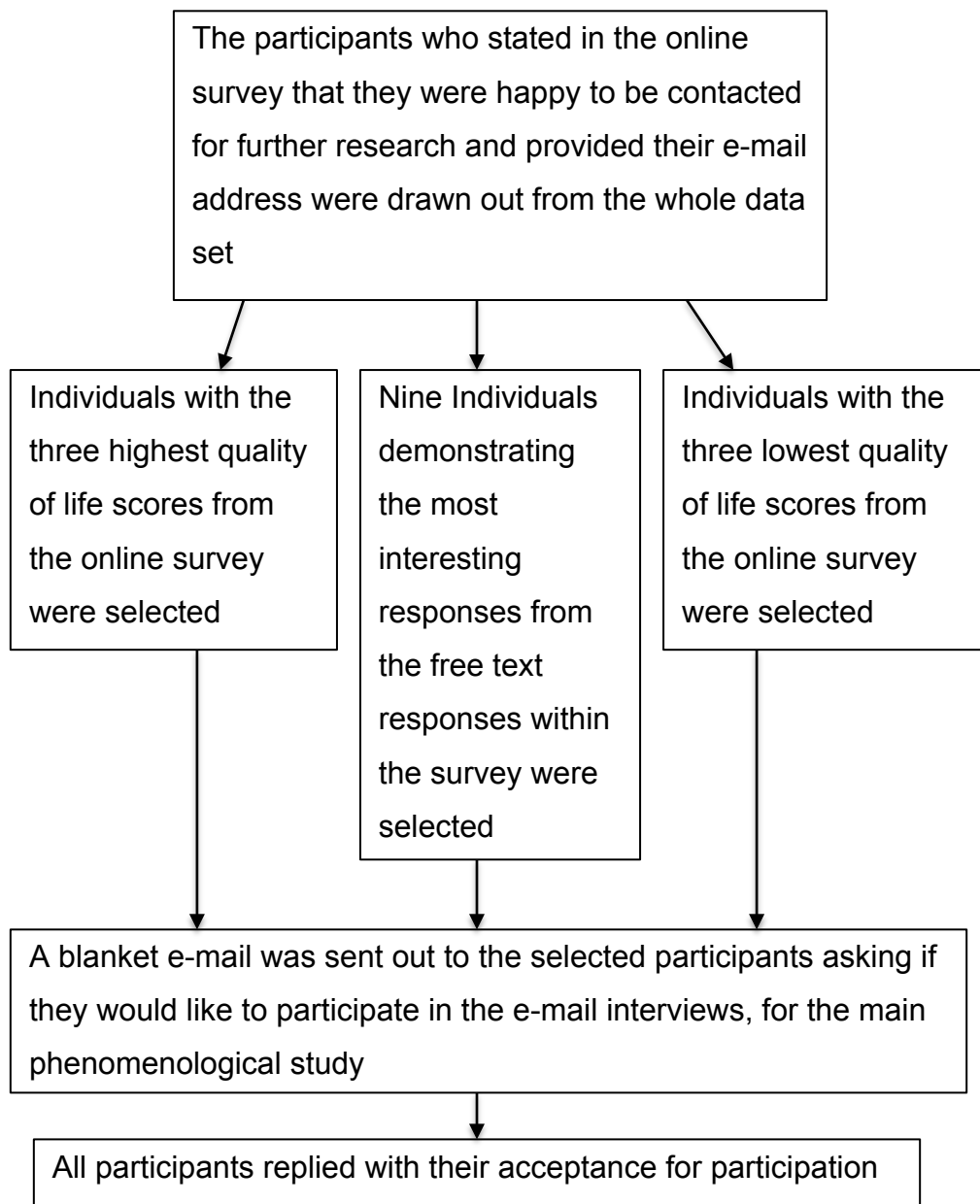


Figure 8.1: Selection and Recruitment of Participants

However, one participant stopped contact early in to the e-mail interview due to suspected technical issues, so another was recruited. Given that the results from the survey data indicate that it was the experience of cancer itself that

was important and that no individual cancer type was consistently lower or higher in terms of quality of life than another, it was decided for this phenomenological investigation to not seek any particular variation in cancer types. This is because its focus was to pursue a variation of cancer types from individuals scoring highest and lowest on the QLACS (Avis et al, 2005) in the preliminary study, as well as those expressing in their qualitative responses, to be suffering significantly from long-term consequences. Within this cancer type variation a variation by age and gender was also sought. This is because, it was also revealed from the statistical analyses, discussed within chapter five that gender was not significantly associated to reported quality of life levels, and age was not significantly associated to experienced cancer type. The demographics and main long-term consequences of the participants used within the main phenomenological study can be evidenced in table 8.1.

Table 8.1

Demographics of the Participants Involved in Study Two of the Research

Participant	Gender	Age	Cancer Type	Months in Remission	QLACS Score	Concerning Long-term Consequences
Keenan	Male	60	Bowel	118	273	Incontinence, digestion issues and body image issues
John	Male	59	Rectal	40	257	Pain, body image issues and incontinence
Joel	Male	46	Acnic Cell Carcinoma	84	243	Depression, fatigue and no motivation
Mary	Female	85	Breast	34	86	Slightly worried about fear of cancer reoccurrence
Gerald	Male	59	Prostate	94	80	"Nothing has caused me concern"
Michael	Male	76	Bowel	60	106	Travel restrictions, eating issues and incontinence

Julie	Female	51	Womb	50	169	Lymphedema, cognitive and mental issues
Sara	Female	51	Breast	72	153	Fatigue and pain
Kirsty	Female	57	Ovarian	22	194	Immobility, pain and fatigue
Jackie	Female	41	Ovarian	60	233	Fatigue, anxiety and infertility
Hannah	Female	44	Blood	202	204	Vertigo, loss of self confidence and change in appearance
Elliott	Male	51	Head and Neck	85	197	Immobility, no strength/energy, cannot eat or drink and feels a burden
Steve	Male	60	Prostate	- ^N	189	Withdrawal, fatigue and memory loss
Demi	Female	45	Endometrial	62	187	Infertility, depression and sexual issues
Jane	Female	42	Lymphoma	59	185	Headaches, fatigue and memory loss
Mark	Male	44	Head and Neck	33	231	Self conscious, paralysis in face, depression and withdrawn

^N = unanswered

8.3 Procedure

Initial contact with the potential participants was via e-mail; first they were sent an invitation to take part in the e-interviews, once interest was shown, information sheets and electronic consent forms were sent, which were all signed and sent back to me (see Appendix 7 for an example) so that I could begin the e-mail interview process. All participants that were asked to take part accepted and were happy to participate in the e-interviews. There was one instance during the interview process where it was questionable whether the e-interview was suitable for one individual, as he struggled to identify any long-term consequences of cancer and its treatment that presented itself as a concern. However, after consulting with my supervisor it was decided to allow the individual to continue the e-interview process. This was due to him providing very interesting responses, vastly contrasting to other participants, which I wanted to explore further. Due to this, the questions for his e-interview were personalised in order to ensure the interview was efficient.

In order to manage the caseload of e-mails efficiently I aimed to start five interviews on the 18th May 2015, five two weeks later on the 1st June 2015 and the remaining five on the 15th June 2015. Therefore, all e-interviews were conducted within a three-month period (see appendix 8 for an example of a completed e-mail interview). However, as previously mentioned, due to technical difficulties with his computer, one participant was withdrawn from the study mid e-interview and so another individual was invited who was happy to

participate and replied with their consent. Therefore one individual started the process out of synch with any of the other groups of interview.

The e-interviews consisted of six pre-set main questions, one sent at the start of each week and each requesting a response within three days. Follow-up questions were asked in between the main questions in order to expand upon the participant's response. I concluded each e-interview by thanking the participant for their participation and stated that the interview was complete. The interview process and the six main questions are shown in figure 8.2 and table 8.2 respectively.

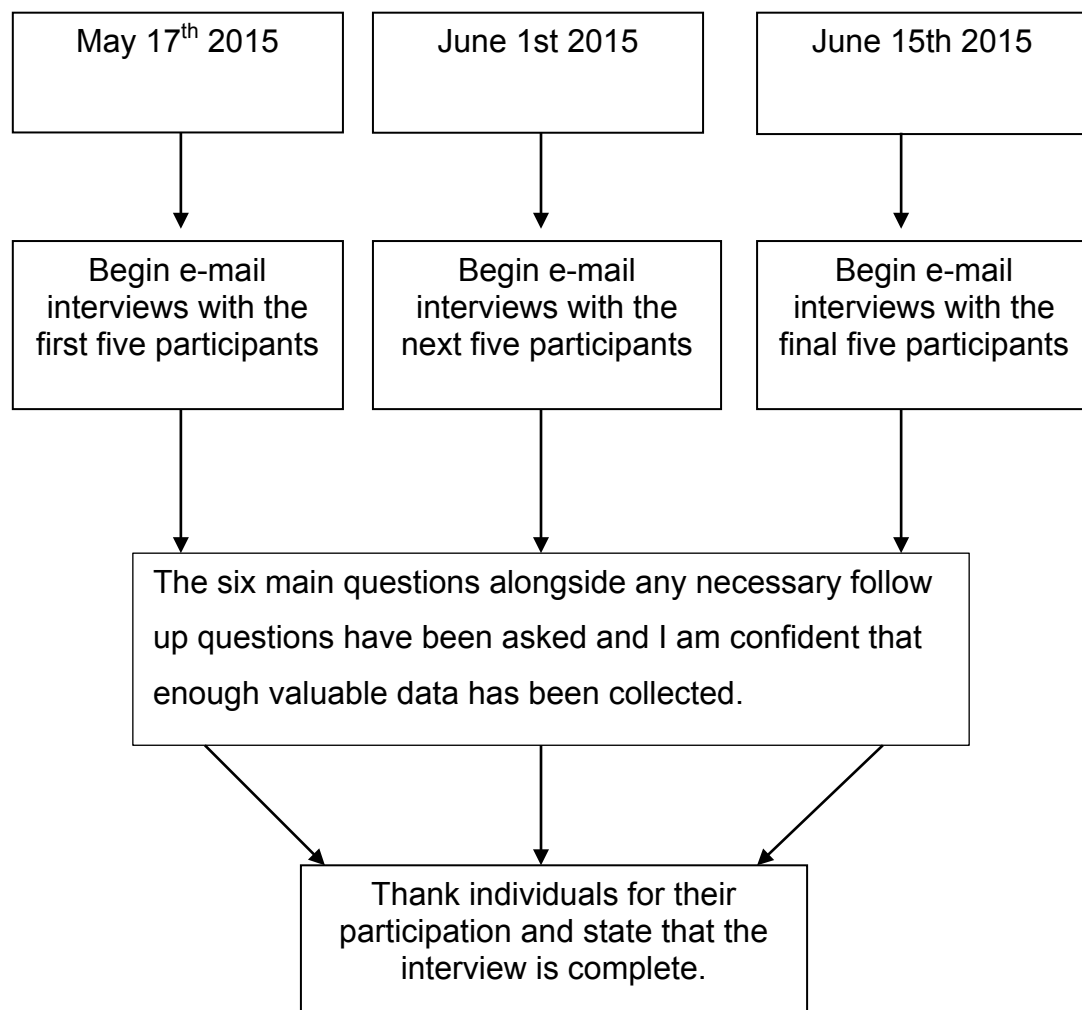


Figure 8.2: E-mail Interview Process

Table 8.2

Main Questions and Possible Prompts for E-Interview

Question Number	Question	Possible Prompts
1	Could you please tell me in as much detail as possible about your experience of long term consequences of cancer and its treatment?	How does this make you feel? Do you feel you were prepared for the consequences you experienced? If so, what prepared you and if not how do you feel you could have been prepared?
2	Please explain to me your methods of coping with your experienced long-term consequences?	Do you have any particular coping strategies? Have these strategies changed with time? Can you give any advice as to what you have found has or hasn't worked?

- | | | |
|---|--|---|
| 3 | How would you say your loved ones have coped with your suffering of such long-term consequences? | How does this make you feel? Is it something you speak about or keep it left unsaid and why do you think this is? |
| 4 | How do you feel others view/treat you in regards to your experienced long-term consequences? | Do you feel that the way they have treated you has differed in relation to before diagnosis/treatment stage and survivorship? How would you like them to treat you in regards to your long-term consequences? |
| 5 | Could you please explain to me your experience of support from organisations such as the NHS hospital staff, GPs, counsellors, support groups? | Do you have any recommendations on how they could improve? Why do you think it is good/lacks? Is the level of support equally available for the |

survivorship stage as it is
diagnosis/treatment
stage?

6a a) Could you now
please explain to me
how you pre cancer self
differs to your post
cancer self?

6b b) What made you join
cancer voices and what
have you got out of the
support group?

8.4 Ethical Considerations

In line with the preliminary study, the main phenomenological study also follows the BPS's ethical guidelines and code of conduct: informed consent, confidentiality, protection from harm, right to withdraw from the study and the right for participants to remain anonymous.

Informed consent is paramount to any study. It was ensured by this research by making sure each participant was sent an e-consent form and that it was responded to and sent back to me before their e-mail interview could begin.

Confidentiality was ensured through the e-mail data being transferred on to word documents, a separate one for each participant and then saved to my personal computer that is password protected. Any paper documents of the data were secured in a locked drawer to which only I hold the key. The e-mail data has and will remain only accessible to myself, my lead supervisor and if absolutely essential, the examiners of my research.

Due to the main phenomenological study purposely exploring a particularly sensitive research topic, protection from harm was paramount during the study. Participants were made aware that if any point, they felt they needed support because of emotions brought on by their participation then they should contact either myself or my main supervisor. They were given our e-mail addresses so they could contact us directly and we would be able to provide them with details of support services relevant to their situation.

Participants within this main study had already taken part in the preliminary study, so had a sound understanding of what the focus of the research was. However, they were made aware of their right to withdraw at any given point during their e-mail participation or before a specific date, afterwards.

Lastly, the right to remain anonymous was guaranteed because like promised to the participants, they were all given a pseudonym in the saved word documents containing their e-mail responses. As previously mentioned, there were all saved on my computer at home, which is password protected. The consent form and information sheet were both online, meaning there are no paper copies, therefore these are all saved to my student e-mail account and have been copied and pasted on to word documents and saved on my personal password protected computer (see Appendix 5 for the used information sheet and Appendix 6 for the consent form).

8.5 Data Analysis

Two analyses were performed upon the gathered e-mail data and each will be discussed in turn within this section. This will be done by first discussing the Template Analysis; the Narrative Analysis will follow.

8.5.1 Template Analysis

In meeting objective (ii) within the second overall aim of the current research, the responses to the e-interviews were analysed using the Template Analysis as described by King (1998; 2012), and utilised for the qualitative analysis of the preliminary study (see chapter four). Template Analysis is a form of thematic analysis that allows for the use of *a priori* themes, which are identified in advance as potentially useful in interpreting the data (King, 2012). It is thus highly suitable for the present research because the survey

conducted prior to the e-interviews has already identified important consequences and experiences, which will be used to define *a priori* themes for analysing the e-mail interview data. In addition, it will enable me to identify important emerging themes within the data and structure it in a meaningful manner (King, 2012). Please refer back to chapter four for a full description and discussion of Template Analysis.

As with the Template Analysis within the preliminary study, no transcription was needed in that of the main phenomenological study either. Due to the data collection method described above, all correspondence was over e-mail, meaning that it was already all written. In order to manage and organise the data efficiently, each participant's full interview was copied, saved and stored on to a word document and saved on to my personal password protected computer at home. The responses of the participants were, and remain, only accessible to myself, my supervisors and if absolutely vital, my examiners. The fact the transcription process is redundant was advantageous to this part of the research for two reasons; firstly, it meant that no data could be lost in the transcription process as can happen due to technical or audibility problems. Secondly, due to transcription of data being a very lengthy process, a lot of time was saved from the responses already being in the written format, meaning that I was able to spend my time focusing on other important aspects of the research.

Following King and Brook's (2017) first step of Template Analysis, each participant's submitted responses were read and reread until I felt immersed

within the data. The second step; preliminary of coding, was then performed on a subset of five participants' interview data, with Van Manen's (1990) line-by-line approach being implemented within it. Five transcripts were chosen for the preliminary coding step of the Template Analysis as this represented just under a third of the total sample used and was felt to be a manageable caseload. For instance, it was not too high so that themes could be lost but was also not too low that numerous themes would be made but later deemed as redundant due to not applying to the wider data set. I believe the Van Manen (1990) approach was advantageous as thoroughly examining each line meant that I could be fully immersed, strengthening my ability to identify text clusters of interest or significance to the aims of the research. Highlighting certain sentences, phrases or paragraphs of interest, which appeared to signify meaning to the explored phenomenon, enabled preliminary coding to develop.

As previously stated, a *priori* themes, based on the preliminary study were incorporated into this analysis. These *a priori* themes were 'changes of self', 'impact of support' and 'fear of cancer reoccurrence'. These codes accelerated some parts of the analysis as I was purposely looking to see if they were also present within the e-mail interview data. However, too much reliance was not held upon these identified *a priori* themes, with them being used as a guide rather than a truth. They were dealt with in this manner in fear of subconsciously overseeing data that contrasted to them, if too much emphasis was placed upon them.

The clustering of this coding was the next process of Template Analysis followed. During this phase, the chosen subset of data was investigated in extreme depth with the clusters of identified text from the previous phase being segmented together, turning identified potential themes in to more definitive 'major' ones. The structure of these identified definitive themes were then focused upon, some consisting of multiple levels, which are referred to as sub themes. Two out of the three *a priori* themes, although somewhat developed, were also present within the e-mail data however, in contrast to the preliminary study and previous literature, 'fear of cancer reoccurrence' was given little focus by the participants. A diagram was then developed using the identified major and sub themes, highlighting the differences of hierarchy between them and how they link together. The conclusion of this process resulted in an initial draft template being developed that was applicable to the first subset of data.

At this point, template development took place, with the initial draft being applied to the remaining set of data. This was performed in two stages, the first was examining the data responses of a further five participants taking into consideration the existing themes and whether or not they represent the further subset of data meaningfully. In instances where it was felt this was not the case, notes were made regarding possible revisions for the template. This included the necessity for new themes to be developed such as *Research Impact*, current major themes to be removed for example, *Power of Support*, as it was seen that this and the major theme, *Variances of Support*, could both be encapsulated under a major theme of *Support*, or, the renaming of

identified themes such as Coping Skills being changed to *Management of Consequences*. Furthermore, an identified theme of *Fears of Abandonment* was altered to just *Fears* as I found abandonment to represent a small minority of fear expressed by participants, meaning the sub themes within it, were also altered accordingly. Once the template was modified to encapsulate the responses of the first ten participants, it was then applied to the remaining six, with the process of template development being repeated.

A final developed template, in which no further modifications were needed and which clearly enable me to answer the research questions, was eventually reached. Modifications made to achieve this template included changing the *Socialisation Issues* theme into *Engagement within the Social World*. Furthermore, both the *Unpreparedness* and *Fears* major themes were completely removed from the template. The reason behind this was that the factors encompassing *Unpreparedness* could all be addressed within the major theme, *Support*. Additionally, when compared to the whole data set, the majority of the factors presented within the major theme, *Fears* appeared to focus more on experiences within the diagnosis/treatment phase of the participant's cancer journey rather than their survivorship phase which is what this research is aiming to explore. The remaining factor within this theme, *Cancer Reoccurrence*, which was added during the development of the first modifications to the template, and was identified as being better suited within the major theme, *Changes to Selfhood* therefore, it was decided for the major theme, *Fears* to be completely removed. The addition of the parallel theme, *The Impact of Cancer Voices* was also established within this final application

of the template, as the responses gained from the participants provided sufficient context to their experienced long-term consequences to be gained. Providing a final modified template, in which no further amendments were needed, meant it could now be used for making sense of the data and interpreting the meanings attached to the phenomena by the participants before writing up the findings of the analysis.

The finalised developed template from this analysis can be seen in figure 8.3 and for comparison purposes the initial template can be found in Appendix 9.

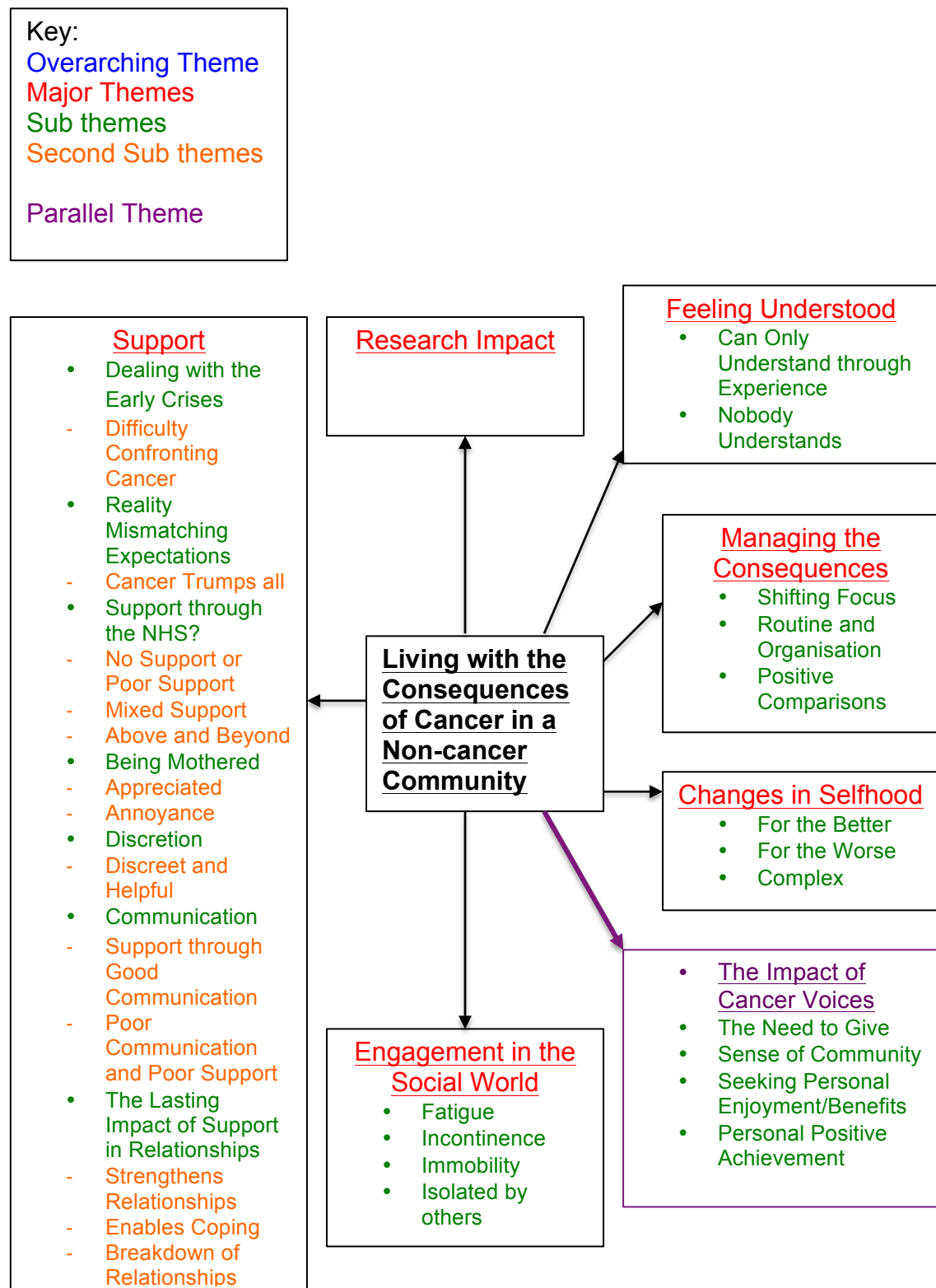


Figure 8.3: Finalised Template of Findings

8.5.2 Narrative Analysis

Although the themes identified from the individuals' responses as a collective from the e-interviews were extremely significant and interesting, I believed it would be advantageous to meet objective (ii) within the current research's overall second aim further, by unpicking these and focus in on the narratives of three of the participants' responses, presenting them as separate case studies. The aim of this was to enable further themes to emerge that would not have done so, when analysed as part of a group. In particular, some individuals appeared to show a contrasting experience to the majority of the participants. Conducting case studies enabled me to delve even further into the presented e-interview data as the Narrative Analysis allowed me to look at individual stories across the interviews as a whole which is somewhat lost in the cross case analysis of the whole data set. Therefore, presenting a small number of more detailed case studies appeared to be the most appropriate way in which to achieve this.

For this section of the study I was looking for participants with interestingly different positions within the e-interview data that highlighted different experiences of cancer survivorship and the interview process as I aimed to use the analysis to gain in depth accounts of these varying experiences. Therefore, in order to be able to gain this depth but not sacrifice breadth a sub-sample of three individuals was decided upon. One participant was chosen due to the fact that she expressed that the e-interview process had given her new insights into her experiences; she also strongly conveys that

knowledge was for her a main coping strategy. Another individual was chosen due to her expressing herself to have suffered the most in regards to her experiences and having shown a low quality of life score on the survey. The third participant was chosen due to the fact that he appeared to have the highest level of quality of life, and because his responses in the free text responses appeared to contrast the majority with some interesting points being made regarding the explored phenomenon. He also expressed distinctive opinions on cancer research and charities. When it came to the interview process, as he was so different from other participants, he needed his own personalised e-interview.

Introduction to Narrative Analysis

Narrative analysis is an umbrella term to describe an array of approaches to analyse data in the form of a story (Riessman, 2005). McLeod (1979) describes narration as a 'basic human activity', as it is something individuals do on a daily basis in order to recall events/memories they have experienced in the past and share them with others (Smith, 2000), alongside when attempting to understand an experience (Mishler, 1986). Sarbin (1986) also extends this point by stating that the process of narration enables individuals to form a structure for their lived experiences. However, whether this behavior is innate or learnt is a debatable subject amongst different scholars with some arguing for it to be a mixture of the two. For instance, Bruner (2010) states his belief that narration, like language, has an intensely innate centre however, the ability to understand the surroundings/experiences of the individual and

their manner in which they construe stories of it, is learnt behaviour. Through recent years, the recognition of narrative theory within social sciences has continued to grow despite the roots of the phenomenon lying within literary research.

The narrative approach is predominantly used by qualitative research in order to elicit and/or construct a story from a subjective encounter, which displays the personal meaning attached to it by the individual/s who have experienced it (Mitchell and Egudo, 2003; King and Horrocks, 2010). There are other approaches that attempt to do this however; the relationship of the story to the research encounter is seen differently amongst them, with only Narrative Analysis foregrounding the story as the main focus of attention. Approaching this research with a constructivist stand point I accept that the narratives expressed by the participants are predominantly subjective and are of them telling how they make sense of their experiences in regards to cancer and its long-term consequences. I aim to explore this perceived experience in depth through the use of narrative analysis, this method appears to be appropriate as it supports not only my previously stated interpretivist stance but also my research aims as they focus on exploring lived experience alongside my data being collected from conducting extensive qualitative e-mail interviews which enabled individuals to express their narrative freely and in their own words whilst being given the chance to reflect on their response/construction of story.

The Listening Guide and how it is Adapted for the Main Study

There are a number of techniques within the narrative approach in regards to analysing gathered data (King & Horrocks, 2010). However; this research employs an adapted version of The Listening Guide which is stated by Gilligan and Eddy, (2017) to have been utilized on an extensive range of research since its official development around thirty years ago.

The Listening Guide is a flexible voice-focused form of analysis (Shapira and Arar, 2017) that enables the researcher to explore the multiple voices that are present within and around us (Gilligan & Eddy, 2017). The Listening Guide prides itself on the method of multiple readings and listenings (Shapira & Arar, 2017), which include the development of I-poems (Woodcock, 2016). This method is argued to be extremely flexible as it allows scholars to adjust the guided listenings in accordance with their research, whether it be the number of listenings incorporated, the order of them or what it is that is listened for (Mauthner and Doucet, 1998).

Furthermore, Petrovic et al (2015) state that although it is not as readily available in current literature as that constructed on verbal interaction the listening guide's application to written data is also possible. Gilligan (2003) also argues this by identifying that the method has been used upon varying forms of data such as letters, diary entries and opinions of the Supreme Court. She also states that as long as it is in the form of the first person, the listening guide can be applied to any transcribed text. These advantages are

evidenced in the work of Petrovic et al (2015) who adapted the Listening Guide in order to critically explore body image and diabetes using written reflective accounts in place of transcribed verbal interviews. It is due to this flexibility and the advantages within the method that the Listening Guide was chosen to analyse the e-interview data for the narrative analysis within the current research.

In accordance with Mauthner and Doucet (1998), I also adapted the listenings focused upon in the current research. Firstly, rather than referring to the analysis as listening one, two, and so on, because this research focused upon e-mail interviewing, the data is provided already transcribed rather than in voice form and so, will be referred to by this thesis as 'readings' rather than 'listenings'.

Following the exploration of the proposed listening guide and researching the area of narrative analysis as a whole I decided it appropriate to encompass three readings, each focusing on answering a different question that I deemed important to my research. These three readings were; Identifying narrative and plots, Identifying tone and structure and Creating 'I-Poems' to demonstrate how participants position themselves within their narrative. Reading one and three are taken directly from the originally presented listening guide however, reading two is taken from my exploration of Murray's (2015) chapter on Narrative Psychology within Smith's (2015) *Qualitative Psychology: A Practical Guide to Research Methods*. Murray (2015) focuses on conducting narrative analysis on the data collected from a sample of

cancer patients and argues for the importance of exploring the way the participants structure their narrative in accordance to the beginning, middle and end and then establishing what tone is presented as they narrate it. I followed guidelines amongst various research studies on making notes that are both reflexive and summarising what is presented.

Coming back to Petrovic et al's (2015) research, in his publication it was also stated that in order to remain aware of his own responses and not allow such reactions to distort his analysis, he asked himself Brown and Gilligan's (1992) suggested five questions throughout. These are:

- In what way do we identify with or distance ourselves from this person?
- In what ways are we or our experiences different or the same?
- Where are we confused or puzzled?
- Where are we certain?
- Are we upset or delighted by the story, amused or pleased, disturbed or angered?

Due to these questions being recommended by the developer of the Listening Guide (Gilligan et al., 2003) and the fact that Petrovic et al. (2015) found them to be useful in his own research I also decided to include them in to the analysis of the current research in order to ensure that my place within the analysis is apparent to the reader. Due to the fact that these questions were for my own reflection and to ensure full focus to the analysis I repeatedly

asked them within my head rather than write them down and so, cannot physically evidence them within the results.

However, how the two types of notes were made and at what times will be further touched upon in the detailed sections below regards each performed reading.

Performing the Analysis

This section will demonstrate how the Narrative Analysis was applied to the e-mail data in accordance to the three incorporated readings of the Listening Guide.

Reading 1: Identifying Narrative and Plots within the Participants' Accounts

This initial reading draws on the approach taken by Doucet and Mauther (2008) following the process of the Listening Guide. Therefore, throughout this stage of the analysis, I thoroughly read and re-read the written accounts of each of the three selected participants. Alongside this, a focused aim of answering the following questions was held throughout; 'What is happening at this point?' and 'What is being focused upon in the presented narrative?' When I found snippets of text demonstrating answers to either of the above questions these were highlighted with a pen in order to stand out from the remaining data.

Furthermore, as I was reading through the data, I made reflective notes down the margins of the printed transcripts in order to ensure that I remained conscious of my own emotions and responses to what was written, consciously ensuring that what I was highlighting and focusing upon, appropriately portrayed the accounts expressed by the individual. This stage of the analysis enabled me to gain valuable insight into how each individual constructed their own story and the plots apparent from their personal experience of long-term consequences following cancer and its treatment.

Reading Two: Identifying Tone and Structure within the Narratives Presented

As with the initial reading, this stage also consisted of thoroughly reading and re-reading the responses of each participant in order to establish how they used structure and tone to set out their written narrative (King and Horrocks, 2010). As with the previous reading, when I came across particular snippets or chunks of data that I believed to demonstrate the tone portrayed by the participant then they were again highlighted, only this time in a different colour. However, due to structure being a property of the narrative as a whole it appeared important to treat it as such. However, sections that illustrated the key aspects of the demonstrated structure within the narrative were highlighted.

The importance of exploring structure has been identified in the work and investigations of a number of researchers (Gergen and Gergen, 1984, cited in Sparkes 2005; Sarbin, 1986; Mischler; Young et al, 1994). Doing this in the current research allowed me to gain valuable insights into the participants' lived experiences. This was through being able to envisage how individuals have formed and come to understand their story of living with long-term consequences of cancer and its treatment, alongside anything they demonstrate to be particularly important in this (Young et al, 1994). Murray (2015) looks at tone and structure in the narrative of cancer patients in his research and states that in order to do this stage of the analysis you must firstly prepare a summary of each of the narrative accounts being explored by looking at what the participant is saying about the beginning, middle and end of their expressed story. This involves exploring whether the participant is implying a stable (does not alter across the three time periods), regressive (steadily declines) or progressive (steadily becomes more positive) structure. Murray (2015) states it is then that you can look at the tone they apply to their narrative throughout.

Murray's (2015) method draws on the analytical tool of Gergen and Gergen (1984) who previously explored the importance of tone and structure within narrative analysis; the current research will also follow this process for this reading. When I began exploring the data it was apparent that both structure and tone interlinked with one another however, I thought that discussing them both together could cause confusion. Therefore, I decided to investigate and

present them as two separate sections but at instances where there is a clear link between them, this would be identified in the text and drawn upon.

The importance of tone within narratives is emphasised by McAdams (1993). He states that individuals' narratives tend to be predominantly pessimistic or optimistic; the former displaying bad events, continuous misfortunes or possible good things being overcast by negativity and the latter demonstrating the occurrence of good things or the presence of hopefulness when faced with bad situations. This seemed to fit my research area well and so I felt McAdams' guidelines for this reading to be appropriate. Therefore, throughout the re-reading of the data I continuously asked myself 'Is the participant's narrative being optimistic or pessimistic?' McAdams (1993) also highlights the importance of imagery within constructed narratives such as asking whether imagery was present and if it was how were the participants using it to form their narrative? However, when exploring the narratives of the three individuals it appeared that rather than using imagery, the participants tended to use metaphors instead when narrating their story. Therefore, the present research will explore metaphoric language within each narrative presented within this reading.

Reading Three - Creating 'I-Poems' from the Presented Narrative

The construction of an I-Poem is different from that of a standard poem (Zambo and Zambo, 2013). An I-Poem is a unique aspect of the Listening

Guide (Gilligan et al, 2003) in comparison to other qualitative approaches to analysing data (Gilligan, 2015). With an I-Poem, whilst you would want it to be as pleasing/interesting to read as possible, its purpose is principally to aid in the interpretation of qualitative data. Gilligan (2015) also describes an I-Poem to have logic in that although it is not linear, it does not enable the reader to seek the pattern in which the 'I' moves, alongside listening for whether the 'I' knows and whether it is aware of the things that it knows. However, 'normal' poems seek to create an aesthetic effect of some form.

In accordance with the steps of the listening guide, this reading focuses on enabling the researcher to understand the first person voice of the involved participants and the way in which they express themselves to others and so, position themselves within their narrative (Gilligan et al, 2008; Hall et al, 2018). Hall et al (2018) also state that although the method of Gilligan's (2003) Listening Guide was not introduced formally until 2003, the creation of I-Poems within this method have already been used to analyse a wide diversity range of research areas.

Typically, this stage of the analysis would also explore the cadences and rhythms within the participant's voice as they speak about this however, due to the current research involving only written accounts this part of the process is irrelevant. Therefore, in order to conduct this reading I firstly read the full written account of each participant and highlighted every sentence with the word 'I' in it, this was not always a full sentence but included accompanying words that I deemed as important to the context surrounding the particular

use of the pronoun. Then on a new word document, whilst ensuring the order in which they were presented in the written accounts remained the same, I placed each highlighted sentence on a different line, all starting with the pronoun 'I'. It is through doing this that I created the pronoun list for each individual (see Appendix 10 for an example of a created pronoun list). Some researchers such as Petrovic et al. (2015) have also found it beneficial to include other pronouns such as 'my', 'me' and 'myself' however, when I looked at my written accounts almost every sentence included one of the alternative mentioned pronouns and so, it would not have been efficient or effective for me to also include them in this reading for my research.

Once the pronoun list for each participant was complete, the pronouns within them were explored in order to create smaller 'I-Poems'. These are used by researchers in order to demonstrate how participants position themselves within their expressed narrative; in this instance them telling of their experience of cancer, its treatment and its long-term consequences. In order to create the 'I-Poem' for each participant I firstly had to re-examine the gathered pronoun lists and make notes on how the word 'I' was used within them. For instance, notes were made if they appeared to demonstrate something in particular or the manner in which they were positioning themselves within the narrative accounts (an example of these notes can be evidenced in Appendix 11). The sections, in which the pronoun list seemed to harbour important and interesting data using the pronoun 'I', were then used to create the finalised I-Poem for each individual.

Chapter Nine:

The Main Phenomenological Study – Template

Analysis Findings

The e-mail interviews proved themselves to be extremely successful in producing very thorough and extensively rich data. Six major themes were identified: *Changes in Selfhood*, *Support*, *Ownership of Consequences*, *Understanding*, *Engagement within the Social World* and *Research Impact*. One parallel theme: *Cancer Voices*, was also identified. This chapter will explore each of these identified major themes and their associated sub themes, in great detail.

9.1 Changes in Selfhood

Similarly to the preliminary study, the long-term effects of cancer and its treatment appeared to be life changing to the individuals experiencing them and in turn changed their sense of self. Throughout the e-mail interview responses, this new sense of self appeared to be either predominantly positive, predominantly negative or a complex mixture of both.

Therefore, this major theme is comprised of the sub themes: *For the Better*, *For the Worse* and *Complex*. Within this research 'sense of self' relates to a wider sense of how the individuals see themselves rather than simply identifying specific changes in their lives.

9.1.1 For the Better

Despite the trauma cancer and its treatment can inflict, a number of individuals expressed how the experience of cancer and its long-term consequences have changed aspects of their sense of self in a more positive nature. For instance, Jane (Lymphoma Cancer) provides the following responses:

I have more confidence; I had procrastinated for years about training to become a Psychotherapist but promised myself that, if I survived the chemotherapy, I would train as soon as I was well enough. I qualified as a Psychptherapist in December 2014.

I'm so grateful to be alive and every day seems wonderful. I don't worry about my health the same, either, which might seem odd & I have no fear of death now.

Another interesting side effect is that I seem to be more empathic & intuitive.

And finally,

I have ongoing health problems, including fatigue & hemiplegic migraine but consider myself extremely lucky & have seen this as a second chance at life.

The feeling of a new gratitude for life is also suggested in the response of Michael (Bowel Cancer) when he says,

I appreciate what I am able to do now much more than I may have done otherwise.

Alongside, John (Rectal Cancer) who states,

The most important difference I think you quickly learn to concentrate on what is actually important in life. Which is your family.

The above suggests that despite Jane enduring severe long-term consequences associated with both cancer and its treatment, she, alongside Michael and John, describes a 'future-orientated' sense of self in that they see their problems in a positive light by comparing them to an even worse outcome; death.

In line with this, Kirsty (Ovarian Cancer) states,

I suppose I have gained in having a more carefree attitude and I do all the things I want to do (which I would have put off before because of work etc).

This supports the point made above but also highlights that due to her lived experiences, Kirsty's way of thinking has changed as she appears to describe a newly felt 'live for the moment' sense of self, with how she comments this suggesting it to be a positive change and so, altering her sense of self for the better.

Similarly, in regards to the change in how she thinks about herself, Mary (Breast Cancer) states,

So my pre-cancer self was very dim about her feelings, only slightly ready to admit they existed at all. My post-cancer self is hopefully rather more open minded.

And, Julie (Womb Cancer) says,

I try not to worry over small stuff or things that I know I have no control over. What is the point of stressing over things that I cannot change?

Alongside,

I am also trying hard to stop allowing myself to be used. I was brought up to understand that if I could do something to help someone then that's what I should do. However, sadly some people then tend to take advantage but because it was a philosophy that I was brought up with I continued to do it. However, now I don't. I will for people I believe to be genuine but if anyone messes me about or tries to take advantage then I will drop them.

And,

I think maybe if I wasn't having to deal with so many of my own issues then it might be different but trying to cope with my own issues and having them made worse by other peoples attitudes or intolerance is hard work.

The statements of Mary and Julie also describe a new sense of self that focuses upon positive thinking. In line with Kirsty, this change is suggested via Mary and Julie's responses to also be beneficial, constituting to a more positive sense of wellbeing. This is shown by the participants suggesting they try not to worry about things beyond their control, such as the behaviour of others. However, instead they try to only worry about things that they have the ability to change and do so with a newly widened open mind.

9.1.2 For the Worse

In contrast to finding positive changes in sense of self amidst the traumatic experience of long-term consequences following cancer and its treatment, a number of individuals highlight that they have felt a predominantly negative change to their sense of self. This can be evidenced in Jackie's (Ovarian Cancer) response when listing all of the ways in which she differs post cancer as she states,

BC- everything was possible- AD everything is limited, BC- able to take on things in multiple- AD -have to divide and cope one thing at a time.

BC- able to keep up with friends- AD struggle to do so, do most socialising with family.

And,

BC - working/ studying/ earning- AD dependant physically and financially, housewife, BC- more confident about the future, AD anxious about the future, feel vulnerable, BC - would describe self as in good health, AD spend much time managing the impact of long-term effects (pain, digestion, anxiety), BC- rarely visited GP, AD frequent visits to GP.

The above statements highlight how the negative effects of cancer and its treatment have seeped into all different aspects of Jackie's life. In addition, when typing, Jackie refers to before cancer as 'BC' and after disease as 'AD' and so, adopts a historic metaphor of transformation as she is referring to Before and After Christ. This in itself emphasises the fundamental change Jackie has experienced.

In line with the long-term consequences of cancer and its treatment having a predominantly negative effect upon one's sense of self Sara (Breast Cancer) says,

In my pre cancer self I had energy and alertness, my brain worked properly. I think I was a bit more confident than I am in some ways now - I don't trust my body so much any more and I still have a bit of trouble making long-term plans because - well you never know what's round the corner. I will make plans, I will not be defeated but now I am stuck with an awareness or inner alertness that I did not have before that things can change in the blink of an eye.

Alongside,

bother I just got distracted and I have forgotten my other thought but that flags up a difference. Pre-cancer me was so much more cognitively able. I could hold so much in my brain, never lost words or forgot people's names.

The responses above suggest that cancer and its treatment have stripped Sara of her much-valued cognitive abilities and in turn has led her to describe a much more 'cautious' sense of self. This highlights that her dance with death, as some may say, has underlined for her the fragility of life, leading to her consciously restricting plans of the future.

Throughout the responses of participants, fear of cancer reoccurrence did not appear to be a major concern in comparison to other long-term consequences. However, when mentioned by participants it was suggested to contribute to a more negative perceived sense of self. The most extreme examples evidencing this are found in the responses of John (rectal cancer) and Joel (Acnic Cell Carcinoma),

John: At the start have spent a lot of time worrying every pain I get is a reoccurrence

Joel: [Change in appearance] reminds me that the cancer can return and may end my life

The above two examples demonstrate how severe fear of cancer reoccurrence can present itself within an individuals life causing their sense of self to become more negative, as they become an individual who is significantly more anxious about their health. Joel's response indicates for fear of cancer reoccurrence to still be a constant issue as he states in his response for it to arise every time he sees the changes cancer has caused to

his appearance. However, John's response suggests it to be at its most extreme at the beginning of his cancer survivor experience and so, suggests this form of health anxiety to decrease over time.

The statements presented within this subtheme predominantly suggest for the participants to either consciously or sub-consciously hold on to the ideology of what they had prior to their cancer experience. This appears to differ to the statements provided in the previous explored subtheme; *For the Better*, as the participants in that section seem to focus on what they have now, in the present. It could be suggested for this difference to explain the extremes of changes within perceived selfhood between the participants within the two groups. For instance, if one constantly perceives to feel a sense of major loss then it could be argued to be possible for them to become fixated on this and be unable to see what they still have and the benefits of this. Whereas, if an individual has an alternate way of thinking and instead is focused upon what they still have in their life then, possibly this can instill a greater sense of appreciativeness in regards to what they have rather than what they have lost amid their traumatic experience.

9.1.3 Complex

Although the above two sub themes demonstrate how long-term consequences of cancer and its treatment can predominantly impact one's sense of self in either a positive or negative manner, a number of individuals identified a new complex sense of self, in that their daily lived experiences

have made them feel a better sense of self in some aspects but worse in others. For instance, the most extreme case of this is shown in the responses of Demi (Endometrial Cancer), when she states,

I think I just want to make sure that “one day” is today rather than sometime in the future.

Alongside,

Although I am not necessarily a big spender, I am more likely to buy things like a good bottle of wine (rather than a cheaper one) when I am with my friends. I think it’s all to do with enjoying each moment as much as possible and buying what I really want rather than second best. But saying that, I am probably less materialistic than I used to be - I don’t buy many “things” but rely on second hand shops for clothes and the occasional paperback. So I tend to concentrate more on experiences and spending time with friends and family these days.

These quotes from Demi mirror those of Jane and John discussed in the first subtheme; For the Better, as Demi also highlights a newly gained perspective on life. Additionally, like John, she also identifies a new sense of what is important in her life with time spent with loved ones being a part of this. Throughout the above, Demi strongly describes a new ‘for the moment’ sense of self with it being suggested that her experience of cancer and its treatment

enabled her to identify the uncertainty of life and in turn give her best effort to live it to the full.

However, Demi does contradict this in her responses as although she has associated her experience of cancer and its treatment in the long-term to having a more positive sense of self in some aspects, she also frequently describes a very negative sense of change. Demi says she believes her life is “ruined” in that she will never be truly happy any more, describing a ‘cheated’ sense of self. This being because cancer has taken away her dream of becoming a mum as she speaks throughout the interview about the devastating effects of being infertile from the treatment and in turn says,

I used to really love listening to music. I don’t do that very often now because I find that tunes I used to like remind me of when I used to be happy, and it is difficult and upsetting to listen to them now as I can’t imagine being happy again. I also have lots of self-pitying thoughts like this “I have had the happiest day in my life and I won’t be happy again”, “ my life has been ruined”, “I don’t know how to get through today” etc etc.

This complex sense of selfhood can also be evidenced in the responses of Keenan (Bowel Cancer) as, in line with Demi, he also implies a new ‘for the moment’ sense of self following his experiences as he states,

Post cancer I realised the fragility of life and importance of doing what you want now rather than wait for next year.

However, again, in comparison to Demi, he also brings to attention the level to which his experiences have negatively changed his sense of self. This can be evidenced when he says,

I was care free before cancer, did things on the spur of the moment, but now I have to plan as I have to accommodate my 'stoma'. I have found living with a Stoma a burden and manage it rather than accept it.

The above demonstrates that although in some aspects Keenan suggests his sense of self has changed positively; he still provides reasons as to why it has deteriorated and describes a 'restricted' sense of self. This highlights that similarly to Demi, Keenan has managed to take away some positives from his harrowing experience but on the whole he still cannot accept his new norm. His responses suggest this to be because of the extreme restriction of spontaneity placed upon him due to his experienced long-term consequences, which, in turn has changed his perceived selfhood to one more negative.

In contrast to this, Mark (Head and Neck Cancer) highlights a more balanced mix of positive versus negative in regards to his perceived change of self. This can be evidenced in his responses below, for instance, when speaking about how he feels to have changed following his lived experience he states that he is now,

more focussed on important people especially my wife and son

This demonstrates a predominantly positive change, and mirrors the described 'new future orientated sense of self presented by both Jane and John discussed in the 'For the Better' subtheme above with again, loved ones being highlighted as important within this. However, he also states in regards to his altered appearance,

My face has been messed up, and it bothers me from time to time as I've mentioned before. It can be a constant reminder that my days are numbered, but also how lucky I've been to get this far.

Mark's physical changes caused by cancer and its treatment appear to cause emotional distress and lead him to describe an inescapable 'the end is nigh' sense of self. However, he then counteracts this by suggesting that he appreciates the life he has even though he has to live with the challenging long-term consequences caused by the cancer and its treatment. This therefore highlights a proportional balance within his new selfhood as he is able to logically combine his experienced negative consequences obtained from his cancer experience, with the more positive he has been able to identify from it.

From the discussion of the above sub themes it is certain that the experience of long-term consequences following cancer and its treatment significantly impacts one's perceived sense of selfhood. It may seem surprising that the

accounts regarding changes to selfhood were in the main positive, given the challenges participants described in relation to their long-term effects of cancer and its treatment during the e-mail interview.

Furthermore, from the findings within the area of *Changes in Selfhood*, the provided statements seem to suggest that on the whole, an individual's attitude and method of thinking in regards to an experienced crisis (glass half full/glass half empty, outlook on life) is what drives them towards the varied evidenced perceptions of altered selfhood as a long-term cancer survivor. Making the new perceived sense of self appearing to be dependent upon the personality traits of the experiencing individual. For instance, it could be suggested for an optimist to describe a *For the Better* sense of self, a pessimist; *For the Worse* and a realistic optimist; Complex, mixed change of perceived selfhood.

9.2 Engagement within the Social World

Engagement within the social world appeared within the analysis to be a crucial major theme demonstrating the participants' lived experiences of long-term consequences following cancer and its treatment. Within the participant responses, this theme appeared to comprise of four sub themes; *Fatigue*, *Incontinence*, *Immobility* and *Isolated by Others*, which will all now be discussed in detail.

9.2.1. Fatigue

Fatigue affects at least 350,000 cancer survivors in the UK (Macmillan, 2013) and so, it is unsurprising to be identified in the responses of the participants as something that affects their engagement within their social world as a cancer survivor. It was strongly identified within the e-mail interview data that the experience of fatigue has a detrimental effect upon the ability to get around and/or socialise with others. This can be evidenced in the responses of Julie (Womb Cancer), who, in regards to her experienced fatigue states,

I rarely go out; maybe once a week at the most. It's a struggle and I often find that I just don't have the energy. If I force myself to go out then I suffer the repercussions for a day or two afterwards

And,

I get very frustrated at not being able to do things. Even simple things like doing the shopping completely knacker me out

Although not said directly, Julie strongly implies that her experienced fatigue causes her issues regarding engagement within the social world. For instance, she suggests fatigue to cause restrictions and implications in her life, meaning she cannot go out without suffering repercussions. These restrictions are also apparent when she says,

I tend to not go out much - maybe once a week and have stopped doing virtually everything that we used to do BC (before cancer!) walking, camping, community stuff etc.

The experience of these restrictions caused by cancer-related fatigue is suggested to subsequently create emotional distress such as feelings of frustration, which can be directly evidenced in the second quote from Julie, above.

In line with fatigue creating social issues, Jackie (Ovarian Cancer) says,

I tend to avoid situations that I find stressful or may cause fatigue or anxiety- filtering phone calls, avoiding being out at the times that children are going to and from school

Jackie's speech mirrors the suggestion of fatigue causing issues in engagement within the social world for cancer survivors. This is because, to some extent she implies for her to purposely set limits on her engagement with the social world in fear of the repercussions her fatigue will arouse. Jackie's statement also suggests how the limitations of fatigue extend for Jackie, beyond the purely physical, in her avoidance of phone calls she feels unable to face.

Jackie's identification of this issue is also evident when she says,

I make sure I have some sort of social contact each day either on the phone or face to face- these days it's mostly with family. This helps with some of the social isolation

Within this, Jackie suggests ways in which she tries to manage her fatigue in order to help relieve her resultant issue of isolation from the social world.

9.2.2 Incontinence

Incontinence is another physical long-term consequence identified by participants as causing issues surrounding engagement with the social world. This can be seen in the following responses of John (Rectal Cancer) when he types,

I have also been suffering from urinary Incontinence. So I tend to stay near to home

Alongside,

It does get quite frustrating not being able to travel far from home and I suppose I have become quite depressed at times

Although John does not himself directly link his experienced incontinence to problems engaging in the social world he does imply this, as he repeatedly tells of his inability 'to travel far from home'. This suggests that engaging with

others would be extremely difficult as he has to 'stay close to home' or where there is a known 'toilet facilities near by'. This is supported further by the fact that he has been experiencing psychological effects from his incontinence as he mentions that he can come 'depressed' and finds its 'frustrating' which in its self highlights a sense of isolation from others and the outside world and the detrimental effect it is having upon his quality of life/wellbeing.

The experience of incontinence causing psychological distress is also shared by Keenan (Bowel Cancer) as he writes,

It causes emotional distress as no one gets used to being incontinent as that is what it is. You are restricted to staying in, in case you have an accident. Emotional distress causes more secretions and stoma is over active

You learn to live with and manage the situation but no matter what, it is psychologically distressing

And,

Anxiety - what if my pouch leaks in public place. When such episodes happen, deep down I wish that I would have been better off dead than surviving with added problems

Here, Keenan, speaking of being 'restricted to staying in' in case of an accident, 'anxiety' and both 'emotional' and 'psychological distress', mirrors the words of John, identifying once again the damaging effects incontinence as long-term consequences can have upon individuals' psychological health. The statement of Keenan in regards to having accidents in public shows the potential severity of the effects of such long-term consequence, making somebody wish they had died instead of living with their incontinence.

In addition to this, Michael (Bowel Cancer) makes statements such as,

I am unable to travel by public transport because my need for a toilet for the disabled can be quite urgent

And,

My wife has sometimes felt that because of my daily limitations and not being able to travel by public transport she missed out on certain aspect of life such as holidays abroad and attending evening functions and events

Once again, the fact of incontinence causing issues regarding individuals getting out and about is highlighted, supporting the points made above. However, what is interesting in Michael's comment is how he not only speaks of the limitations it brings to his own social life but how his wife has to endure them too. This shows how incontinence does not only affect the social aspect

of cancer survivors' daily lives but also has the ability to affect that of those close to them and in Michael's case, his wife.

The statements presented within this subtheme powerfully identify the magnitude of chaos that can be brought to the lives of those experiencing the long-term consequence, incontinence. This is shown through the representation of both psychological and physical issues for the survivor as well as the impact on the lives of the participants' significant others.

9.2.3 Immobility

The data suggests immobility to also be a major factor contributing to experiences regarding engagement within the social world. For instance, Hannah (Blood Cancer) makes the following statements,

In relation to the needing to be accompanied it is very frustrating. I am very independent so do not like having to rely on others. Also it mean I am unable to plan anything without checking whether others are free to accompany me

It detrimentally affects my quality of life and is very isolating. I live in a village so if I can't arrange a lift it is very expensive to go out to see friends, shopping etc so I tend to stay in.

Hannah's statements imply her experienced immobility to have caused significant restrictions within her life with regards to her engagements with the social world. This in turn, has proved particularly damaging to her perceived state of independence, as she feels as though she can no longer be the person she was prior to cancer or live the life she appeared to enjoy. This appears to cause her psychological and emotional issues alongside lowered quality of life.

The point above is also mirrored in the following response from Elliott (Head and Neck Cancer) as he states,

Recently has been my mobility as I cannot walk very far. We were both very active and whilst I get around in the car, motorbike or push bike we don't walk together now which I know Jayne misses a lot.

This quote not only supports the previous one of Hannah in identifying the link between mobility issues and being unable to socialise as they had before cancer and its treatment, but also interlinks with the previously mentioned subtheme; Incontinence. For instance, Elliott, like Michael, suggests long-term consequences of cancer and its treatment to affect the lives of the cancer survivors' significant others alongside their own. This is clearly felt by the participant enough to express it in their responses, suggesting it to cause them particular emotional distress.

The above quotes presented in this subtheme show a clear link between engagement and place within the social world issues. Another quote presented in the responses of a different participant supports this suggestion, however it does so in a more subtle manner. Kirsty (Ovarian Cancer) says,

My friends close by sometimes get a bit impatient when I am walking slowly, needing a rest or obviously in pain. Sometimes I think they consider that I am playing for sympathy as 'we all have problems' as one put it! And sometimes friends get a bit cross when I have to cancel something.

Here, Kirsty (Ovarian) cancer suggests she does try to socialise but struggles to do so without being affected by her long-term consequences. This appears to be causing problems between her and her friends as she can no longer physically do the same things as her peers, her account suggests engaging with them is no longer as enjoyable and can lead to tension between them.

9.2.4 Isolated By Others

Issues of engagement in the social world were also identified as being due to the behaviour of those around participants, which resulted in them experiencing isolation. The most drastic example of this is evidenced in the response of Joel (Acnic Cell Carcinoma) when he states,

The worst was my ex wife, who would not let me see my young son, as she said cancer made me dangerous to him. I fought through the courts and got contact, but it cost me a fortune.

This statement shows the extreme to how deprived of contact one can become from the people they value most dear to them through the actions of others. It could be expected for this to cause emotional distress as it suggested in Joel's statement that he fought hard to resolve this issue. In addition, this statement could be seen to interlink with the major theme; Understanding, as it shows a clear lack of understanding about cancer and its treatment from Joel's ex wife.

Alternative examples, although not as extreme as the one above, can be seen in the statements below. For instance, Michael (Bowel Cancer) says,

They [family friends] seem to assume the very worst and think that I am totally incapacitated both physically and mentally. Even after having been given assurances to the contrary they ask my wife the same questions. They can also make excuses for not including me in some activities because they say that it would have been "too much for you" that is without checking with me first!

And Jane (Lymphoma Cancer) says,

I also find the isolation I feel difficult. I lost virtually all my friends when I was ill, partly because of the cancer diagnosis, as I was given five weeks to live at first and I think people found it hard to deal with and partly because my fiancé was killed five weeks into my cancer treatment. I think people found it too much and stopped contact

The above quote from Michael illustrates his friends purposely not inviting him to certain social events and so, isolating him from the friendship group. In addition, similarly to the statement provided by Joel above, this could also interlink with the major theme; Understanding, as Michael's friends do not understand what he is and is not capable of and just assume that he cannot participate in any activity. However, Michael does state in his response that he has assured them that this is not the case but they still continue to isolate him, so may be another factor is at play here alongside a lack of understanding. For instance, when comparing Michael's quote with Jane's it is plausible to suggest that embarrassment on the part of others with them finding it 'hard to deal with' may play a part alongside lack of understanding.

The above quote from Jane's does not directly link social issues to long-term consequences of cancer and its treatment in the same manner as the alternative mentioned quotes. However, as discussed above, it does strongly link the experience of cancer to being isolated by her friends making her unable to engage in the social world as she did prior to cancer. Although Jane's comment suggests the experienced isolation from her friends followed the cancer diagnosis, rather than the long-term consequences that have

arisen from it, she does describe the isolation to be a long-standing issue.

This demonstrates the period of time isolation by others can continue to affect cancer survivors, alongside the psychological consequences such as isolation that can arise from it.

The above sub themes provide solid evidence that the long-term consequences of cancer and its treatment can have a detrimental effect on individuals' ability to engage with the social world and that these restrictions can have significant negative psychological consequences. In addition, it also highlights how others either subconsciously or indeed consciously can cause individuals to feel socially isolated from those they deemed close friends and/or family because of how they are treated in regards to their experience of cancer and its treatment and the long-term consequences that arise from this.

As can be seen throughout this section, the theme *Engagement within the Social World* focuses upon how different long-term consequences of cancer and its treatment can cause a variety of negatively perceived issues regarding participants' experiences of the social world. However, it is important to note here that one participant appeared to present himself as being the exception to the rule. For instance, Elliott (Head and Neck Cancer) describes his most extensive long-term consequence as being no longer able to eat and having to be peg fed. As an outsider you could expect this to cause social issues as eating and drinking are seen as general socialising activities. However, Elliott says,

The eating, which most people are shocked about is really not a big deal for me. In fact we regularly go out for meals and with friends as you soon realise that food and drink are the main catalyst for socialising. It's also handy for Jayne as I can be relied upon to drive seeing I now don't drink and strangely I have even taken up cooking!

And,

foodwise we still go out with friends just as much, however Jayne very much misses cooking for me

Within his account, Elliott makes a point of identifying that his engagement with the social world has not been affected by his severe long-term consequence. He states he still goes out and socialises with others even though he cannot always join in with the activities taking place. He does not suggest that he suffers from any psychological distress from this change in his engagement within the social world but does consider his wife to be affected to some extent. The statements of Elliott suggest issues that arise from experienced long-term consequences of cancer and its treatment cannot always be explained as being solely black or white. They also suggest that personal context is important to the manner in which different individuals experience long-term consequences of cancer and its treatment.

9.3 Support

There appeared to be a general consensus amongst participants regarding the support experienced in their cancer journey. On the whole, this described feeling a lack of support from others in regards to their experience of cancer and its treatment.

9.3.1 Dealing with the Early Crises

When speaking about support, many individuals reflected on upon experiences within the early crisis situations (time of diagnosis and during/ immediately after treatment) alongside their experience in the long-term. Although this research's focus is upon exploring the long-term consequences of cancer and its treatment, experienced by cancer survivors, looking at their experiences in the diagnosis and treatment phase of their cancer journey is also relevant. This is because, by doing this, the context of their long-term consequences can be understood. In the crisis situations those significant to the participants either responded by being unable to confront the experienced cancer, most likely (according to participants) due to them being unable to bear the thought of one of their significant others experiencing cancer, or did whatever they could to show the suffering individual that they are not alone. For instance, Jane (Lymphoma Cancer) demonstrates the case of individuals finding it too difficult to directly confront the cancer when she says,

My Dad made it clear as soon as he heard about my diagnosis and that I initially had only had five weeks to live, that he would not be coming to visit me in hospital under any circumstances. Nor did he want to hear about my treatment, or how I was progressing. He sent me a text everyday saying he hoped I was ok and wanted me to send him a text back saying I was ok but he didn't want any further contact, even though he only lived 35 miles drive away

At first glance, it could appear that Jane's father is quite heartless, however, it seems quite likely from her comment that he just cannot bear to directly confront his daughter's cancer. This could perhaps be due to a fear that his feelings would become too overwhelming. Jane does provide support for this suggestion later in her account as she tells of how generous he has been since being faced with financial difficulties.

There are a number of statements supporting this notion of significant others finding it too difficult to confront the experiencing individual's cancer, with Michael (Bowel Cancer) providing one of them as he states,

My wife, one year younger than myself, found it very difficult in the early stages following diagnosis to accept the situation and tended to almost bury her head in the sand. She was reluctant to accompany me to my appointments with my consultant at first but she soon realised that it was not only to my benefit that she came with me but for her own also

A second example is when Hannah (Blood Cancer) states,

Others stopped keeping in touch presumably because they can't cope with the side effects

In contrast to this, Elliott (Throat Cancer) gives a good example of significant others demonstrating he was not facing the cancer alone when he states,

My treatment started in November and so we [him and his wife] did not spend that Christmas alone, due to my daily trips to hospital for radiotherapy, they all came to Yorkshire and prepared Christmas and Boxing Day dinner... My parents then stayed with us for 7 weeks looking after both Jayne (who had started a new job) and taking me to the hospital everyday

Alongside,

She [his wife] made a massive sacrifice both financially and career wise in taking the 6 months off with me in 2010. At this time she also switched her job as a civil servant with a National role to one in local government so that she did not have to be away as much and could quickly be on hand for me

Here, you can see that Elliott's parents and wife showed their support by becoming much more present during the crisis situation as his parents moved in with their son and daughter in law and his wife made significant sacrifices to her career in order to show him he was not alone and that they were there for him throughout. Again, there are many statements from different individuals that describe similar experiences but the one I will share is by Demi (Endometrial Cancer), who states,

My mum and dad have been marvelous, I stayed with them for about 6 weeks after my surgery and they cooked me (and my visitors) healthy meals, tried to distract me

Here, Demi's account mirrors that of Elliott's as her parents also wanted to be with their child constantly and take care of her during her time in need, in order to show their support.

There is much more that could be said in regards to the way people showed their support during the crisis situation however, in this thesis the main focus is beyond initial treatment and so, I will now concentrate on that. However, it can be said that the things/situations occurring in the participants' lives during/just after treatment set the tone for how they have dealt with their longer term problems, which will be discussed below.

Within people's accounts of support beyond initial treatment there appeared to be four reoccurring sub themes present, of which were, 'Reality Mismatching

Expectations', Available Support', 'Being Mothered', 'Subtleness and Communication' and the 'Power of Support'. These will now be discussed below.

9.3.2 Reality Mismatching Expectations

It is clear from the accounts of numerous participants that the reality of their situation regarding support was different to the one they had expected. This is shown in a number of scenarios for instance, Demi (Endometrial Cancer) states,

One person who didn't (and still hasn't) contacted me since my illness is my cousin- we weren't especially close but I had been her bridesmaid a couple years before and we always got on well when we saw each other at family events. I was really hurt and am still really quite angry. I didn't even get an e-mail or text when I thought my cancer had spread. My aunt, uncle and her brother came to visit me. She knows I've been upset about it as I told my aunt... My aunt tells me she was depressed about other stuff at the time, which might be true but I don't see that as a valid excuse

This statement implies a sense of family obligation, in that she expected her cousin to show some form of support even if experiencing issues herself. It is interesting to see how Demi, through her suggestion of depression not being

a valid excuse for no contact, downplays the seriousness of this health issue and implies an implicit ranking of cancer above depression.

In addition to this, Demi (Endometrial Cancer) also states,

Another close friend kept telling me about when her mum had a hysterectomy and I really had to be quite blunt and tell her it wasn't fair to compare the two experiences and I didn't want to hear about it

Looking at the above statements there appears to be a sense of expectation regarding how others should (or should not) respond and there does not appear to be any empathy towards their possible difficulties in knowing how to respond. This suggests that Demi has a 'cancer trumps all' attitude in regards to how others relate to her long-term consequences of cancer and its treatment.

In line with this, Kirsty (Ovarian Cancer) also states,

Sometimes I think they consider that I am playing for sympathy as 'we all have problems' as one put it! And sometimes friends get a bit cross when I have to cancel something

The level of emotional support given to the participants also did not match what they expected. For instance, Sara (Blood Cancer) says,

How do I feel, not heard I suppose, not supported, not 'with'. I don't expect a lot of TLC but it would be nice for someone to listen even if they do not know what to say to help

In line with this, the level of emotional support given to the participants by healthcare professionals did not match expectations as Kirsty (Ovarian Cancer) says,

There is very little help given by any medical staff after treatment ends, even when having 3 monthly assessments to check for reoccurrence (I still have these after 3 years post-op) no-one ever asks how you are coping

This is supported by Jane (Lymphoma Cancer) when she states,

Emotionally, there wasn't really an awful lot of support from the medical staff at all

This also extends to the emotional support given by professionals to the significant others of the participants and can be evidenced when Keenan (Bowel Cancer) states,

Cancer is a big burden on family and friends. They all go through the same trauma but do not get the necessary help. Very few health care professionals address what the loved ones must be feeling

The above statements highlight a strong sense of reality being different to what the participants imagine it should be. This could be due to the participants being unprepared for the way in which they would be cared for by family, friends and healthcare professionals following their cancer treatment as many are surprised by this difference in support. There are a number of possible reasons as to why this could be the case, however the one that strikes as the most probable could be interlinked with the Major theme, *Understanding*. It is possible that people may appear to fail in being supportive in the eyes of the participant, simply because they do not have a sound understanding of what the participant is experiencing.

9.3.3 Support from Healthcare Professionals

During the interviews with participants, there seems to be much talk about the support received/not received from the NHS for both themselves and their significant others in regards to their long-term consequences of cancer and its treatment. Some individuals have experienced good support, however, the majority seem to agree that not enough is offered. For instance, throughout the interview John (Rectal cancer) makes statements such as,

At my last check up, I asked why I was still suffering with the pain when others I know are able to ride a bike etc, she basically said that they will be few and far between. She did try to refer me to a urologist via my GP for the water work issues, however my GP just said that you

don't need to go there, and that was that. Unfortunately I think he only sees that prostate cancer causes these types of side effects not rectal cancer

It seems very clear that once treatment is done very little help seems available and not enough is done about the side effects that patients are left with

I have had very little support or help from anywhere

Alongside,

However by far, the biggest problem is trying to get any help or advice from either my GP or my colorectal nurse or consultant

These statements could also interlink with the *mismatched expectations* sub theme as it is clear within the individuals' accounts that they expected for there to be a greater pool of support after treatment, particularly psychological support. This implies that support for individuals within the survivorship phase of their cancer journey is extremely sparse with it being a major concern of the involved participants, as their long-term needs are not being met.

In contrast to this, a minority of participants, suggest that they had some sort of service available to them however, they found it to be inappropriate for the

specific situation they were in. Examples demonstrating this can be seen below:

The only experience of professional counseling that I had in hospital was horrendous. The counselor just kept telling me I was really brave: not at all helpful and as a psychotherapist myself, a grossly inappropriate thing for any counselor to say – Jane (Lymphoma Cancer)

I have only been to one support group but it was in London and too far to travel on a regular basis... there are no groups for oral cancer or late effects from Leukemia locally – Hannah (Blood Cancer)

I was the only person there who had had cancer and was nil by mouth so again there was no-one else to speak to who is in a similar position – Hannah (Blood Cancer)

A second support group I have attended was set up particularly for my tumour type and age group is based in London- unfortunately that distance is the problem – Jackie (Ovarian Cancer)

Support and care services here are very limited!!...We have a small cancer support group that I went to when I was first diagnosed but they are mainly all older women who were diagnosed with breast cancer, and nice as they all are, it wasn't what I needed at the time or indeed

now. Its more of a social meeting every month for a cuppa and some home baking whereas at the time I wanted to talk to someone who knew what I was going through and somewhere to get information from... We've had no help and support other than from my Macmillan nurse...General support over the past 5 years has been dire and I feel like I've dropped off the radar of both my oncologist and Gynecologist. My GP told me (before she left) that my health is as good as it's going to get and I should just learn to accept it – Julie (Breast Cancer)

Support groups appear to be very difficult to access in the first instance, then when participants manage to gain this access, the groups seem to be unable to meet the needs of the participants in regards to their experienced long-term consequences. Whether this is due to, no sense of community within the group, the group being used as a social gathering rather than support group, or due to the individuals running them appearing to lack in training. The only exception to this appears to be the care received from Macmillan, as the participants only express positive experiences in regards to support from the organisation. This contrasts to the predominantly negative experiences expressed by participants in regards to alternate support services they have come across.

It is also highlighted in the above statement from Julie that she has difficulty in accessing support from her GP. This can be evidenced on numerous occasions throughout the accounts of the participants. For instance, Jane (Burkitts Lymphoma) shows this when she says,

I didn't receive any support from my GP, who actually misdiagnosed my cancer, saying it was bad posture and definitely not cancer

And John (Rectal Cancer), who states,

I believe my GP likes to get me out of his surgery as soon as possible...I have got to the stage when I go to my GP's that I am wasting his time some how, and due to all that is going on health wise you never get long enough to go through it all due to time

And lastly, when Sara (Breast Cancer) comments,

In the last couple of weeks I have finally summoned the energy to go back to the GP and try to push forward on what might be any underlying causes but even that is a hurdle because she sets her phone to ping at ten minutes and you are done even if you are not, so you have to make another appointment which can be three weeks hence, and if I am honest I am tired of seeing doctors because all I want is to feel well! There is no time for looking at the whole picture but just the presenting problem despite my best efforts to advocate myself and then fobbed me off with her pet theory, I felt unheard and a bit defeated

This statement also interlinks with the mismatching of expectations subtheme as it is clear that Sara expected the doctor to be helpful in finding the cause and possible treatment of her worsening fatigue however, in reality this is not the support she has experienced. With the above statements the main contributor to GP's failing to support the long-term needs of the participants, appears to be having a lack of available time. For instance, both Sara and John, suggest that they feel rushed when they go to their GP for help in regards to their long-term issues following cancer, feeling they are not given to time for effective support to be given or a proper conversation to be had. This results in participants feeling they are not viewed as worthy of the GP's time and them having to put up with their long-term needs being unmet.

Although the above shows that some individuals have experienced very poor support by GP's this is not the case for everyone as Jackie (Ovarian Cancer) states,

The GP I currently most frequently opt to see (it is a group practice) has also been very supportive. I did start opting to see her after diagnosis- as the last GP I saw refusal to refer back to the consultant on my request may have delayed my diagnosis which may have meant full hysterectomy would not have been needed

This, is echoed by Hannah (Blood Cancer), who comments,

I have mixed support from GP's. My current GP is fantastic and can't do enough for me. My previous GP ignored my symptoms and refused to give me pain medication or to sign me off work before I saw the consultant when I was diagnosed with tongue cancer and given 3 months to live!) Despite the pain I was in, I was unable to swallow or speak clearly and that I had lost over 1.5 stones in weight all she kept telling me was that I had a vitamin deficiency and was suffering from stress

The above accounts demonstrate that even when participants refer to positive experiences of support from NHS services, in this case GP's, it is quite often contrasted with bad experiences they have previously had. This highlights that it is not often that an individual experiences solely positive support.

Although not from his GP, Mark (Head and Neck Cancer) expresses the high quality of support he has experienced from Macmillan, adding to the point that there is some good support given by the NHS. For example he makes the following statements,

macnurse- incredible, once activated by us after GP advice Oct 11.
Caring, understanding, professional, pro-active, filled in benefit forms for me. Made a huge difference. Got us psychological support immediately when we said we weren't coping. Organised application for mac grant for £400 which meant I got and paid for 8x £50 trains to London for rt Dec11/Jan 1

mac psy support- perhaps the most incredible person in the whole process, apart from my wife. Understanding, caring, considerate, measured, gentle, funny

Marilyn [Macmillan Nurse] helped Lara and I come back together when we were falling apart. She helped me understand how Lara was feeling

The above statements show that In terms of care/support, the cancer charity Macmillan, appears to be the exception to the rule as positive experiences of support from them seems to be paramount in the responses of Mark. This appears to also be the general consensus amongst other participants, with another example being Julie (Womb Cancer), who states,

We've had no help and support other than from my Macmillan nurse

Alongside,

I was so sad to lose my Macmillan nurse last June as she had been my rock throughout my cancer journey. She had become a close friend and had not only helped me through my own cancer journey but was also there for me when my Mom was diagnosed and later died in the space of 5 weeks

The above statements significantly highlight the strong positive impact the Macmillan organisation has upon individuals who are dealing with the after effects of cancer. The way in which the charity is spoken about by the participants suggests that not only does the help they provide, psychologically help them but it appears to make such a negative experience much more bearable as they support the participants in ways which lifts some of the burden they carry/have to deal with on a daily basis. However, the possibility of selection bias must be acknowledged here, as it was from the Macmillan Cancer Voices support group that the participants were recruited. Therefore, their sustained participation within the group itself could imply them to have positive feelings towards the organisation.

9.3.4 Being Mothered

Parents of some of the participants seem to show support to their children by reverting back to caring for them as they did when they were young children. For instance, Kirsty (Ovarian Cancer) states,

Mother initially fretted when I returned home and still phones me in the morning and evening to make sure I am ok...she insists on carrying things for me. As regards to my PN She worries about the stairs to the flat, insists I phone to say I am ok when I have been out (even if I go to her house which is about a quarter a mile away). She worries constantly

Here, Kirsty suggests that her mother helps out with things that she may not have necessarily helped with if cancer had not been experienced, that Kirsty is in fact capable of doing for herself alongside, worrying more than expected about her daughter's wellbeing. It could also be suggested from this comment, that her mother's over-attentiveness is a response to her own extreme worry, rather than that of Kirsty's. Furthermore, she goes on to highlight that mothering can in fact be very unhelpful as she says,

When I had a lump investigated recently she was panicking, then she likes me to stay at her house so she can keep an eye on me. Slowly she is learning to let go a little, but the slightest setback and she is back to square one...I find it intrusive and irritating sometimes that mother fusses so much, I understand her concern but feel like reminding her that they took my reproductive system out-not my brain! I know what I can/can't manage and resent being told

This shows that sometimes mothering can become overpowering and although it is done with the best intentions it can be unhelpful, hindering the quality of life and wellbeing of the cancer survivor.

9.3.5 Discretion

Other individuals expressed support in alternative ways for instance; some of this support was discreet and can be seen in the following statements:

My wife Lara is also very supportive when I get extremely hungry and then irritable usually mid-morning, feel low because my face is slumping more than usual because I'm tired or poorly and go out for bike rides at the weekend to help me feel better and more positive, leaving her to look after Rowan - Mark (Head and Neck Cancer)

They (family) know I don't like people fussing over me, but I am always aware that allowances and adjustments are being made - Elliott (Throat Cancer)

My family have coped well, unobtrusively supporting me – Mary (Breast Cancer)

My 10 year old son Rowan helps me a lot by pointing to his own right side lower lip in a very discreet way, so I can wipe the food away from my face – Mark (Head and Neck Cancer)

The above statements highlight that the significant others of some of the participants have shown extremely positive support by being very discreet in the way they provide help, as to not become overpowering or belittling. This appears to have been well received by the cancer survivors as the participants involved speak in a positive manner in comparison to others, such as the quotes presented in the *Being Mothered* sub theme, suggesting this type of support to be beneficial to one's quality of life/wellbeing as they are not being intrusive or overpowering.

9.3.6 Communication

It is also clear through the accounts that *communication* is a key contributor to the way in which participants perceive support to be received. This can be seen in the comment of Mark (Head and Neck cancer), when speaking of support from friends as he states,

They have been incredibly supportive too [friends]. Sending incredible words of encouragement and love on numerous occasions over the time during surgery and RT, responding to my detailed update e-mails to them at that time, and even now three years on sending positive messages when I tell them I'm going for a review at the Marsden or dealing with unknown lumps

This is supported by the comments of numerous other individuals, with some examples of these being:

My best friend is brilliant though, he is supportive and undemanding. When I am having a particularly bad time he usually sends me a card or text saying how proud he is of how I keep going which helps – Kirsty (Ovarian Cancer)

I tend not to let my feelings show, so they are not aware of how I feel most of the time. When I do make a comment, they are always positive in response – Joel (Acnic Cell Carcinoma)

Others are fantastic. Even after all these years when people phone my parents it is always me they ask about first...I do have supportive friends but most live a distance away and have young families so the support is via telephone – Hannah (Blood Cancer)

This is supported further as participants also associate a lack of communication with poor support with examples of this being,

Others stopped keeping in touch presumably because they can't cope with the side effects – Hannah (Blood Cancer)

How do I feel, not heard I suppose, not supported, not 'with'. I don't expect a lot of TLC but it would be nice for someone to listen even if they do not know what to say to help – Sara (Breast Cancer)

These statements demonstrate the importance of good communication in providing positive support as without it participants feel unheard or assume others cannot cope with their experienced side effects, which is bound to negatively impact their quality of life. The responses also highlight the different forms communication can take in regards to support. Participants suggest communicating over the telephone to be just as advantageous as

being face-to-face as they find both to provide positive support in regards to their experienced long-term consequences. These in turn, appear to have positive effects upon them as individuals as they feel valued and heard.

9.3.7 Power of Support

Above, I have demonstrated the different ways in which support has or has not been shown to the participant in regards to their long-term consequences of cancer and its treatment. However, not only do they speak about this, they also express that difference in support leads to differences within their everyday life. For instance, receiving support that was viewed as positive seemed to reflect positively in their relationships and everyday life with long-term consequences of cancer. This can be evidenced directly in the following statements,

I have got a lot closer to my mother and a sister who lives a short walk away...The support of my husband and family are a large part of my coping, both for physical and emotional support – Jackie (Ovarian Cancer)

I have become much closer to my parents and the rest of the family who regularly call to see how I am. We also get together on a much more regular basis despite living across the UK and abroad... The cancer and its consequences has been an emotional rollercoaster however, with support from both family and professionals it has brought

us even closer together and made our relationship stronger for which I am eternally grateful – Elliott (Head and Neck Cancer)

[her family] spend a lot of time with me now, visiting and going out in London. My mum and I have started having a luxurious holiday together each year- we have always got on well but have become closer – Demi (Endometrial Cancer)

I think our relationship has actually improved since my cancer – Jane (Lymphoma Cancer)

The above statements suggest positive support regarding participants' cancer experience strengthens and sustains relationships and provides a positive aspect to a challenging experience. Alongside this, participants suggest the experienced rollercoaster of living with long-term consequences to ease, because of positive support received from significant others.

In contrast to this, support viewed to be poor or entirely absent appeared to negatively impact individuals' sustained relationships and/or their ability to cope with every day situations. For example, Jane (Lymphoma Cancer) states,

My brother doesn't like to discuss the cancer and tries to down play it, even to the point where he sometimes hints I should be over the headaches and memory problems I have- or even that I'm putting them

on, which is very upsetting to me at times. I would never be able to confide in him

This is also the case with Julie (Womb Cancer) in regards to her relationship with her GP as she says,

My GP told me last year that this is about as good as its going to get health wise and I should just learn to accept things and get on with it. Needless to say I haven't been back since

And,

Each day is a struggle but I just get on with it. I rarely go out; maybe once a week at the most, it's a struggle and I often find I just don't have the energy

These statements suggest that negative support from both significant others and healthcare professionals can lead to the breakdown of relationships as well as negatively affecting the participants' psychological wellbeing. This is because the participant's concern regarding what their significant others think of them because of their long-term consequences, causes emotional distress. This then leads to withdrawal, as the participants do not feel they can seek comfort from them at times of need.

The accounts within this sub theme highlight that there is a strong relationship between level of support in regards to long-term experiences and sustained relationships with poor support appearing detrimental to the participants' quality of life/wellbeing.

9.4 Feeling Understood

To be understanding, you must show a sympathetic awareness or tolerance (Oxford Dictionary; n.d.). Throughout the e-mail interviews, the concept of understanding - appeared to be an important factor contributing to the participants' experiences of long-term consequences of cancer and its treatment. The experienced levels of understanding received from others varied between the participants. However, it was clear that the participants hold the view that nobody can understand their experiences of cancer and its long-term consequences unless they have either experienced the phenomenon personally, or have done so through a significant other. Therefore, this theme is comprised of two sub themes: *Can only understand through experience* and *Nobody Understands*.

9.4.1 Can Only Understand Through Experience

First of all, if participants had relationships with people who also shared an experience of having cancer then it was suggested through their e-mail responses for these individuals to be the only ones who were able to

understand their situation. This was stated directly by a number of participants:

Unless they have been through it themselves they have no concept of how it changes everything– Kirsty (Ovarian Cancer)

As for friends, well only those close friends who have had cancer themselves understand – Julie (Womb Cancer)

We don't seem to grasp anything like real facts until we are ourselves affected or may be a very close friend or relative of somebody affected
- Mary (Breast Cancer)

The best understanding I get is from fellow cancer sufferers who know what it is to live with chronic conditions – Keenan (Bowel Cancer)

The above responses imply for a sense of shared experience to be the only, or at least, the best way to feel understood in regards to their long-term consequences of cancer and its treatment, This is shown as participants suggest that the presence of an individual who shares their experiences in regards to cancer and long-term consequences, to be the only instance in which they experience any level of understanding.

9.4.2 Nobody Understands

For the participants who did not have any significant others surrounding them who had also experienced cancer, then a feeling that nobody understood their struggle appeared to be present. Some participants describe this lack of understanding in relation to professionals like their GP's, as can be seen in the accounts from the following individuals:

GP has little understanding of the procedure or of the consequences or side effects of treatment, so he does little to help - John (Rectal Cancer)

And,

A lot of GPs do not know much about stoma and some may never even have a patient with stoma during their entire career so have to battle to explain and be understood - Keenan (Bowel Cancer)

These statements appear to contradict the standard expectation of a GP as it is generally expected for a one to embrace the knowledge and understanding necessary enough to be able to medically treat their patients. The above quotes however, imply GPs lack sufficient medical knowledge due to lack of clinical experiences regarding facets of long-term consequences following cancer and its treatment.

Demi (Endometrial Cancer) describes a lack of understanding from her work place as she says,

My head of dept expected me to come in for the 2 weeks after my diagnosis and before my surgery but I had some really awful symptoms and couldn't have. I was made to feel quite guilty about that. And she also talked me into going back to work before I was ready

Alongside,

I told my line manager one day I felt like killing myself and didn't care about the work, and all she said to me was 'I don't want you to care about it, I just want you to do it'. That felt a bit like a smack in the face

These comments are powerful as they show the extent to which misunderstanding can reach. Victimisation is apparent here because Demi seems to have been punished for not being able to do things because of her long-term consequences of cancer and its treatment. This demonstrates how a lack of understanding from employers can negatively affect cancer survivors' quality of life as Demi is being made to feel guilty about things out of her control, which in turn affects her satisfaction at work.

Additional examples supporting the notion of nobody understanding, can be seen below:

People don't seem to believe that I can really still be so fatigued 5 ½ years after my diagnosis and I do get the impression at times that people think I'm putting it on– Jane (Lymphoma Cancer)

I don't think I am overstating it when I say that no one gets what I mean when I say I am fatigued. I have colleagues say they are tired too and they tell me I will feel better after a good nights sleep or that I need a holiday. No idea at all – Sara (Breast Cancer)

A lot of my symptoms cannot be seen and are completely misunderstood e.g fatigue is believed to be the same as tiredness so if I mention fatigue I am told everyone gets tired so should just get an early night. Very frustrating! The pressure results in me worrying a lot which affects my ability to relax and go to sleep – Hannah (Blood Cancer)

They [other people] have no concept of long-term consequences or that reconstructive surgery does not put you in the same position as you was pre-cancer – Hannah (Blood Cancer)

There are a number of themes within the accounts of Hannah's. The first is invisibility, as Hannah states the feeling that her fatigue is misunderstood due to the fact that you cannot physically see it, which then leads to her experiencing frustration. Legitimacy also appears to be a concern for Hannah as she writes about the inaccurate expectations that she should be 'back to

normal' and that fatigue is the same as general tiredness. This is also evidenced by the above quotes of Sara and Julie. This shows as an issue affecting quality of life as Hannah also links it to anxiety and insomnia. Finally, it is highlighted in the above quotes that the experience of long-term consequences of cancer and its treatment creates a new normality in that what was once ordinary for the individuals, is no longer the case alongside, the suggestion that their pre cancer 'normality' may not ever be retrieved.

On the whole, the above statements within this section identify a lack of feeling understood as negatively affecting one's quality of life, with implications for notions of normality and chronicity. For instance, participants speak a lot about 'normality' and 'new normality' however; their concept of what is normal post cancer tends to be different from that of individuals around them who have not experienced cancer themselves. For the participants, a new normality includes a loss of what they once had – for example, having less energy. Whereas, individuals around them who had not experienced cancer seem to believe that once treatment is over then the experiencing individual will revert back to their former 'normal' self. This point links to chronicity because as touched upon previously, when it comes to long-term consequences many "cannot be seen" and so, because of this and due to the fact that the experienced individual is now post treatment, other people hold an expectation that they should be back to their normal pre cancer self. This in turn causes the legitimacy of some individuals' complaints to be questioned which can then lead to further stress.

9.5 Managing the Consequences

It appeared throughout participants' accounts that having some sense of ownership over their experienced long-term consequences through various management techniques, was important in enabling them to continue in their day-to-day lives. Three management techniques stood out within the responses and so, this theme is comprised of three sub themes: *Shifting Focus*, *Routine* and *Organisation* and *Positive Comparisons*.

9.5.1 Shifting Focus

Distracting one's self from thinking about experienced long-term consequences through finding something else to focus on, appeared to a main management technique of the participants in order to minimise the effects of their experienced long-term consequences of cancer and its treatment. Comments directly evidencing the use of distraction are shown in the following quotes:

I deal with this and depression in the same ways- by keeping busy –
Demi (Endometrial Cancer)

I mostly distract myself – Sara (Breast Cancer)

I also try to keep my mind occupied – Kirsty (Ovarian Cancer)

However, when asked about ways of managing their long-term consequences in order to minimise their effects, some individuals highlighted specific ways they shift their focus to do this, whether this is through work, hobbies, or helping others. A sample of these can be evidenced in the following accounts:

Distraction is fantastic for taking your mind off your problems, especially as us men cannot multi task, so Joanne tells me! Sitting at home thinking about your problems is the worst thing possible so any distraction is good such as listening to music, gardening or searching the net – Elliott (Head and Neck Cancer)

I think the reasonably effective advice is to embark on something you find interesting and so keep busy– Mary (Breast Cancer)

I paint to forget my problems, painting for me is very therapeutic and I attend a painting class once a week. I also believe that the best way to get over your problems is to help others – Keenan (Bowel Cancer)

The above quotes demonstrate how participants shift focus from their experienced long-term consequences, to the participation of an enjoyed hobby. This appears to be a therapeutic management technique in the eyes of the participants as doing this, restricts negative thought about their long-term consequences occurring. However, the quotes also imply the participants look away from their experienced consequences rather than facing them, which in the long run, may not be so beneficial to their health. Furthermore, other

participants imply shifting focus to their career to be beneficial. This is shown in the comments of Jane (Lymphoma Cancer) as she states,

As soon as I was well enough I began a ten-week part time course.
This gave me something to work towards and focus on... I continued working on further courses and qualified in December 2014. I also worked on my second book...and am now working with an American author on a book on near death

The above quotes demonstrate that a conscious shift of focus by the participants is beneficial towards their perceived quality of life. However Mary (Breast Cancer) suggests that at times, her significant others unintentionally shift it for her. For instance, she states,

I am also somewhat distracted from my own health, by health problems in the family

The quotes within this section, demonstrate that not only does a shift in focus whether intentionally by the participant themselves or through significant others' needs, restrict negative thoughts about experienced long-term consequences but as demonstrated by Jane, one's career can also strengthen from it, therefore, making a positive from a negative situation.

It must be noted, that the participants within this section are not necessarily presenting a denial narrative but are simply emphasising that sometimes they

do need a break from thinking about their experienced long-term consequences, which is beneficial to their health.

9.5.2 Routine and Organisation

An alternative way of coping with experienced long-term consequences appears within the written accounts to be through having a sense of routine and organisation, which can be evidenced in the following comments:

It is important for me to have a routine to fit everything in. Medication four times a day and has to be at least four hours apart. There are exercises to do for the various side effects. My feed in the morning takes an hour, at lunchtime 40 minutes and in the evening two and a half hours. There is also the mid morning water/feed and the afternoon water to fit in. On top of that I have to fit work in, hospital appointments and having a life – Hannah (Blood Cancer)

I manage my personal daily health problems by maintaining an ordered way of life and having a rather strict daily routine ...As I am aware of the probability of a leak I wake up every two hours or thereabouts to check my pouch for the early signs of leakage and at that time usually take the opportunity to empty the pouch so as to lessen the consequences if a full leak should occur – Michael (Bowel Cancer)

The above quotes demonstrate that a sense of order and structure by the participants is key to feeling in control of their experienced long-term consequences and minimising the damaging effects of them.

Being organised is also shown through pacing ones self and planning the day/s ahead for instance, Jackie (Ovarian Cancer) states,

I needed to prepare physically the day before making sure I had a slow day, taking adequate rests, having a bath in the evening rather than leaving it to the morning (I find showering tiring) filtering phone calls (again long or difficult calls can be tiring), planning an 'easy' to make meal for the evening

Furthermore, Elliott (Head and Neck Cancer), makes the comment,

I create bucket lists and to do lists (just like I did at work). I prioritise these making sure there is a good mix of enjoyable ones such as car and bike track days/hot air balloon trips (Groupon is great for these bargains), some healthy ones, some healthy ones like going to the gym/swimming twice a week and cycling, boring ones like shopping/decorating projects for Joanne [wife] and finally giving/mentally stimulating ones like hospital work and Macmillan projects...I use the daily/weekly planner on my iPhone breaking down the lists into bite sized chunks. Each night before I go to sleep I reflect

on my day and re book any activities I have not achieved that day or add new ones – Elliott (Head and Neck Cancer)

Here Elliott is planning for the future with a positive and optimistic focus by compartmentalising and reappraising his priorities whilst specifically making plans for enjoyable activities. This interlinks with the *Shifting Focus* sub theme as participants within that section also describe focusing on participating in something they enjoy in order to manage their long-term consequences.

Mirroring Elliott, Steve (Prostate Cancer) also plans his daily activities however, rather than doing so to keep busy like Elliott, Steve plans in order to help him remember things he needs to do, due to his long-term consequence of memory loss. For instance, he states,

As regards to remembering to do things, I put everything into MSN calendar, which links with my phone, tablet and PC, also means I can check my calendar from just about anywhere, seems to work reasonably well.

The above accounts show that having a sense of control is of key importance to enable individuals to cope with their long-term consequences of cancer and its treatment. This is interesting as they have had no control over their experience of cancer and its treatment and so claiming ownership of their long-term consequences and managing them is something that they are able

to have control over. This seems to be important for the wellbeing of the individuals.

9.5.3 Positive Comparison

The final way in which individuals suggest they manage their long-term consequences is through positive thinking and comparing themselves to others in less fortunate circumstances following their cancer experience. Examples of responses evidencing this are shown in the following statements:

I think about how lucky I am to be alive and focus on the things I can do. I think about how lucky I am to have the love and support from my wife, family and friends and also think about the people who are in a far worse position than me. I believe life is for living – Elliott (Head and Neck Cancer)

The only thing I do is remind myself that I am lucky- I could have died or have other serious disabilities and that others are a lot worse off
- Joel (Acnic Cell Carcinoma Cancer)

The above statements show that the individuals use positivity as a way in managing their long-term consequences through the act of making downward comparisons. This makes them more tolerant of their experienced long-term consequences as they compare having them to the alternative prospect; death, or more harrowing perceived long-term consequences. These positive

comparisons appear to be beneficial towards one's quality of life as the participants appear excited about their life.

9.6 Research Impact

With any type of research it can be expected for individuals to be affected in some way or another by their participation; however, the method of the current research appeared to benefit the participating individuals.

Within the written accounts of the participants, it was strongly implied that the e-mail interviewing method of research was seen as therapeutic by a large minority of participants. For instance, Mary (Breast Cancer) appears to emotionally benefit from the e-mail interview style of methodology. This is evidenced throughout her written accounts and can be seen in the following examples:

I believe that your questions are helping me to have insight into my own emotions and that that is an excellent thing for me. Thank you.

Whoever thought of your research and decided on interviews by e-mail, is somebody to whom I owe a big Thank You because the explanations that I give you keep on showing me interesting things to understand about myself

And,

Your e-mail interviews are a new idea for me but, as I have mentioned earlier, I have gained a little insight into my feelings through answering your questions-valuable

The above comments show that Mary suggests the e-mail interviewing method to be cathartic. This being because, she demonstrates to have gained a new understanding of herself in regards to her experienced long-term consequences which, she states to be 'excellent' and 'valuable'.

Other participants mirror this perceived therapeutic experience of e-mail interviewing, For instance, towards the end of her e-mail interview Julie (Womb Cancer) states,

It's been a pleasure to help your research and it has helped me to re evaluate things in my mind

Your questions often make me think about my experiences in a new way, so it's actually quite a cathartic experience for me

I have really enjoyed talking to you it has allowed me to think about areas of my experience that I may not always have considered

And finally,

I enjoyed the questions as it made me think about everything that happened in a different way

Julie's accounts highlight the growth of positive feelings towards me [the researcher], demonstrating the presence of a researcher-participant relationship being formed. This is supported when she says, 'your questions' instead of 'the questions'. More importantly, the e-mail interviewing method appears to have enabled Julie to gain a new perspective towards her long-term experiences. This suggests the method was experienced as therapeutic, because it has positively enabled her to re-evaluate aspects of her experiences which she would otherwise not have thought about, with her suggesting this to be 'cathartic'.

The thoughts of Julie, regarding the e-mail interviewing process to be somewhat therapeutic is supported by other participants as John (Rectal Cancer) states,

It's been good to actually vent my frustrations for once

And, Kirsty (Ovarian Cancer) also makes the comments,

Thanks Jade. I have enjoyed the experience and found it quite therapeutic having to think about the questions and how I felt about things - so thank you too!

The above accounts reinstate the e-mail interviewing method as being therapeutic, alongside, demonstrating the e-mail interview method to benefit both the researcher and the participant, showing a key advantage of its use within research.

9.7 The Impact of Cancer Voices

Alongside the six major themes within the revised final template, a parallel but yet equally as important theme; *Cancer Voices* was drawn from the data during the Template Analysis. It is no surprise that this subject is interwoven within the responses of all the participants who completed the e-mail interview process; participant were asked their reasons for joining the cancer support group as well as what, if anything, they have gained from their participation. The responses gained from these questions are important to the present research as the sample of participants were recruited from the online Cancer Voices support group, meaning that important context regarding their motives for joining the group in the first instance could be gained. Furthermore, the responses also provide an insight in to how the participants' involvement within the group, shapes their experiences of long-term consequences. In total, four sub themes were evident from the Template Analysis with these being: *The Need to Give*, *Sense of Community*, *Seeking Personal Enjoyment/Benefits* and *Personal Positive Achievement*.

9.7.1 The Need to Give

It is apparent that the opportunity to give something to others was of key importance for participants when deciding to join the online Cancer Voices support group. This was presented in two forms, giving something back and giving information on their experience; both of these, will now be explored.

A number of individuals highlighted the importance of them being able to 'give something back'. This can be seen in the following quotes when speaking about the reasons behind joining Cancer Voices,

I joined Cancer Voices to give something back to Macmillan as the nurse I had in hospital was fantastic - Hannah (Blood Cancer)

its the giving something back, no matter how little that helps and makes you feel so much better, if not more attractive!!! - Elliott (Head and Neck Cancer)

Macmillan gave a lot to me in terms of support during treatment and I wanted to give back - Jackie (Ovarian Cancer)

Because I wanted to give something back to those that helped me, and if it helped to improved future services, it requires input from those that have gone through the illness - Joel (Acnic Cell Carcinoma)

I feel like I am contributing to something, giving back in a way for all the amazing care I have been given and on the receiving end of - Sara
(Breast Cancer)

The above quotes suggest for the participants to feel indebted to the Macmillan charity and owe them their participation as a means of acknowledging the care/support provided to them and thanking them for it. Furthermore, it is implied by Elliott, a participant with challenging long-term consequences, that 'giving something back' has positive effects upon his quality of life and perceived sense of self.

Additionally, individuals claimed to have joined the group due to being able to give others information learnt through their personal experience, in order to 'make a difference'. For instance, Jane (Lymphoma Cancer) states,

I joined because I was told there were opportunities to help various charities and organisations in matters related to cancer".

John (Rectal Cancer) supports this further as he states,

I joined cancer voices as the job description (or the want of a better word) stated "use your cancer experience to help make a difference

And lastly Kirsty (Ovarian Cancer) makes the comment,

I wanted to help inform people about cancer, about the symptoms of (in my case) ovarian cancer. But mostly to tell people not to be afraid, to see their doctor as soon as they have a concern and that it is no longer an automatic death sentence - there is hope! I also wanted to tell the 'experts' that actually the true experts are the cancer voices.... and they need to listen

It is obvious from the above quotes that the need to share their experience and what they have learnt from it is extremely important to the participants. This can be through providing general information about symptoms, giving advice they deem necessary or to simply share their experience in the hope of making a difference to that of someone else. It is also implied that the participants believe that from their personal experience, they can teach the 'experts' behind the group things in order to improve the running of it and other research.

Therefore, it is predominantly suggested within the statements provided in this section, for the participants' participation within the support group to be selfless, with it being for the benefit of others rather than themselves.

9.7.2 A Sense of Community

Alongside the ability to give something to others, another reason behind the decision to join the Cancer Voices support group is the longing to find

somebody who has shared their experience and in turn a sense of belonging. This is evident when Hannah (Blood Cancer) states,

I also hoped to meet other people who had been through a similar journey

Furthermore, Julie (Womb Cancer) and Kirsty (Ovarian Cancer) support this by echoing the words of Hannah, but also expanding upon them. For instance, Julie states,

I think I joined Cancer Voices because I was looking for other womb cancer women to share experiences and information. Being isolated means I wasn't likely to find anyone to talk to so going online was the only option. It enabled me to meet other women in the same situation as me and be able to chat etc

And, Kirsty makes the comment,

I wanted to interact with others who had been through similar experiences, and I wanted to offer support to others

These quotes suggest finding a sense of community in that they are not alone, was paramount to participants' initial joining of the online cancer support group. It is also suggested that their participation within the group then shapes their experiences in regards to their long-term consequences,

with introduction to others in the same predicament being a great benefit. Is it suggested that the knowledge of not being alone shapes participants' experiences of long-term consequences in a more positive manner. This is achieved through the participants being able to share their experiences of long-term consequences, which in turn, appears to make living with them, more bearable.

9.7.3 Seeking Personal Enjoyment/Benefits

In contrast to the previously mentioned sub theme; The Need To Give, a large minority of individuals also identify their joining of Cancer Voices to be down to seeking their own enjoyment and/or benefits, implying an overlap of reasons behind their participation. This can be evidenced in the following responses,

I determined to give my time to Cancer voices in activities that I enjoy and this has turned out well over the last two years. I am comfortable with e-mail and have taken part in a few surveys conducted by e-mail –
Mary (Breast Cancer)

I do all these things to help other people and also myself – I read that doing things to help others can be a good way to reduce depression and it definitely helps to volunteer and meet other people and to try to make a difference - Demi (Endometrial Cancer)

Joining Cancer Voices seemed an opportunity to learn more about what people who support those with cancer are doing in that support. many people donate to charities but don't have a clue what happens to their money. but having benefitted directly from that money - with my 2x grants, benefits advice, psych counselling - I wanted to make a contribution and help. I don't think I feel I owe anything more than my thanks for what I've received in support, but it's always been a pleasure to help with Macmillan in any way- Mark (Head and Neck Cancer)

And,

I wasn't hoping to get anything for myself out of doing the macmillan voices, other than provide the opportunity to do some volunteering in a way that suited my skills – Gerald (Cancer)

The above quotes highlight that some individuals were drawn to joining the Cancer Voices group as they believed it would be beneficial for themselves, whether this be minimising psychological distress, using their acquired skills to seek enjoyment or just to conduct their own research into the charity. Therefore, it could be suggested by their participation being an enjoyable experience for this to benefit their quality of life in regards to their experienced long-term consequences of cancer and its treatment.

This is not to say that the chance to help others is not a factor in their wish to join as both Demi and Mark do acknowledge helping others to be a key advantage. However, it does highlight that such participation is also an enjoyable and beneficial experience for its members who do not necessarily require support, which is a great advantage for the support group.

9.7.4 Personal Positive Achievement

Whilst speaking about their participation within the Cancer Voices support group, a minority of individuals highlighted specific personal advantages from their participation. For instance, Demi (Endometrial Cancer) states,

I have been asked to do further talks which made me feel a sense of accomplishment and pride that I had managed to be useful and people had liked the talk. When I was first ill, I struggled for a long time to even talk about it without crying so I felt that was quite a step forward for me. So it helps me to do these things

Here, Demi associates her participation within the group to personal positive achievement with her suggesting her participation to have also benefited her psychological state as she is now, thanks to the support group, able to speak about her cancer experience.

This is also echoed by Jackie (Ovarian Cancer), who states,

I have gained some skills in terms of expressing myself, some confidence in that I am not alone in this, I have met others in a similar situation (a sense of community) – Jackie

This quote also implies participation within Cancer Voices to be associated with personal positive achievement. Jackie implies this by expressing her involvement within the group to heighten her skills of communication and build up her confidence, Jackie's quote also interlinks with the previously explored sub theme *Sense of Community* as she implies the meeting of others in similar positions to be advantageous to her level of confidence.

On the whole, it is identified that one's participation within the Cancer Voices online support group contributes to the shaping of their experiences in regards to their long-term consequences of cancer and its treatment in a positive manner. It also shows some interesting advantages associated by the participants to joining the support group, which may be beneficial to those working within the Macmillan charity or to any scholars wishing to explore this area of study.

Chapter Ten:

The Main Phenomenological Study - Narrative

Analysis Findings

This chapter will present the findings of the three readings within the Narrative Analysis. This will be done by presenting the findings of each reading separately and will conclude with a synthesis, pulling the findings together.

10.1 Reading One - Identifying Narrative and Plots within the Participants' Accounts

This section will present the findings for all three participants separately, starting with Jane, then moving on to Mary and finally, Gerald. My reflective notes will also be presented at the end of this section as it was during this reading that they were made.

10.1.1 Jane

When focusing on the accounts of Jane, it appeared paramount that her constructed narrative consisted of four major plots which condensed into further sub plots in order to capture her personal story based on her experiences of long-term consequences of cancer and its treatment and the current research. Figure 10.1 below demonstrates how these plots and sub plots link together with the four major plots highlighted in red; *Fatigue, No*

Labels on Me, Blindness of Phenomenon and Therapeutic Impact of Research. The sub plots that can be seen are highlighted in orange; *Changes in Selfhood, Frustration, Isolation, Cancer is My Past, No Choice: Not a Hero, Lack of Knowledge, Restricted Support and Re-Evaluation.* Most of these are simple however, *Fatigue* highlights a more complex set of sub plots as a reoccurring cycle is apparent between *Fatigue, Changes in Selfhood, Isolation* and *Frustration* and this can be seen by the black lines in figure 10.1 below. Also, within the major plot of *Fatigue*, it can be seen that the sub plot; *Changes in Selfhood* is collapsed further; identifying two more sub plots within it, these are highlighted in blue. Different scholars present their identified plots/themes in various ways (Geib, 2012; Chmielewski, 2017; Golding & Hargreaves, 2018) however; I feel them to be highlighted most clearly in the hierarchical diagram format illustrated in figure 10.1.

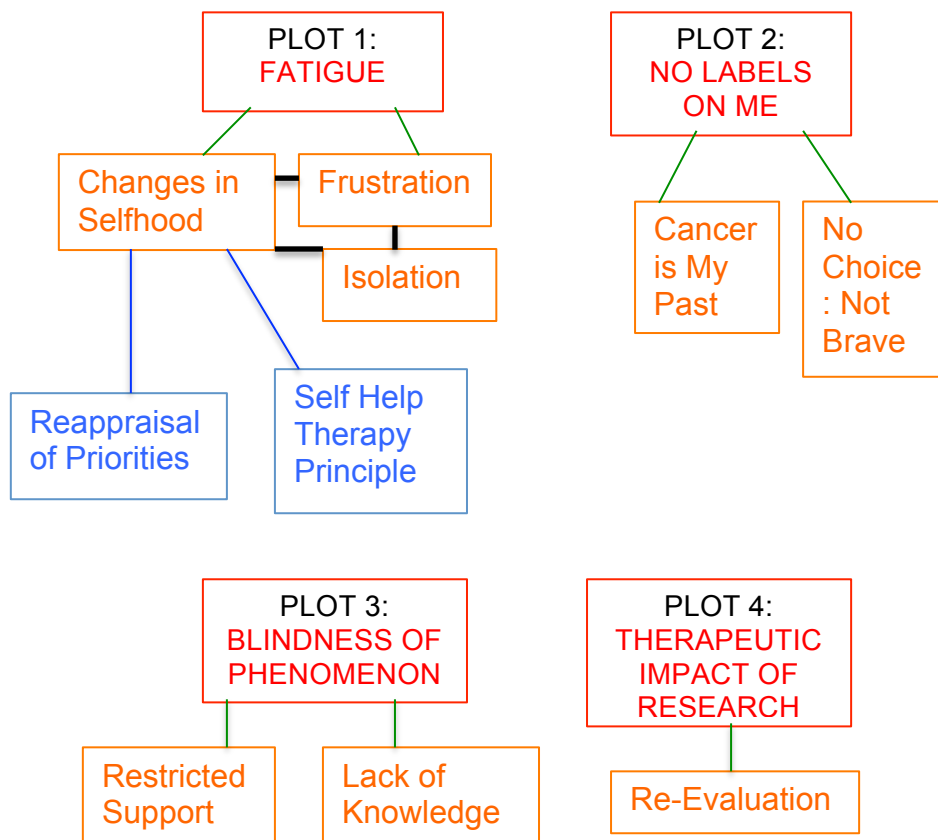


Figure 10.1: Plots Identified in Jane's Written Accounts

10.1.2 Mary

Mary's constructed narrative encompassed five plots; *Management of Consequences*, *Mixed Support*, *Glass Half Full*, *Changes in Selfhood* and *Research Experience* which are highlighted in red in figure 10.2. The majority of these plots encompassed two further sub plots within each of them however, both plot four; *Changes in Selfhood* and plot five; *Research Experience* only comprised of one, these sub plots are highlighted in orange and are; *Distraction*, *Information Gatherer*, *Therapy/Group*, *Care During*

Treatment, Positive from a Negative, Emotional Insight and Developed Relationship.

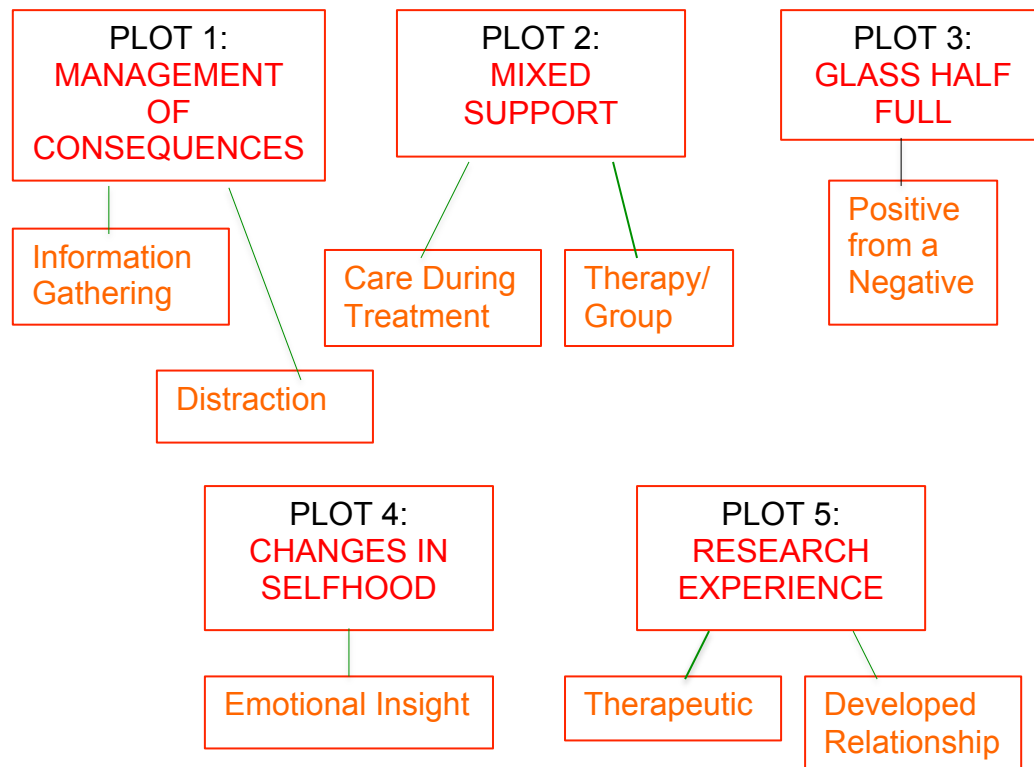


Figure 10.2: Plots Identified in Mary's Written Accounts

10.1.3 Gerald

Gerald's story was not as complex as Mary or Jane's with his narrative consisting of three plots; *Un-Traumatic*, *Mathematician* and *Critical*, these are presented in figure 10.3, highlighted in red. These plots contained the developed sub plots; *Relaxed Approach*, *No Big Deal*, *Reliance on Statistics*, *Charities*, *Organisations* and *Research*, which are identified in figure 10.3 and highlighted in orange. As can be seen from figure 10.3 the major and sub

plots constructed in Gerald’s narrative are very contrasting to those of Mary and Jane, identified in figure 10.1 and 10.2 above.

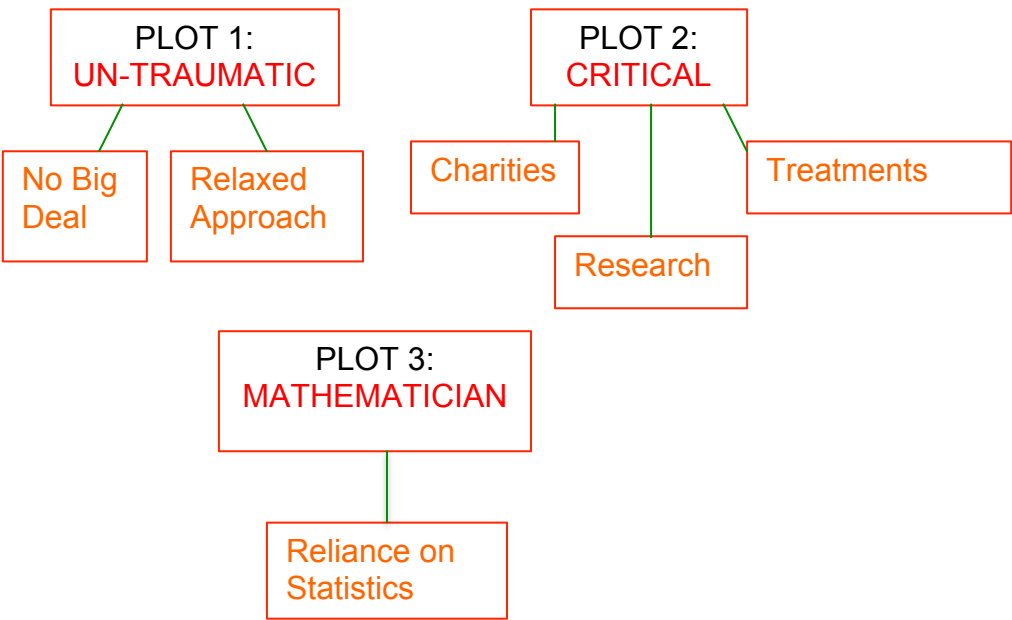


Figure 10.3: Plots Identified in Gerald’s Written Accounts

10.1.4 Reflections

My personal reflections were noted down during the identification of the above plots within each participant’s responses. Brown and Gilligan (1992; cited in Mauthner and Doucet, 1998) suggest researchers present these notes separately to those identifying and describing the emerged plots and so, my reflections throughout this reading can be evidenced in table 10.1.

Table 10.1

Reflective Notes for Reading One

Participant	Reflective Notes
Jane	<ul style="list-style-type: none"> • Jane's experience was very harrowing and the initial stage coincided with the unexpected death of her fiancé – May be linked to the reason why she tries to distract from being identified as having any sort of association to cancer ('survivor'; 'patient'). • Focusing on other situations coinciding with her cancer experience could affect my interpretation- focus only on cancer experience. • No control; therefore reflect herself to be unworthy of 'hero' title. • Contradiction; Describes extremely distressing consequences and changes in selfhood but then expresses a

sense of luck to be alive - May
be her way of outweighing the
negatives with the positives?

Mary

- Mary is a rather mature participant –may be this has reflected in her expressed plots and her optimism? (wiser; closer to reaching end of life as she states in comparison to a younger individual)
- Likes to be in control of her consequences but aware and anxious of chance of reoccurrence – cancer still in control of her?

Gerald

- Very openly states he is against my type of research- this could affect interpretation if not cautious
- Contradiction? - says cancer experience was insignificant ('benign') but yet is so involved with different cancer fields

The above table demonstrates the importance of this process within reading one, as the notes within it display how the researchers own perceptions of the gathered data can affect the interpretation of the participants' experiences if not taken into account.

10.2 Reading Two: Identifying Tone and Structure within the Narratives Presented

This section will present the findings of the second reading within the performed Listening Guide. Similarly to reading one, this section will present the findings of each involved participant separately.

10.2.1 Jane

This section will present the findings of reading two, associated to the narrative of Jane.

Structure

Jane's narrative appears to be based upon a progressive structure. This is highlighted throughout Jane's narrative as firstly she tells in her story about the previously mentioned distress that adds on to her traumatic cancer diagnosis however, as she narrates her experiences from the beginning of her diagnosis to the end (present day), it appears within her story that as time passes she becomes more positive.

Tone

Within Jane's narrative she tells of a joyful life prior to cancer with her being in good health and having positive relationships. However, she narrates to have then been overcome with a series of unfortunate events that included her diagnosis of cancer coming with a life expectancy of five weeks alongside, the sudden, tragic death of her fiancée. Despite this though, she narrates herself as remaining optimistic and holding on to positive thoughts with regards to recovery and dealing with her situation. Jane does not shy away from including in her story that she has found her cancer experience difficult and narrates her continued suffering from severe long-term consequences of the

cancer and its treatment to be on a daily basis. She tells of being aware of the major challenges she needs to overcome in her aid to recovery from these but she remains hopeful through all of this and determined that she can build herself back to how she was pre-cancer. This is evidenced throughout her narrative whilst narrating that she now uses her experiences to reappraise the positives she has in her life rather than draw upon the negatives. This optimistic tone; finding the positives out of a bad situation, also supports the previously discussed progressive structure of Jane's narrative as she tells of her traumatic negative experience (at the beginning) but then narrates in a more positive manner as her story continues to the end.

Metaphoric Language

Jane does appear to use metaphor imagery within her constructed narrative with an instance being when she says "a lot of people in my life inevitably drifted away". Here she uses the metaphor 'drifted' to describe her loss of relationships within her cancer experience and to imply these to be broken gradually. Within this, there is an important implication that this loss in relationships is something almost natural, rather than blaming them or being angry. This being, as she narrates the situation as being a normal occurrence. This supports the identified established optimistic tone within Jane's narrative as she chooses a less negative manner of presenting the loss of these people from her life than she could have done.

This is the strongest form of metaphoric language used by Jane however, it can be seen to be slightly touched upon when she uses the metaphor 'ploughed' when suggesting where money needs to be invested to improve services. The use of this metaphor in the context of her narrative does support the identified established optimistic tone. This is because rather than just being critical of readily available services for cancer survivors Jane narrates her story in a manner, which suggests ways in which they can be improved and so, demonstrates optimism.

10.2.2 Mary

This section will present the findings of reading two performed upon the narrative of Mary.

Structure

Mary's narrative appears to be built upon a stable structure, with clear demarcation between the beginning (diagnosis and treatment), the middle (recovery from short-term effects of treatment) and the end (present day) of her story. Within this structure Mary tells of her experienced challenges due to cancer and its treatment but also attempts to associate them to positive aspects of her life. Therefore, because this structure is consistent throughout Mary's narrative it can be established as stable.

Tone

Mary's cancer narrative was and still is in some respects, challenging. However, it is evident throughout the narration of her story that she has attempted to remain optimistic, reappraising the positives she have taken from such a negative experience such as, her suggested new interest in all things oncology and her new sense of open-mindedness in regards to experienced feelings. There are some aspects within Mary's narrative, which contradict this optimistic tone and suggest her to hold more of a realist view in respects to some of her feelings and life expectancy. However, on the whole, Mary expresses an optimistic narrative telling of how she uses her experiences to find enjoyment in her life and so intertwines with her established structure.

Metaphoric Language

Metaphoric language appears to be strongly used in two instances within Mary's presented narrative. For instance, she says within her story, "I'm well in the geriatric age group and maybe not supposed to make waves". Here, Mary uses the metaphor 'make waves' when narrating her perceived perception that her more mature age makes her feel as though she should not make a fuss or complain about her long-term consequences of cancer and its treatment or her experience of the journey in general. The second instance is where she says,

I seem to prefer to be informed to hiding in the bushes without current information

The metaphor 'hiding in the bushes' appears to be used by Mary within her narrative in order to tell of how she seeks information and is more comfortable being informed of her cancer/treatment/long-term consequences/possible future factors. Rather than, being blind to knowing what to expect or what is happening, or 'hiding in the bushes' as she words it. This way of narration by Mary could be suggested to be her way of expressing how she 'copes' day to day.

10.2.3 Gerald

This section will present the findings of reading two performed upon the narrative of Gerald.

Structure

When considering the structure of Gerald's narrative things appear to be more complex than for the previous two participants. For instance, when speaking solely about his experience from initial diagnosis (the beginning of his narrative) onwards through the treatment and recovery of it (middle) and finally to the present day (the end of his narrative) his structure is consistently stable and so, appears to hold the same structural platform. This being through his telling of his cancer experience as being "no big deal" alongside,

“not unusual or noteworthy” throughout all the time periods of his presented story.

However, when narrating parts of his story that focus upon how his experience of cancer has affected his feelings on cancer charities such as Macmillan, available treatments or research conducted within the cancer phenomenon his expressed structure changes in to one more regressive. His narration manner alters from one that is stable in telling of a ‘not noteworthy’ experience, in to one that becomes extremely critical and negative in regards to telling about his thoughts and feelings on the above matters within his story. This demonstrates that as a whole, the structure of Gerald’s narrative is complex however, when just focusing upon his narration in regards to his story relating to the lived experience of cancer, its treatment and the long-term consequences of it, like the aim of the research intends, then Gerald incorporates a stable structure for his narrative.

Tone

In contrast to his responses in the preliminary study, in his written narrative, Gerald tells of his entire cancer experience at time of diagnosis to the present day as being, in his words, ‘benign’ and ‘not actively pleasant but not markedly concerning’. Due to this, and him directly saying so, he tells of his sense of self to remained unaltered. This appeared interesting and was the reason behind Gerald needing tailored interview questions in comparison to the other participants. Gerald’s tone throughout his narration appears to be of

a realist manner. For instance, in regards to his experience in both the short and long-term Gerald constantly tells of how the facts and figures presented through his own research and from healthcare professionals influenced his mind set on his treatment, survival and long-term life. It could be suggested for this to be the reason as to why Gerald appears to incorporate a realist tone within the narration of his story rather than appearing optimistic or pessimistic.

However, as like with the established structure, when focusing on the narration of his story in regards to how his experience of cancer has affected his feelings on cancer charities such as Macmillan, available treatments or related research his tone also alters from that of a realist to that of a pessimist. For instance, the narration of his story tells of him appearing to struggle in finding anything positive to associate to them. Gerald is not shy in his narration when telling of how he believes his cancer experience to enable him to be so critical of cancer charities, treatments and related research. In line with Gerald's chosen structure, the tone of his narrative is also complex when looked at as a whole. However, when solely focusing upon his experiences of cancer, treatment and its long-term consequences, Gerald's tone throughout his narrative in regards to these aspects, appears to be that of a realist.

Metaphoric Language

Gerald does not incorporate any metaphors in the narration of his story; this could be suggested as supporting his realist tone as he only focuses upon facts and figures whilst telling his story through a matter of fact approach.

10.3 Reading Three - Creating 'I-Poems' from Presented Narratives

This section will present the findings from the narratives of each participant within reading three of the performed Listening Guide.

10.3.1 Jane

I got my five year all clear

I still have almost constant headaches and migraines

I also suffer from fatigue to a great extent

I was very active

I cant do anything stressful

I really have to ration my energy levels

I also find the isolation I feel difficult

I lost virtually all my friends

I think people found it hard to deal with

I am so grateful to be alive

I cant exercise the way I used to
I try to make sure I walk
I qualified as a psychotherapist
I think our relationship has improved
I do feel now that my cancer can be discussed

I now only tell people if I really have to
I hate being told how 'brave' I am!
I had no choice
I don't feel I did anything remotely brave
I think the overwhelming thing is
I want to move on from being a cancer patient
I don't see myself as a survivor
I want to just see me as me

I have a very strong sense of calm
I need to find ways to build up my life
I have really enjoyed talking to you

Jane's pronoun list was shortened in to a three part I-Poem; the first, demonstrating an overall picture of her experience in varying areas of her cancer journey; the second focusing upon her perceived cancer status and/or identity and the third focusing upon the present day.

The first part of the presented I-poem suggests Jane positions herself as being very much debilitated by the effects of cancer, its treatment and its long-term consequences. She does this by using the word 'I' to predominantly demonstrate through comparison of her pre and post cancer self, what it has caused her to lose (good health, energy, friends, ability to socialise or exercise). The remainder of this part of the I-Poem shows Jane as positioning herself to be able to identify the positives. For instance she uses phrases such as, 'I am', 'I try', 'I qualified', 'I think' and 'I do' to demonstrate how she manages her experienced consequences, what she has gained since, improvements on relationships and an appreciation of life.

As you can see within the second part of the I-Poem, Jane is using the pronoun 'I' to position herself as being separate from cancer. That she had no choice in being a part of it and now that she is clear of it she does not want to be associated with it, she has her own identity, not one dictated by her experience.

The final part of Jane's I-Poem focuses on how she positions herself in the present tense of her narrative. She does this by using the phrases, 'I have' and 'I need' for instance, 'I have' is used to demonstrate positive experiences in the present such as her temperament and although not strictly long-term consequence focused, her enjoyment from participating in the present research. Furthermore, she uses 'I need' to suggest what she needs to do in order to experience more positive experiences.

As a whole, it is also evident that Jane demonstrates a predictable pattern of 'I' movement. For instance, throughout she uses the pronoun to assert positivity but then follows by incorporating it to imply negativity and/or asserts negativity then follows by implying it to incorporate positivity. For instance, in the first section she says 'I am' before following with 'I cant'. In the second section she uses the phrases, 'I want' 'I don't', 'I want'. Then in the final section she says, 'I have', 'I need' and 'I have'. This suggests that being yields to not being, wanting yields to not wanting and having yields to needing. Therefore, indicating it likely for one to predict the way in which the 'I' will move.

10.3.2 Mary

I am currently only slightly anxious about the prospect of metastases

I have quite a lot of sources of information

I am trying to learn the details of this possible cell behavior

I do continue to read oncology,

I have a nearly 80% chance of being alive in 2 more years

I find that knowing this information is helpful

I seem to prefer to be informed,

I found his difficulty comforting

I felt he was supportive.

I am ungracious about his concerns

I have shared very little of what I have learnt

I do find that speaking about the fact of having cancer is quite difficult

I wish to be reasonably open

I think this may be a form of face the facts

I find I don't want to rub in uncomfortable facts

I thought I was making a fuss

I felt very upset for months

I had "It's not safe, you know"

I told my GP that I felt uncomfortably angry

I joined a local group

I have not looked back

I don't know if we could have managed better

I had identified a personal problem with anger

I would need to find another counsellor

I have not done this

I don't know if we could have all done better

Mary's finalised I-Poem is presented in four separate parts. The first part suggests she positions her self as a being intertwined with her experienced cancer. For example, it focuses on how she continues to deal with experienced long-term consequences by attempting to gain as much knowledge as possible surrounding her cancer type, suggesting this enables her to feel in control and be prepared for particular outcomes. This is done through the use of the pronoun phrases; 'I am', 'I have', 'I do', 'I find' and 'I seem'.

The second part of the I-Poem focuses upon support received and her responses to it. Within this, although she suggests she had received positive levels of support from her husband, she positions herself away from it. It could be suggested that this was so she can appear strong to him, as though she had no concerns about her health. For instance, she used phrases 'I found' 'I felt' to describe his support and then 'I am' 'I have' to describe how she separates herself from it.

The third section focuses upon Mary's perceived relationship with her experienced cancer and like the previous section, Mary uses the pronoun 'I' to position herself as being separate from it. This is because it is suggested she is not able to comfortably identify herself as being involved with cancer in fear of making others uncomfortable.

The final part of the I-Poem demonstrates Mary positioning herself again, as being intertwined with her experienced cancer but mainly for it facilitating her actions rather than controlling them. She suggests that her GP was unsupportive, making her feel she was making an un-needed fuss, leaving her upset and ignoring her emotions when she said she felt distress, is what led her to join a local cancer support group, not her experienced consequences from it. I am aware all of this cannot be evidenced in the I-poem however, when considering Mary's full narrative, the context is clear. In the second half of this section, she uses the phrase, 'I have' followed by, 'I don't know' twice, this suggests that whenever Mary acknowledges something she has ('I have

not looked back'), she follows it with something she does not, (I don't know).
This demonstrates a discerning pattern of the movement of the pronoun 'I'.

10.3.3 Gerald

I consider myself cured and this is the only consequence of the treatment

I would say my experience of cancer was relatively benign

I would not go as far as saying actively pleasant but not markedly concerning

I had prostate cancer

I was more than happy to follow the watchful waiting strategy and do nothing

I was lucky in living near to one of the two centres

I was comfortable assuming that all would go perfectly

I was back at work very quickly and working at full pace from the start.

I think relatives often feel greater stress than the person with cancer

I probably pay more attention to cancer issues in the press

I am less likely to approve of expensive cancer drugs

I think that having had cancer I feel more able to say

I am more likely to and feel free to criticise cancer charities

I am more likely to be cold blooded and analytical of cancer issues

Gerald's pronoun list was also shortened to one, two part I-Poem. The first section involves Gerald as positioning himself as not only being separate from his experienced cancer, but also as being separate from relatives sharing his experience. He implies this is due to him being relatively unaffected by

cancer, its treatment and associated long-term consequences. This is evidenced throughout; for instance, he uses the phrases 'I consider' and 'I had' to describe cancer as being in his past whilst identifying with not have any long-term consequences of cancer and its treatment. Furthermore, he repeatedly uses the phrase 'I was' to describe positive aspects of his experience (happy to follow advice, lucky to be close to treatment, comfortable with his chances and quickly back at work). This adds to the suggested positioning of being separate to his cancer experience as he frequently mentions his experience of cancer and its treatment as having been un-concerning and not affecting him. This part of the I-Poem ends with him using the phrase 'I think' in order to position himself as also being separate from his family as he describes them as suffering greater stress than he ever has in relation to his experiences regarding cancer, its treatment and long-term consequences.

The second part of the I-Poem suggests Gerald's connection to cancer as something he had and then 'got through'. This part of the I-Poem appears to revolve around Gerald describing how unhappy he is with current cancer charities, research and treatment. He seems to suggest that what they present does not reflect his perceived experience or that he feels what is stated to be wrong. It is apparent in this section for Gerald to use the previously suggested sense of connection/loss of connection to justify these critical opinions of cancer research and charities.

Although the resultant I-Poems are longer than some presented in past research, the Listening Guide is a very flexible method with no set rules on how big or small they need to appear. The reason for why the I-Poems are this length in the current research is because, although reduced from the pronoun list, I felt that to reduce them any further would cause important, rich data to be lost as I deem all that are displayed now, of equal importance.

10.4 Narrative Synthesis

The completed Listening Guide method within narrative analysis provided extremely interesting data in regards to all three of the participants selected for this second analysis, which extends that previously gained during the Template Analysis presented in chapter five. Performing the three guided readings enabled a deeper insight to be gained with regards to the lived experiences of the three chosen participants, alongside the way in which they narrate these experiences. However, guidance regarding how to draw together a concluding synthesis from the readings is somewhat sparse within the Listening Guide literature. This lack of guidance proved to be a challenge and I see this as an important limitation to consider within the use of the Listening Guide. I had to consider a way in which I could pull together what had been learnt from the analysis but without retelling what had already been told in each of the three readings. I decided the best way to conclude this analysis would be to draw together the key insights learnt from each of the readings and then provide a summary for each of the three participants. The summaries for each participant would focus upon using what has been learnt

from the three readings in order to present their holistic narrative in a manner different from that displayed in the previously performed Template Analysis.

The resultant summaries developed from this for each of the three participants are presented below.

10.4.1 Jane

Jane tells her story as one that identifies cancer as being a traumatic experience with debilitating long-term consequences that have contributed to a change in her identified sense of self. This can be evidenced within all three of the readings performed within the Listening Guide. For example, reading one identifies the key plot *Fatigue* as being present throughout Jane's narrative. This is because, within her narrative, Jane tells of how her experience of fatigue has caused her psychological distress alongside changing her perceived sense of self. Additionally, the identified tone presented within reading two suggests Jane tells her story in a manner that does not shy away from her feelings regarding her severe long-term consequences. This is alongside her reflecting back to her sense of self prior to cancer and identifying the differences between her then and now self, caused by her experience of long-term consequences following cancer and its treatment. Finally, the first part of the developed I-poem in reading three also focuses upon this point. For example, a section for illustration purposes reads,

I got my five year all clear
I still have almost constant headaches and migraines
I also suffer from fatigue to a great extent
I was very active
I cant do anything stressful
I really have to ration my energy levels
I also find the isolation I feel difficult
I lost virtually all my friends

The above I-poem supports this point as line by line it shows how Jane narrates this part of her story in a way that tells of her cancer experience being traumatic and still bringing daily struggles within her life. Alongside, signifying how her pre and post cancer self differ because of them. This implies the nature of Jane's experience regarding cancer and its treatment to be life changing as she portrays herself to have become to a certain extent, debilitated by the long-term consequences associated with it.

In spite of identifying the daily struggles brought about by experienced long-term consequences of cancer and its treatment within her narrative, Jane also portrays herself to have a glass half full persona. This can be evidenced in reading one through the identified further sub plot; *Reappraisal of Priorities* within the sub plot, *Changes in Selfhood*. Reading two supports this point further through both the identified progressive structure and optimistic tone. For example, the tone of Jane's narrative shows how she acknowledges the major challenges she has faced and still does face from her experience of

cancer and its treatment but remains optimistic throughout and reappraises the positives of her life rather than focusing in on the negative. Jane's portrayed optimism could also explain the progressive structure she applies to her narrative. This is because, the beginning of her story focuses upon her traumatic experiences during the diagnosis and treatment phase of her cancer journey. However, as her story progresses, so does the structure of her narrative as she portrays herself to become more positive over time. The above arguments suggest the nature of Jane's experience to be detrimental in regards to her health but also life affirming. This is because it appears to enable more positivity within her life as she portrays herself to focus on what she has rather than on what she has lost.

Jane positions herself within her constructed narrative as being separate from cancer. She describes her cancer as being something that she has experienced and not something that she is. This is particularly evident in reading one and three of the Listening Guide. For instance, reading one identifies the major plot, *No Labels on Me* and associated subplots; *Cancer is My Past* and *Not Brave* in Jane's narrative. This is because she takes a strong stance in portraying herself as being an individual who views cancer as being in her past and so, does not want her present self to be associated to it. Within this approach to her story telling, she also implies that another reason for positioning herself in this manner is because she does not view herself as being 'brave' as others suggest. She states that she had 'no choice' in her experience and therefore does not comprehend herself to have done anything to warrant being viewed as 'brave'. These points are also evident in the

second part of the developed I-poem within reading three, which reinstates Jane's applied position within her narrative. For example it reads,

I now only tell people if I really have to
I hate being told how 'brave' I am!
I had no choice
I don't feel I did anything remotely brave
I think the overwhelming thing is
I want to move on from being a cancer patient
I don't see myself as a survivor
I want to just see me as me

As can be seen, this I-poem supports the claim of Jane telling a story in which she positions herself as being separate from her cancer experience. In each line Jane's I-poem focuses upon not letting her cancer experience, shape her selfhood. This part of the I-poem therefore implies the nature of Jane's experience as being one beyond her control and not one she wishes to be defined by.

Jane's narrative also highlights for the method of e-mail interviewing enabling her story telling to be advantageous to her sense of self. This is evidenced in the major plot, *Therapeutic Impact of Research* identified within the first reading of the performed Listening Guide. This is because, Jane's narrative suggests for the e-mail interviewing method to act as a form of therapy,

enabling her to re-evaluate her experiences. Of which, could be suggested to enable her to construct a richer, more valid cancer narrative.

10.4.2 Mary

Mary presents her narrative as one identifying cancer to be something she has experienced and overcome, but that continues to exist within her daily life. For instance, she does acknowledge experiencing long-term consequences within her story telling. However, she focuses upon portraying herself as an individual who relies upon reading current research upon her cancer and long-term consequences in order to manage/take ownership of them. This can be seen in readings one and three within the Listening Guide. For example, reading one identifies the major plot *Management of Consequences* and associated sub plot *Information Gatherer* within Mary's narrative. Mary casually suggests in her story telling that her being knowledgeable of her experiences is beneficial to her wellbeing. Additionally, the first part of the I-poem within reading three particularly focuses upon this point;

I am currently only slightly anxious about the prospect of metastases

I have quite a lot of sources of information

I am trying to learn the details of this possible cell behavior

I do continue to read oncology,

I have a nearly 80% chance of being alive in 2 more years

I find that knowing this information is helpful

I seem to prefer to be informed

As evidenced, this I-poem suggests Mary positions herself within her story as an *Information Gatherer* in regards to all areas of her experienced cancer. She suggests within her story telling that knowing this information provides comfort due to her being more knowledgeable on what could present itself as worrying for example, a reoccurrence.

Additionally, Mary positions herself within her narrative as being an individual who successfully draws out positives from negative experiences. For instance, she tells her story in a manner that identifies cancer as being a negative experience but also reappraises the positives within her life that have occurred from it. She portrays herself as an optimistic individual even when faced with experiences that could lead to death. This is particularly evident in reading one and two of the Listening Guide. For instance, reading one identifies the major plot *Glass half Full* and its associated sub plot, *Positive from a Negative* alongside the major plot *Changes in Selfhood* and its associated sub plot *Emotional Insight*. Here, Mary tells a story which highlights herself as having an optimistic attitude towards life, always seeking out the positives of a negative situation, as well as positioning herself within her narrative as somebody whose sense of self has altered through her cancer experience in a positive manner.

Additionally, the tone within reading two shows Mary's cancer narrative as identifying the presence of continuing challenges but portrays her to be an individual who faces these with optimism. This shows to be through the reappraisal of the positives within her life, which the narrative implies to be

credited to her cancer experience. Examples of such positives suggested within Mary's cancer narrative are her newly gained interests in oncology and her experienced cancer type alongside her newly gained sense of open-mindedness. This suggests Mary's cancer experience as being one that is challenging but unable to undermine her optimistic persona. This is also supported by the stable structure of Mary's presented story, identified within reading two of the Listening Guide, where her optimistic persona is portrayed throughout the beginning, middle and end of her narrative.

Mary's narrative also identifies that the present research itself, though the method of e-mail interviews, provides the platform for her story telling which she presents as a highly positive aspect. This can be particularly seen in reading one as the major plot *Research Experience* and associated sub plots *Therapeutic* and *Developed Relationship* are identified within Mary's narrative, which draw attention to what she portrays as the therapeutic effects of discussing her cancer experience with me as a researcher over a period of time. For instance, Mary draws attention to how the e-mail interview enables her to reflect upon her cancer experience in a new light as she implies the method to enable her a new insight into her own emotions alongside, showing her new things to understand about herself.

10.4.3 Gerald

Gerald's narrative is one of identifying cancer as something that he has faced and dealt with and does not want to position himself as being changed in any

way by it. This is because he narrates it as something belonging in the past that is not viewed by him as being an interesting experience within his life. Evidence of him telling his story in this manner is suggested within all three readings of the performed Listening guide. For example, reading one identifies the key plot *Un-traumatic* in Gerald's narrative as he takes a very relaxed approach in his story telling, implying it to be '*No Big Deal*'. Gerald's applied Un-traumatic plot to his narrative could be suggested as being a contributing factor behind him choosing to position himself in the manner he does. He implies that the nature of his experience do not warrant any significant interest, which could also explain his narrative's stable structure identified within reading two. Finally, every pronoun line within the first part of the I-poem developed within reading three of the Listening guide, focuses upon Gerald supporting this claim. For example, one part of the I-poem reads,

I consider myself cured and this is the only consequence of the treatment

I would say my experience of cancer was relatively benign

I would not go as far as saying actively pleasant but not markedly concerning

I had prostate cancer

I was more than happy to follow the watchful waiting strategy and do nothing

I was lucky in living near to one of the two centres

I was comfortable assuming that all would go perfectly

I was back at work very quickly and working at full pace from the start.

I think relatives often feel greater stress than the person with cancer

As can be seen, each line within this presented I-poem supports the claim of Gerald telling a story in which he positions himself as being separate from his cancer experience. This is because each line implies a relaxed approach to his constructed narrative with the suggestion of no upheaval being caused in regards to his self or life. This implies the nature of Gerald's experience regarding cancer and its treatment to be 'relatively benign' and not life or self-changing in any way.

Throughout his story Gerald also narrates himself to be a man who relies upon statistics in order to assess an experienced situation. This can be seen in the identified plot *Mathematician* and associated subplot *Reliance on Statistics*, within reading one of the Listening Guide. Therefore, showing Gerald to use reference to statistics in order to portray himself as being a rational man following a simple, logical course.

Gerald also tells in his narrative that he feels his personal experience of cancer justifies his criticism of aspects of how cancer as a phenomenon is dealt with, such as by cancer charities, research and in readily available treatments. This is evidenced particularly in reading one and three of the Listening guide. This is because in reading one *Critical* is identified as a major plot within Gerald's narrative in which *Charities*, *Research* and *Treatments* are all presented subplots. Additionally, in reading three the second part of the developed I-poem focuses solely on this point for example, it reads,

I probably pay more attention to cancer issues in the press

I am less likely to approve of expensive cancer drugs

I think that having had cancer I feel more able to say

I am more likely to and feel free to criticise cancer charities

I am more likely to be cold blooded and analytical of cancer issues

The above ways in which Gerald narrates this part of the story suggests that as a survivor he sees himself as something of an expert in the cancer phenomenon as he has personally lived through it. However, Gerald tells his story in a way in which he does not consider any other outcomes alternative to his. Such as, experiencing a cancer type with more detrimental facts and statistics associated with it; nor does he acknowledge cancer treatments, charities and research that may be experienced differently by others.

As can be seen above, performing the three readings of the Listening Guide upon Jane, Mary and Gerald's narrative has enabled me to draw out important and interesting aspects that were not as obvious in the previously performed Template Analysis.

Chapter Eleven:

Discussion

This final chapter will focus upon discussing how the findings of the present research compare and contrast with the research literature, identifying key contributions it makes towards it. While the findings of the preliminary study have already been discussed in chapter four, I will make reference to them where they help strengthen or clarify from the main study. I will begin by presenting a summary of both the Template Analysis and Narrative Analysis findings and follow with a discussion of the issues identified within them alongside, how these concur or contrast with previous literature. My reflections on the research will follow, focusing on the methodology, analyses, the research as a whole and my place within it. The identified strengths and limitations of my research will then be presented, and the significant contributions to knowledge the research provides will be highlighted. The chapter will then conclude by demonstrating the implications for future research and practice the present study provides.

11.1 Summary of Findings

11.1.1 Preliminary Study; Statistical Analysis Summary

There were a number of key findings identified from the statistical analyses. For instance, there appeared to be no significant relationship between cancer

type and quality of life scores, showing that previous research linking quality of life to cancer type does not seem to apply here. Similarly, it was also found for there to be no significant relationship between age and quality of life, which guided the main study to incorporate a wide range of ages within its sample. Furthermore, against the common consensus amongst research, the statistical analyses also suggested that the majority of individuals accepted and used the status, 'cancer survivor'. However, no significant relationship was identified between cancer status and quality of life scores. Therefore, suggesting identified cancer status to be determined from how individuals want to be seen rather than the severity of their cancer experiences. In line with previous research, it was also identified that quality of life levels decreased as health anxiety levels rose and so; this was considered throughout the main phenomenological study. Finally, no significant gender differences were identified in the quality of life scores obtained.

11.1.2 Preliminary Study; Template Analysis Findings Summary

Three major themes were identified in the Template Analysis of the free text response within the preliminary study; *Unpreparedness*, *Selfhood* and *Support*. All three of these major themes were comprised of sub themes and in a number of cases, further sub themes. Please refer back to figure 4.2 in chapter four to see a full breakdown of the identified major and sub themes.

11.1.3 Main Phenomenological Study; Template Analysis Findings

Summary

Six major themes were identified in the Template Analysis of the e-mail interview study findings: *Support, Changes in Selfhood, Ownership of Consequences, Engagement in the Social World, Understanding, and Research Impact*. All of these were comprised of sub themes with some including further second sub themes. The Parallel Theme, *Cancer Voices* was identified, as it was through the Cancer Voices support group that the participants were recruited. Therefore, it was important to reflect on this as the e-mail responses provide interesting data in regards to it. A full breakdown of all the identified major and sub themes can be seen in figure 8.3 in chapter eight.

An original contribution to knowledge from this analysis was that the e-mail interviewing method appeared to provide a therapeutic platform for a number of the participants. Participants stated that the method enabled them to re-evaluate their experiences and gain a richer understanding of their selves and their feelings. Furthermore, the participants stated that the e-mail interviewing method provided them with a channel to vent out their felt frustrations in a manner beneficial to their wellbeing. This was due to the fact that they were able to reflect on their feelings and the reasons behind them when constructing their responses.

A further contribution from the Template Analysis was an understanding of the ways in which the experience of long-term consequences following cancer and its treatment altered participants' sense of self. Although this change was apparent in almost all of the participants' responses, their experiences of it showed considerable contrast. For instance, a number of individuals express their experiences to change their sense of self for the better and be positive, such as gaining a new appreciation of life, becoming more open-minded or being more future-orientated. However, others describe this change to be self-destroying with reasons behind this being, a significant loss of confidence in themselves or them becoming restricted from being the person they were, in their abilities to do daily common tasks which they enjoyed prior to their cancer experience.

A common issue shared by the majority of participants was the manner in which their experienced long-term consequences of cancer and its treatment caused their engagement within the social world to become restricted and in turn, cause the individual to experience psychological issues alongside lowered perceived quality of life. However, it was particularly surprising within this finding to discover that a number of participants suggest their experienced social isolation, restricting their engagement within the social world to be due to the actions of others rather than their experienced long-term consequences. For instance, it was suggested through the participants' responses that their friends purposely isolated them from social occasions. This was suggested to be because of ill-advised thoughts that the cancer survivor would be unable to participate in their activities because of their long-

term consequences. This appeared to happen even following reassurance from participants to their friends, that this was not the case.

11.1.4 Main Phenomenological Study - Narrative Analysis Findings

Summary

The three readings guided by the Listening Guide within the Narrative Analysis provide extremely rich results for each of the three participants with regards to how they narrate their story. A short summary representing the findings for each participant within this analysis is presented below.

Jane

Jane's narrative comprised of four major plots; *Fatigue*, *No Labels on Me*, *Blindness of Phenomenon* and *Therapeutic Impact of Research*. The structure of her story presenting these plots was steadily progressive in that she begins speaking of her diagnosis in a negative narration but as time goes on within her narrative she becomes more and more positive in her reflections of her experiences. Her tone throughout remains optimistic; she does identify challenges and struggles within her story in regards to her long-term consequences but she tells of how she faces these by finding positives out of a dark situation.

Mary

Mary's narrative is based upon five major plots; *Management of Consequences*, *Mixed Support*, *Glass Half Full*, *Changes in Selfhood* and *Research Experience*. The structure of her narrative remains stable throughout her telling of the beginning, middle and end of her story as she continuously balances her negative experiences with ones more positive. Her tone is predominantly optimistic but has minor realist aspects within it. In short, Mary is a very 'glass half full' individual.

Gerald

Gerald's narrative is comprised of two plots; *Un-traumatic* and *Critical*, and greatly contrasts to the previous two individuals in various ways. His structure is stable as throughout his story he narrates his experience from the beginning to the present day to be 'not interesting' and 'not noteworthy'. His tone throughout is that of a realist as he narrates himself to be a man of facts and tells of the importance of these facts to his perceived experiences.

11.2 Discussion of Key Contributions

The main phenomenological study produced a number of findings due to the e-mail interview data being analysed very thoroughly in two different separate ways addressing the second overall aim of the current research. This section will briefly discuss the findings of the analyses that appear to make an

important contribution to available research whether this is through terms of novelty or reassessment or, by showing a new perspective of something. The four contributions of focus here will be, the manner in which selfhood changes, the lack of emphasis upon fear of cancer reoccurrence, feeling understood and the benefits of e-mail interviewing. The section following will then focus upon a wider range discussion of findings, exploring all the findings regarding experiences deemed of significance within the present research and relating them to previous literature.

11.2.1 The Manner in which Selfhood Changes

The present research succeeded in meeting its second overall aim and associated objectives (as presented in Chapter Two) through in-depth investigation in to cancer survivors' lived experiences through the use of the e-interviewing method. This highlights the importance of recognising changes within selfhood, due to experienced long-term consequences, as being long-term and persistent rather than a straight switch. Furthermore, it is apparent that these changes occur due to a constant negotiation and renegotiation of their sense of self taking place throughout the experiencing individuals' lives due to their long-term consequences of cancer and its treatment. This is particularly evidenced within the cases involved in the Narrative Analysis. This demonstrates to be a key contribution to knowledge as it identifies a new perspective of exploring selfhood, following the experience of long-term consequences of cancer and its treatment.

11.2.2 Lack of Emphasis upon Fear of Cancer Reoccurrence

The present research also provides novel findings in relation to fear of cancer reoccurrence. Where a mass of the available literature suggests fear of reoccurrence to be a significant concern amongst cancer survivors (Koch et al., 2013; Lebel et al., 2013; Simard et al., 2013; Simonelli et al., 2017), the current research contrasts this notion by suggesting it is not at the forefront of individuals' daily lives. In my email interviews they emphasise other daily issues and do not tend to speak much about fear of cancer reoccurrence.

These findings also therefore, provide an alternative perspective towards fear of cancer reoccurrence. They suggest that when an individual's account of their life experience is broken down and explored day-by-day, other issues regarding experienced consequences of cancer and its treatment highlighted above fear of cancer reoccurrence come to light. Examples of issues emphasised by individuals as being of concern on an everyday basis are the ability to run errands without fear of needing the toilet when none are available, have a meal with family or friends or being included in social activities within their friendship group and not being left isolated due to lack of understanding.

This is not to deny that cancer survivors fear the reoccurrence of their disease. However, if too much attention is focused on this it may mask the importance of the kind of day-to-day issue noted above that seriously reduce their quality of life.

11.2.3 Feeling Understood

Furthermore, in meeting the current research's second aim of exploring in depth the lived experience of long-term consequences of cancer and its treatment through the e-interview method and subsequent Template Analysis in particular, the current research highlights the importance of recognising a shared experience of cancer and its long-term consequences, as being paramount for a level of understanding to be achieved by others, in the eyes of the cancer survivor. It is emphasised that an adequate level of understanding cannot be achieved through any amount of textbook knowledge, academic study or healthcare professional. These findings are strongly evidenced through the Template Analysis performed in the main phenomenological study. This demonstrates to be a key contribution to knowledge as it introduces a new perspective towards exploring understanding of the long-term consequences of cancer and its treatment.

11.2.4 Benefits of E-mail Interviewing

E-mail interviewing has already been utilised by some scholars (Cook, 2012; Stacey and Vincent as cited in Wai Man Lo, 2016) but is still acknowledged as a relatively new research method. The present study acknowledges this and answers the appeal of scholars for more research to become readily available so that the advantages and disadvantages of e-mail interviewing can be discussed (Stacey & Vincent, as cited in Wai Man Lo, 2016).

As well as adding to the body of available research incorporating e-mail interviewing, this thesis makes a specific further contribution in terms of highlighting how participants can experience the method as beneficial – even therapeutic. A number of participants stated on multiple occasions throughout their participation that the e-mail interview method acted as a form of therapy, enabling them to gain a better understanding of their selves and gain ‘valuable’ insights in to their felt emotions in regards to their experiences of cancer and its long-term consequences. This therefore shows that not only has the current research been successful in meeting its second aim and associated objectives (i and ii), but it has also been successful in demonstrating this relatively new method to be greatly beneficial for both the researcher and participant involved.

11.3 Discussion of Experiences Faced within the Present Research

Now that a summary of the findings from both analyses has been presented, this chapter will focus on the identified experiences within the present research and present a discussion of them, identifying the over-arching issues that are presented in the findings across both the Template and Narrative Analyses. The decision to present the over-arching issues across both analyses was made in order to minimise any repetition as a number of issues were identified by both analyses. Alongside, enabling the most important issues to be given more focus and attention in comparison to those deemed less significant by the participants. Although this chapter’s main focus is upon

the main phenomenological study, the findings from the preliminary study will also be referenced on occasions where they aid the reinforcing of a particular point.

11.3.1 Discontinuity

Discontinuity is a paramount over-arching concept presented consistently across both the Template and Narrative analyses in regards to individuals' experiences. This apparent discontinuity is demonstrated in a number of different facets within the individuals' daily lives alongside, the lives of those close to them. As previously discussed in chapter five, this thesis refers to discontinuity, as something that evidences a break with the past. Therefore, any aspect of a participant's or their significant others' life showing to stop its normal pattern and alter following, and due to, cancer and its treatment, will demonstrate discontinuity and will be referred to as such, in this section. The different aspects by which discontinuity can be seen will be explored below.

Quality of life

Throughout the analyses, it was strongly evident that discontinuity occurs within one's quality of life from the experience of cancer, its treatment and long-term consequences. One factor contributing to this appeared to be the social support received during this time. For instance, it was found within the data that social support appeared to be a major contributor in regards to how participants perceived their lived experience and the impact this had upon it

and their sense of self. This supports previous literature such as Mellon et al. (2006), whose research (as we saw in chapter one) on the quality of life of cancer survivors and their close others, found social support to be a consistent predictor for perceived quality of life.

However, the present research delves further in to this area and through the use of qualitative methods, is able to identify the participants' explanations behind this such as how received support or the lack of it impacts them and why they feel this to be. One example of this can be evidenced where a number of individuals describe a lack of support from friends causing them to experience isolation. This appears to be perceived as either being intentionally or through their 'friends' being unconsciously aware of the repercussions of their actions or lack of them. The participants express this to result in the experience of psychological issues, which can impact upon their quality of life. This demonstrates discontinuity within one's quality of life, as it is suggested for relationships with friends to be positive, meaning that isolation was of no concern, prior to cancer. However, the experience of long-term consequences has in turn, restricted such positive relationships, causing a lowered quality of life.

It has already been said that the experience of long-term consequences causes discontinuity within one's quality of life. However, it is suggested in the Template Analysis within the main phenomenological study, that an attempt to regain their prior quality of life, enabling them to continue in their day-to-day life is made by the participants. This is performed through the attempt to take

ownership of their experienced long-term consequences by devising management techniques for them. Three management techniques in particular stood out within the responses: *Shifting Focus*, *Routine* and *Organisation and Reappraising Priorities*. This acts as a key contribution of the present research as it identifies how one's quality of life is affected by long-term consequences of cancer and its treatment. However, it then goes on to address what individuals do when attempting to control this change in their perceived quality of life levels and minimise the discontinuity of it.

Within both the Template Analysis and the Narrative Analysis, individuals suggest their cancer experience to also have a negative psychological impact upon their spouses/significant others. Therefore, suggesting their quality of life to also experience discontinuity, as they suggest it to be detrimentally affected, because of the participants' experience of cancer. This impact is implied in some cases to be just as significant or even of higher significance than it is to the individual directly experiencing cancer. This is in line with numerous previous studies (Bultz et al., 2000; Mellon et al., 2006; Northouse et al., 2007; 2010; Kim and Given, 2008). For instance, Northouse et al. (2007) focused upon the psychological impact cancer has upon participants' spouses and suggests that significant others not only suffer from emotional strain but also a lowered quality of life. Therefore, illustrating a discontinuity within their quality of life to form as, similarly to the experiencing individual, this aspect within it is suggested to have been positively stable over time prior to their close other experiencing cancer. However, due to their experience of it, this continuing perceived quality of life appears to be broken and alter in a

negative manner. Both the participant and significant others experiencing this discontinued quality of life is also in line with previous research, as Northouse et al. (2010) conducted a meta-analysis to investigate the importance of support groups and concluded from it that both the individual diagnosed and their significant others form as one unit in regards to their reactions of the experience.

Relationships within the Social World

One of the most impacting factors of long-term consequences following cancer and its treatment is the discontinuity of individuals' relationships within the social world. It is evident in both the analyses that experienced long-term consequences restrict individuals' ability to engage within the social world and alter friendships that are suggested to have been unproblematic prior to their cancer experience. This is in line with previous literature surrounding long-term consequences of cancer and its treatment. For instance, both Danker et al. (2010) and Howard et al. (2014) as discussed in chapter two, also identify for long-term consequences of cancer to cause social isolation. This appears to be due to the individuals' engagement within the social world becoming discontinued and/or restricted. This is clearly in line with the present research as it was found within the analyses for individuals to express damaging social isolation issues to form due to their experienced long-term consequences. However, the present research expands upon this knowledge by identifying this social isolation to not always be due to the actions of the experiencing individuals. For instance, some participants suggest their experience of

discontinuity within their relationships in the social world to be down to the actions of others causing them to become socially isolated. Perhaps the most extreme case of this is a father, [Joel], being restricted from seeing his son by his ex wife due to his experiences of cancer.

There are a number of long-term consequences that are perceived as leading to a restriction and/or discontinuity within the social world in the present research. For instance, fatigue, immobility, incontinence, and isolation from others are all apparent within the responses of the participants. This is in line with previous literature to an extent, as that readily available and discussed in chapter two does imply fatigue and incontinence to be detrimental long-term consequences experienced by many cancer survivors (Dunberger et al., 2010; Lange & de Velde, 2011; Schmidt et al., 2012; Meneses-Echavez et al., 2015). For instance, Meneses-Echavez et al. (2015) identify fatigue as being a common long-term consequence of cancer and its treatment with Schmidt et al. (2012) exploring fatigue on a sample of breast cancer survivors and finding it to have a damaging effect upon various aspects of their daily lives.

However, by relating fatigue to the discontinuity of relationships within the social world, the present research expands upon the discussed available knowledge.

The phenomenological methodology behind the present research is valuable in contributing to, and supporting readily available knowledge in this area. It enables detailed exploration in to the most concerning resultant issues from experienced long-term consequences. Therefore, meaning that information

can be gathered in regards to how the experiencing individual believes these issues can be overcome.

The findings from both the Template Analysis and Narrative Analysis in the main phenomenological study also strongly suggest that no matter the relationship between them, participants feel that the only people to understand their situation and associated feelings are individuals who have personally experienced cancer themselves. This demonstrates a discontinuity in relationships to arise following cancer and its treatment as participants suggest for their cancer experiences to leave them unable to connect in an important way with their significant others, like they could and did, before cancer. This is expressed to leave participants feeling as though they need mutual understanding and can only seem to receive this from fellow cancer survivors.

This can be evidenced through the major theme; *Understanding*, identified from the Template Analysis performed upon the e-mail interview data. Alongside, through the recognised major plot; *Blindness of Phenomenon* within the narrative of Jane, provided by reading one of the performed, Listening Guide. Additionally, the findings of the Template Analysis within the preliminary study also identify this finding within the developed major theme, *Support*. This lack of understanding regarding the participants' experienced cancer type and long-term consequences is shown within the responses to be a surprise to them.

This finding is in line with the work of Meier et al., (2007) who explore the reasons behind individuals using the internet for support. They found from their Content and Thematic Analyses that one reason individuals join online support groups is to receive emotional support that they are not currently experiencing. Therefore, suggesting the people in their lives are unable to understand their situation, meaning they must seek it from those who have experienced it themselves online. This finding can also be supported by the alternate major theme, *Cancer Voices*, identified by the Template Analysis in the main phenomenological study; participants in the present research said they joined online support groups in order to feel a sense of community, by finding someone who can understand their situation. This suggests for individuals to not feel that those around them are capable of understanding their situation and/or feelings in regards to it. However, this issue will be discussed in further depth shortly.

11.3.2 Healthcare Provision

The present research also identifies healthcare provision to be another issue to arise within the lives of the participants following the experience of cancer. Both the Template and Narrative analyses within both the preliminary and main phenomenological study suggest that only a minority of the participants had solely positive experiences in regards to the provision of healthcare services during their cancer journey. However, the majority of participants suggest this care/support became and continued to be, turbulent once they begin their cancer journey, comprising of both positive but predominantly

negative experiences. These negative experiences focused upon the needs of the participant being unmet by the health care professionals which in turn, suggest to negatively impact the individuals' psychological health. Some individuals imply GP's not holding enough knowledge on various cancer types and long-term consequences to be the reason behind the inadequate support/care received from them. The above points therefore demonstrate how the support/care from healthcare professionals alters once they began their cancer journey.

The findings from the present study suggesting for individuals to experience mixed support from healthcare professionals in regards to their cancer experience is in line with previous research. For instance, Treanor and Donnolly (2016) also found through their Narrative Analysis on the interview data of cancer survivors for GP and healthcare experiences to vary. Additionally, the findings are also in line with Ntinga and Maree's (2015) research focusing upon performing thematic analysis on the interview data of sixteen cancer survivors. This is because they identified, appropriate professionals for example, GP's, failing to meet the health care needs of the individual as being a major theme within participants' data. Ntinga and Maree (2015) support the present research further as they also highlight among their findings that participants suggest medical practitioners lack in knowledge regarding their experienced cancer, resulting, in them feeling to have received adequate care/support from them. However, the present research extends upon the previous research as it also explores how their experiences of healthcare provision affect them as individuals such as, causing them

psychological issues from feeling either forgotten about, unheard, or like they are not deemed as important as individuals with alternative cancer types.

11.3.3 Changes in Selfhood

It is important to note here, that what is discussed in this section could also be suggested as often exemplifying a sense of discontinuity, as previously discussed. However, it is explored separately because of its high significance within the gathered data as it extends on research readily available by identifying how and why long-term consequences affect one's perceived selfhood.

It appears through both the Template and Narrative Analyses in the main phenomenological study alongside the analyses of the preliminary study, that a change in one's sense of self is apparent as an important over-arching concept within the findings. This refers to an instance where an individual's selfhood prior to cancer is perceived as being changed due to their cancer experience and in particular, the long-term consequences of it. This thesis uses the concept 'selfhood' rather than 'identity' as the aim of the present research is to explore the participants' lived experiences of long-term consequences following cancer and its treatment alongside, how these experiences in turn, affect them as individuals. Selfhood focuses upon an individual's lived experience of self; who they feel themselves to be, and identity is primarily concerned with how people categorise themselves in relation to others. Due to the aim of the present research, and that selfhood is

one of Van Manen's (1990) presented existential fundamentals that are also drawn upon in chapter three; it was decided for the selfhood concept to be incorporated into this research. This does not mean that this thesis does not take into consideration the implications the two concepts carry for one another, as the present research does acknowledge that they are not completely unrelated and so, will also include identity references. However, the focus will remain on the concept of selfhood.

Previous research does explore how a cancer experience changes the perceived identity of an individual (Morris et al., 2014; Cheung & Delfabbro, 2016; Davis et al., 2016; Smith et al., 2016). For instance, identifying individuals to endorse the 'cancer survivor' status (Deimling et al., 2007; Davis et al., 2016). This is supported by the findings of the preliminary study within the present research. The statistical analysis showed that the majority of individuals refer to themselves as now being a 'cancer survivor', indicating their identity to have altered from their cancer experience. However, the main phenomenological study findings expand on this knowledge and identifies the ways in which one views their sense of self to alter; therefore exploring personal existential change to how one views themselves rather than the 'type' of individual they categorise themselves to be. Some participants describe this change in perceived selfhood due to long-term consequences of cancer and its treatment, as encompassing some positive alterations (new appreciation of life through downward comparisons, future-orientated goals, re-evaluated perspective on life, more sensitivity to the feelings of others).

For instance, a large minority of participants suggested they now use their experienced long-term consequences to often make downward comparisons- thinking about others worse off than themselves or who had lost their battle to cancer and not survived like the participant. This resulted in the participants feeling a new appreciation and gratitude for life, feeling lucky to be alive and so, wishing to make the best of a bad situation. The finding of participants comparing themselves to others, who had lost their life to the same disease or had survived but with greater damaging long-term consequences, ties in to the concept of 'cancer survivor guilt' discussed in chapter two. The research surrounding 'cancer survivor guilt' (Quinn et al., 2013; Marker, 2015; Perloff et al. 2019) identifies these downward comparisons to have damaging effects upon the individuals making them, through feeling guilty for surviving. In the findings of the involved research, the concept 'cancer survivor guilt' is identified as being of significant concern to cancer survivors. However, this research demonstrates the opposing effect downward comparisons can have on cancer survivors, as like previously mentioned, participants identify them to cause a new appreciation of life to be gained, having a positive effect.

This is in line with the research of Treanor and Donnolly (2016) who explore the long-term consequences of cancer survivors, with their findings touching upon the manner in which the experience of them affects the participants. For instance, they found that participants made peer comparisons in regards to experienced long-term consequences and comparing themselves to people worse off, resulted in them becoming more positive and 'thankful' to be alive. Additionally, Ntinga and Maree (2015) also highlight for individuals to

experience negative long-term consequences but still remain positive in regards to their future, However, although touching upon this, Ntinga and Maree (2015) and Treanor and Donnolly (2016) do not explore how this relates to changes in the participants' perceived selfhood in any depth, unlike the present study.

However, these, and other participants within the study, also present a number of negative alterations to their sense of self ('ruined my life', restricted from being the person they was through anxiety, self-consciousness, fatigue, restriction from social world, pain etc.). This finding was suggested by the majority of participants to be due to being restricted from the person they were prior to their cancer experience, because of their experienced long-term consequences. Long-term consequences such as fatigue, immobility or digestion issues to name a few, was associated to restricting individuals' ability to live their life as they did prior to cancer, as they inhibited the participants from socialising with friends or their ability to go out alone to do simple daily tasks. The Template Analysis highlights that this in turn, caused a new negative, withdrawn and isolated sense of self to develop.

This is in line with the previous work of Ntinga and Maree (2015) through their qualitative study in South Africa as they also found experienced long-term consequences to deprive their participants of living their lives as they did prior to their cancer experience. However, the present research explores how and why long-term consequences doing this, affects one's sense of self.

11.3.4 Fear of Cancer Reoccurrence

It was identified in the findings of the main phenomenological study that fear of cancer reoccurrence was an issue for only the minority of participants, when discussing their experiences of long-term consequences following cancer and its treatment. This is in contrast to much previous research, including the preliminary study within this research, which suggests fear of cancer reoccurrence to be a major concern of cancer survivors (e.g. Lebel et al., 2013; Simard et al., 2013; Simonelli et al., 2017). This is demonstrated perfectly in one participant's [Mary's] response as she states, 'I am currently only slightly anxious about metastasis though I know it is possible'. Indeed, some participants do not refer to fear of cancer reoccurrence at all. A possible explanation for this contrast in findings could be the participants' involvement within Cancer Voices. For instance, them being part of the support group may provide them with positive information and reassurance as they are in communication with other individuals who have shared their experience of cancer.

However, in the minority of cases when fear of cancer reoccurrence was suggested to be a major concern it appeared in the response of one participant to have a time limit. It was stated by this individual, that at the beginning of his survivor experience he spent a lot of time worrying that every pain felt was a reoccurrence, but he implies this to no longer be the case. This is in line with the research of Treanor and Donnolly (2016) who also found that fear of cancer reoccurrence minimises over time.

It must be noted that, although, the Template Analysis and Narrative Analysis in the main phenomenological study suggest that on the whole, fear of cancer reoccurrence is not of top priority to the participants, it is more prevalent and expressed as a greater concern within the findings of the preliminary study. A possible explanation behind the main phenomenological study contrasting with both the preliminary study and previous literature, could be due to fear of cancer reoccurrence not being a major focus within the present research. For instance, in the main study of this research, participants are not directly asked about fear of cancer reoccurrence or any other long-term consequence in particular, but are asked to describe the long-term consequences of most concern to them. Previous literature and the preliminary study contrast this, as they purposely explore the consequence of fear of cancer reoccurrence within their research. For example, the QLACS scale within the online survey used in the preliminary study, directly asks the participant if they are worried about a cancer reoccurrence, making it certain for the consequence to be addressed. Whereas, the main phenomenological study does not ask any direct questions in regards to fear of cancer reoccurrence as it aims to identify the consequences of concern through the responses of the participants.

Therefore, it is possible that because the preliminary study addressed the consequence within the QLACS scale, it became present within the participants mind for the remainder of the survey and influenced their comments within the free text responses. However, by the main study only specifically talking about fear of cancer reoccurrence when it was identified by the participant within the context of how long-term consequences affect their

life as a whole, the consequence seems of less concern to them, as other long-term consequences viewed as more concerning in regards to their every day lived experiences were being highlighted.

11.3.5 Feeling Understood

Throughout the participants' responses, there is an over-riding sense of lack of understanding from others. The infrequent occasions where participants described feeling genuinely understood always related to interactions with other cancer survivors. This suggestion could seem just like common knowledge as it makes sense for people unfamiliar with a phenomenon to struggle to completely understand it. However, the data within the responses provide a new way of looking at the lack of understanding experienced. Such failed understanding is evidenced throughout all the participants' relationships and in particular those with healthcare professionals such as GPs. The majority of negative experiences with GPs appear to relate to their having a lack of understanding regarding the participants' situation in regards to long-term consequences, resulting in them feeling unheard and unsupported alongside causing psychological distress. However, if participants find genuine understanding only from fellow survivors, it is not surprising that GPs – however medically expert – cannot provide this kind of understanding. This suggestion is strengthened by data focusing upon relationships with friends and family with the most powerful being by Michael (Bowel Cancer), who tells of how his friends have isolated him from his social group by no longer inviting him to activities as they worry about him being incapable of participating due

to his long-term consequences of cancer and its treatment. However, the participant stresses that his friendship group have been told repeatedly what he is and is not capable of, therefore, again suggesting knowledge to not be the key to understanding, but personal experience. These findings could be seen to provide some further explanation to the results of previous research exploring social isolation experienced by cancer survivors (Danker et al., 2010; Howard et al., 2014). Furthermore, these findings could be suggested to align with those of Ntinga and Maree (2015), as they state that cancer survivors believe healthcare professionals to fail in meeting their needs similarly to the present research. However, the participants within the research of Ntinga and Maree (2015) suggest this to be due to a lack of knowledge, whereas the current research suggests it to be more of a lack of understanding, due to the majority of them having not personally experienced cancer themselves. These findings could also suggest reasons why online cancer support groups are so popular amongst survivors and why so many join to find informational and emotional support (Meier et al., 2007).

11.3.6 Benefits of E-mail Interviewing

It was identified in the findings of both the Template Analysis and Narrative Analysis within the main phenomenological study that individuals associated their participation with the e-mail interviews to be therapeutic, mirroring the benefits of therapy. This is evidenced through the major theme; *Research Impact* within the Template Analysis and the major plot; *Therapeutic Impact of Research* identified within reading one of the Listening Guide. For instance, a

number of individuals describe the e-mail interview process as being “cathartic” and “valuable” alongside, stating for it to enable them to re-evaluate their experiences in regards to their long-term consequences and gain new insights into their selves as beings. This therefore, provides a key contribution to knowledge, as this does not appear to be highlighted by previous research exploring e-mail interviews.

Furthermore, the findings of both analyses within the main phenomenological study also indicate the forming of a relationship between the researcher and participant. This refutes the research of James (2016) as he suggests this would be difficult to achieve. However, by providing small details of my daily life in the sent e-mails, a trusting relationship with the participants seemed to develop quite quickly. This supports the research of Ratislavova and Ratislav (2014) as they suggest face-to-face contact may not be necessary for a researcher-participant relationship to develop. Additionally, these findings also appear to be in line with the research of James and Busher (2012) who argue for the importance of good rapport within e-mail interviewing to enable a trusting researcher-participant relationship to be formed.

11.3.7 Cancer Voices Participation and Shaped Experiences

Due to the sample incorporated being from the Macmillan Cancer Voices online support group, the main phenomenological study also explored the participants’ membership within it. It was found through the identified major theme; *Cancer Voices*, within the performed Template Analysis, that the

participants' membership within this specific cancer support group shapes their experiences of long-term consequences following cancer and its treatment in a more positive manner. For instance, one participant [Julie] in particular, associates finding a sense of community within the support group to a reduction in severity of her long-term consequence of isolation. Therefore, implying her participation to positively shape her experience of isolation. This long-term consequence is previously discussed in the sub section, *Relationships within the Social World* of this chapter and is highlighted to be a significant concern amongst the participants. This demonstrates how beneficial participation within the online support group can be to cancer survivor's daily life as it can minimise, to an extent, their experienced long-term consequences. The finding of individuals using support groups to gain a sense of community in regards to their experienced long-term consequences of cancer and its treatment is in line with previous research. For instance, Meier et al, (2007) used Content and Thematic Analysis on data gained from online support groups used by cancer survivors and found that from the analyses that individuals within the groups reassured others that they were not alone in their experiences. Therefore, demonstrating a sense of community being present.

Participants also suggest within the main study that supporting others in regards to their experienced long-term consequences is beneficial to themselves as well as those they are supporting. For example, as identified in the developed major theme, *Cancer Voices*, within the Template Analysis, one participant [Elliott] identifies that 'giving something back' and helping

others has an extremely positive effect as, even though he is suffering from challenging long-term consequences himself, helping others makes him feel so much more positive about himself and his experiences. Furthermore, in the major theme; Ownership of Consequences, another participant [Michael], directly states that distracting himself by helping others through Cancer Voices, helps him stay in control of his long-term consequences, minimizing their affect, as he is not spending time dwelling n them. Therefore, illustrating his participation positively shapes his experiences regarding his long-term consequences. The notion of participants joining the online support group to help others is in line with the research of Meier et al, (2007), whose findings suggest that individuals offered support within it, much more than they requested it. However, the present research extends on this by identifying how helping others also benefits the individual as well as those they are helping.

As mentioned in chapter seven, some individuals participated within the Cancer Voices support groups for personal satisfaction and gratification as identified in the major theme; Cancer Voices developed from the Template Analysis. This was suggested by the participants to positively affect their quality of life as their participation meant they could take part in activities that bring them joy. It is also implied that this participation shapes their experiences of long-term consequences following cancer and its treatment in a positive manner. For instance, Mary, in the major theme: Cancer Voices, suggests she participates as she enjoys the activities encapsulated within the group. However, in the major theme; *Ownership of Consequences*, she states

how embarking on something of interest is key in regards to her managing her long-term consequences of cancer and its treatment and restricting negative experiences of them. This shows how participating in Cancer Voices in order to take part in activities you enjoy, helps positively shape experiences of long-term consequences through the method of distraction. This is somewhat contrasting to previous research. However, this could be due to 'Cancer Voices' being a large online support network and so, unlike the majority of support groups encompasses a variety of activities within it. Whereas, the standard online support groups mainly just provide a platform for people to communicate over.

From discussing the findings of the present research in regards to the use of support groups, it is apparent that the Cancer Voices format of online support appears to have served the participants well, providing numerous benefits for their participation. Furthermore, this discussion significantly highlights how participation within Cancer Voices, positively shapes peoples experiences of cancer in the long-term survivorship phase.

11.4 Reflections

This section will explore my experienced thoughts and feelings present throughout the research process with this encompassing both the used methodology and analyses alongside, reflecting upon my place within the research and what I have learnt from it.

11.4.1 Reflections on Methodology; E-mail Interviews

I noted my thoughts and feelings throughout the e-mail interviews and subsequent data analysis process within the main phenomenological study in order to ensure that I was continuously aware of my emotions, which I will now reflect upon within this section.

In regards to the whole e-mail interview process, I felt at ease throughout, with each participant involved. I feel this was due to the fact that I was able to fully reflect upon my responses before sending them and so, was confident in the wording, appropriateness and effectiveness of them. Therefore meaning, there was little worry of participants taking anything out of context and misinterpreting what I was trying to say which I was very cautious about due to the sensitivity of the area under study. Additionally, I believe this strategic reflection of responses also aided the forming of a researcher-participant relationship, which added to my being at ease. Feeling that I had a relationship with the participants made me more comfortable communicating with them about more sensitive topics within the e-mail interviews. The fact that the participant could not see me, or I them, also enabled this comfort as it provided me with the courage to be more forthright in regards to asking necessary follow-up questions than I might have been face-to-face. This being because, I feel that there are some that were needed, which I would have still found challenging despite the formed researcher-participant relationship, to ask in a face-to-face context but did so, without hesitation due to the interview being via e-mail. An example demonstrating this is when speaking to a lady

[Jane] who told me that she tragically lost her fiancé in the same time period of being originally told she had only weeks to live due to her cancer and then was also told by her father that he was cutting ties with her and would not visit her before she died. Upon reading this, I then knew I needed to ask follow up questions regarding this significant lack of support from her father as it would help me explore how it impacted upon her perceived cancer experience. I was easily able to do this with strategic reflection upon my response however; if I was in face-to-face contact with this participant [Jane] I believe I would have struggled to appropriately and efficiently delve further in to this seemingly traumatic experience within her cancer journey.

Taking the multiple points discussed above in to consideration, it is evident that they demonstrate e-mail interviewing to be an extremely advantageous method of data collection.

The e-mail interviewing method was also very time efficient, as it required no transcribing of data due to it being already written down. This in turn, made the analyses and write up period much faster.

The main benefit I found the method to hold throughout the e-mail interviewing process was flexibility. It allowed me to easily work around particular obstacles during the interviewing process. For example with one particular participant I practically redesigned the whole interview in order to suit their situation in regards to the present research. I doubt I would have been able to do that in a face-to-face interview as I would have panicked at

his initial response and would not have known how to continue the interview. In addition, the e-mail method also allowed me to seek guidance from my supervisor on how to handle this particular situation, which again, I would not have professionally been able to do in a standard face-to-face interview. Another example as to why I found the e-mail interviewing method very flexible is that during the interviewing process of the present research a number of traumatic events occurred in my personal life (lost my grandma, granddad and young brother in law very suddenly and unexpected, alongside being admitted to hospital with ill health for ten days, all in the space of three months). However, the flexibility of the method meant that I was still able to continue the interviewing process whereas, if I was conducting face to face interviews I would have most likely had to cancel on numerous participants which would not have given a very good impression and would have caused delays in my plans.

As a whole, I rather enjoyed the e-mail interview process. I felt honoured that the participants were so interactive and allowed me to be a part of such a personal experience in their lives. Readily available literature suggests e-mail interviewing to restrict the ability of researcher and participant to form a relationship. However, my experience of performing e-mail interviews was quite the opposite. For instance, the participants were open in their responses and with us having continuous communication over a number of weeks we began to share snippets of our lives within the responses and in turn built a relationship.

In addition to this, it was extremely pleasing to hear that the participants also felt the method of interviewing to be beneficial. This was expressed through them stating it to have positive effects upon their own well being alongside them finding the experience to be therapeutic.

Reflecting upon Guba's (1987) criteria of establishing trustworthiness, I feel that applying them in the way described in chapter three was very successful to this research. This is because by constantly having them in mind throughout the research I was able to stay grounded within it and not lose focus, ensuring that each factor was achieved.

11.4.2 Reflection on Template Analysis

The Template Analysis I carried out enabled me to use what I had learnt from the qualitative aspect of the previous preliminary study in order to create a-priori themes. This proved to be extremely advantageous; as it emerged that a couple of the identified themes within the template analysis of the main phenomenological study were also present in that within the preliminary study. The guided steps of the template analysis also enabled me to immerse myself within the gathered data as it was necessary to read and re read each individual's interview responses in order to be able to perform the analysis accurately. Note that due to the data being already transcribed, I was not able to use the transcription process as a method of becoming familiar with the data.

The flexibility of the method also proved to be greatly beneficial. It allowed the focus to be distributed to each identified theme in accordance with how important and relevant they were to the research. Therefore, enabling themes that appeared of more importance to the participants to have a greater focus.

As a whole, the process of applying Template analysis to the data enabled me to see what appears most paramount in regards to the long-term experience of consequences following cancer and its treatment to the participants as a collective. This analysis opened my eyes to just how common the negatively experienced chronic consequences are amongst survivors and how they have various impacts upon the different aspects of their lives and sense of self. It was however, pleasing to find that participants also used such a traumatic experience in order to create new positive aspects of their life or new sense of self. This to me was really interesting and somewhat unexpected as previous to beginning my research I had not considered this to be a possibility. It did appear within the brief qualitative aspect of the preliminary study but I was doubtful it would remain when taking a deeper more personal approach.

11.4.3 Reflection on Narrative Analysis

The three 'readings' performed within the narrative analysis were carefully guided by the Listening Guide and so, once I understood what each 'reading' was asking for, I found the process of completing them relatively easy. However, once the 'readings' were complete the lack of any joined up guidelines on how to pull the analysis together in order to complete it was a

problem. This made it very difficult to understand what should be done next and caused confusion in how it should be presented. This was a challenging aspect to the narrative analysis and demonstrates a limitation of the current literature describing the use of the Listening Guide. However, I found the results of each reading to be extremely interesting as they provided me with something new for each individual, which I had not previously considered with the previous Template Analysis. Therefore, I found the process of it greatly beneficial and thought provoking.

11.4.4 Reflection on my Place in the Research

Throughout the present research, I was aware that as an individual I might be perceived as vastly different to the people in my sample. For example, I am a relatively young woman exploring the participants' sensitive personal experiences of cancer and its long-term consequences in order to graduate in my studies. I was conscious of the possibility that some participants may see me as performing this research solely for that purpose and so, may be slightly wary in how they respond to my questions. Therefore, I believed it imperative to remember throughout that I am not a survivor of cancer and its treatment like the sample and so, not to suggest I have the same understanding as one. I also tried to put aside any understanding I had prior to the research due to my own experiences regarding family and friends' experiences. This was done in order to focus on the story narrated by the individuals in the present study. For instance, I acknowledged my expectations of the main study which, arose from the findings of the preliminary study and used these expectations

to create *a priori* themes for the incorporated Template Analysis. I ensured that *the a priori* themes were tentatively attended to and that I was self-critical of the themes that appeared to develop within the main study.

In addition, I also wanted to ensure that my own interpretations did not become judgments that would hinder the research. Therefore, as previously mentioned I made reflective notes both through the Template and Narrative analyses in order to ensure that I stayed focused on the story of the participant.

I also wanted the participants to be aware that I do care about their experiences within the cancer phenomena and so, at times where I felt empathy or alternative emotions, I ensured I made this known to the participant in the right professional manner. In practice, this also helped the forming of a researcher-participant relationship.

11.4.5 Reflection on Thesis as a Whole

Both as a researcher and from family and friend connections I was aware that chronic consequences exist; for example I have a family member/friend whose esophageal cancer resulted in significant long-term changes to diet. However, the process of the present research taught me just how significant these consequences can be across all areas of an individual's life. Alongside, opening my eyes to how misguided individuals' perceptions are in regards to

people's health once cancer treatment has ended, and how such significant experiences in regards to long-term consequences, are often not spoken of.

By speaking to a number of differing individuals who personally have to live with long-term consequences of cancer and its treatment and construe their experiences in different way, the present research has enabled me to gain a deep awareness and insight in to the phenomenon that I doubt I could develop from anywhere else. I believe this new awareness and insight in turn, has caused me to become more open-minded in regards to the health of others I come across in my everyday life, as well as my professional role as a researcher.

11.5 Strengths and Limitations of the Main Phenomenological Study

As mentioned within the literature review, the number of individuals surviving cancer and living with its long-term consequences is continuing to increase. Therefore, it is imperative for the lived experiences of these individuals in regards to their consequences to be explored in order for a valid understanding of their experience to be gained and in turn, support to be made available when needed. This phenomenon was explored thoroughly before the main phenomenological study began, this being through the reading of previous literature but mainly via the previously presented preliminary study. For instance, my preliminary, mixed method study, along with my review of the literature, provided a solid platform for the main

phenomenological study. This being through providing invaluable insight into different aspects of the chosen phenomenon in order to enable any potentially damaging decisions to be avoided, in regards to what to include and focus upon (or not) within the main phenomenological study. This was mainly in regards to identifying the right people to interview and gain a sense of what sort of issues individuals may experience in the main study.

The incorporation of e-mail interviews is also a solid strength of the present study, as it demonstrates how this relatively new method may be successfully used for future research purposes. In addition, it also highlights how using e-mail interviews not only proved beneficial for the researcher and present study but also the participants. My Template and Narrative analyses that they found their participation within the e-mail interviews to be therapeutic and so potentially beneficial to their health.

However, with strength must come limitation and so, it is important to identify that in the present research. For instance, in the main phenomenological study, due to methods used and time allocated, the sample was restricted to sixteen individuals, fifteen of whom fully completed the e-mail interview process. Furthermore, three of these were also included to present as case studies within the additional narrative analysis. This could be argued by some to be disadvantageous with the implication that the results from such a small sample are incapable of representing the wider population. However, qualitative research focuses upon the ability of gaining a rich, in-depth understanding of the personal lived experiences of individuals within the

studied phenomena. Therefore, the resultant deep understanding gained from the e-mail interaction with the incorporated individuals enabled a valuable insight in to lived experiences of individuals suffering from long-term consequences of cancer and its treatment and the impact it has on their every day lives. In addition, the participants were aware of my student status throughout the research process and so, it must be acknowledged that it is plausible for subject bias to have come into play within some aspects of the e-mail interview. It could be that some participants may hold their own perceptions of my intentions within the research due to my student status. Therefore, it is plausible for them to perhaps provide response they believe society to view as 'correct' or 'acceptable' and/or shape their responses in regards to what they believe the research aims to find. Alternatively, as I am not a professional within the phenomenon under study, it is possible for some to subconsciously construct their responses in regards to their acknowledgement of my limited knowledge when compared to professionally trained individuals.

Finally, the sample was all from the Macmillan Cancer Voices support group. This could raise questions regarding the research's validity, as the participants are arguably on there for support due to their suffering from their experience of cancer and its treatment. Therefore, some may argue for the sample to be limited as it is unlikely for individuals to form membership of a support group if they perceive themselves to have been unaffected by their experience of cancer, making it more likely for participants to tell of negative consequences. However, during the present research, many positive

experiences were also described alongside, the telling of negative consequences.

11.6 Implications for Future Practice and Research

In meeting the current research's overall third and final aim (to provide healthcare professionals who support cancer survivors with insights for practice), the findings from this study suggest that healthcare professionals treating and supporting cancer patients can provide more effective support in both the long and short-term, by acknowledging the need for more advanced expectation management, as there is a high likelihood that cancer and its treatment will lead to side effects and consequences which are present a long time following the successful treatment. This supports the mission of both the NCSI and Macmillan in regards to supporting individuals with long-term consequences from cancer and its treatment. For instance, the "throwing light on the consequences of cancer and its treatment" document (Macmillan, 2013) suggests that improving knowledge and awareness of possible consequences during and following treatment to be of key importance, as it helps individuals identify at which points of their experiences they need support. They also suggest for healthcare professionals such as the individuals' GP to be aware of 'potentially embarrassing' consequences and identify whether these are a concern to their patient as well as other issues they could have or be at risk of developing. However, the accounts of the participants do not demonstrate that GP's raised such issues with them in their experiences. Macmillan (2013, p.15) state through their "throwing light

on the consequences of cancer and its treatment” that the biggest restriction of being able to improve available support services is the healthcare professionals’ lack of knowledge and understanding of the long-term consequences that can develop following cancer and its treatment. Therefore suggesting an explanation behind the participants’ perceived lack of support from their GP’s, this is also supported by the findings of the present study.

The present research also identifies the need for healthcare professionals, working with cancer survivors, to take into consideration and recognise the continuous renegotiation that can occur in regards to one’s selfhood due to their experience of long-term consequences of cancer, therefore meeting the third overall aim of the current research, as presented in the previous paragraph. This is important as it is suggested from the present research that cancer survivors will need different approaches of intervention at different stages of their survivorship journey depending on their experiences at that time. This means that regular contact needs to be had between healthcare professionals such as cancer specialists and the cancer survivor so that amendments to support, in regards to managing changes to self can be made when necessary to ensure the needs of the survivor are met. This is also touched upon by NCSI’s (2013, p.96) “principles for preventing or managing consequences of treatment” strategy, as they state the long-term ‘monitoring ‘ of patients through follow ups, to be a key principle in achieving this.

It may also be advantageous for future research to perform an in-depth investigation on individuals’ sense of selfhood at different trajectories of their

survivorship phase, for example, one year into remission, three years into remission and five years into remission. This will enable a more solid exploration into the renegotiation process of one's selfhood, due to their long-term consequences of cancer and its treatment alongside, exploring the time and manner of the apparent changes within it, in greater depth than the present research.

The findings in regards to '*Feeling Understood*', also enables the current research's third and final aim to be met as they suggest that healthcare professionals such as GPs may benefit from being more forthright in acknowledging that they cannot fully understand the patients' long-term consequences, as well as being clearer about their abilities to ease long-term consequences. Participants believed GPs in particular to show an uncaring attitude towards particular consequences of concern; however, when I explored these they appeared to be health issues very difficult or impossible to treat. Therefore, it could be the case that GPs are not ignoring patients' particular health concerns but rather are focusing on the concerns they can help. Highlighting this more clearly could enable patients to feel more heard and supported as well as feeling more understood. Furthermore, these findings suggest any future practice would benefit from focusing its development upon the cancer survivors' experience rather than typical textbook knowledge.

The Cancer Voices support group appears to have served the participants well, as they highlight numerous benefits of their participation. The present

study adds to the majority of existing research in the area of cancer support groups as it explores a cancer support group with a survivorship phase sample rather than focusing upon the diagnosis/treatment phase of their journey. Therefore, it could be beneficial for future research to add to this and explore the use of various cancer support groups used by cancer survivors in the survivorship phase of their cancer journey and their participation within them. For instance, identifying how various groups differ in their approaches to providing support and the impact the different approaches have upon the cancer survivors' participation within them, not to mention their perceived quality of life. This would be advantageous as it would add to my findings and enable a greater discussion to be had amongst scholars regarding the research topic. Furthermore, the exploration of different online support groups by researchers, with identification of particular factors within them that positively and/or negatively affect one's quality of life in regards to experienced long-term consequences would be beneficial to all support networks. This is because the findings from various cancer support groups could be used to inform the development of those readily available to ensure the best possible support is given to the cancer survivors.

On the whole, the importance of patient centeredness and being holistic is stressed by the developed recovery package of NCSI (cited in, Macmillan, 2013), however, through their "throwing light on the consequences of cancer and its treatment" report Macmillan (2013) suggest the reality of stretched services means that barriers are placed on the ability to apply them. Therefore, it could also be beneficial for research to further explore the

reasons behind this and ways in which already available services could be adopted to encompass the application of this, enabling the needs of cancer survivors to be met.

11.7 Conclusions

The present research adds knowledge to the limited literature surrounding the relatively new method of e-mail interviewing, enabling a wider discussion to be had regarding the advantages and disadvantages of it. Furthermore, a new finding that has implications for future research is a large minority of the participants identifying the method of e-mailing interviewing to be therapeutic, benefiting their experiences of particular issues – in the case of the present research – long-term consequences of cancer and its treatment.

Previous research suggests that long-term consequences of cancer influence one's perceived self and/or identity. However, I would argue that selfhood is different from identity, though the two are of course linked; identity emphasises how we categorise ourselves ("am I this sort of person or that sort of person?") while selfhood emphasises the lived experience of self ("this is what it feels like to be me"). This notion of selfhood is important to explore, particularly as the majority of research focuses more on identity. By choosing to focus upon selfhood, this research is able to show the complex ways, particularly through the Narrative Analysis, in which selfhood is negotiated and renegotiated by the participant, rather than simply identifying a

categorical change to have occurred (i.e. going from the “cancer patient” to “cancer survivor”).

A surprising finding is that fear of cancer reoccurrence is not particularly prominent in the majority of participants’ accounts, even though previous research and the preliminary study to an extent, which also has a sample including long-term survivors, find that it is. However, the majority of previous literature has arguably used methods that may tend to foreground fear of cancer – for example, by highlighting it in questionnaire items or by making it an area of exploration within a one-off semi-structured interview. Because the present study involved collecting participant-led accounts of the impact of long-term consequences over a period of several weeks, there was perhaps more scope for the issues that bothered participants on a day-to-day basis to emerge. The present lack of focus upon fear of cancer reoccurrence by participants in the main study does not mean that they have put cancer out of their mind. For instance, they are still very conscious of their lives being affected by a number of alternate long-term consequences. Therefore, it is possible that fear of reoccurrence may be so imprinted within participants’ minds that it has become background whereas, the day-to-day issues are constantly present. For example, not being able to go to places because of fear of urgently needing the toilet or not being able to meet friends because they do not understand the participant’s long-term consequences, causing them to feel isolated from the group.

A fresh way of understanding the long-term consequences that cancer survivors experience and their effect on a daily basis is also provided by the current research, particularly through the Template Analysis within the phenomenological study. This research shows how complex the ability of 'feeling understood' can be, emphasising the importance of straight forward, effective communication by healthcare professionals to cancer survivors alongside, the need of a sense of community to be felt amongst the survivors. This being as it is suggested by the participants that only cancer survivors can truly hold an adequate level of understanding in regards to the phenomenon.

To conclude, the present research suggests the experience of long-term consequences to be dependent upon various factors such as, support, understanding, managing of consequences and engagement with the social world. This is because the participants' experiences within these facets appear to shape how they perceive their long-term consequences, with this perception then guiding their lived experience of them (positively/negatively/unaffected) and their reflected sense of self.

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Appendices

Appendix 1 – Message to cancer voices members regarding the online survey

Dear Cancer Voice members,

We are giving you the opportunity to take part in a very exciting new project within the cancer research area. We are interested in the long-term consequences of cancer and its treatment and how they affect those who experience them. The National Cancer Survivorship Initiative organisation states that there are currently 2 million people in the UK living post cancer with this number being expected to increase by 3% per year. Therefore, it is extremely important that a sound knowledge and understanding is held by professionals and policy-makers about the prevalence of long-term consequences and their impact upon people's daily living in order to ensure services and in turn, lives can be improved.

In order to be eligible to take part in this research you must be over the age of 18, English speaking and in the remission phase of your cancer journey. If you feel that participation may be too upsetting for you please do not take part.

If you are interested in taking part in this research and fit the eligibility criteria please click on the link below.

Appendix 2 – The Online Survey with the included information sheet and informed Consent Form

The Long Term Consequences of Cancer and its Treatment

Start of Block: Default Question Block

Dear Potential Participant,

It is important before deciding whether or not to participate in the present study that you are aware of what your participation will involve and why the research is being conducted. Please read the information below carefully.

What would my involvement entail if I was to participate in the study?

Taking part in this research involves you completing a survey sent to you by the researcher. This survey will ask you questions in relation to your cancer experience post treatment as the aim of the survey is to explore different cancer types and the different long-term consequences associated with them. At the end of the survey you will be asked whether you would be willing to be approached to take part in a follow-up e-mail interview. It is entirely up to you whether you agree to this, and even if you do provide contact details you may still choose not to take part in the e-mail interview.

Who is the researcher?

My name is Jade Cash. I am a PhD student in the School of Human and Health Sciences, University of Huddersfield.

Why is the research being conducted?

Even when they are no longer suffering from cancer, people may suffer ongoing problems associated with the disease and/or its treatment including such things as fatigue, incontinence, psychological problems and sexual difficulties. We need to know more about such problems and how they affect people. This piece of research is being conducted in order to explore the impact of different long-term consequences caused by cancer and its treatment for different cancer types.

Do I have to take part?

Absolutely not! It is entirely up to you whether you take part. If you feel that you would find it too upsetting, please do not take part.

Will my participation stay anonymous?

The research will be subject to ethical guidelines given by the School of Human and Health Sciences and will follow the British Psychological Society (BPS) code of ethics. You, alongside all other participants, will remain anonymous by being given a pseudonym. This means that you will be given a fictitious or alternative name in order to stop other people being able to identify you. In addition, the paper copy of the surveys will be locked in a drawer with only the researcher and the researcher's supervisor having the keys to access them and the electronic surveys will be kept and accessed on a private password protected computer.

Will my participation be kept confidential?

Yes it will!

What If I decide I no longer want to take part?

You have the right to withdraw your participation in the study at any point during its conduction without giving an explanation and do not have to answer any specific questions if you do not wish to.

How do I request withdrawal of my data?

If you wish to withdraw your data then all you have to do is simply contact the researcher and express your wish to withdraw your data alongside providing your unique identification number that you will be given once you have completed the survey. The researcher will then remove your data from the research and you will be no longer involved in the investigation. However, this cannot be done once the data has been analysed and so, it is important you do this by the 1st November 2014.

What will happen to the findings of this study?

The findings of this study will be reported in a thesis and published in relevant journals. In addition to this, it is highly likely that they will be presented at a number of conference presentations.

Please do not hesitate in contacting me (u1057168@hud.ac.uk) or my main supervisor, Nigel King (n.king@hud.ac.uk) via email if you have any queries regarding the research.

Yours Faithfully,

Jade Cash.

Page Break

Thank you for taking part in the present research. Please complete this consent form to show that you are content with the information you have been presented with in relation to what the research entails, that you are aware of the research aims and that you still wish to take part in it. Please click on the answer you feel is correct for the following 5 questions.

1. Do you know why the research is being carried out?

☐ Yes (1)

☐ No (2)

2. Has the researcher given you the chance to ask any questions you may have about the research you have been asked to take part in?

☐ Yes (1)

☐ No (2)

3. Do you understand that if you so wish, you can withdraw your participation in the research at any time throughout the conduction of it?

☐ Yes (1)

☐ No (2)

4. Do you understand that you can ask for the answers gained from your participation in the research to be withdrawn, up to the 1st November 2014?

☐ Yes (1)

☐ No (2)

5. Are you happy for the answers you give to be used in the research report as long as you remain anonymous at all times?

☐ Yes (1)

☐ No (2)

If you are happy to continue please click on the consent box below for the survey to appear on your computer screen.

☐ **CONSENT** (1)

Skip To: End of Survey If If you are happy to continue please click on the consent box below for the survey to appear on yo... != CONSENT

Page Break

Display This Question:

If If you are happy to continue please click on the consent box below for the survey to appear on yo... = CONSENT

Q1 What is your gender?

☐ Male (1)

☐ Female (2)

Q2 How old are you?

Q3 What is your marital status?

☐ Single (1)

☐ Married/Civil partnership (2)

☐ Separated/Divorced (3)

☐ Living with partner (4)

☐ Widowed (5)

Q4 Are you currently responsible for the care of any other adults or children?

☐ Yes (1)

☐ No (2)

Q4b If you answered '**Yes**' to the above question please use the box below to state the carer responsibilities you hold.

Q5 What type(s) of cancer have you experienced? Please select **all** that apply.

- ☐ Breast (1)
- ☐ Lung (2)
- ☐ Bowel (3)
- ☐ Prostate (4)
- ☐ Skin (5)
- ☐ Blood (6)
- ☐ Bladder (7)
- ☐ Pancreatic (8)
- ☐ Oesophagus (9)
- ☐ Unknown primary (10)
- ☐ Other (11)

Q5b If you answered '**Other**' to the above question please use the box below to state which type(s) of cancer you have experienced.

Q6

How would you describe your current cancer status? Please select **all** that apply to you.

- ☐ A cancer survivor (1)
- ☐ Cancer free (2)
- ☐ In remission (3)
- ☐ Other (4)

Q6b If you answered '**Other**' to the above question please use the box below to state how you see yourself in terms of your cancer status.

Page Break

The next section of this questionnaire will explore the different kinds of cancer experience you have had. I want to ask firstly about any primary cancers. Remember: Primary cancer refers to where the cancer started for example, if you have cancer that starts in the stomach then you have primary stomach cancer.

Q7 In the box below please state your experienced primary cancer. If you have experienced **more than one** please talk here about your **most recently experienced primary cancer** and you will have the opportunity later in the survey to speak about other primary cancers.

Q8 What stage was this cancer at diagnosis?

- ☐ Stage 0 (1)
 - ☐ Stage 1 (2)
 - ☐ Stage 2 (3)
 - ☐ Stage 3 (4)
 - ☐ Stage 4 (5)
 - ☐ Do not know (6)
-

Q9 How long have you been in remission from this experienced cancer type?

- ☐ Years (1) _____
 - ☐ Months (2) _____
-

Q10 Have you experienced **more than one** primary cancer?

- ☐ Yes (1)
- ☐ No (2)

Skip To: Q11 If Have you experienced more than one primary cancer? = Yes

Skip To: Q19 If Have you experienced more than one primary cancer? = No

Q11 Please state your alternative experienced primary cancer.

Q12 What stage was this cancer at diagnosis?

- ☐ Stage 0 (1)
 - ☐ Stage 1 (2)
 - ☐ Stage 2 (3)
 - ☐ Stage 3 (4)
 - ☐ Stage 4 (5)
 - ☐ Do not know (6)
-

Q13 How long have you been in remission from this experienced cancer type?

- ☐ Years (1) _____
 - ☐ Months (2) _____
-

Q14 Have you experienced **more than** two types of primary cancer?

- ☐ Yes (1)
- ☐ No (2)

Skip To: Q15 If Have you experienced more than two types of primary cancer? = Yes
Skip To: Q19 If Have you experienced more than two types of primary cancer? = No

Q15 Please state the remaining primary cancer type in the box below.

Q16 What stage was this cancer type at diagnosis?

- ☐ Stage 0 (1)
 - ☐ Stage 1 (2)
 - ☐ Stage 2 (3)
 - ☐ Stage 3 (4)
 - ☐ Stage 4 (5)
 - ☐ Do not know (6)
-

Q17 How long have you been in remission from this experienced cancer type?

- ☐ Years (1) _____
 - ☐ Months (2) _____
-

Q18 If you have experienced **more than three** primary cancers please state the ones you have not previously mentioned below alongside the stage of the cancer at diagnosis and how many years of remission you are currently in from it. If you have not experienced more than three primary cancers please skip to the next question.

Page Break

Q19 Have you experienced any secondary cancers? (**Remember:** If some of the cancer cells separate from the primary cancer and settle somewhere else in the body, then this is a secondary cancer. For instance, if you have liver cancer that has spread to the lungs then you have primary liver cancer with secondary lung cancer).

☐ Yes (1)

☐ No (2)

Skip To: Q20 If Have you experienced any secondary cancers? (Remember: If some of the cancer cells separate from... = Yes

Skip To: Q1D18 If Have you experienced any secondary cancers? (Remember: If some of the cancer cells separate from... = No

Q20 Please state your experienced secondary cancer type here. If you have experienced **more than one** secondary cancer then please talk here about your **most recently** experienced secondary cancer.

Q21 How long have you been in remission from this experienced cancer type?

☐ Years (1) _____

☐ Months (2) _____

Q22 Have you experienced **more than one** secondary cancer?

☐ Yes (1)

☐ No (2)

Skip To: Q1D18 If Have you experienced more than one secondary cancer? = No

Skip To: Q23 If Have you experienced more than one secondary cancer? = Yes

Q23 Please state below your alternative experienced secondary cancer type.

Q24 How long have you been in remission from this experienced secondary cancer?

☐ Years (1) _____

☐ Months (2) _____

Q25 Have you experienced **more than two** secondary cancers?

☐ Yes (1)

☐ No (2)

Skip To: Q26 If Have you experienced more than two secondary cancers? = Yes

Skip To: Q1D18 If Have you experienced more than two secondary cancers? = No

Q26 Please state below your remaining experienced secondary cancer type.

Q27 How long have you been in remission from this experienced cancer type?

☐ Years (1) _____

☐ Months (2) _____

Q28

If you have experienced more than **three** secondary cancers please state the ones you have not previously mentioned below alongside how many years of remission you are currently in from it. If you have not experienced more than three secondary cancers please skip to the next question.

The following section of this survey will ask you a number of questions based on factors that can affect individuals' quality of life. Please answer each question using the scale shown below to indicate the trueness of each statement for you within the past four weeks by selecting the most appropriate response.

Q32 In the past four weeks have you:

	Never (1)	Seldom (2)	Sometimes (3)	About as often as not (4)	Frequently (5)	Very often (6)	Always (7)
1. Had the energy to do the things you wanted to do? (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. Had difficulty doing activities that require concentrating? (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. Been bothered about having a short attention span? (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. Had trouble remembering things? (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. Felt fatigued? (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. Felt happy? (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. Felt blue or depressed? (7)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8. Enjoyed life? (8)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9. Worried about little things? (9)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10. Been bothered about being unable to	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

function
sexually? (10)

11. Not had
the energy to
do the things
you wanted to
do? (11)

☐☐☐☐☐☐☐☐

12. Been
dissatisfied
with your sex
life? (12)

☐☐☐☐☐☐☐☐

13. Been
bothered by
pain keeping
you from
doing things?
(13)

☐☐☐☐☐☐☐☐

14. Felt tired a
lot? (14)

☐☐☐☐☐☐☐☐

15. Been
reluctant to
start new
relationships?
(15)

☐☐☐☐☐☐☐☐

16. Lacked
interest in
sex? (16)

☐☐☐☐☐☐☐☐

17. Felt your
mood was
disturbed by
pain or its
treatment?
(17)

☐☐☐☐☐☐☐☐

18. Avoided
social
gatherings?
(18)

☐☐☐☐☐☐☐☐

19. Been
bothered by
mood swings?
(19)

☐☐☐☐☐☐☐☐

20. Avoided
your friends?
(20)

☐☐☐☐☐☐☐☐

21. Had aches
or pains? (21)

☐☐☐☐☐☐☐☐

22. Had a positive outlook on life? (22)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
23. Been bothered by forgetting what you started to do? (23)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
24. Felt anxious? (24)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
25. Been reluctant to meet new people? (25)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
26. Avoided sexual activity? (26)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
27. Felt pain or its treatment has interfered with your social activities? (27)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
28. Been content with life? (28)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

The next set of questions ask you specifically about the effects of your cancer and its treatment. Again, for each statement, indicate how true each of these statements are to you in the past four weeks.

In the past four weeks have you:

	Never (1)	Seldom (2)	Sometimes (3)	About as often as not (4)	Frequently (5)	Very often (6)	Always (7)
29. Appreciated life more because of having cancer? (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
30. Had financial problems because of the effects of cancer treatment/surgery? (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
31. Worried that your family members were at risk of getting cancer? (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
32. Realised that having had cancer helps you cope better with problems now? (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
33. Were self conscious about the way you look because of cancer or its treatment? (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
34. Worried that your family members might have cancer causing genes? (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
35. Felt unattractive because of your cancer or its treatment? (7)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
36. Worried about dying from	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

cancer? (8)							
37. Had problems with insurance because of cancer? (9)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
38. Were bothered by hair loss from cancer treatment? (10)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
39. Worried about the cancer coming back? (11)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
40. Felt that cancer helped you recognise what is important in life? (12)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
41. Felt better able to deal with stress because of having cancer? (13)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
42. Worried about whether your family should have genetic tests for cancer? (14)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
43. Had money problems that arose because of having cancer? (15)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
44. Felt people treat you differently due to changes in your appearance from cancer or its treatment? (16)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
45. Had financial problems due to a loss of income as a result of cancer? (17)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
46. Felt that whenever you experienced worried it was	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

cancer again? (18)

47. Been
preoccupied with
concerns about
cancer? (19)

☐

☐

☐

☐

☐

☐

☐

The next section of the survey will provide you with 18 questions. Each question consists of a group of four statements. Please read each group of statements carefully and then select the one which best describes your feelings over the past six months.

Q32 1.

	Please select the statement most true to you (1)
I do not worry about my health (1)	<input type="radio"/>
I occasionally worry about my health (2)	<input type="radio"/>
I spend too much of my time worrying about my health (3)	<input type="radio"/>
I spend most of my time worrying about my health (4)	<input type="radio"/>

2

	Please select the statement most true to you (1)
I notice aches/pains less than most other people my age (1)	<input type="radio"/>
I notice aches/pains as much as most other people my age (2)	<input type="radio"/>
I notice aches/pains more than most other people my age (3)	<input type="radio"/>
I am aware of aches/ pains in my body all the time (4)	<input type="radio"/>

3

	Please select the statement most true to you (1)
As a rule i am not aware of bodily sensations or changes (1)	<input type="radio"/>
Sometimes I am aware of bodily sensations or changes (2)	<input type="radio"/>
I am often aware of bodily sensations or changes (3)	<input type="radio"/>
I am constantly aware of bodily sensations or changes (4)	<input type="radio"/>

4

	Please select the statement most true to you (1)
Resisting thoughts of illness is never a problem (1)	<input type="radio"/>
Most of the time I can resist thoughts of illness (2)	<input type="radio"/>
I try to resist thoughts of illness am often unable to do so (3)	<input type="radio"/>
Thoughts of illness are so strong that I no longer even try to resist them (4)	<input type="radio"/>

5

	Please select the statement most true to you (1)
As a rule I am not afraid that I have a serious illness (1)	<input type="radio"/>
I am sometimes afraid that I have a serious illness (2)	<input type="radio"/>
I am often afraid that I have a serious illness (3)	<input type="radio"/>
I am always afraid that I have a serious illness (4)	<input type="radio"/>

6

	Please select the statement most true to you (1)
I do not have images (mental pictures) of myself being ill (1)	<input type="radio"/>
I occasionally have images of myself being ill (2)	<input type="radio"/>
I frequently have images of myself being ill (3)	<input type="radio"/>
I constantly have images of myself being ill (4)	<input type="radio"/>

7

	Please select the statement most true to you (1)
I do not have any difficulty taking my mind off thoughts about my health (1)	<input type="radio"/>
I sometimes have difficulty taking my mind off thoughts about my health (2)	<input type="radio"/>
I often have difficulty taking my mind off thoughts about my health (3)	<input type="radio"/>
Nothing can take my mind off thoughts about my health (4)	<input type="radio"/>

Page Break

8

	Please select the statement most true to you (1)
I am lastingly relieved if my doctor tells me there is nothing wrong (1)	<input type="radio"/>
I am initially relieved but the worries sometimes return later (2)	<input type="radio"/>
I am initially relieved but the worries always return later (3)	<input type="radio"/>
I am not relieved if my doctor tells me there is nothing wrong (4)	<input type="radio"/>

9

	Please select the statement most true to you (1)
If I hear about a illness I never think I have it myself (1)	<input type="radio"/>
If I hear about an illness I sometimes think I have it myself (2)	<input type="radio"/>
If I hear about an illness I often think I have it myself (3)	<input type="radio"/>
If I hear about an illness I always think I have it (4)	<input type="radio"/>

10

	Please select the statement most true to you (1)
If I have a bodily sensation or change I rarely wonder what it means (1)	<input type="radio"/>
If I have a bodily sensation or change I often wonder what it means (2)	<input type="radio"/>
If I have a bodily sensation or change I always wonder what it means (3)	<input type="radio"/>
If I have a bodily sensation or change I must know what it means (4)	<input type="radio"/>

11

	Please select the statement most true to you (1)
I usually feel at very low risk for developing a serious illness (1)	<input type="radio"/>
I usually feel at fairly low risk for developing a serious illness (2)	<input type="radio"/>
I usually feel at moderate risk for developing a serious illness (3)	<input type="radio"/>
I usually feel at high risk for developing a serious illness (4)	<input type="radio"/>

12

	Please select the statement most true to you (1)
I never think I have a serious illness (1)	<input type="radio"/>
I sometimes think I have a serious illness (2)	<input type="radio"/>
I often think I have a serious illness (3)	<input type="radio"/>
I usually think that I am seriously ill (4)	<input type="radio"/>

13

	Please select the statement most true to you (1)
If I notice an unexplained bodily sensation I don't find it difficult to think about other things (1)	<input type="radio"/>
If I notice an unexplained bodily sensation I sometimes find it difficult to think about other things (2)	<input type="radio"/>
If I notice an unexplained bodily sensation I often find it difficult to think about other things (3)	<input type="radio"/>
If I notice an unexplained bodily sensation I always find it difficult to think about other things (4)	<input type="radio"/>

14

	Please select the statement most true to you (1)
My family/friends would say I do not worry enough about my health (1)	<input type="radio"/>
My family/friends would say I have a normal attitude to my health (2)	<input type="radio"/>
My family/friends would say I worry too much about my health (3)	<input type="radio"/>
My family/friends would say I am a hypochondriac (4)	<input type="radio"/>

Page Break

For the remaining questions please think about what it is like with a serious illness

15

	Please select the statement most true to you (1)
If I had a serious illness I would still be able to enjoy things in my life quite a lot (1)	<input type="radio"/>
If I had a serious illness I would still be able to enjoy things in my life a little (2)	<input type="radio"/>
If I had a serious illness I would be almost completely unable to enjoy things in my life (3)	<input type="radio"/>
If I had a serious illness I would be completely unable to enjoy life at all (4)	<input type="radio"/>

16

	Please select the statement most true to you (1)
If I had a serious illness there is a good chance that modern medicine would be able to cure me (1)	<input type="radio"/>
If I had a serious illness there is a moderate chance that modern medicine would be able to cure me (2)	<input type="radio"/>
If I had a serious illness there is a very small chance that modern medicine would be able to cure me (3)	<input type="radio"/>
If I had a serious illness there is no chance that modern medicine would be able to cure me (4)	<input type="radio"/>

17

	Please select the statement most true to you (1)
A serious illness would ruin some aspects of my life (1)	<input type="radio"/>
A serious illness would ruin many aspects of my life (2)	<input type="radio"/>
A serious illness would ruin almost every aspect of my life (3)	<input type="radio"/>
A serious illness would ruin every aspect of my life (4)	<input type="radio"/>

Q72 18

	Please select the statement most true to you (1)
If I had a serious illness I would not feel that I had lost my dignity (1)	<input type="radio"/>
If I had a serious illness I would feel that I had lost a little dignity (2)	<input type="radio"/>
If I had a serious illness I would feel that I had lost quite a lot of dignity (3)	<input type="radio"/>
If I had a serious illness I would feel that I had totally lost my dignity (4)	<input type="radio"/>

Page Break

The final section of the survey will ask you some more open questions in relation to your experience of long term consequences of cancer and its treatment. Please be open and honest giving as much detail as you can in your answers.

Q33 Please list three consequences that have caused you the most concern.
(Remember: These could be any physical or psychological consequences such as: Incontinence or sexual problems, issues with eating or stomaching food and feeling self conscoius about the way you look or not wanting to go out).

Q34 Please briefly explain in the box below why these are a concern to you.

Q35 What, if anything, has surprised you in your journey of living with cancer?
Please explain your answer.

Q36 What, if anything, has surprised you in your experience of living with long term
consequences from cancer and its treatment? Please explain your answer.

Please use the space below to write anything you wish to share that has not already
been addressed by this survey in relation to your experience of long term
consequences due to your cancer and its treatment.

Would you be willing to participate in an email interview in the future to speak about the long-term consequences of cancer in greater depth?

☐ Yes (1)

☐ No (2)

If you answered yes to the above, please enter your email address so I can contact you. Please be aware that this information will NOT be shared at any time during or after the conduction of the research and will be destroyed once the data has been analysed.

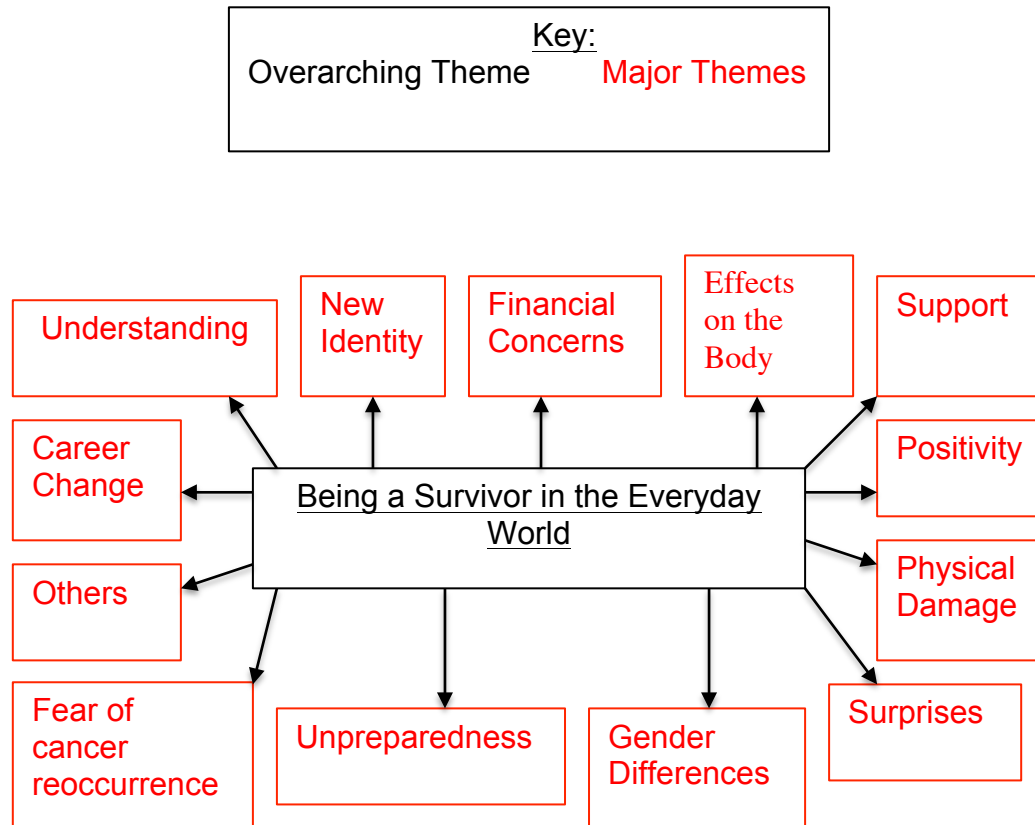
Q84 Thank you for taking the time to complete this survey, it is much appreciated.

Q74



Appendix 3 – The Initial Template within the Template

Analysis for the Preliminary Study



Appendix 4 – Blanket email sent to the selected participants for e-mail interview

Hi,

My name is Jade and I am carrying out research on the lived experience of the long-term consequences of cancer and its treatment.

You recently completed a questionnaire for me via the cancer voices support group and stated that you would be interested in participating in email interviews focusing on such consequences in further detail. If you are still interested in doing this then please get in touch by emailing me back and I will send you the information sheet explaining what the email interviews will focus on and how they will be conducted enabling you to decide whether or not you are still happy to participate and give your consent.

Thank you very much for your time.

Best Wishes

Jade Cash.

Appendix 5 – Information sheet sent to the selected e-mail interview participants

Human and Health Sciences
University of Huddersfield
Queensgate
Huddersfield
West Yorkshire
HD1 3DH
Email: Jade.Cash@hud.ac.uk

Dear Potential Participant,

It is important prior to deciding whether or not to take part in the present study that you are fully aware of what your participation will involve and why the research is being conducted. Please read the information below carefully.

Who is the researcher?

My name is Jade Cash. I am a PhD student in the School of Human and Health Sciences, University of Huddersfield.

What would my involvement entail if I was to participate in the study?

Your participation will involve you being interviewed by me via email and answering questions in relation to your experiences of long-term consequences due to your cancer and its treatment. The email interview will begin in May 2015 and will be conducted over a six week period. I will send you a question once a week and would appreciate a reply within three days however; upon receiving a response I may send follow up questions within the same week to expand upon what has been said. Once the interview is complete and I feel I have enough information then the interview will be brought to an end and you will be thanked for your participation. You will also be given the chance to ask any questions.

Why is the research being conducted?

This piece of research is a follow-up to the survey previously conducted which examined the nature and impact of long-term consequences of cancer on people currently in remission. However, this section of the research aims to explore in depth the different long-term consequences experienced by individuals who have received treatment for different cancer types. These e-mail interviews will enable me to gain a deeper understanding of how long-term consequences of cancer affect individuals' daily lives. It will form part of the work included in my PhD thesis.

Why have I been chosen to take part?

You have been chosen because you completed my online survey and indicated there that you would be happy to take part in a follow-up online interview.

Do I have to take part?

Absolutely not! It is entirely up to you whether you take part. If you feel that you would find it too upsetting, please do not take part.

Will my participation stay anonymous?

The research will be subject to ethical guidelines given by the School of Human and Health Sciences and will follow the British Psychological Society (BPS) code of ethics. You, alongside all other participants, will remain anonymous by being given a pseudonym. This means that you will be given an alternative name in order to stop other people being able to identify you. In addition to this, the transcript of your interview will be kept in a locked drawer to which only the researcher and the researcher's main supervisor will have the keys to. An electronic copy of your email interview will be kept on a password protected computer and any audio files will be kept for five years following thesis publication.

Will my participation be kept confidential?

Researcher-participant confidentiality will apply throughout and after the study with your involvement and anything you said will be kept confidential. If any direct quotes from your email interview are used in reports, publications and/or in my PhD thesis these will be made anonymous. However, in the unlikely event that you were to reveal experiences of abuse, serious medical malpractice or your own or others' involvement in criminal activity, I would be obliged to consult with my supervisors and potentially to report this to appropriate authorities.

Do I have to answer all the questions asked of me?

No, you do not have to answer any specific questions if you do not wish to.

What If I decide I no longer want to take part?

You have the right to withdraw your participation from the study at any point during the conduct of the research without giving an explanation.

What if I want to withdraw my data?

You may also ask that for your data to be removed from the study after the e-mail interview process has finished. However, it will not be possible to do this once findings of the study have been written-up; you would therefore need to contact me to request withdrawal of data via my e-mail address below before the 1st of July 2015.

What will happen to the findings of this study?

The findings of this study will be reported in a thesis and published in relevant journals. In addition to this, it is highly likely that they will be presented at a number of conference presentations.

Please do not hesitate in contacting me (jade.cash@hud.ac.uk) or my main supervisor, Nigel King (n.king@hud.ac.uk) via email if you have any queries regarding the research.

Yours Faithfully,

Jade Cash.

Appendix 6 – The consent form for the e-mail interview participants

Consent Form

Thank you for taking part in the present research. Please read this consent form to identify that you are content with the information you have been presented with in relation to what the research entails, that you are aware of the research aims and that you still wish to take part in it.

1. Do you know why the research is being carried out?
2. Has the researcher given you the chance to ask any questions you may have about the research you have been asked to take part in?
3. Do you understand that if you so wish, you can withdraw your participation in the research at any time during its conduction?

4. Do you understand that you can ask for the answers gained from your participation in the research to be withdrawn, up to the 1st July 2015?
5. Are you happy for the answers you give to be used in the research report as long as you remain anonymous at all times?

If your answer is **yes** to the above questions and you have no questions in regards to the research then please send the researcher an email stating the following phrase;

"I have read the consent form and have had the chance to ask questions. I know that I can withdraw myself from the research at any time with no questions asked and withdraw my data before the 1st July 2015. I hereby give my ongoing informed consent for the current research".

If you answered **no** to any of the above questions please email the researcher and these will be made clear to you. Once you have been in contact with the researcher and are happy to take part in the current research then please send the researcher an email stating the following phrase;

"I have read the consent form and have had the chance to ask questions. I know that I can withdraw myself from the research at any time with no questions asked and withdraw my data before the 1st July 2015. I hereby give my ongoing informed consent for the current research".

Thank you for your participation.
Yours Faithfully,
Jade Cash.
(jade.cash@hud.ac.uk)

Appendix 7 – An example of a Completed Consent form

Hi Jade

"I have read the consent form and have had the chance to ask questions. I know that I can withdraw myself from the research at any time with no questions asked and withdraw my data before the 1st July 2015. I hereby give my ongoing informed consent for the current research."

Appendix 8 – An example of the data gained during the e-mail interview of one participant [Kirsty]

Monday 18th May 2015:

Hi,

Thanks again for agreeing to participate in this email interview.

I would like you to think of a particular consequence of your cancer and/or its treatment that has bothered you in the past few weeks. Describe for me one (or more if you like) incident in which this has happened and how you felt about it.

I look forward to your response.

Best Wishes

Jade.

Tuesday 19th May 2015:

Hi Jade

There are so many ways in which you are permanently affected both physically and emotionally, but I will select two examples.

I have peripheral neuropathy in both feet and hands which causes many problems. About four weeks ago I went for a long walk in the sunshine. I have very little sensation in my feet so I have to walk very carefully, especially on uneven surfaces or stairs as I cannot feel where my feet are in relation to obstacles. I enjoyed my walk, got home and kicked my shoes off only to find

my toes covered in blood. I had blistered my toes but did not feel it, so by the time I got home I had taken the skin off my toes which because of the associated poor healing has taken until now to heal over - consequently I have been unable to wear anything other than sandals since. I have to be so very careful when I am out as anything caught under my foot (a common hazard with sandals) can cause further problems. It does put me off going out sometimes as it doesn't seem worth the risks.

Another issue which has bothered me lately is that of stress and depression. I have gone from having a very stressful job (which I loved) pre cancer to being unable to deal with the simplest problem or irritation. I now go to pieces at such times and just sit in my flat feeling defeated. There is virtually no support after treatment and you begin to question your sanity at times. There are constant pressures to 'get back to work' and be 'yourself' again but you are still trying to find the new post-cancer you and to deal with the emotional and physical fallout of diagnosis and treatment. I find my tolerance level is zero towards others and really can't be bothered with people lately.

I hope this is the sort of thing you are looking for, let me know if it is enough detail.

Regards

Friday 22 May 15:

Hi,

Firstly I would like to apologise for my late response, I am afraid we had a bereavement this week as my sister's boyfriend sadly lost his life and so, I have not been able to reply as fast as I had liked. So please forgive me.

Wow what you said about your feet sounds pretty painful! Have you sought any help in regards to this problem? Is there anything you can have in order to fix this ie, special shoes may be?

Your response is really interesting! Just a few little questions to follow up on some of your points before I send you the next main question next week.

Just to be clear is peripheral neuropathy a consequence of your cancer or of treatment?

Also, you say you have constant pressures to get back to work, where/who are these pressures from?

Best Wishes

Jade.

Friday 22 May 15:

Hi Jade

Sorry to hear of the loss of your sister's boyfriend, a sad time for all concerned.

The PN is a known side effect of carboplatin, the main treatment for ovarian cancer. It has many unpleasant side effects some of which can be permanent (I also developed tinnitus as a result of the chemo and that is also permanent). I take Gabapentin for the pain in my feet and have to wear flat

shoes as my balance is not great, it was still spreading but seems to have settled down - it is in my feet and up to my knee on the left, also in both hands.

The pressure to return to work started as soon as chemo ended which is when the slow process of recovery starts (you have to relearn your body's responses and capabilities again as everything has changed). It was the DWP and I have to battle constantly to keep any benefits - thank goodness my cancer specialist nurse is so supportive otherwise I couldn't cope!

One of the comments you hear most from the day treatment ends is 'you can get back to normal now' but you never can be the person you were before cancer - why don't people get that? I had two massive operations, lots of internal parts of me are missing, I had poison injected into me for six months and have to be checked every three months to see if it is back..... how normal is that?

Take care

23 May 15:

Hi,

Right I see, thanks for clearing that up for me. I am glad that you found your specialist nurse so supportive. I understand what you are saying and I completely agree with you.

Thank you for answering these follow up questions for me, I will send you the next question on Monday.

Best Wishes

Jade.

25 May 15:

Hi,

Hope you had a good weekend,

Could you please explain to me how you manage your experienced long term consequences of cancer and/or its treatment?

Best Wishes

Jade.

25 May 15:

Hi Jade

I have a care plan in place with my GP and have access to a wonderful Cancer Specialist Nurse at the hospital. That gives some support but mainly I just have to grin and bear it. There is very little help given by any medical staff after treatment ends, even when having 3 monthly assessments to check for recurrence (I still have these after 3 years post-op) no-one ever asks how you are coping. There seems little understanding of the impact of cancer diagnosis on patients, although a nurse in CT when I had a scan last month did say that many patients suffer PTSD afterwards....

So really I just put up with the various problems that cancer and treatment have left me with, I try to eat healthily and exercise when I am able and take medication the doctor has prescribed. I listen to my body and know when I need to rest, sometimes for several days. I make plans to do things but family and friends are used to me cancelling at the last moment when I know I am not up to it, but I feel it is important to keep trying.

I also try to keep my mind occupied (doing a law degree at the moment) and try not to dwell too much on what has happened to me. If you think about it too much it really brings home what you have been through so I try to keep it at the back of my mind, but sometimes it does overwhelm me.

Regards

26 May 15:

Hi,

So, healthy eating, exercise and keeping busy seems to work for you. Is there any particular coping strategies you have tried that you have not found successful? Also, Is there any particular advice you would give other cancer survivors on how to deal with long-term consequences of cancer and its treatment?

Best Wishes

Jade.

26 May 15:

I think it is all a compromise, you just do the best you can but it is a steep learning curve for sure. I went for counselling but didn't find it particularly helpful as unless they have been through it themselves they have no concept of how it changes everything. A lot of the advice was a bit trite to be honest - one thing cancer sufferers have in common is courage, and many will have already looked deep within themselves in order to summon the strength to cope.

Advice I would give to cancer patients/survivors is that everyone is different and your cancer journey is personal to you - it does not matter how others cope/deal with it, what matters is how you get through it in what ever way works for you. Also, be kind to yourself and allow yourself to be frightened, sorry for yourself, happy, sad, angry - you feel and are entitled to all of those emotions.... but remember to laugh too, it really does help no matter how dark things seem. And once the battle is won (although often not the war) allow yourself time to get to know the new you, and time to grieve for the old you.

27 May 15:

Thank you very much for your response it is extremely interesting and helpful.

I will send you the next question on Monday. I hope you have a good week.

Best Wishes

Jade.

27 May 15:

Thanks, you too!

1 June 15:

Hi,

Hope you had a good weekend!

Could you please explain to me in as much detail as possible how would you think your close family and friends have coped with your suffering of such long term consequences?

Best Wishes

Jade.

01 June 15:

Hi

My brother refuses to face the fact that I had cancer and also tries to ignore my long-term side effects! He saw me after the first op but kept away for most of my treatment as he found it hard to cope with. He now puts everything down to age and considers me fit and well, he won't listen to anything else and changes the subject if mum or I say I am struggling at all. He is a total ostrich!

Mother initially fretted when I returned home and still phones me in the morning and evening to make sure I am ok. Because of the hernia repairs I have to be careful lifting anything and she insists on carrying things for me. As regards my PN she worries about the stairs to my flat, insists I phone to say I

am home ok when I have been out (even if I go to her house which is about 1/4 mile away). She worries constantly.

Other family and friends don't see me very often and I don't say anything about my problems so they mainly think I am fine now. My friends close by sometimes get a bit impatient when I am walking slowly, needing a rest or obviously in pain. Sometimes I think they consider that I am playing for sympathy as 'we all have problems' as one put it! And sometimes friends get a bit cross when I have to cancel something - my best friend is brilliant though, he is supportive and undemanding. When I am having a particularly bad time he usually sends me a card or a text saying how proud he is of how I keep going which helps.

Part of the problem is that I don't talk about my problems much as people don't really want to know. I just clench my teeth and smile....

Another effect is that when I go for my blood tests every 3 months Mum always feels sick with anxiety for a few days before I get the results. When I had a lump investigated recently she was panicking, then she likes me to stay at her house so she can keep an eye on me. Slowly she is learning to let go a little, but the slightest setback and she is back to square one!

Kirsty

Sent from my iPad

03 June 15:

Hi Kirsty,

Thank you so much for that very detailed response, although I must say I have never heard anyone being called an ostrich before so that is a new one for me to use.

It is nice to see that your mother worries about you, do you find this helpful or do you sometimes feel in some instances it can make you feel/worry worse?

Your best friend sounds amazing, it is really nice to see you have some good support even though not everyone understands.

How would you like your friends to be with you in instances as you have mentioned, do you think if you told them more about your problems they would understand more and be more supportive?

Best Wishes

Jade.

03 June 15:

Hi Jade

I find it intrusive and irritating sometimes that mother fusses so much, I understand her concern but feel like reminding her that they took my reproductive system out - not my brain! I know what I can/can't manage and resent being told...

I think if I told my friends how bad I feel sometimes that they would back off - people often don't want to hear about the negatives or be reminded of their own mortality. I want my friends to be pleased to see me rather than avoid me! Oddly, if they ask about my treatment they often react as though they may throw up when you tell them, so why ask!

I think that it is rather like a bereavement in that initially everyone rallies round and is supportive but after a few months (and just when you need it most) they think you are over it and the support goes. Like with bereavement you are numb at first (and concentrating on fighting the cancer) and realisation comes much later but by then you are pretty much alone with it. The Macmillan advert saying 'no one should face cancer alone' shows that even the 'experts' don't really understand (cancer and life after cancer would be better!)

Kirsty

05 June 15:

Hi Kirsty,

Yes I think that I would feel the same way too.

I can also see how frustrating your situation is with your friends as it seems you cannot win either way.

Your comparison to bereavement is very interesting and helpful as it enables me to understand your situation a little more and I will try and pitch the idea to

macmillan about their advert as I bet you are right and they have unintentionally not considered life after cancer as much as they should have.

I hope you have a brilliant weekend and I will speak to you on Monday with the next question.

Best Wishes

Jade.

08 June 15:

Hi,

I hope you had a good weekend!

I know we have spoke about your close family and friends but could you now please explain to me how you feel others (colleagues/ acquaintances) view/treat you in regards to your experienced long term consequences?

Best Wishes

Jade.

08 June 15:

Hi Jade

Colleagues not so good - they made a determined (and successful) effort to remove me from my post when I was struggling before the cancer diagnosis as they thought I was suddenly being slow and lazy! If they couldn't show sympathy or support when I was suffering from and subsequently diagnosed with cancer (that's when they actually got rid of me) then I very much doubt I would have fared better with the permanent side effects!

Other people can be interesting. I go to the gym several times a week when I am able, the instructors are superb and very supportive. Other gym members can be judgemental - I have very little leg lift and have to crawl on and off some pieces of equipment which raises eyebrows! It doesn't occur to them that there may be a reason and I have people glaring or sniggering at my strange approach. Some when they know why make a huge effort to ignore me or look away, but some become encouraging.

Casual acquaintances don't usually comment but sometimes I see the exasperation when I am walking slowly or can't get up onto something. It is amazing how judgemental people can be when they don't know the facts!

Kirsty

08 June 15:

Hi Kirsty,

I completely agree on your comment about people being judgemental without knowing facts it is saddening how naïve some people can be. How would you prefer these people to react/act in these instances? Would you rather they be upfront and talk to you?

Best Wishes

Jade.

08 June 15:

I would prefer them to look after their own affairs and leave me to mine!

People do seem to think they have the right to judge or comment on things that are no concern of theirs.... If I walk slowly, stumble, drop things, crawl onto exercise equipment etc. as long as my actions do not impact directly on someone I fail to see why it is anything they need to worry about or become involved with! The arrogance of mankind never ceases to amaze me ☐

If people feel the need to understand then yes, I would prefer them to ask but generally I just want to get on with things! I never mind highlighting the benefits of being aware of symptoms and getting diagnosed, along with saying how great the hospital have been with me so if asked anything I tend to discuss that rather than my issues.

08 June 15:

That is completely understandable and you are right it is nobody's business but your own. Thank you very much for being so honest in your replies. I will email you again on Monday with the next question and I hope you have a good week.

Best Wishes

Jade.

15 June 15:

Hi Kirsty,

Good morning, I hope you had a good weekend!

I know we may have slightly touched upon this in our previous emails but could you now please explain to me in as much detail as possible, your experience of support from organisations such as the NHS hospital staff, GP's, counsellors, support groups, e.t.c?

Best Wishes,

Jade

15 June 15:

Hi Jade

I had a good weekend thanks, hope you did too.

The hospital was fantastic. The two surgeons were brilliant and both were caring and supportive. They both did amazing work and the scars are so neat - which matters! I went through many sections at the hospital and was met with kindness and professionalism throughout. The support from my cancer specialist nurse has been, and still is, brilliant - she goes way beyond her duty and genuinely cares about us all. An unbearable, frightening time was made bearable by these incredible people and the support and care they have given me.

My GP has been good too, she is understanding and supportive but the system is poor. It is a minimum 3 week wait to see either a doctor or nurse if not an emergency and then you have 10 minutes.... hardly time to discuss problems!

There is little support out there other than the medical staff dealing with your illness. There is not much emotional support unless you can get to a centre [names a specific place]- a brilliant place but an hour on the bus each way plus a 30 minute walk each way is not something you can do during treatment! There is little support outside the main cities and most of the population don't live there....

So, a mixed bag - the support from those entrusted with my care had been exemplary but there has been no support from elsewhere. Therefore, the physical effects have been addressed but not the emotional issues.

Kirsty.

16 June 15:

Hi Kirsty,

That is incredibly interesting. I admit ten minutes is not a lot of time at all for a thorough assessment. So, if you were to recommend any suggestions in terms of support it would be to have more emotional support accessible around the different towns and cities?

Best Wishes

Jade.

16 June 15:

Yes, it is hard to even get out of bed during chemo and for months afterwards you have serious bouts of fatigue so you can't go anywhere unless it is close. People are not well enough to drive and can't manage on public transport (platinum based chemo means you have no immunity for the 6 months of treatment and it is compromised for a long time afterwards so there is a real risk of infections) so unless you live in a major city there is nothing. Outreach services would be good, or online conferencing maybe.... the support groups on Facebook are very good but sometimes you need more, even if it is just reassurance that you're not crazy!

Ideally I think a network of people who have experienced cancer who could mentor new patients would be good, or locally arranged support meetings.

Kirsty

18 June 15:

Good Afternoon,

Hope you are having a good week!

Thank you very much for your response to that follow up question, it is very enlightening and I will keep your suggestions in mind throughout my research. I hope you enjoy the rest of your week and I will email you on Monday with the last main question.

Best Wishes

Jade.

22 June 15:

Good afternoon Kirsty,

I hope the weather is not as bad where you live as it is where I live.

I have two questions for you to conclude our email interview, these are:

- 1) Could you please explain to me if and how your pre cancer self, differs to your post cancer self?
- 2) What made you join cancer voices and what have you got out of the support group?

I understand I am asking for a lot from you this week with me asking two questions, so please take your time.

I look forward to your response.

Best Wishes

Jade.

22 June 15:

Hi Jade

No, the weather is vile here! Lots of heavy showers and a cold wind - so much for summer ☐

I will answer in 2 parts if that is ok. First part about how I am different now...

There are obviously physical differences such as scarring, adhesions, internal scar tissue etc which all make me less mobile than I was before. I need more rest, feel nauseous quite often, plus of course the hearing loss and the chemo induced peripheral neuropathy. My spatial awareness and concentration have suffered too.

There have also been emotional changes. I am less confident than I was, I travel less and am wary of going too far from home in case I feel unwell. I am more aware of the fragility of life but at the same time I seem to have developed a 'who cares' attitude. I am less patient and less tolerant, I think it has made me more selfish in ways such as I have discarded people from my life who I didn't really like or who I found tedious... I find I can't be bothered with trivialities or small talk now. Most of all, I have an attitude of nothing matters in the grand scheme of things - whatever we do in life, however successful we are or how much money we make we still die!

I suppose I have gained in having a more carefree attitude and I do all the things I want to do (which I would have put off before because of work etc), but have lost in the fact that I am acutely aware of my own mortality and that of those I care about. I am definitely a very different person post cancer!

Regards

Kirsty

22 June 15:

Hi Jade

The 2nd part of the question.

I joined Cancer Voices for two reasons. Firstly, I wanted to interact with others who had been through similar experiences, and I wanted to offer support to others. As you will have gathered over the weeks we have been communicating one of my bugbears is the lack of emotional support for patients and their carers. I wanted to see what was 'out there' and found cancer voices.

The second reason was that I wanted to help inform people about cancer, about the symptoms of (in my case) ovarian cancer. But mostly to tell people not to be afraid, to see their doctor as soon as they have a concern and that it is no longer an automatic death sentence - there is hope! I also wanted to tell the 'experts' that actually the true experts are the cancer voices.... and they need to listen.

Regards

Kirsty

28 June 15:

Hi Kirsty,

Sorry for my late response I was admitted to hospital on Tuesday morning and am still in now and only just fit enough to use my laptop.

Thank you very much for answering those questions, your responses are very helpful. You say you joined cancer voices to see what is out there, was you happy with the emotional support you have received from the support group?

I do agree with you that the true experts are the members of cancer voices and that is why I thought it vital I speak to individuals such as yourself to gather my information.

Best Wishes

Jade.

28 June 15:

Hi Jade

I am sorry to learn that you are unwell and hope you soon recover.

I have found cancer voices useful in allowing me to help people in their research, also I review books for them which I enjoy. I haven't found the forums etc to be as useful though. When I was first diagnosed and throughout treatment they were really helpful but I find them too disjointed now. There is a lot of help within the cancer network for 'newbies' but again not so much for those in remission or living with cancer.

Take care of yourself.

Regards

Kirsty

29 June 15:

Hi Kirsty,

Thank you very much for your response, I think you have given me all the detail I was hoping for and so, this concludes our email interview. Thank you so much for taking part in my research I greatly appreciate it. If you have any questions or queries regarding the data/research please do not hesitate to email me.

Best Wishes and all the luck in the future,

Jade.

29 June 15:

Thanks Jade. I have enjoyed the experience and found it quite therapeutic having to think about the questions and how I felt about things - so thank you too!

Take care and I hope your research progresses well. I also wish you a speedy return to health

Kirsty

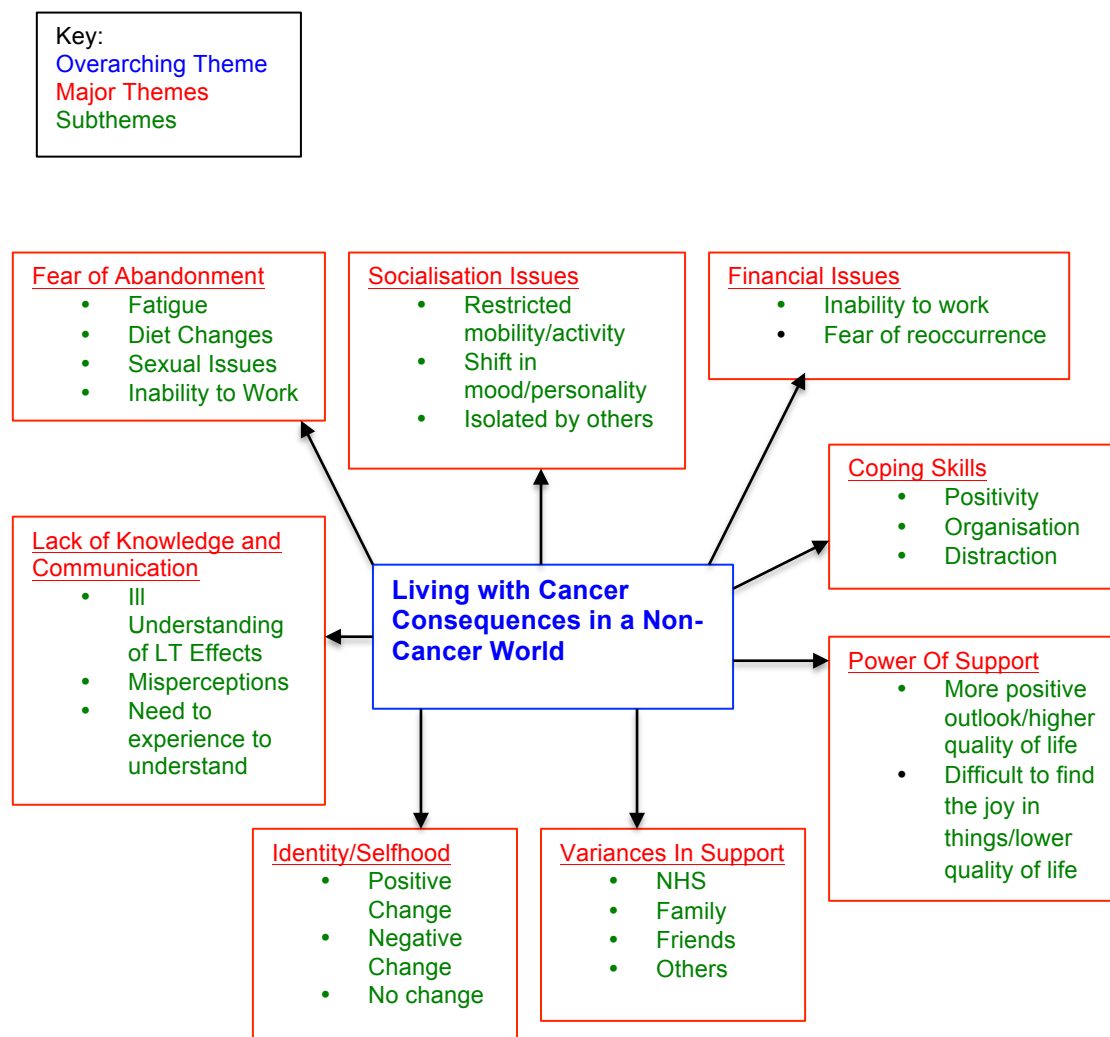
02 July 15:

I am feeling much better now thank you. I am extremely glad that you have enjoyed our interaction, it makes the experience all the more enjoyable for me. If you have any questions or queries in the future do not hesitate to contact me.

Best Wishes

Jade.

Appendix 9 – The initial template within the Template Analysis for the main study



Appendix 10 – An example of a pronoun list created within reading three of the Listening Guide

Jane

I got my five year all clear in February
I still have almost constant headaches and migraines
I also suffer from fatigue to a great extent
Prior to cancer I was very active
Now if I do too much it can put me back a couple of weeks
This recently happened when I was counseling for two hours and also had
visitors arriving
I had to take time off from my counseling as a result
Its taken three weeks to get back to the energy level I was at
I cant do anything stressful or that I don't enjoy without it having a very
negative effect on my energy levels
I really have to ration my energy levels now which is frustrating
I also find the isolation I feel difficult
I lost virtually all my friends
I was given five weeks to live at first and I think people found it hard to deal
with
Im so grateful to be alive and recognize how lucky I am
Trying to get my life back to where it was is difficult though and the isolation I
feel is hard
The fact I cant exercise the way I used to is really irritating and I find it very
frustrating
I try to make sure I walk for twenty minutes if im well enough every day
I qualified as a psychotherapist in December last year and learning how to
counsel other people has actually helped me come to terms more
It takes a lot to worry me or get me down since I had that experience
I think our relationship has improved since my cancer
My mum has, I feel, changed since my cancer

I do feel now that my cancer can be discussed
I would never be able to confide in him
Some people don't seem to believe that I can really still be so fatigued
I do get the impression at times that people think I'm putting it on
Theres a definite inhalation of breath from people if I mention I've had cancer
I now only tell people if I really have to
The other thing I hate is being told how 'brave' I am!
I had no choice in what happened to me I don't feel I did anything remotely
brave
I think the overwhelming thing is how people really don't know how to react to
cancer
I rarely discuss it with people nowadays anyway because I want to move on
from being a cancer patient
I don't see myself as a survivor
I want to just see me as me
I think emotionally there wasn't really an awful lot of support
Since my cancer I have a very strong sense of calm
I need to find ways to build up my life
I have really enjoyed talking to you it has allowed me to think about areas of
my experience that I may not always have considered
I enjoyed the questions as it made me think about everything that happened
in a different way

Appendix 11 – An example of the notes made on one participant's [Mary's] pronoun list when exploring how the word 'I' was used to create the resultant I-poem

<p>Present Tense</p> <p>- I am / I have / I wonder I do / I find / I read / I seem I think / I believe / I give I am / I suppose / I can I hope / I wish</p> <p>Positive</p>	<p>Thoughts & feelings</p> <p>- I wonder / I think / I believe I am / I should / I suppose I wish / I thought</p> <p><u>Case Study- Mary</u></p>	<p>Past Tense</p> <p>- I was / I did / I felt / I found / I had / I spent I thought / I told I wanted / I used to</p>
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I am not perspective about other peoples (or my own) feelings
 The diagnosis of breast cancer- no surprise once I felt the lump- left me
 dismayed and overwhelmed
 I was then angry
 I did not expect to feel like this
 I am currently only slightly anxious about the prospect of metastases
 I have quite a lot of sources of information
 I am trying to learn the details of this possible cell behavior
 I have gone from being interested in the physiology and pathology of the skin-
 as a dermatologist – to making an attempt to learn oncology
 What will you ask next I wonder it is good to write this sort of thing
 I do continue to read oncology, in particular about breast cancer but much
 less urgently than I used to
 I have a nearly 80% chance of being alive in 2 more years and a bit less than
 40% in 7 years.
 I find that knowing this information is helpful in trying to be reasonable and
 enjoying what I have got
 I am also somewhat distracted from my own health by health problems in the
 family
 I am spending quite a lot to be able to read the New England journal of
 medicine and JournalWatch- but that's my choice
 Some of the information I read is personally scary
 I seem to prefer to be informed, to hiding in the bushes without current
 information
 I think the reasonably effective advice is to embark on something you find
 interesting and so, keep busy
 I found his difficulty comforting in some way
 I felt he was supportive. He was also a great support through my treatment
 I am ungracious about his concerns
 I have shared very little of what I have learnt about breast cancer
 She knew from my phone calls and text messages I was suffering
 psychologically
 I had been helped by the HOPE course and she concluded that I was feeling
 better
 I believe your questions are helping me to have an insight into my own
 emotions and that is an excellent thing for me
 Whoever thought of your research and decided on interviews by email is
 somebody whom I owe a big thank you because the explanations that I give
 you keep on showing me interesting things to understand about myself
 I should think nearly all my friends don't want to know more
 I spent a lot of time at the beginning complaining about how bad my feelings
 felt
 This was a seriously taboo subject and still is I suppose in some cultures
 I did tell my immediate family, but cautiously
 I did not want to tell any but very close friends at the beginning
 Some people like flowers and cards and signs of good wishes but I found that
 I quite dreaded that

I do find that speaking about the fact of having cancer is quite difficult but I
wish to be reasonably open
I think this may be a form of face the facts
I find I don't want to rub in uncomfortable facts
I thought I was making a fuss and it was apparent the specialist nurse quite
kindly thought so too
I felt very upset for months that I had not had any form of chemotherapy
properly discussed with me
It isn't difficult to think of a better way to explain the lack of chemo than the
reply I had "It's not safe, you know"
I told my GP that I felt uncomfortably angry; she replied sympathetically
"You're allowed" but made no other suggestions.
I joined a local group run by a remarkable woman who had no personal
experience of cancer but had been a carer
I have not looked back
I don't know if we could have managed better at least without using up scarce
resources
I had identified a personal problem with anger that was obviously not going to
disappear in one more session
If I wanted to continue I would need to find another counselor
I have not done this
I don't know if we could have all done better with a little extra time or if that is
an unrealistic idea
I now think that the brief experience of something very similar to how groups
therapy is described marked the turning point for me
I did take part in the HOPE course about a year after diagnosis and found it
very helpful indeed
I can now agree with the many people who, although they found that a
diagnosis of cancer was devastating experience, write that their experience
has its good side
My pre-cancer self differs I hope quite a lot to my post-cancer self
Previously I had not thought about how little insight I have into my own
feelings