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**Lived Experiences of Registered Learning
Disability Nurses and Palliative Care
Professionals in Caring for People with
Communication Difficulties and a Learning
Disability Experiencing Distress in Palliative
Care Settings: A Hermeneutic
Phenomenological Study**

SALLY KETCHEN ARREY

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

University of Huddersfield

September 2014

Dedications

To my dad (Jonas Arrey) and my mum (Margaret Arrey) for their encouragement and selfless love and faith in me.

To God be the Glory

Copyright statement

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Abstract

Learning disability (LD) affects around 2.5% of the population in the United Kingdom. Yet, the phenomenon of caring for people with communication difficulties and a learning disability (PCDL) experiencing distress within palliative care settings is not fully understood.

This study aims to gain an in-depth phenomenological understanding of how Registered Learning Disability Nurses (RNLDs) and Palliative Care Professionals (PCPs) identify and respond to the distress of PCDL in palliative care settings.

The objectives are: (a) to critically explore the lived experiences of RNLDs and PCPs who care for PCDL experiencing distress in palliative care settings; and (b) to critically explore factors which determine how PCDL express distress in palliative care settings.

Hermeneutic phenomenological methodology incorporating a constructivist perspective was followed. Purposive sampling was used to capture professional and demographic attributes from LD nursing homes, community LD teams, and hospices. Thirteen participants consisting of eight RNLDs and five PCPs were interviewed.

Data was collected by semi-structured, audio-recorded interviews, field-notes, and demographic questionnaires. Data analysis was thematic following Van Manen. Ethical approval was gained from the university Research Ethics Panel and from individual research locations.

The findings indicated that Knowing by building relationships; Positivity in successful caring outcomes; Humane care; Moral duty of care; Time to care; Comfortable care environment; and Future perspectives encapsulate the primary strategies used to identify and respond to the distress of PCDL. An essence statement portrayed the understood meaning of the fundamental nature of participants' experiences of caring for PCDL. The essence statement also informed both the development of a 'New Theoretical Model of Palliative and End-of-care for PCDL within Palliative Care Settings', and a prototype 'Checklist to enable social and healthcare professionals to self-evaluate their personal professional practice and the holism of care provided to PCDL in palliative care settings'.

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The Author

I studied at the University of Bradford for both undergraduate and postgraduate Nursing, and in 2009, was awarded an MSc in Nursing, which incorporated a Postgraduate Diploma in Health Professional Education. Prior to enrolling for Nursing, I studied Literature at undergraduate and postgraduate levels at the University of Yaounde Cameroon, and was awarded a Bachelors of Arts Degree in English Literature and Postgraduate Diploma in English Literary studies.

Chapter One: Introduction

The title of this thesis is '*Lived experiences of Registered Learning Disability Nurses and Palliative Care Professionals in caring for People with Communication Difficulties and a Learning Disability experiencing distress in palliative care settings: A Hermeneutic Phenomenological Study*'.

The thesis is an in-depth phenomenological study guided by Van Manen's (1990, p.28) hermeneutic phenomenology "*in pursuit of knowledge*". It is based on the lived experiences of Registered Learning Disability Nurses (RNLDs) and Palliative Care Professionals (PCPs) who had or are still caring for people with communication difficulties and a learning disability (PCDL) experiencing distress in palliative care settings. The term 'people' as used in this thesis encapsulates other terminologies, which are generally used to address this population such as clients or service users. The term 'people' is symbolic of the government's emphasis on valuing this population with the view that they should be considered, irrespective of their physical disabilities and genetic conditions, as citizens too with the need for legal and civil rights, independence, choice, and social inclusion (Department of Health (DH), 2001a, 2009).

Chapter one is composed of eight sections. Section one presents the research question for this study. Section two explicates the aim and objectives. Section three describes the statement of the problem of the phenomenon of caring for PCDLD experiencing distress in palliative care settings. It provides the extent of the palliative care problem faced by PCDLD in relation to the health problems and life-limiting conditions that people with learning disabilities (PLDs) suffer from. This is also in relation to the demographical character of PLDs and recent government initiatives to promote palliative care policy and practice for this population in the United Kingdom (UK). Section four delineates the rationale for the study. This details the background that inspired my interest in the phenomenon under study, in terms of my personal experience and a brief summary of the critical review of existing literature. Section five provides the relevance of the study. Section six consists of the contextual definitions that will be used in the study. These include definitions of PLDs, communication difficulties, distress, lived experience, palliative care settings, PCPs, RNLDs, learning disability nursing, palliative care, and End-of-life care. Section seven encompasses the overview of the different chapters of this thesis and section eight provides the chapter summary.

1.1 The research question

The research question, aim and objectives were determined by careful critique and analysis of background literature to the study, which focused upon those who care for PCDLD experiencing distress in palliative care settings. This resulted in the question:

What is the experience of being a Registered Learning Disability Nurse (RNLD) or a Palliative Care Professional (PCP) caring for an individual with communication difficulties and a learning disability experiencing distress within a palliative care setting?

1.2 Aim and objectives

The aim of the study was to gain an in-depth phenomenological understanding of how RNLDs and PCPs identify and respond to the distress of PCDLD in palliative care settings.

The objectives were:

(a) To critically explore the lived experiences of RNLDs and PCPs who care for distressed PCDLD in palliative care settings.

(b) To critically explore the perceptions of RNLDs and PCPs about factors which determine how PCDLD express distress in palliative care settings.

1.3 Statement of the problem

There is increasing recognition of the need for palliative care to be accessible to a wider-patient group other than cancer and the promotion of holistic and quality care as an important goal of care for people with learning disabilities (PLDs) and palliative care needs (DH, 2003, 2006; National Council for Hospice and Specialist Palliative Care Services, 2005; National Council for Palliative Care, 2006; National End of Life Care Programme, 2006; World Health Organisation (WHO), 1998). However, despite the recognized importance of the need of accessibility to palliative and quality care by PLDs, the phenomenon of caring for distressed people with communication difficulties and a learning disability (PCDLD) in palliative care settings is not fully understood and remains fraught with many problems. Many of these problems are related to the interdependency of healthcare bureaucracy and cultures operating within organisations, and mostly, concerns about healthcare staff's abilities to identify the palliative care needs and distress of individuals they care for predominantly, when challenged by their

communication difficulties (Brown, MacArthur and Gibbs, 2005; Evans, Beattie, Sloane, and Hurley, 2012; Gibbs 2002; Regnard, Mathews, Gibson and Clarke, 2003).

It is also recognized that PLDs suffer from many health problems and life-limiting conditions such as cardio vascular disease, respiratory diseases and swallowing problems (Dysphagia) (Evans et al., 2012; Hogg and Tuffrey-Wijne, 2008). They also suffer from the class one carcinogen helicobacter pylori, which is linked to stomach cancers, gastric ulcers, and lymphoma, and has been shown to have a high prevalence in PLDs, especially those with Down's syndrome because of their genetic disorder (Evans et al., 2012; Hogg and Tuffrey-Wijne, 2008). Nevertheless, there is a considerable improvement in the life expectancy of PLDs due to advances in medical and social care, advocacy and self-advocacy, and the support of enriching lives (McCarron and McCallion, 2007). It has been acknowledged that the relative risk of death is high for PLDs under thirty years but beyond that it approximates the normal population (DH, 2001a). There is a likelihood that PLDs who survive into early adulthood, may live into old age. The death rate for PLDs only begins to show a steep climb after the age of sixty-five years (DH, 2001a). Increased longevity has implications for carers and services (DH, 2001a). As PLDs live longer, they are likely to die over a longer period of time and are likely to experience the effect of aging including increased risk of developing cancer, and other life-limiting conditions such as dementia (Alzheimer's Society 2008; Dowrick and Southern, 2014; Lakey, Chandaria, Quince, Kane and Saunders, 2012; Mohan, Bennett and Carpenter, 2009). Moreover, dementia has associated symptoms such as distress resulting from memory loss, mood changes and depression, and problems with communication and reasoning (Lakey et al., 2012). The increased risk of developing Alzheimer's dementia (AD) especially for people with Down's syndrome has become an increasingly important issue (Alzheimer's Society, 2008; Mohan et al., 2009). In a report on end-of-life care (EoLC) helping people to a good death, Davis (2011) explained that due to their genetic conditions, PLDs are four times more likely than the general population to develop dementia. They are also more susceptible to develop a life-threatening disease five to ten years ahead of the general population and survive for a shorter time (Davis 2011), which is indicative of the need for palliative care to be accessible to this population. Furthermore, it has been recognized that there are 835,000 people living with dementia in the UK in 2014, and by 2015 that figure will be 850,000 (Dowrick and Southern, 2014). This indicates that dementia is a significant clinical concept that needs to be extensively researched by care and research communities in order to ensure optimum patient/client care.

From a demographical perspective, the prevalence of PLDs in the general population of the United Kingdom (UK) is expected to increase by approximately 1% annually for the

next ten years leading to a 10% growth by 2020 (Michael, 2008). However, accurate statistical details for this population remain problematic (Emerson et al., 2011). Recent data from Improving Health and Lives (IHAL) called: *People with Learning Disabilities in England* (Emerson et al., 2011), indicated that there are no definitive record of how many people there are with learning disabilities in England because of poor access to services and poor records. However, Emerson et al. (2011) estimated that there are 1.191,000 in total, comprising 286,000 children (0-17 years), and 905,000 adults (18 years and above), which equates to approximately 2.25 per cent of the population. Moreover, Emerson and Hatton (2004) highlighted that specialist services would be mostly aware of people with severe learning disabilities because they are registered with such services. Consequently, the majority of people, who had less severe learning disabilities, but may still have significant support and health needs, are likely not to be known by those services due to poor records (Emerson and Hatton, 2004). Arguably, such individuals may not receive timely and appropriate holistic care that includes palliative and end-of-life care (EoLC).

As a strategy to promote quality holistic care, the DH (2001a, 2001b, 2006, 2010) has emphasized the significance of putting PLDs at the heart of all nursing and healthcare interventions. This is through the incorporation of a person-centred care approach, which empowers the PLDs to make healthy choices about their lifestyles, and also enhances the involvement of their voices in their care and treatment. The Department of Health stated that:

It should never be assumed that people are not able to make their own decisions, simply because they have a learning disability (DH, 2001b, p.1).

Additionally, in 2010, the Department of Health set up an organisation called: *Improving Health and Lives: Learning Disability Observatory* (IHAL), aimed at providing knowledge and information to enable health and social care agencies to improve the health and general well-being of PLDs in England. IHAL was in response to Recommendation 5 in *Healthcare for All: Report of the independent inquiry into access to healthcare for people with learning disabilities* (Michael, 2008). Recommendation 5 of the report stated that:

To raise awareness in the health service to the risk of premature avoidable death, and to promote sustainable good practice in local assessment, management and evaluation of services, the Department of Health should establish a learning disabilities Public Health Observatory. This should be supplemented by a time-limited Confidential Inquiry into premature deaths in people with learning disabilities to provide evidence for clinical and professional staff of the extent of the problem and guidance on prevention (Michael, 2008, p.10).

This view is in line with the government White Paper, *Healthy Lives, Healthy People: Our Strategy for Public Health in England* (DH, 2010). The White Paper recognized the challenges in meeting patients' health needs, and also ways of empowering individuals to make healthy choices about their lifestyles, and incorporating the patient's voice in their own care and treatment within their local communities. However, I would argue that empowering people to make healthy choices and involving peoples' voices in all decisions relating to their care and treatments, can be problematic for distressed PCDLD requiring palliative care especially, when there is a lack of appropriate measures in place to ensure that their communication modes are taken into consideration (Mansell, 2010). This could be the case particularly when investigative procedures for diagnosis and treatment plans are intrusive and persistent and some PLDs may not understand the relevance, and withdraw their active cooperation, which may potentially delay timely and optimum care (Brown et al., 2005).

In view of these existing problems, which are closely related to the complex health needs and life-limiting conditions of PLDs and the ever-increasing population of terminally ill PLDs in England (Evans et al., 2012), it is vital to establish examples of good practice of care through empirical research. This could potentially improve access to quality supportive and specialist palliative care by people with learning disabilities (PLDs) in general, and in particular, distressed people with communication difficulties and a learning disability (PCDLD). Therefore, an imperative aspect of this study is to examine how RNLDs and PCPs identify and respond to the distress of PCDLD in palliative care settings and also, identify factors which determine how PCDLD communicate distress in palliative care settings.

1.4 Rationale for the study

The background to this hermeneutic phenomenological study is founded upon my personal experience as a RNLD and the critical review of relevant literature. My interest in caring for distressed PCDLD in palliative care settings was developed from working with adults with learning disabilities and complex health needs and the realisation that providing optimum palliative care to distressed PCDLD was inadequately addressed. In particular, I was affected by a personal experience of caring for a man with a life-limiting condition, in a community-based setting, who died unexpectedly. This man was forty-five years old with severe learning disabilities and profound communication difficulties. He was investigated for regurgitation, swallowing difficulties, irregularity in bowel movement, persistent weight loss, recurrent chest infection and possibly pain. The staff noted that he would insert his hand into his mouth almost to his wrist and make

groaning sounds throughout the day. Involvement of a multi-disciplinary health professional approach in his care eventually resulted in the identification of problems of secretion retention by the speech and language therapist, and pneumonia by the doctor and he received treatment for these. Medical advice was later sought for pain and possibly distress, however he was not perceived as distressed because the groaning sounds he made were not unusual for him. He was prescribed a daily dose of Paracetamol and no further treatment or investigation was considered for distress. His condition quickly deteriorated with significant weight loss, persistent diarrhoea and death. When he died, he was thought to have pneumonia and possibly bowel cancer. In this man's case, the important element was his inability to communicate his distress in a way that carers and staff could interpret. Despite the intention of quality care and support from the carers, he died with just mild analgesic prescribed for pain control and no intervention for other causes of distress such as psychological or spiritual factors. As a member of the staff team, I was left to query if this was due to misdiagnosis or our lack of confidence in our intuitive observational skills in identifying the distress signals from this man or PCDLD in general.

It is difficult to explain my immediate feelings after the man died. To say that I felt angry would be inadequate. This man had the right to a quality of life like any other human being except that his needs were sometimes not understood because of his inability to communicate in a socially acceptable way. I felt humbled by the experience, which portrayed not only my own ignorance at the time, but the general limitations or short comings of a healthcare system that was meant to have provided him with the all-inclusive, supportive, and specialist care that he required. Grant (1995) and Richardson (2002) suggest that services and resources are not seen as independent of one another but seen in a wider perspective, to generate more cost-effectiveness when putting forward new proposals to meet patients' needs. Upon reflection, I realised at the time that staff at the unit, including myself, had provided him with what we thought was the best possible care that our skills and knowledge base allowed but that had not been enough. It might be that we should have been more proactive in our care approach, especially in terms of articulating our clinical concerns to other healthcare professionals, which could have contributed more beneficially in the quality of person-centred care provided to this man.

My experience of providing care for this man alongside the critical review of existing literature, which is discussed in Chapter two of this thesis, reveals a scarcity of applicable and dependable research that could contribute knowledge to how RNLDs and PCPs identify and respond to the distress of PCDLD in palliative care settings. The literature indicated that distress, as a construct, has been confused with issues of

definition (Ridner, 2004). This definitional dilemma of distress extends to the applicability of the term, especially when used to describe that which is experienced by PCDLD in palliative care settings.

Although, Regnard et al.'s (2003) paper and Regnard et al.'s (2006) study emphasized that distress did not have a common meaning among carers and was not only related to pain, other existing literature rarely portrayed distress as a continuum or from a holistic perspective encompassing physiological, psycho-social or spiritual distress for PCDLD. Rather, distress is portrayed from disparate angles including physiological, psychological, and communication perspectives. For example, physiological perspective related to the experience of pain, (Donovan, 2002; Foley and McCutcheon, 2004; Hadjistavropoulos and Craig, 2002; Hadjistavropoulos, LaChapelle, Macleod, Sinder, and Craig, 2000; Hunt, Mastroiannopoulou, Goldman, and Seers, 2003; Manfredi, Breurer, Meier, and Libow, 2003). A secondly, psychological perspectives relating to emotional issues and grief (Conboy-Hill, 1992; Ryan et al, 2005; Summers and Witts, 2003). Finally, communication perspectives linked to communication difficulties (Black and Hyde, 2004; Cartlidge and Read, 2010; Todd, 2005; Tuffrey-Wijne and McEndhill, 2008; Whitehouse, Chamberlain and Tunna, 2000). Moreover, it would appear none of the literature identified was specifically focused on the meaning of the phenomenon of caring for people with communication difficulties and a learning disability (PCDLD), in terms of how RNLDs and PCPs identify and respond to their distress in palliative care settings and what they perceived as the fundamental nature of their experience of caring for this population.

Therefore, the current study takes the view that a problem exists in relation to the care of distressed PCDLD in palliative care settings particularly in terms of how RNLDs and PCPs identify and respond to their distress. Also, this study upholds the view that distress is a holistic concept because of the problems associated in defining or differentiating distinct facets of the term (Abelloff et al., 2000; Collins Thesaurus of the English Language, 2002; Newman, 1994; Ridner et al., 2004). In this study distress will be perceived in its entirety as an umbrella term, or a spectrum encompassing distinct concepts in terms of spiritual, physiological, and psycho-social distress factors. It is envisaged that this view will provide an in-depth understanding from a phenomenological perspective of the RNLDs' and PCPs' lived experiences of caring for this client group in palliative care settings.

1.5 Relevance of the study

It would appear that the extant literature (Black and Hyde, 2004; Cartlidge and Read, 2010; Conboy-Hill, 1992; Donovan, 2002; Foley and McCutcheon, 2004; Hadjistavropoulos and Craig, 2002; Hadjistavropoulos et al., 2000; Hunt et al., 2003; Manfredi et al., 2003; Regnard et al., 2006; Ryan et al., 2005; Summers and Witts, 2003; Todd, 2005; Tuffrey-Wijne and McEndhill, 2008; Whitehouse et al., 2000) were not specifically focused on the meaning of the phenomenon of caring for PCDLD in terms of how RNLDs and PCPs identify and respond to their distress in palliative care settings. Therefore, collating RNLDs and PCPs' experiences may add to the growing body of empirical knowledge for this population. It is anticipated that such knowledge may provide health and social care professionals with understanding about providing comfort and optimal care for this population. It may also provide insight into the essence or fundamental nature of the phenomenon of caring for them in palliative care settings, which may inform the creation of a model of palliative and end-of-life care (EoLC) for PCDLD experiencing distress in palliative care settings. Additionally, such knowledge could contribute to planned changes to policy, health and educational curriculum. It may also prove fundamental in the development of care approaches to meet the palliative and EoLC care needs of this population within the ever changing phase of palliative care.

1.6 Contextual Definitions

For purposes of clarity it is necessary to define certain terms that will be used in this study. Also, to ensure that the title of this study: *'Lived experiences of Registered Learning Disability Nurses and Palliative Care Professionals in caring for People with Communication Difficulties and a Learning Disability experiencing distress in palliative care settings: A Hermeneutic phenomenological study'* appropriately reflects the content, it is crucial to specify that 'learning disability' as encompassed in the title relates to any category of learning disability (mild, moderate, severe or profound) that an individual is diagnosed with.

1.6.1 People with learning disabilities:

The Department of Health's (2001a) definition of learning disabilities was adapted in this study to depict people with learning disabilities. Emerson and Heslop (2010), in their first publication of IHAL, entitled: *'A working definition of Learning Disabilities'*, acknowledged that a definition of learning disability could be drawn from the Department of Health which stated that: learning disability included the presence of:

A significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with a reduced ability to cope independently (impaired social functioning); which started before adulthood, with a lasting effect on development (DH, 2001a, p. 14).

In the UK the definition of LDs encapsulates significant limitation in intellectual functioning (intelligence quotient below 70), and significant limitations in adaptive behaviour as expressed in conceptual, practical and social skills, which originates before the age of 18, (Schalock et al., 2010). It affects around 2.5% of the population in the UK (DH, 2001a) with numbers expected to rise every year (Emerson and Hatton, 2008).

Learning disabilities (LDs) is an umbrella term, which covers different levels or degree of learning disabilities. Currently in the UK there are four categories of LDs namely: mild, moderate, severe and profound LDs (DH, 2001). A person with a mild learning disability (LD) has an IQ score that ranges from 50-70. The individual is often able to attain basic educational skills. Many are quite self-reliant in meeting their activities of living such as personal self-help skills. In some cases the person can live independently with support from a carer or a family (DH, 2001a).

A person with a moderate LD has an IQ score that ranges from 35-50. A person with a severe LD has an IQ score of about 20 to 34. The person may have very basic care skills and may have difficulty learning new skills. They may require help in everyday activities, lacking in social skills such as holding a conversation, and many have difficulty in understanding new or complex information. Some may have minimum speech or may not speak at all (DH, 2001a).

An individual with a profound LD has an IQ score of less than 20. They may have great difficulty communicating and rely on facial expressions, body language and behaviour to communicate. Some may use a small range of formal communication such as symbols, speech and signs (DH, 2001a).

1.6.2 Communication difficulties:

For people with learning disabilities (PLDs), communication difficulties could sometimes be genetically linked to their condition. However, for some people, communication difficulties could be acquired. Acquired communication difficulties in adults may be attributed to acquired physical difficulties, language impairment, cognitive impairment or a combination of all three (Beukleman and Garrett, 1998). In this study, communication difficulties are described in terms of problems associated with communication due to neurological impairments related to the genetic disorders of PLDs, and other neuro-degenerative diseases such as dementia for PLDs. As explained in section 1.6.1 above,

due to the nature of an individual's learning disability they may lack the ability to communicate verbally and non-verbally and also, lack the intellectual and social skills to communicate their needs or understand information (DH, 2001a). Difficulties in communicating could become even more problematic for PLDs when they develop dementia, which has related symptoms including memory loss and problems with communication and reasoning (Lakey et al., 2012).

1.6.3 Distress:

Distress is considered as a holistic concept in this study. This is because distress lacks a generic meaning as demonstrated by the predominant challenges associated with defining or differentiating the distinct components that embody this concept such as physiological, psycho-social and spiritual distress (Abelloff, 2004; Newman, 1994; Ridner, 2004). Hence, in this study, distress will be perceived in its entirety as an umbrella term, or a spectrum encompassing distinct concepts in terms of spiritual, physiological, and psycho-social distress factors. Anandarajah and Hight (2001) explain that spiritual distress and spiritual crisis occur when an individual is powerless to find sources of meaning, hope, love, peace, comfort, strength and connection in life or when conflict occurs between their beliefs and what is happening in their life. In the context of this study, spiritual distress is grief caused by the non-presence of cultural or religious activities or routine activities that individuals consider as essential in their lives. Physiological distress relates to pain. Psycho-social distress relates to emotional issues such as depression or grief that individuals might experience, which are directly linked to what is happening in their environment. It is envisaged that this view will provide an in-depth phenomenological understanding of the RNLDs' and PCPs' lived experiences of caring for PCDLD experiencing distress in palliative care settings.

1.6.4 Lived Experience:

In explicating the complexity of defining terminologies used in qualitative research or phenomenological inquiry, in a keynote address during the Third Nordic Interdisciplinary Conference on Qualitative Research, Van Manen stated that:

It is... naive to say that the qualitative researcher aims to describe 'what appears in consciousness', 'lived experience', 'the intentional object', or 'the things themselves'. All these notions begin to disintegrate when we ask what is really meant in them (Van Manen, 2006, p.715).

In this study, lived experience will be perceived as the human experience of being a learning disability nurse or a palliative care professional who had or is still caring for a distressed person with communication difficulties and a learning disability in a palliative care setting. The RNLDs' and PCPs' lived experiences include their experiences relating to how they identify and respond to the distress of PCDLD in palliative care settings, and also, their perceptions of the factors which determine how PCDLD communicate distress in palliative care settings.

1.6.5 Palliative Care Settings:

Within the context of this study, palliative care settings will be recognized as any setting where individuals are receiving any form of supportive or specialist palliative care treatment. The setting did not have to be a hospice or intensive care unit. It could be a community based nursing home, a private home, day services, a respite, a residential or supported living care setting where there are nurses and other professionals in attendance to meet a person's holistic need including dying and death.

1.6.6 Palliative care professionals:

In the context of this study Palliative Care Professionals (PCPs) comprised of clinical nurse specialists, a palliative care nurse, and palliative care social workers who are directly involved in the care of PCDLD experiencing distress in a palliative care setting.

1.6.7 Registered Learning Disability Nurses:

Registered Learning Disability Nurses (RNLDs) work for various statutory and independent agencies. They practice in a wide range of settings. These include nursing homes, independent living homes, residential care homes, supported living and family homes. RNLDs also practice in specialist settings such as community nursing, child health, mental health, forensic, treatment and assessment services and challenging behaviour units (Nursing and Midwifery Council (NMC), 2010). In the context of this study RNLDs included community learning disability matrons, nursing home managers, staff nurses and RNLDs with specialist training in older adults with dementia, epilepsy and health facilitation who are directly involved in the care of PCDLD experiencing distress in a palliative care setting.

1.6.8 Learning Disability Nursing:

In this study, the adapted working explanation of learning disability nursing was drawn from NMC (2010). Learning disability nursing encompasses care provided by RNLDs to people of all ages with a learning disability. It involves promoting individuals' autonomy, rights, choices and social inclusion in the healthcare system. Care is provided in person-centred ways, promoting individuals' strengths and abilities, championing their rights as equal citizens, optimising their health and promoting their safety. It entails the use of innovative ways of communicating with people with learning disabilities (PLDs) to promote health and educate them in healthy living strategies. Care provided include complex nursing needs, mental health problems such as dementia, and also supporting people in aspects such as hereditary, sexual health and pregnancy. The RNLDs work in inter-professional teams, often educating and supporting other health care workers and professionals, to care for PLDs.

1.6.9 Palliative care:

Palliative care has been mostly related to cancer or terminal care and has since evolved to include other terminologies such as supportive, specialist and general palliative care. Supportive care can sometimes include all services, both generalist and specialist that may be required to support people with life-threatening illness (National Council for Palliative Care, 2005). The National Council for Hospice and Specialist Palliative Care Services (1995) portrayed palliative care as the actual total care of patients whose disease is not responsive to curative treatment. Control of pain, nausea, fatigue and other physical symptoms, and psychological, social, and spiritual problems is paramount to the goal of achieving the best possible quality of life for the patients and their families. Also, palliative care can be given alongside other treatments and sometimes patients/clients whose illnesses can be cured may need palliative care (Sue Ryder Centre for Palliative Care, 2011). Furthermore, the WHO (1998) has described the goal of palliative care as the achievement of the best quality of life for patients and their families, consistent with their values, regardless of the location of the patient, by providing pain and symptom relief, spiritual and psychosocial support from diagnosis to end of life and bereavement.

For the purpose of this study, the adapted working definition of palliative care was drawn from the WHO (2008), which described palliative care as an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early

identification and impeccable assessment and treatment of pain and other physical, psychological and spiritual problems.

1.6.10 End-of-Life Care (EoLC):

EoLC in this study was understood as: "*palliative care when death is imminent*". (European Society of Medical Oncology, 2008 cited in O'Connor, 2008, p.8).

1.7 Overview of the chapters of the thesis

The purpose of Chapter one is to introduce the thesis. It locates this thesis as an in-depth hermeneutic phenomenological study based on the lived experiences of RNLDs and PCPs who had, or are, still caring for PCDLD experiencing distress in palliative care settings.

Chapter Two is the critical review of significant research literature. It identifies and appraises key research to date, which places the study in context in terms of identifying the gaps in research knowledge and practice. The chapter comprises four main sections. Firstly, an overview of the critical review process is provided. Secondly, a critical review of existing literature relating to the care of distressed PCDLD in palliative care settings is discussed. The critical review will demonstrate recognized good practice, ineffective practice or the paucity of knowledge relating to the care of this population in palliative care settings. The goal is to synthesize the current knowledge supporting the study, which will also inform the study's aim, objectives and research question. Thirdly, a summary and the significance of the study will be presented in terms of any research assumptions derived from the literature.

The focus of Chapter Three is to explain the methodology: Van Manen's (1990, p.28) hermeneutic phenomenology "*in pursuit of knowledge*", which underpinned this study guided by the research paradigm, epistemology and philosophical influences. It includes an overview of how phenomenology evolved into a recognized philosophical tradition and subsequently became a research methodology. Also, a rationale for locating the study within Van Manen's (1990) hermeneutic phenomenology is provided.

Chapter Four presents the overall design in terms of the procedural methods selected to address the research question, and the study's aim, and objectives. A detailed explanation of the study's setting, population, sampling, data collection methods and resources, data analysis, and ethical considerations are provided. The design is

completed with an elucidation of how Van Manen's (1990) six research activities were divided into related parts of this study to emphasize how data is synthesized and the structure of a hermeneutic phenomenological text.

In Chapter Five data analysis is discussed in terms of the isolation of findings or the sub themes and main themes. It includes three sections. First, the findings generated from utilizing steps one to four of the 'six steps data analysis process' (see Figure 5.1, p.95) are explicated. Lastly, a conclusion and chapter summary is provided.

Chapter six comprises of the critical interpretative account of the findings generated in this study. It includes steps five and six of the 'six steps data analysis process' (see Figure 5.1, p.95). The critical interpretative account integrates relevant prevailing research literature and theory. In particular, the theory of nursing as caring within the context of Watson's (1999, 2001) transpersonal caring relationships. It also, includes Boykin and Schoenhofer's (2001) nursing situation and the imagery of the Dance of Caring Persons.

Step five of the 'six steps data analysis process' (see Figure 5.1, p.95) is examined first. This is in relation to the wider significance of the identified and presented main themes (see Table 5.1, p.122) as essential structures of the participants' lived experiences within the framework of Van Manen's (1990) life-world existentials of spatiality (lived space), corporeality (lived body), temporality (lived time), and relationality (lived relationships or communality).

Second, step six of the 'six steps data analysis process' (see Figure 5.1, p.95) is addressed. This will necessitate that the essential themes are further examined. The intention is to identify the essence of the phenomenon of caring for distressed people with communication difficulties and a learning disability (PCDLD) in palliative care settings, from the perspective of the Registered Learning Disability Nurses (RNLDs) and Palliative Care Professionals (PCPs) who have lived the experience. It is envisaged that what will be identified as the fundamental nature of the phenomenon of caring for this population may inform the creation of a proposed model for palliative and EoLC for this client group. In both steps five and six of the data analysis process, the examination of the findings will include relevant research literature and theory. Finally, a chapter summary will be provided.

Chapter Seven presents the discussion of the strengths and limitations of this study. It consists of four sections. Firstly, the strengths and limitations of the study in terms of the selected methodology and methods, and reflections on the breadth and depth of the study are explicated. Secondly, the implications and recommendations to practice,

policy, education, and research are discussed. Thirdly, the plans for dissemination of the findings to learning disabilities and palliative care professionals, other health and social care professionals, and to practice and research communities in general will be explained. Finally, the chapter summary will be provided.

Chapter Eight is the final chapter of this study. It encompasses the final reflections and highlights the original contributions of the study to knowledge. It also provides a conclusion for the study.

1.8 Chapter summary

This introductory chapter has provided a brief background to the research area, the overall rationale, and relevance of the study to palliative care for PCDLD, and the contextual or operational definitions used in the study.

The following chapter presents a critical review of literature. It will identify, appraise, scrutinize and synthesize key research to date, with the goal of placing the study in context in terms of identifying the gaps in research knowledge and practice. It explicates how the synthesis of the current knowledge supporting the study, also informed the study's aim, objectives and research question.

Chapter Two: Literature Review

This chapter is a comprehensive critical review of the literature. It identifies and appraise key research to date, which places the study in context in terms of identifying the gaps in research knowledge and practice. The chapter is composed of four main sections. Firstly, an overview of the critical review process will be provided. Secondly, a critical review of existing research literature relating to the care of distressed people with communication difficulties and a learning disability (PCDL) in palliative care settings is discussed. The critical review will demonstrate recognized good practice, ineffective practice or the paucity of knowledge relating to the care of this population in palliative care settings. It synthesizes the current knowledge supporting the study, and illustrates how it informed the study's aim, objectives, and research question. Finally, a summary and the rationale for the study will be presented in terms of any research supposition derived from the literature.

2.1 Overview of the critical review process

A comprehensive critical review of literature was undertaken following a systematic approach to the review guided by the process outlined by the Centre for Reviews and Dissemination (CRD) University of York, (2008). The review of the literature encompassed the search for experiences of caring in relation to the problem of caring for PCDLD experiencing distress in palliative care settings as explained in Chapter One, Section 1.1 (see Appendix 1, pp.236-237) for a diagrammatical representation of an overview of the critical review process.

2.1.1 Search strategy

The review of the existing literature took into consideration the relevance to the search terms. The PIOC (population, intervention, outcome and comparison) framework (Richardson et al., 1995) was used to categorize the main keywords and concepts for searching the electronic databases. This was in order to demonstrate the transition from the general to the specific in terms of how the literature search and review would eventually inform the study's research question, aim, and objectives. The search question utilized was: 'What is known about RNLDs and PCPs experiences of caring for distressed people with communication difficulties and a learning disability in palliative care settings?' The search terms included 'people with learning disabilities', 'distress', 'learning disabilities', 'people with learning disabilities and palliative care', 'palliative care', 'communication difficulties', 'dementia', and 'end-of-life-care'.

The components of the PIOC framework relevant to the search terms were classified as follows: population referred to Registered Learning disability nurses (RNLDs) and Palliative Care Professionals (PCPs) or healthcare professionals caring for distressed PCDLD in palliative care settings. Intervention related to the care provided by RNLDs, PCPs or healthcare professionals to PCDLD experiencing distress in palliative care settings. Outcomes related to significant knowledge found in the reviewed literature. Comparison encompassed the relation or difference between existing knowledge of good practice and ineffective care, and the resultant implications to the care approaches used for PCDLD experiencing distress within palliative care settings.

2.1.2 Conduct of the search

The dates for the literature search ranged from 1988 to 2013, which intended to include seminal and relevant research literature on a narrow research topic. Suitable search terms as stated in Section 2.1.1 were used to access electronic databases such as Ovid; Cochrane Library; PubMed; Web of Knowledge; CINAHL; Science Direct; PsychINFO; Medline and also, the National Health Service (NHS) and Department of Health databases.

As a result of limited empirical research relating to the search question that could be attained from the aforementioned databases, the search was also widened to include credible websites (see Appendix 1, pp.236-237) for websites incorporated within the diagrammatical representation of the overview of the critical review process.

The University of Huddersfield's search engine 'Summon' was also used to add to the comprehensive and integrated search of print journal articles, E-journals, E-books, and government reports. Additionally, the search engine makes allowances for searches to be narrowed-down to the specific pertinent context. In this case, specifically in relation to the search for applicable subject material on people with learning disabilities, palliative care, learning disabilities, people with learning disabilities and palliative care, communication difficulties, dementia, distress, and end-of-life care (EoLC).

The university library general and subject indexes, abstracts and bibliographies, author and classification catalogues facilitated hand searching of specialist journals, and some textbooks on learning disabilities, and palliative care. The inclusion criteria were that:

- The literature had to be scholarly publications and peer-reviewed journal articles, book chapters or book reviews, and conference papers or records, which considered people with learning disabilities, people with learning disabilities and

palliative care, learning disabilities, palliative care, communication difficulties, distress, dementia, and EoLC.

- Also, the articles had to be written in the English language.

Articles were excluded if:

- They were not written in English or translated into English.
- Articles were also excluded if they were not relevant to the subject area or were judged to be of poor quality, and therefore incredible. Cormack's (2000) framework for critical analysis was used throughout to assess the retained articles (see Appendix 2, pp.238-240).

Additionally, different journals were regularly searched throughout the duration of this study for valid referred articles dealing with the key terms. The identified appropriate articles were read and critically analyzed (see Appendix 3, p.241).

Given the span of literature considered in the search, a large volume of literature was accessed. In an attempt to manage the volume of literature, the search was refined using both the literature inclusion criteria and the proposed framework for the hierarchy of evidence-based research (Guyatt et al., 1995; Polit and Beck, 2008; Sackett et al., 2000). The incorporation of the framework for hierarchy of evidence-based research also enhanced the credibility of this study (see Figures 2.1 and 2.2, p.32). This was in terms of searching attainable research relating to the subject area, which could be realistically classified within the higher graded theoretical levels of evidence-based research and also, progressively include significant literature from the middle and lower levels of the evidence-based hierarchy such as systematic reviews of descriptive, qualitative, and physiological studies; single descriptive, qualitative and physiological studies; opinions from authorities and expert committees (Polit and Beck, 2008), (see Figure 2.2, p.32). As an exception to how a traditional scientific approach would be implemented, research literature, which were not graded in the evidence-based hierarchy and are not original empirical studies such as a comment piece, position paper, and critical reviews that were of significance to the subject area were also read and critically analysed (Polit and Beck 2008).

Example 1 of Hierarchy of Evidence-based Research (Guyatt et al, 1998; Sackett et al, 2000):

Evidence-based research design	Hierarchy
Systematic reviews and meta-analysis	Level 1
Randomised Controlled Trials (RCT) with definitive results	Level 2
Randomised Controlled Trials with non-definitive results	Level 3
Cohort studies	Level 4
Case-Control Studies	Level 5
Cross Sectional Studies	Level 6

Figure 2.1 Examples of Hierarchy of Evidence-based Research applicable to all articles

Example 2 of Hierarchy of Evidence-based Research (Polit and Beck 2008):

Evidence-based research design	Hierarchy
Systematic reviews of randomised and non-randomised clinical trials	Level 1
Single randomised and non-randomised clinical trials	Level 2
Systematic review of correlational and observational studies	Level 3
Single correlational and observational studies	Level 4
Systematic reviews of descriptive, qualitative, and physiological studies	Level 5
Single descriptive, qualitative, and physiological studies	Level 6
Opinions from authorities and expert committees	Level 7

Figure 2.2 Examples of Hierarchy of Evidence-based Research applicable to all articles

Furthermore, irrelevant articles were discarded and relevant full individual papers were critically appraised.

2.1.3 Search results

The search strategy identified 372 articles, which seemed to comply with the search question and inclusion criteria. Two hundred and ninety-nine articles were excluded based on the language, title, and the content of the abstracts, which were not relevant to the search question. Seventy-three articles were retrieved and critically appraised. Subsequently, 52 articles were excluded based on reading the full text. Finally, 21 articles and a book chapter were included in the review.

2.1.4 Data extraction

Summary content of twenty-one relevant literature were tabulated in the quality assessment matrix which included the authors' names and titles of the studies, the aim, design, sample size, findings, and validity (see Appendix 4, pp.242-273). The Quality assessment matrix provided an overview of studies and papers specifically related to the subject area. Some of the retained literature also had relevance to distress, dementia, palliative, and EoLC for people with learning disabilities. As the research developed, additional literature was incorporated within the discussions to deepen understanding and analysis of the study's findings.

2.1.5 Data Synthesis

The twenty-one articles that were retained and critically analyzed included the following:

Table 2.1 Types of articles retained

Type of Articles	Authors' Details
Seven Critical reviews	Hadjistavropoulos and Craig (2002); Foley and McCutcheon (2004); Hogg and Tuffrey-Wijne (2008); Ryan et al. (2005); Tuffrey-Wijne and McEndhill (2008); Llewellyn (2011) and Regnard et al. (2003).
One Systematic review	Manfredi et al. (2003).
Four Case studies	Li and Ng (2008); Black and Hyde (2004); Porter, Ouvry, Morgan, and Downs (2001); and Summers and Witts (2004).
Three Mixed methods studies	Regnard et al. (2006); Cooper (1997); and Hadjistavropoulos et al. (2000).
One Descriptive Phenomenological study	Donovan (2000).
One Pilot study	Whitehouse et al. (2000)
One Grounded theory study	Hunt et al. (2003).
One Qualitative study	Cartilidge and Read (2010).
One Position paper	Read (2005).
One Comment piece	Todd (2005).

Of the twenty-one articles reviewed, three studies: Donovan (2002); Li and NG (2008); and Regnard et al. (2006) were specifically related to the lived experiences of RNLDs in caring for people with learning disabilities (PLDs) who may be distressed or in pain. Eight articles: Donovan (2002); Foley and McCutcheon (2004); Hadjistavropoulos and Craig (2002); Hadjistavropoulos et al. (2000); Hunt et al. (2003); Manfredi et al. (2003); Regnard et al. (2003); and Regnard et al. (2006) all emphasized the difficulties in identifying distress in people with learning disabilities. The articles related to distress but most specifically from the perspective of pain. One case study, Summers and Witts (2003), and one critical review, Ryan et al. (2005), and a book chapter by Conboy-Hill (1992) were particularly related to psychological distress. This was in terms of psychological distress, which was experienced by PLDs or specific to cancer patients. Three case studies: Black and Hyde (2004); Todd (2005); Whitehouse et al. (2000); one qualitative study: Cartlidge and Read, (2010) and one critical review of literature, Tuffrey-Wijne and McEndhill (2008) emphasized that the communication difficulties of PLDs affected the expression of distress and thus had an impact on how professionals identified and responded to their distress.

All articles were chosen for their specific contribution to knowledge relating to the care of distressed PCDLD in palliative care settings. Some of the studies were based on the lived experiences of healthcare professionals and not necessarily the experiences of RNLDs or PCPs, and dealt with the care of patients and PLDs experiencing pain or distress from dementia, cancers and other life-limiting conditions. It was observed, at this stage, that more empirical research is needed especially in the area of palliative and EoLC received by this population.

2.2 Caring for distressed PCDLD in palliative care settings in the literature

Distress relating to PCDLD was mostly portrayed in the literature from the perspective of pain and also in association with some evidence of communication and psychological aspects of distress. For purposes of clarity, I provide an explanation of the content of the retained literature stating why they were selected. I also explain the focus of the papers and studies used in this review in terms of the specific aspect or perspective of distress that the author(s) alluded to as far as the care of PCDLD experiencing distress in palliative care settings was concerned.

2.2.1 Distress

In relation to human emotions, distress has been described as relating to physical or mental anguish or suffering (Newman, 1994). It also relates to extreme mental anguish and psychological suffering (Collins Thesaurus of the English Language, 2002). Distress has also been referred to as suffering, pain, worry, anxiety, torture, grief, misery, agony, sadness, discomfort, torment, sorrow, woe, anguish, heartache, affliction, desolation and wretchedness (Collins Thesaurus of the English Language, 2002).

Ridner (2004) emphasized that distress has been frequently used in nursing research to describe patient discomfort related to signs and symptoms of acute or chronic illness, pre or post-treatment anxiety or compromised status of foetuses or the respiratory system. Distress is also used by healthcare professionals in the context of physical, emotional, and spiritual conditions. For example, it has been recognized that symptom distress is used by oncology nurses to mean the degree of physical or mental upset caused by a specific symptom such as fatigue (Rhodes and Watson, 1987), and measures such as physical exercise have been known as safe, and practical intervention to minimise fatigue for cancer patients or those recovering from it (Kirshbaum, 2005). Additionally, Abeloff, Armitage, Lichter and Niederhuber (2000) proposed that in oncology nursing settings, distress can be perceived as a psychological concept. In this context psychological distress refers to the general concept of maladaptive psychological functioning in the face of stressful events (Abeloff et al., 2000). Furthermore, Heliker (1992) claimed that distress can also mean spiritual discomfort although the concept of spirituality and spiritual distress might be difficult to understand as the "*definition is dependent upon the perspective of the conceiver*" (Heliker, 1992, P.16).

2.2.2 Pain perspective of distress

Utilizing Cormack's (2000) framework for critical analysis, see (Appendix 2, pp.238-240), Regnard et al.'s (2006) mixed methods study entitled '*Understanding distress in people with severe communication difficulties: piloting and assessing DisDat*' was selected and critically analyzed because of the rigour in the presentation of the methods. This was in terms of the aims, sample population and findings, which had relevance to the search terms of my study and to the care of distressed PCDLD in palliative care settings. Furthermore, Regnard et al.'s (2006) mixed method study incorporated an abstract, which clearly outlined the purpose, methods, main findings, and conclusion of the study. Data collection and analysis methods were stated and the authors' literature reviews were up-to-date at the time when the study was done. Although limitations or

recommendations for future study were not clearly stated, the study incorporated ethical considerations in terms of participants' anonymity.

Mixed method studies are not high on the hierarchy of evidence ladder (Polit and Beck, 2008; Sackett et al., 2000) and the use of mixed methods in research studies have resulted in debate from researchers arguing that the two paradigms differ ontologically and epistemologically (Hussein, 2009; Thomas, 2003a). However, in exceptional cases mixed method studies can be critically analyzed if they have relevance to the phenomenon under study (Polit and Beck, 2008) and where the authors of the particular study demonstrate that mixed methods were used as a validity procedure to merge multiple and different sources of information to inform the categories or themes of the study (Cresswell, 2000, 2003; Thomas, 2003b). This was the case with Regnard et al.'s (2006) study.

Regnard et al.'s (2006) study aimed to pilot and assess the Disability Distress Assessment Tool (DisDAT), developed by a palliative care team working with people with learning disabilities (PLDs). DisDAT was used to record a range of signs and behaviours of when a person is content or distressed. DisDAT was piloted with a sample of 16 carers and 8 clients. It was assessed with 56 carers and 25 patients, most with severe communication difficulties. Interviews were conducted with 10 carers of 10 of the patients, who were also observed for distress cues during different activities. The study identified the following findings: (a) Distress did not have a common meaning amongst carers and was not only related to pain; (b) DisDAT could be used to identify a variety of distress cues but the cues were not specific to a particular cause; (c) the authors identified that there was no evidence that pain had specific behaviours or signs; (d) the pilot and assessment phases portrayed that distress was a valuable clinical construct; and (e) DisDAT was easy to use by carers and it mirrored patients' distress communication as recognized by carers, which provided carers with evidence for their instinctive observations (Regnard et al., 2006).

Regnard et al.'s (2006) findings have emphasized the difficulties in identifying distress experienced by people with learning disabilities (PLDs) in terms of pain, spiritual, or psycho-social distress. I argue that as a valuable clinical construct as delineated by Regnard et al. (2006), it is vital that more experimental studies are undertaken to address distress in particular, that which is experienced by PCDLD in palliative care settings through in-depth investigation of the lived experiences of RNLDs and PCPs. Hence, that is the focus of my study's inquiry.

More so, in a mixed method study entitled: '*Measuring movement exacerbated pain in cognitively impaired frail elders*' by Hadjistavropoulos et al. (2000), the sample size consisted of 58 frail elders comprising 28 males and 30 females with 28 of the participants having significant cognitive impairments. Hadjistavropoulos et al. (2000) examined the utility of both self-report and nonverbal measures of pain in frail elders experiencing exacerbations of chronic musculoskeletal pain. As an emphasis on pain and its measurement, they acknowledged that it was problematic to distinguish cues of pain from other sources of physical or emotional distress and using pain tools in people with severe communication difficulties was still hindered by the inability to guarantee that physical pain is being measured, rather than other causes of distress (Hadjistavropoulos et al., 2000). Also there was recognition that some categories and features can be used to identify pain such as guarding, bracing, grimacing, sighing, and rubbing (Hadjistavropoulos et al., 2000). However, they also explained that facial responses to pain differed as a function of the patients' cognitive status with those patients who are more cognitively impaired being more responsive (Hadjistavropoulos et al., 2000). Hadjistavropoulos et al. (2000) also examined the comparative usefulness of three different approaches, namely: objective assessments of facial reactions using the Facial Action Coding System, and observational assessment of reactions of the face as well as the entire body and self-reported pain using the coloured visual analogue scale.

Despite the argument that mixed methods studies combine two paradigms that differ ontologically and epistemologically (Thomas, 2003a) the increase in the popularity of mixed methods research (Cresswell and Plano Clark, 2007), which combine both quantitative and qualitative techniques is useful if it is intended to achieve a greater comprehensiveness than could be obtained by using either one on its own (O'Cathian et al., 2007). This was the case with Hadjistavropoulos et al.'s (2000) study. As a limitation of the study, Hadjistavropoulos et al. (2000) identified that some of the measures utilized would be unwieldy for use in clinical situation. However, they argued that these measures are suitable as outcome measures within the context of clinical trial methodology (Hadjistavropoulos et al., 2000). They concluded that investigations of pain in elders with cognitive impairment should employ varying types of assessment tools (Hadjistavropoulos et al., 2000). They recommended the need for future work that focuses on the development of simplified versions of these tools to use in clinical practice, and for the development and inclusion of nonverbal measures among those who attend to the needs of this population (Hadjistavropoulos et al., 2000).

From these findings, it would appear that there was little or no evidence that such observations can be transferable to other distressing situations especially for PCDLD in palliative care settings.

A systematic review of literature entitled '*Pain assessment in elderly patients with severe dementia*' by Manfredi et al. (2003) encompassed relevant issues relating to communication difficulties associated with neurological impairment and learning disabilities. In their findings, Manfredi et al. (2003) recognized that clinicians' observations of facial expressions and vocalization are a means of assessing the presence of pain. However, Manfredi et al. (2003) acknowledged that such observations do not demonstrate the intensity of the pain especially in patients unable to communicate verbally because of dementia. They concluded that most research studies dealing with distress have attempted to identify pain (Manfredi et al., 2003). Although some studies take the view that physical pain can be identified, they have mostly focused on children and adults undergoing painful procedures, or on patients who can self-report pain (Manfredi et al., 2003). This begs the question whether such evidence misrepresents those PCDLD whose distress might not necessarily be solely pain related and whose expression of distress is by 'alternative communication'. According to Glennen (1997) and Regnard et al. (2006) people with severe learning disabilities and communication difficulties can communicate using alternative communication such as non-verbal signs and behaviours.

A likely limitation of a systematic review is that the findings are not based on the author's original empirical inquiry. However, it has been acknowledged that the findings from systematic reviews may contribute significantly in the development of evidence-based practice (Johnson and Austin, 2008; Mullen et al., 2008; Trinder and Reynolds, 2000).

From these findings it would seem that there is a need for more empirical research studies specific to the distress experienced by PCDLD especially in palliative care settings. This is in terms of the distress that is comprised of physiological, spiritual, and psycho-social distress factors, particularly, given the recognition that within acute settings healthcare staff use assessment tools associated with the experience of physical pain rather than distress (Jones, 2003). Therefore, this study is specifically tailored to investigate lived experiences of RNLDs and PCPs who care for distressed PCDLD in palliative care settings. It is anticipated that it may provide in-depth evidence on current practices in the care of this client group, which could potentially contribute to planned changes in care approaches.

Also, in a critical review of literature comprising articles and case studies focused on detecting pain in people with an intellectual disability (ID) by emergency department nurses, Foley and McCutcheon (2004) accentuated that the assessment of pain in people with an ID is often a difficult task complicated by idiosyncratic reactions or vague descriptions. This is especially the case when the person with an ID is also unable to verbally communicate their discomfort (Foley and McCutcheon, 2004). They explained that in most cases it is unlikely that the emergency department nurse would have met the person with the ID as a result detecting pain by observing behaviour or using self-report measures is also improbable to succeed (Foley and McCutcheon 2004). Also, not knowing the person with ID can lead staff to make incorrect clinical judgements and decisions that could potentially result in poor patients' outcomes (Foley and McCutcheon, 2004). Foley and McCutcheon (2004) concluded that the assessment of pain remained vital to the role of the emergency department nurse in order to provide comfort and determine the presence of illness. However, they also concluded that the effectiveness of interpreting pain behaviour was dependent on an ability to recognize behaviour caused by pain. Regrettably the person with an intellectual disability (ID) may be vague about the location and nature of their pain, or if they cannot self-report, their behaviour may be idiosyncratic (Foley and McCutchoen, 2004).

The articles reviewed in Foley and McCutcheon's (2004) paper were current at the time the paper was written and a summary and introduction, which identified the problem of assessing pain in people with intellectual disability was provided. The strengths and limitations of the article were not provided. However, Foley and McCutcheon (2004) provided a conclusion recommending the conduct of research that would investigate what happens to people when they attend Emergency Departments, which could potentially determine the most effective method of pain assessment for this population. It would appear that, although this paper is based on a critical review of literature and not an empirical study, Foley and McCutcheon (2004) have provided pertinent knowledge relating to the care of people with ID by recognizing the problem of assessing pain in this population and the need for appropriate pain assessments measures to determine the presence of illness and provide comfort to this client group. This resonates with the need for promoting quality holistic care provided to people with learning disabilities (DH, 2001a, 2001b, 2006, 2010). Foley and McCutcheon's (2004) paper has attempted to identify distress, which was pain related. However, the focus of their paper was not on the experiences of care provided by RNLDs and PCPs to PCDLD experiencing distress in palliative care settings. Consequently, this emphasized the need to undertake more research in the area of palliative care provided to relieve the distress of this population within palliative care settings, especially because pain assessment tools used

in acute hospitals are perceived as not being responsive to the specific needs of people with learning disabilities (Davies and Evans, 2001).

Donovan's (2002) study entitled '*Learning disability nurses' experiences of being with clients who may be in pain*' was critically analyzed because of the concise and informative title; the clearly stated methodological approach and methods; and identified ethical considerations. Donovan's study (2002) included an up-to-date literature review at the time when the review was done, which identified that no research had been found relating to RNLDs' and pain recognition, although the ability of general nurses to recognize pain was well documented and indicated that they had problems in that area (Donovan, 2002). Donovan's (2002) study used a descriptive phenomenological approach, and focused on RNLDs' experiences of being with clients who may be in pain but cannot communicate their feelings verbally. Phenomenological approaches are deemed suitable for researching lived experiences (Moran, 2000; Munhall, 2007; Van Manen, 1990). The sample size comprised of eight RNLDs. Small sample sizes could be problematic in terms of generalization of the findings (Munhall, 2007; Silverman, 2010). However, the in-depth nature of Donovan's findings and discussions are in line with the view that small sample sizes are suitable where the researcher seeks to gain an in-depth understanding of the phenomenon under study (Munhall, 2007; Silverman, 2010). Additionally, due to the in-depth nature of phenomenological studies, small sample sizes are often more fitting (Munhall, 2007; Van Manen, 1990). A likely limitation of phenomenological studies is the inability of a researcher to explain the philosophical underpinnings, which have guided the selection of a specific phenomenological approach (Munhall, 2007; Van Manen, 1990). However, Donovan (2002) clearly positioned her study within descriptive phenomenology following Husserl and explained how bracketing, which is fundamental to Husserlian phenomenology was achieved in the study.

Donovan's (2002) findings identified five themes: (a) the importance of caring relationships with the clients, (b) recognizing changes in verbal and nonverbal behaviour, (c) searching for meaning in clients' behaviour, (d) negotiating with other health professionals and (e) sharing in the clients' feelings. Donovan (2002) emphasized that not perceiving pain for PLDs could lead to unnecessary suffering and long-term tissue damage, and may even be fatal. Donovan's (2002) study did not include recommendations. However, it encompassed implications for practice, which highlighted the role of the nurse as consisting of dealing with other health professionals, acting as advocates for clients in getting better services, and supporting the use of diagnostic tests such as X-rays and blood tests (Donovan, 2002). Donovan (2002) concluded that nurses greatly valued their relationship with their clients, which could be therapeutic. Donovan (2000) also explained that this client group used a wide range of both

conventional and non-conventional forms of verbal and non-verbal communication. However, to emphasize the difficulties in identifying pain in PLDs, Donovan (2002) claimed that functional speech usage by a person with learning disabilities cannot indicate that the client can self-report pain. Therefore, RNLDs have to negotiate on the client's behalf with other healthcare professionals (Donovan, 2002).

From these findings, I suggest that on the one hand, the study appears to have recognized issues related to the care of PLDs who may be in pain but conversely, the findings seem to point to the scarcity of literature in particular phenomenological studies, which relate to distress that encapsulates not just pain but also spiritual and psychosocial distress concepts. Therefore, it is crucial to effectively manage and treat pain and other aspects of distress experienced by PLDs (Hadjistavropoulos and Craig, 2002; Hadjistavropoulos et al., 2000). I propose that in order to ensure that such treatments are made accessible to this client group there is need for more evidence-based studies by professionals, in particular, RNLDs and PCPs directly involved in their care within palliative care settings, thus, this will be an essential thrust of my study.

Hunt et al.'s (2003), grounded theory study called '*Not knowing – the problem of pain in children with severe neurological impairment*' was selected for inclusion in the review because of the thoroughness in the presentation of the methods, in terms of the aim, sample size and findings, which had significance to distress particularly pain and its management in children with severe neurological impairment. Furthermore, Hunt et al.'s (2006) grounded theory study incorporated an abstract and introduction, which clearly acknowledged the problem under study. Ethical considerations and a conclusion were provided (see Appendix 2, pp.238-240). Hunt et al. (2004) identified a limitation to the study as the inherently uncertain and ambiguous nature of the territory and the knowledge that a child's experience can never be entirely captured.

It is recognized that the biggest barrier to the use of grounded theory is a researcher's lack of skills needed to effectively practice the approach, which might compromise the findings of a study (Cresswell, 2003; Thomas, 2003b). However, when the approach is effectively utilized it results to "*an interpretation of events that suits the particular conditions of those events...*" (Thomas, 2003b, p.10). This was the case with Hunt et al.'s (2003) study. The sample size comprised of twenty parents and twenty-six healthcare professionals. The study aimed to gain an understanding of the context in which pain occurs and of issues that could affect pain assessment and management in this group (Hunt et al., 2003). The study also aimed to explore the diagnostic and clinical decision-making processes used by parents and healthcare professionals in relation to pain in

children with severe to profound neurological impairment (Hunt et al., 2003). The main findings were that three forms of knowledge are needed for optimal pain assessment and management namely: knowing the child; familiarity with children with the same or similar conditions; and knowing the science (Hunt et al., 2003). Hunt et al. (2003) explained that differentiating cues of pain from other sources of physical or emotional distress can be difficult. Hunt et al. (2003) also recognized that to be able to effectively identify distress, professional carers are required to document signs and behaviours in both content and distressed situations, and should utilize clinical decisions to identify the cause. Hunt et al. (2003) concluded that pain relief can be compromised by systems of care that fragment rather than integrate care.

Whilst the focus of Hunt et al.'s (2003) study has been on the assessment and management of pain in children with severe neurological impairment, it however, had some relevance to the difficulties associated in differentiating signals of pain from other sources of distress for people with learning disabilities in general as elucidated by Regnard et al. (2006). Therefore, I propose that there is a need for more empirical research to be performed that deals with the care of PCDLD experiencing distress in palliative care settings because this population have higher health needs than the general population but they experience high levels of unmet and unrecognized health needs (Cooper et al., 2004; NHS, Health Scotland, 2004).

A critical review of literature by Hadjistavropoulos and Craig (2002) entitled '*A theoretical framework for understanding self-report and observational measures of pain: a communications model*' was also considered as important to distress, specifically pain. The aims of the paper were: to provide a rationale for the use of self-report and observational strategies using a Communications Model and to examine factors that govern the utility and validity of such strategies in the measurement of pain (Hadjistavropoulos and Craig, 2002). The findings indicated that automatic expressive behaviours are subject dependent upon higher mental processes and that observational measures can be used and have clinical utility as indices of pain when self-report is not available; for example in infants, young children, people with intellectual disabilities or brain damage, and seniors with dementia (Hadjistavropoulos and Craig, 2002). Observational measures are also useful when self-report is questioned and even when credible self-report is available (Hadjistavropoulos and Craig, 2002). The Communication Model proposed by Hadjistavropoulos and Craig (2002) took into account the role of various human developmental stages of pain experience and expression. The paper concluded that both observational and self-report measures are essential in the

assessment of pain because of the unique information that each type contributes (Hadjistavropoulos and Craig, 2002).

Although Hadjistavropoulos and Craig's (2000) paper was not an experimental study and not high on the hierarchy of evidence ladder (Polit and Beck, 2008; Sackett et al., 2000), the title is concise and informative and the abstract and introduction clearly identified the problem and aims. The authors also provided a definition of key terms such as self-report, unobtrusive observations, and observational strategies which enhanced lucidity. The conclusion provided recognized the limitation of the paper based on the fact that many of the propositions involved in the Communication Model of pain were based on an amalgamation of findings from extant literature (Hadjistavropoulos and Craig (2000). However, a recommendation for future research, which could help specify with greater precision the degree to which specific instruments rely on automatic versus higher mental processes (Hadjistavropoulos and Craig, 2002) was provided.

Based on this critical review by Hadjistavropoulos and Craig (2002), I suggest that the emphasis on the identification of pain both from the perspective of those who can self-report pain and through observations by professionals, could be indicative of the gap in knowledge related to empirical studies dealing with the management of distress that is not only pain related for people with learning disabilities (Regnard et al., 2006). Moreover, it has been acknowledged that if a person is presenting behaviours of distress whether psychological, emotional, or physical in origin, these are comparable and inseparable and warrant thorough investigation (Clark et al., 2003; Regnard et al., 2006).

In an article entitled '*Difficulties in identifying distress and its causes in people with severe communication difficulties*', Regnard et al. (2003) focused on communication problems linked to severe learning disability and dementia. The authors provided a discussion based on extant research literature and an experimental case study on a man with severe learning disability who was diagnosed with multiple liver metastases from an unknown primary cancer and treated with paracetamol. The article was selected for inclusion in the critical review because the succinct title and the content of the paper especially, the case study had relevance to my search question.

Regnard et al. (2003) explained that through the partnership working between a palliative care team and learning disability teams founded in 1999 at Northgate hospital in the North East of England, it was recognized that identifying distress and its causes for PLDs suffering from life-limiting illness through cancer, dementia or other conditions was

problematic for various reasons. This was because distress could be pain or psychosocial but it was determined by what an individual said it was. This has an implication for people with severe communication problems (Regnard et al., 2003). Additionally, Regnard et al. (2003) emphasized that in patients with severe communication problems, distress may present as reduction in activity, which could be interpreted as contentment or increase in activity, which could be interpreted as challenging behaviour. Also, Regnard et al. (2003) identified that there appears to be a language of distress, typically detected by patients' family and professional carers but professional carers' interpretations of distress were implicit rather than explicit (Regnard et al. 2003). From existing literature, Regnard et al. (2003) highlighted categories of features that have been used to identify pain or distress. For example, aggression, wincing, holding the head, and moaning as features to identify pain; and noisy breathing, absence of contentment, body tension, and increased body movement as features to identify distress (Regnard et al., 2003). They acknowledged that pattern recognition of distress cues for communicating patients had been used in palliative care since 1992; however, such pattern recognition has been challenging for people with communication problems. Regnard et al. (2003) concluded that distress in people with profound communication problems has been sparse; pain or distress scoring tools in this population is questionable because of a lack of evidence that any single cause of distress produces distinct signs. They recommend that it is important to document the context in which distress occurs and apply clinical decisions to identify the cause (Regnard et al., 2003).

This paper seemed to have provided important knowledge relating to identifying distress and its causes in people with communication problems. Regnard et al. (2003) explained that the case study was based on 'real life' and it was included in the paper to illustrate the type of situation that professionals may be faced with in practice. It is apparent from the content that this paper is a critical review of literature but the authors called the paper an 'article' and it is not clearly stated whether it is a critical or systematic review. The aim of the paper is not clearly stated under a sub-heading; although this is inferred by a statement in the content which states the 'focus' of the article. Also, there are no identified sub-headings for introduction, findings, and discussion.

2.2.3 Psychological perspective

In an existing paper based on a critical review of literature titled '*How to recognize and manage psychological distress in cancer patients*', Ryan et al. (2005) highlighted the need to recognize and manage psychological distress in cancer patients. Ryan et al. (2005) explained that distress is common in cancer patients but it is often unrecognized

and untreated. They claimed that anxiety and depression can mimic the physical symptoms of cancer treatments and consequently emotional distress may not be detected (Ryan et al., 2005). The paper identified some barriers to cancer patients expressing their psychological concerns such as patients normalising or somatising their feelings, and recommended strategies such as basic communication techniques to enable oncologists to recognize and manage the psychological distress of their patients (Ryan et al., 2005). The paper is focused on cancer patients in the general population thus, indicates the need for research and service communities to take into account psychosocial and spiritual aspects of distress in particular, for PCDLD in palliative care settings (DH, 2003, 2006; National Council for Palliative Care, 2005; National End of Life Care Programme, 2006). Furthermore, some existing literature has identified the scant recognition of psychological distress in terms of grief experienced by people with learning disabilities (PLDs). For example, in her book entitled *'Am I Allowed to Cry'* Oswin (1991) underlined that historically the recognition of, and the permission to grieve, have often been denied to PLDs. Oswin (1991) explained that professionals and family believed people with limited cognitive abilities also lacked the ability to grieve. Sometimes they are denied news of the loss of a relative on grounds that it will upset them (Oswin, 1991). Subsequently, when this book was republished in 2000, Oswin acknowledged that there was still poor support for individuals following personal loss or the death of a loved one.

Also, in a book chapter by Conboy-Hill (1992) called *'Grief, Loss and People with Learning Disabilities'*, Conboy-Hill (1992) suggested that a failure to identify the impact of loss on PLDs was a result of the need to believe that PLDs did not grieve and consequently, rationalizing the approaches used to care for them. This also meant that when their behaviour was recognized as difficult, which was perhaps related to psychological distress or complicated grief, the PLDs were either sedated or 'trained out of it', often without reference to the possibility of an emotional cause (Conboy-hill, 1992). Conboy-Hill (1992) described her experience of working in a learning disability institution with bereaved individuals and narrated how they were frequently diagnosed as having behavioural disorder. However, Conboy-Hill, (1992) explained that in reality many of the PLDs diagnosed as having behavioural issues had experienced multiple deaths in their ward, they had been told the deceased had 'gone away', and they had also been excluded from mourning rituals. Conboy-Hill (1992) also relayed how some PLDs were consigned to be in the hospital 'body gang': a group of people who operated only at night, removing deceased residents from the ward to the mortuary.

Conboy-Hill's (1992) focus is distress, in terms of grief experienced by PLDs as a result of death or loss. Arguably, there is little or no emphasis on the view that the experience

of grief might include more than just an understanding of death by the person with a learning disability as it could be related to distress (grief) at a lack of understanding of the changes taking place in an individual's body due to the progression of their disease trajectory in a palliative care setting. This is especially, because individuals have varied grieving patterns (Coop, 1998) and the involvement of PLDs in personal or any form of bereavement is either limited or non-existent (Read, 2006).

It has been acknowledged that greater flexibility might be required, in order to increase the evidence-base concerning psychological distress regarding bereaved individuals who have a learning disability. Northway (1998) in her reflections on engaging in participatory research, recognised that, it is not only communication issues that need to be addressed when undertaking investigations, but also, the scope of research studies may need to be adapted to maximise the level of participation with people with learning disabilities (PLDs). She proposed the use of qualitative research such as participatory research. Such flexibility would allow for both general and personal accounts of grief by PLDs, which could contribute towards increasing health and social care professionals' understanding of possible reactions to grief by PLDs, hence, enhancing the appropriateness of care provided.

For example, Summers and Witts (2003) used a case study approach, which demonstrated the flexibility of the investigators in terms of their inquiry into the '*Psychological intervention for people with learning disabilities who have experienced bereavement*'. Case studies are not in a position of prominence on the hierarchy of evidence ladder (Polit and Beck, 2008). Also the findings of cases studies may not be suitable for generalisation to a larger population because the focus is sometimes on a single individual or unit (Flyvbjerg, 2006; Stake, 2005). However, cases studies can be included in the critical analysis of the literature of a research study in exceptional cases, where the case study demonstrates that the phenomenon under study is in a complex and novel area and where the researcher seeks a rich holistic account of the phenomenon (Polit and Beck, 2008). Also, it has been argued that what we learn in a particular case can be transferred to similar situations (Roberts et al., 2004; Stake, 2005).

Summers and Witts (2003) examined the experience of a young woman with learning disability after the death of her father. The focus of their case study was distress, in terms of grief experienced by PLDs as a result of death or loss. Summers and Witts (2003) took into consideration current theoretical understandings of bereavement and loss, and described the assessment, formulation and psychological treatment of a woman with learning disabilities with close reference to these understandings. A

psychological intervention is described, which utilized both psycho-educational and psychodynamic approaches (Summers and Witts, 2003). Their case study portrayed that the woman was confused about the meaning of death because when informed about her father's death her comments varied between her dad being in hospital, in heaven, and unwell (Summers and Witts, 2003). She also talked about wanting to attend the dad's funeral, although, she had been informed it had already taken place. It emerged that the woman's existing family members had not allowed her to attend the funeral (Summers and Witts, 2003). Summers and Witts (2003) recognized that rather than case studies and descriptive studies there is still need for more quantitative or large-scale bereavement studies, in order to be able to generalise the findings.

Whilst Summers and Witts' (2003) study focused on the conceptualisation of psychological distress in relation to grief, the authors also pointed to the significance of distress as a clinical construct and this resonates with Regnard et al.'s (2003, 2006) view about the difficulties associated in differentiating sources of distress from other signals of pain for people with learning disabilities.

2.2.4 Communication perspective

One of the difficulties in identifying distress in people with learning disabilities who have severe communication difficulties has been related to the view that distress may present itself as withdrawal, silence, or a reduction in activity thus upholding the concept that suffering often results in loneliness and alienation from others (Younger, 1995). A case study by Porter et al. (2001) entitled: '*Interpreting the communication of people with profound and multiple learning difficulties*' was selected for inclusion in the critical review because the title and the content had relevance to my search terms. A likely limitation of a case study is that the small sample size affects generalization of the findings (Flyvbjerg, 2006). However, it has been argued that case studies use multiple approaches and are increasingly being used in practitioner research both in social work (Shaw and Gould, 2001) and nursing (Anthony and Jack, 2009). In this case study, Porter et al. (2001) emphasized that the difficulties in identifying the distress of this population was exacerbated due to the difficulties also faced by professional carers in interpreting the communication of people with profound and multiple learning difficulties, and in estimating the ability of adults with learning disabilities to communicate. Reduced activity in a person with a learning disability may be wrongly interpreted as contentment and increased activity may be misinterpreted by professional carers as challenging behaviour (Porter et al., 2001). In addition, Porter et al. (2001) emphasized that the recognition of a distress cue is intuitive rather than a conscious act and therefore

professional carers do not routinely document and monitor these cues. Also, even when attempts have been made to adapt the clinical decision making protocols for communicating patients with advanced cancer, as used in palliative care for people with severe communication difficulties, there is the likelihood of carers disagreeing about how to interpret the response of people with profound and multiple learning disabilities (PPMLDs) and the meaning of cues (Porter et al., 2001). This is especially because for many PPMLDs their behaviour may be idiosyncratic (Porter et al., 2001). Thus, Porter et al. (2001) concluded that more evidence-based reflections on practice could provide a vital aspect of validating communication concerns.

A pilot study by Whitehouse, Chamberlain, and Tunna (2000) entitled: '*Dementia in people with learning disability: preliminary study into care staff knowledge and attributions*' was critically analyzed. Pilot studies are not in a position of prominence on the hierarchy of evidence ladder (Polit and Beck, 2008). Furthermore, it is argued that pilot studies are likely to be "*under-discussed, underused and underreported*" (Prescott and Soeken, 1989, p.60) especially because full reports of pilot studies are rare in research literature (Van Teijlingen, Rennie, Hundley and Graham, 2001). However, it has been recognized that pilot studies could provide useful data in "*preparation for the major study*" (Polit et al., 2001, p.467) or they could be used by researchers for "*qualitative data collection and analysis on a relatively unexplored topic, using the results to design subsequent quantitative phase of the study*" (Tashakkori and Teddlie, 1998, p.47).

Whitehouse et al.'s (2000) pilot study was selected because the title is informative and the content had relevance to the search question and terms of the current study. Additionally, in line with Van Teijlingen, Rennie, Hudley and Graham's (2001) view on good pilot studies, rather than presenting just an aspect of the pilot study, Whitehouse et al. (2000) provided a well-structured and fully reported pilot study. Whitehouse et al. (2000) provided a summary and an introduction, which clearly stated the problem that exist in terms of lack of standardized assessments to identify changes in an individual's behaviour associated with the early onset of dementia. The aims, methods, settings, data collection methods and procedures, ethical considerations, results, and a discussion encompassing the limitation of the study and implications were provided. Also, I suggest that as trained counsellors the authors were knowledgeable in the subject area. Whitehouse et al.'s (2000) study had a reasonable sample size comprising of 21 members of care staff (key-workers) in residential homes for PLDs provided by Solihull healthcare NHS Trust, in the United Kingdom. A limitation was identified in relation to the sample size around issues with generalization (Whitehouse et al., 2000).

The study aimed to: (a) assess the level of knowledge concerning aging and dementia of staff working with older adults with learning disability; (b) explore the likelihood of staff pursuing an appropriate referral through the identification of signs commonly associated with dementia; and (c) assess the attributions staff give to behaviour changes commonly associated with dementia (Whitehouse et al., 2000). Whitehouse et al.'s (2000) study identified that staff have knowledge of aging at a comparable level to that of college students. Also, Forgetfulness was a sign staff would most expect to see if they believed someone had dementia. Change in behaviour ascribed to dementia was perceived by staff as uncontrollable and staff were pessimistic about being unable to change behaviour (Whitehouse et al., 2000). They emphasized that it is not just patients who have communication difficulties but also, professional carers have problems understanding their communication (Whitehouse et al., 2000). Some professional carers viewed changes in behaviour as part of the disease trajectory that was unlikely to change, thus suggesting that it is unlikely that such a change in behaviour will be investigated as one resulting from distress caused by dementia (Whitehouse et al., 2000).

It is apparent from the content that this was an experimental pilot study but Whitehouse et al. (2000) did not specify the specific type of pilot study. However, the authors provided implications of the study in terms of staff training needs and explained that as a result of this pilot study, they have developed and piloted a staff induction pack entitled '*Working with Older Adults with a Learning Disability*', which is designed to achieve this aim (Whitehouse et al., 2000). I suggest that the findings from Whitehouse et al.'s (2000) study had relevance to the recognized need to provide quality holistic care to people with learning disabilities (DH, 2001a, 2001b; 2006) and emphasized the need for palliative care to be accessible to this population (DH, 2003, 2006; National Council for Palliative Care, 2005; National End-of-Life Care program, 2006).

Issues relating to communication in End-of-Life Care (EoLC) for a dying person with a learning disability have also been identified in a comment piece by Todd (2005), which was based on his reflections about '*surprised endings and the dying of PLDs in residential services*'. Todd (2005) emphasized that despite the move towards people becoming more involved in the management of their own dying there was little evidence that PLDs had opportunities to talk about their dying because staff felt it would be too overwhelming for them. Besides, residential staff had little understanding of the palliative care support their clients required and due to past bad experiences with clients' hospitalisation were resistant to external support (Todd, 2005). As a result, there was no established communication link between the learning disability residential home staff and

the specialist palliative care professionals (Todd, 2005). Consequently it was unlikely that all the dying needs including distress of a person with a learning disability will be met. Todd (2005) concluded by emphasizing the need for joint working between learning disability and palliative care services.

Tuffrey-Wijne and McEndhill's (2008) critical review called: '*Communication difficulties and intellectual disability in end-of-life care*' was critically analyzed because of the rigour in the presentation of the findings and the general structure of the paper. This was in terms of the aims and findings, which had relevance to my search question, search terms and the care of PCDLD in palliative care settings. The paper also, included an abstract, which identified the problem of communication difficulties as an obstacle in providing effective palliative care to people with intellectual disability (ID). There is no introduction but the paper began with leading questions, which clearly identified the problem of communication difficulties and ID and could be inferred as a rationale for the paper. Tuffrey-Wijne and McEndhill's (2008) paper provided operational definition of terms, conclusion and implications for practice.

Tuffrey-Winje and McEndhill (2008) mapped the communication difficulties experienced by people with intellectual disabilities within a palliative care setting. Tuffrey-Winje and McEndhill (2008) based their paper on previous research dealing with their personal professional experiences in both palliative care and learning disabilities services. They recognized that communication problems resulting from two main sources can delay timely diagnosis and symptom assessment as well as the provision of psychological support to clients (Tuffrey-Wijne and McEndhill, 2008). The two main sources of communication problems explored by Tuffrey-Winje and McEndhill (2008) were: (1) The failure of professionals to communicate accurately in order to be understood by the clients and, (2) the reluctance of carers to disclose the truth for fear of upsetting the client or fear that the client will be unable to cope with information about their condition. Although Tuffrey-Wijne and McEndhill's (2008) paper has identified the communication difficulties experienced by PLDs and also, the difficulties staff faced in communicating with this population in palliative care settings, it would appear that there is still need for more empirical research relating to the holistic care of this client group in palliative care settings. This is in terms of empirical research from which health and social care professionals can draw in order to inform care provided to meet the increasing palliative care needs of this client group (DH, 2010). This is especially the case because it has been acknowledged that the idiosyncratic expressions of distress by PLDs may be wrongly attributed to their learning disabilities by acute hospital staff who lacked confidence and ability when communicating with this population (McConkey and

Truesdale, 2000) and this may have bearings on the outcome of care provided (Mencap, 2004).

Read's (2005) position paper called: '*Learning disabilities and palliative care: recognizing pitfalls and exploring potential*', portrayed the significance of communication as a key principle for all people receiving palliative care. Position papers are not included in the hierarchy of evidence ladder (Polit and Beck, 2008; Sackett et al., 2000). See (Figures 2.1 and 2.2, p.32). However, as an exception Read's (2005) position paper was critically analyzed because the aims and the findings were clearly stated and were considered to have significance to palliative care for people with learning disabilities in general. Moreover, the title is informative and indicates the content. The paper included an abstract, which identified the aim of the paper and mentioned a recommendation for practice development. An introduction is not stated under an identified heading albeit; the opening paragraph served this purpose. It defined learning disabilities and palliative care and indicated prevalence of learning disabilities in the UK and also the problems related to access to palliative care by PLDs (Read, 2005). At the time when the paper was published the literature included was current.

The aims of Read's (2005) paper were: (a) to introduce the recognized challenges (or pitfalls) inherent in providing high quality palliative care to people with learning disabilities; and, (b) to explore the future potential and possibilities in delivering appropriate palliative care to this vulnerable population (Read, 2005). The paper indicated four themes under challenges to providing palliative care as: (1) Poor health status of PLDs with a contributing factor being communication impairment, which meant poor diagnosis of symptoms and difficulties to treat; (2) Ambivalence and discrimination; (3) Difficulties in providing holistic care; and, (4) The challenge of the disability culture (Read, 2005). Read's (2005) paper also identified five themes under exploring the possibilities and potential namely: Practice development; Resources; Research, a route to good practice; Collaborative working, and Good practice initiatives (Read, 2005).

Read's (2005) paper included a conclusion and provided the following recommendations: The need for more research to deal with baseline statistical information such as a national database of the numbers and types of palliative conditions of PLDs. The inclusion of disadvantaged groups in the systems exploring existing palliative care services; regular audit and evaluation of good practice in palliative care services to accommodate the changes in palliative care and develop appropriate approaches for all people in need of palliative care (Read, 2005). It would appear that these recommendations are a reiteration of the increasing recognition of the need for palliative care to be accessible to a larger patient group other than cancer and especially for PLDs (DH, 2003; 2006; National End-of-Life Care program, 2006).

Cartlidge and Read's (2010) study entitled '*Exploring the needs of hospice staff supporting people with an intellectual disability: a UK perspective*' was critically analyzed because of the concise and informative title; the clearly stated methodological approach and methods; and identified ethical considerations. Cartlidge and Read's study (2010) included an up-to-date literature review at the time when the review was done, which identified that for certain groups in the society, accessing appropriate healthcare may be hampered by difficulties. For example, while people with ID may have additional healthcare needs, they often struggle to acquire the healthcare they require, particularly when they have a life-limiting condition (Cartlidge and Read, 2010). The study was conducted in a North Staffordshire hospice and the authors used a qualitative approach to explore hospice staff perceptions of their own professional needs while caring for a person with an ID who required palliative or terminal care within the hospice setting. The methods included two questionnaires and a focus group discussion. Despite being a qualitative method, Cartlidge and Read (2010) explained that focus group produced new insights derived from group discussions and thus, participants learn from each other (Krueger, 1998).

The sample size comprised of the following: 26 inpatient hospice staff responded to the questionnaires and the focus group was composed of 17 staff drawn from both the hospice at home team and the inpatient unit. The strength of focus group is the production of data through social interaction (Holloway and Wheeler, 2009). However, Cartlidge and Read (2010) were able to identify a weakness of their study as the large focus group, which was problematic in terms of management. This weakness could be eliminated by conducting two focus groups instead of one (Cartlidge and Read, 2010).

Cartlidge and Read's (2010) findings identified (a) challenges relating to communication in terms of staff ability to determine if the person with ID understood their illness; (b) managing the health condition of the patient; (c) knowledge and understanding of ID and required skills; and, (d) collusion especially when professional carers or family members disguise the truth in an attempt to protect others. The study provided a conclusion and recommendation emphasizing the importance of collaborative working and training to prepare hospice workers to care for this population. Although not specifically related to distress this study had significance to palliative and EoLC for this population. It seemed to reiterate the need for more empirical studies that would be specifically tailored to identify how RNLDs and PCPs identify and respond to the distress of PCDLD in palliative care settings.

2.2.5 Experiences of caring

This section presents the scope of meaning related to the phenomenon of caring in terms of RNLDs or PCDs' experiences of caring as portrayed in the prevailing literature. It has been asserted that caring is the central value of nursing (Watson, 1999; Boykin and Schoenhofer, 2001) and nursing as caring focuses on "*nurturing persons living caring and growing in caring*" (Boykin and Schoenhofer, 2001, p.11). In addition, "*caring is lived moment to moment and constantly unfolding*" (Boykin and Schoenhofer, 2001, p.2). Arguably, the implication here is that caring, and the development of caring competency by the RNLDs, and PCPs, or other health, and social care professionals, occurs over a lifespan which encapsulates the optimum health, the diagnosed conditions, the dying phase, the EoLC and settings, and also, the deaths of the people they care for. Moreover, there is a recognized need to tailor care to meet the needs of people, especially their EoLC (DH, 2008a). Many people are now encouraged to choose their preferred place of care, especially, their EoLC settings, (DH, 2008a). However, in comparison to the early 1900's when most people were laid out in their family homes, and it was the most common place to die, nowadays the number of people who die at home has reduced to 18% with 58% of deaths occurring in NHS hospitals, 17% in care homes, 4% in hospices and 3% elsewhere, such as in prisons or through accidents (DH, 2008a).

These figures, suggest that a deskilling of the lay-population (non-healthcare professionals) has occurred, and also, care and death have been professionalised (Komaromy, 2004). Consequently, there is an implication that, it is the nurse (in this case the RNLD or PCP), or the auxiliary member of staff who deals with the care of an individual in the last instants of their life. This emphasizes the need for more empirical research to evidence good practice of care for this population in palliative care settings and also at the end of their lives (National End-of-life Care Programme, 2006). As far as the provision of palliative and EoLC is concerned, it is essential to mention that over the years dominant theories have contributed significantly to how health, and social care professionals provide palliative and/or EoLC and such theories, have also, fashioned how lay people, health, and social care professionals, understand and respond to psycho-social distress such as grief (Neimeyer, 2001; Payne, 2008). Additionally, providing care that alleviates suffering, and the effect of grief have been debated within social sciences for nearly a century (Neimeyer, 2001), commencing with Freud's '*Mourning and Melancholia*' in 1917, which concentrated on the incredible loss of life during the First World War (Payne, 2008). Freud's '*Mourning and Melancholia*' recognized the similarities and difference between grief and depression, and also, his elucidation, was perceived as the first description of normal and pathological grief, resulting to further enquiry that has

subsequently evolved into an in-depth portrayal of how loss has such a deep effect on people (Payne, 2008).

Subsequently, social scientists have proposed other theories about grief such as: Glaser and Strauss's (1965) '*Awareness of Dying*', and Glaser and Strauss, (1968) '*Time for Dying*'. Notwithstanding, it can be suggested that the later publication of the book called '*On Death and Dying*' by Elizabeth Kubler-Ross in 1969, which focused on 'talking to the dying' was revolutionary in that, it challenged medical protective practices where individuals were often refused information. Kubler-Ross was a hospital psychiatrist, and she incorporated reports from her work with over two hundred patients who were dying and who narrated similar accounts of how they experienced their situations. Their accounts included experiences of denial and isolation, anger, bargaining, depression, and acceptance (Kubler-Ross, 1969, 1997). Furthermore, this book resulted in some mixed reactions comprising of positive and negative critique, which Kubler-Ross viewed as a personal test to ascertain if she could "*take negativity and hostility*" (Schatzman, 2004, p.48). Hence, in an attempt to provide explanation of her findings, Kubler-Ross outlined the patients' experiences of denial and isolation, anger, bargaining, depression, and acceptance as five stages of grief, a process which has mostly been construed as linear, and has also, been criticised by some theorist, and clinicians as mechanical (Cowan and Murphy, 1985; Worthington, 1989). Also Coop (1998) argued that people have a much more varied trail within their experiences rather than systematically go through the five stages. Moreover, the five stage linear model of grief has been considered as superficial, inadequate, and misleading, especially because it developed from people facing their own impending death and not grief from bereavement (Corr, 1993).

In addition, it has been argued that coping with bad news, dying and death is more complex than five stages and there is no prescribed way in which people should cope with death and dying or is there a wrong or right way to die (Tuffrey-Wijne, 2013). This view is affirmed in a sense by Kubler-Ross herself, as illuminated in the opening paragraph of '*On Grief and Grieving*' which stated:

The stages have evolved since their introduction, and they have been very misunderstood over the past three decades. They were never meant to help tuck messy emotions into packages. They are responses to loss that many people have, but there is not a typical response to loss, as there is no typical loss. Our grief is as individual as our lives. Not everyone goes through all of them or goes in a prescribed order (Kubler-Ross and Kessler, 2004, p.1).

Given the aforesaid debate about the conceptualisation of emotional distress, especially, grief, one can suggest that it is even more confusing when related to that which is experienced by PLDCD within palliative care settings, and also, the fact that health and social care professionals are faced with the challenge of understanding this population,

taking into consideration their genetic conditions, cognitive abilities and communication difficulties (Brown et al., 2005; Tuffrey-Wijne and McEndhill, 2008; Tuffrey-Wijne, 2013). Furthermore, the theories or conceptualisation of grief makes little or no mention of PLDCD. Kubler-Ross's (1969, 2004) focus was on dying patients who could self-report their experiences of loss at their impending death. Unlike, Kubler-Ross (1969, 2004), some existing literature that have attempted to explore the issue of grief for people with learning disabilities have focused on grief experienced by them due to a loss and not specifically related to their impending death within a palliative care setting (Conboy-Hill, 1992; Oswin, 1991; Summers and Witts, 2003).

Li and Ng (2008) utilized a descriptive case study approach to explore EoLC in terms of nurses' experiences in caring for dying patients with profound learning disabilities. It has been recognized that the variable standards in the conduct of case studies may affect the credibility of the findings (Yin, 2009). However, case studies can provide "*an in-depth exploration from multiple perspectives of the complexity of a particular project, policy, ...or system in real life context*" (Simons, 2009, p.21).

The goal of Li and Ng's (2008) case study was to identify areas of expertise and shortcomings in the specific knowledge and practical skills of nurses in the care of dying patients with profound learning disabilities in one NHS primary Care Trust in the UK (Li and Ng, 2008). Drawing from the experiences of caring for patients with profound learning disabilities, they emphasized their expertise as RNLDs in using their knowledge of their patients to externally observe certain disease-related changes in their patients such as dramatic weight loss (Li and Ng, 2008). However, their study underscored that uncertainty and ambiguity in the patho-physiological knowledge of both malignant and non-malignant diseases led to delayed diagnoses and timely intervention in the EoLC for this client group (Li and Ng, 2008). Consequently, they emphasized the need for training by RNLDs and PCPs, and also the need to develop a structured observational tool in learning disability nursing to identify disease-related personality and physiological changes (Li and Ng, 2008). Li and Ng (2008) concluded that peaceful dying for this client group could be achieved through good working relationships.

Black and Hyde's (2004) case study called: '*Caring for People with Learning disability, colorectal cancer and stoma*' takes a similar point of view. The study aimed to examine autonomy, consent, treatment, palliative care and death relating to individuals with profound learning disabilities and challenging behaviour, who also have colorectal cancer and a stoma (Black and Hyde, 2004). The findings identified by Black and Hyde (2004) included the need for plans to accommodate patients with profound learning disabilities. Their study identified that longevity in PLDs has increased substantially over recent

years, and as the life expectancy of this client group increases so does the risk of colorectal cancer (Black and Hyde, 2004). They also emphasized the necessity of a meticulous and competent medical and nursing care to meet the needs of PLDs, especially since the transition of PLDs from institutions to the community (Black and Hyde, 2004). They recognized that staff anxieties in caring for PLDs can be reduced by ensuring person-centred protocols that accommodate PLDs and by effective discussions with Multidisciplinary Teams (MDT), and ongoing clinical support team (Black and Hyde, 2004). Also, the nature of learning disabilities is diverse therefore, MDT need focus attention to deal with a range of issues PLDs may have (Black and Hyde, 2004). Similarly, understanding how PLDs communicate was important and understanding of consent issues and relevant material to help PLDs was fundamental (Black and Hyde, 2004). The findings of this study seem to indicate that there is the need for more empirical research studies in the care of this population in palliative care settings in order to address the problem of lack of knowledge, information and an adequate planning system in working with PLDs who require palliative and EOLC (DH, 2006; 2010).

Llewellyn's (2011) paper entitled: *'The needs of people with learning disabilities who develop dementia: A literature review'* was critically analyzed because the content had relevance to my search question and terms. The general structure of the paper was thorough and included an introduction that clearly identified the problem related to PLDs living longer and increasingly developing age-related conditions including dementia, and the challenges this poses to palliative care services (Llewellyn, 2011). In line with Cormack's (2000) critical appraisal criteria, a rationale for the study, the search terms, and databases were clearly identified.

In this paper, Llewellyn (2011) considered the challenges related to the increased number of older people with learning disabilities (PLDs) together with the diagnosis and management of dementia. Llewellyn (2011) also reflected on the needs of PLDs experiencing dementia. The findings were classified under distinct sections namely: medical needs; social needs; needs of carers; needs of peer groups; models of support and services (Llewellyn, 2011). In terms of medical needs, Llewellyn (2011) identified the primary medical need for PLDs who develop dementia as the need for timely and accurate detection and diagnosis of the disease. This was especially as a result of their varied degrees of learning disabilities and communication difficulties, which had an impact on the diagnosis of dementia and the tools needed to make a diagnosis (Llewellyn, 2011). Llewellyn (2011) identified from the literature 27 different tests related to diagnosis of dementia and that a number of tools have been used to aid

diagnosis and assessment for PLDs. Llewellyn (2011) pointed out that no single tool could accurately diagnose dementia in PLDs who were presenting with possible symptoms. The paper recognized a problem with carers' diagnosis due to a culture of caring in which, things are done for PLDs rather than encouraging them to be independent as such, dementia symptoms may be unnoticed (Llewellyn, 2011). Furthermore, high staff turnover could lead to failure of support staff to recognize changes, which could be indicative of early dementia. PLDs also experience other health problems such as thyroid malfunction, depression, and diabetes that could mimic or coexist with dementia (Llewellyn, 2011). Llewellyn (2011) illuminated that both early and longitudinal assessments by carers are vitally important to the diagnosis and management of dementia, and these require some understanding of the signs and symptoms which might affect PLDs at this phase of their lives.

Llewellyn's (2011) paper also recognized the following social needs: deficiencies of services to meet the complex needs of PLDs who develop dementia; general practitioners see dementia as untreatable thus they may not refer PLDs to specialist services; and family carers do not approach services until they are unable to cope. Some of the literature that Llewellyn (2011) reviewed recommended that the concept of 'ageing in place' (Kerr, Cunningham and Wilkinson, 2006; Watchman, 2003) was ideal for PLDs who develop dementia with the possibility of adapting the environment to ensure this (Watchman, 2003). Other recommendations mentioned in extant literature reviewed by Llewellyn (2011) included better training for staff and creating an outreach model of care (Kerr et al., 2006).

In terms of carers needs, Llewellyn's (2011) paper indicated that it was difficult to separate the needs of PLDs from the needs of their carers because they both impact on each other. Also, Llewellyn (2011) recognized the need for training on the normal processes of ageing and the indicators of changes, which signal a dementing process to workers, carers, peers and family (Wilkinson, Kerr and Cunningham, 2005). Moreover, the risk of staff burnout due to trying to meet the new challenges dementia poses in the care of the client (Wilkinson et al., 2005). Llewellyn (2011) also pointed to the need for the development and use of widely flexible financial package and the development of a Dementia care pathway (Gwent Healthcare NHS Trust, 2005).

In terms of the needs of peer groups, Llewellyn (2011) emphasized that when changes occur in a person with dementia, this could have profound impact on others in the same care setting. Therefore, dementia awareness for other clients and support was needed (Wilkinson, Kerr and Rae, 2003).

In terms of models of support, Llewellyn (2011) identified person-centred approaches including cognitive work, reminiscence work and informal reality orientation. Early screening and Diagnostic Clinical Support; and Dementia Care Mapping were also identified (Llewellyn, 2011). In relation to services needed to meet the needs of PLDs who develop dementia, Llewellyn (2011) acknowledged from the review that PLDs and dementia should have the same access to specialist dementia services as those without dementia (Hatzidimitriadou and Milne, 2005; Watchman, 2003). Llewellyn (2011) also pointed out the recommendation for partnership working between learning disability services and Mental Health Trusts and Housing Agencies (Hatzidimitriadou and Milne, 2005).

Llewellyn's (2011) paper was not specifically based on how Registered Learning Disability Nurses (RNLDs) and Palliative Care Professionals (PCPs) identify and respond to the distress of people with communication difficulties and a learning disability (PCDL) experiencing distress in palliative care settings. However, it would appear that Llewellyn's (2011) recommendations point to the need for more experimental research in good practice in the care of people with learning disabilities who develop dementia and associated symptoms such as distress; depression and related health issues like unexplained weight loss (Prasher, Metsegharun and Haque, 2004).

Empirical research investigating experiences of RNLDs and PCPs who care for distressed PCDL in palliative care settings is crucial because it has been recognized that people with learning disabilities in the terminal stages of dementia may need specialist care to meet their particular needs (Cosgrave, 2000).

Hogg and Tuffrey-Wijne's (2008) paper called '*Cancer and intellectual disability: A review of some key contextual issues*' was selected for inclusion in the critical review as an emphasis on the health related issues that PLDs suffer from which demands access to palliative care. Although not an empirical study, the range of articles reviewed included peer-reviewed studies and reports which had appeared in journals in the past twenty-five years and background documents from government departments (Hogg and Tuffrey-Wijne, 2008). Moreover, the paper had relevance to the search terms and search question of my study. The title is concise, informative and clearly indicates the content. A summary and introduction are provided which identified the issue to be research as: the increasing focus on cancer in learning disabilities research from different perspectives (Hogg and Tuffrey-Wijne, 2008). The methods clearly stated the search strategy and identified the databases and range of literature reviewed. The paper also provided a conclusion and a recommendation for future research into the ways in which

appropriate screening can be made available to both men and women with learning disabilities (Hogg and Tuffrey-Wijne, 2008).

Hogg and Tuffrey-Wijne (2008) aimed to gain information on the incidence and prevalence of cancer for PLDs in both institutional and community settings. From the review, Hogg and Tuffrey-Wijne (2008) identified that the incidence, prevalence and trends in the population of PLDs showed a general increase in cancer of all types in PLDs. Also, community studies indicated that the prevalence of cancer in PLDs is closer to that found in the general population. The studies indicated a general lack of information on survival rates in PLDs and cancer (Hogg and Tuffret-Wijne, 2008).

They also pointed out that some studies listed the specific cancers identified in PLDs or provided a cause of death (Hogg and Tuffrey-Wijne). The studies could not produce a tumour profile due to the diversity of PLDs with respect to ability level and associated characteristics, and the etiological heterogeneity of PLDs especially relating to chromosomal and genetic causations (Hogg and Tuffrey-Wijne, 2008).

Hogg and Tuffrey-Wijne (2008) explained that some of the studies reviewed, indicated that ageing had an impact in terms of lifespan influences on the development of cancer as individuals aged. Also some studies identified environmental factors such as smoking, alcohol consumption, and the high prevalence of *Helicobacter pylori* which is linked to bowel cancer.

The paper portrayed that little is known about the impact of transition from institution to the community in terms of the incidence of cancer among women with learning disabilities (LDs) either generally or in relation to breast or cervical cancer; and that some studies indicated an increased risk of colorectal cancers but reduced risk of breast cancer in comparison to women in the general population (Hogg and Tuffrey-Wijne, 2008). However, there was an identified limited data on the prevalence or incidence of breast cancer in women with LDs especially because screening for breast cancer for this population is lower than for the general population. This was also as a result of the difficulties in undertaking cervical screening for women with LDs and the need for both paid and family carers support to facilitate this (Hogg and Tuffrey-Wijne, 2008). The reviewed literature indicated that the incidence of stomach cancer was high in men with learning disabilities and with those in the general population. Men with learning disabilities had lower incidence of prostate cancer and increased testicular cancer in men with profound and severe learning disabilities, and some deaths for PLDs could be avoided (Hogg and Tuffrey-Wijne, 2008). Hogg and Tuffrey-Wijne (2008) concluded with

an emphasis on the key role of paid and family carers, and the need for awareness of the illness and the causative factors. It would appear that given the prevalence of cancer in this population as highlighted by this critical review, the emphasis on the recognized need for palliative care to be accessible to this client group remains a predominant issue that research and service communities need to address.

2.3 Outcome: Significance of the study

Following the literature search and critical review it was concluded that there was a scarcity of applicable and dependable empirical research on how RNLDs and PCPs identify and respond to the distress of PCDLD in palliative care settings. The studies indicated that distress as a construct has been confused with issues of definition (Abeloff et al, 2000; Newman 1994; Rhodes and Watson, 1987; Ridner, 2004). This definitional dilemma of distress extends to the applicability of the term, especially when used to describe that which is experienced by PCDLD in palliative care settings. Furthermore, existing literature have portrayed distress from different perspectives such as physiological (Donovan, 2000; Foley and McCutcheon, 2004; Hadjistavropoulos and Craig, 2002; Hadjistavropoulos et al., 2000; Hunt et al., 2003; Manfredi et al., 2003; Regnard et al., 2006) or from psychological perspective relating to emotional issues and grief (Ryan et al, 2005; Summers and Witts, 2003), and communication perspectives (Cartlidge and Read, 2010; Porter et al, 2001; Read, 2005; Todd, 2005; Tuffrey-Wijne and McEndhill, 2008; Whitehouse et al., 2000) but rarely as a continuum or from a holistic perspective encompassing physiological, psycho-social or spiritual factors for PCDLD. Moreover, very little clinical attention was specifically focused on the meaning of the phenomenon of caring for this client group in terms of how RNLDs and PCPs identify and respond to their distress in palliative care settings. Debatably, collating RNLDs and PCPs' experiences may add to the growing body of knowledge anticipated to provide health and social care professionals with understanding about providing comfort and optimal care to distressed PCDLD. Furthermore, such knowledge could prove fundamental in the development of care approaches to meet the palliative care needs of this population within the ever changing phase of palliative care. There is a need for more empirical studies that will be influential in attaining quality and optimum care for the distressed PCDLD in palliative care settings.

As a result of this critical review of literature and taking into consideration the problem of caring for distress PCDLD as identified in Chapter One, section 1.3 of this thesis (see pp.15-18), I developed a research question for this study and the aim and objectives as follows:

Research Question: *What is the experience of being a RNLD or a PCP caring for an individual with communication difficulties and a learning disability experiencing distress within a palliative care setting?*

Aim and objectives: The aim was to gain an in-depth phenomenological understanding of how RNLDs and PCPs identify and respond to the distress of PCDLD in palliative care settings.

The objectives are:

(a) To critically explore the lived experiences of RNLDs and PCPs who care for distressed PCDLD in palliative care settings.

(b) To critically explore the perceptions of RNLDs and PCPs about factors which determine how PCDLD express distress in palliative care settings.

2.4 Chapter Summary

This chapter has provided a comprehensive critical review of literature. Key research were identified and appraised to identify the gaps in research knowledge and practice. The chapter consisted of three main sections namely an overview of the critical review process, a critical review of existing literature relating to the care of distressed PCDLD in palliative care settings, and the rationale for the study. The critical review demonstrated recognized good practice, ineffective practice and the paucity of knowledge relating to the care of distressed PCDLD in palliative care settings. The critical review of the literature also informed the research question, aim and objectives. In the following chapter I will discuss the philosophical underpinnings and the chosen Methodology for this study.

Chapter Three: Methodology

The chosen methodology for this study is Van Manen's (1990, p.28) hermeneutic phenomenology "*in pursuit of knowledge*". The chapter encompasses seven sections. Section one provides the research paradigm and includes my personal view of the world. Section two presents the epistemology. Section three presents the philosophical influences in terms of the foundations of phenomenology. Section four provides a rationale for locating this study within Van Manen's (1990) hermeneutic phenomenology. Section five outlines phenomenology as a research methodology. Section six presents ethnography as a methodology that was considered for this study and rejected in favour of Van Manen's hermeneutic phenomenology. Section seven is the chapter summary.

3.1 Research Paradigm

It has been recognized that the selection of a research methodology is dependent on the paradigm that guides the research activity and the paradigm is viewed as the basic belief system or world views that guides the research (Dobson, 2002; Guba and Lincoln, 1994; Munhall, 2007). Also, a paradigm is perceived as a world view, a general perspective and a way of breaking down the complexity of the real world (Munhall, 2007; Patton, 2001). A paradigm has also been described as an interpretative framework which is guided by a set of beliefs about the world, and how it should be understood and studied (Denzin, 2009; Guba and Lincoln, 1990; Munhall, 2007). There are three categories of such beliefs namely: ontology, epistemology and methodology (Denzin and Lincoln 2001, 2003; Schulze, 2003).

Ontology deals with beliefs about the nature of reality and humanity and encompasses the researcher's understanding of what it means to be in the world and what is real to them (Schulze, 2003). Epistemology has been described as the theory of knowledge that informs the research (Denzin and Lincoln, 2009; Schulze, 2003) in terms of the study of the nature of knowledge and the process by which knowledge is acquired and validated (Gall et al., 1996, 2006). Methodology reflects the researcher's stance and describes how they know the world or gain knowledge of it (Schulze, 2003; Silverman 2010).

3.1.2 My Personal view of the world influenced by my nursing knowledge

Porter-O'Grady (2003) explains that nurses are fundamentally knowledge workers because they combine a broad array of information and knowledge from a range of

sources and bring that synthesis to bear on nursing care. In addition, Peterson and Bredow (2009) explained that the knowledge that nurses require to practice, which encapsulates their view of the nature of their caring world, has been conceptualised by Carper (1978) as consisting of four distinct patterns namely: (a) empirics, the science of nursing; (b) aesthetics, the art of nursing; (c) personal knowing, the interpersonal nature of nursing; and (d) ethics, the moral component of nursing. Inherent in my world view is an adherence to these principles. Therefore, this research encompasses these tenets.

Empirical knowledge has been described as knowledge formed in association with scientific hypothesis that are tested by observation or experiments (Munhall, 2007). It has been emphasized that the sources of empirical knowledge comprises research and theory and model development (Peterson and Bredow, 2009), which for a practising nurse should be interpreted within the context of specific clinical situations (Manias and Street, 2000; Peterson and Bredow, 2009). This accounts for the choice of the research topic, which is directly linked to my past experience of a clinical situation.

Aesthetic knowing (the art of nursing) encapsulating nursing empathy and creativity has been criticised as a psychological phenomenon that has been uncritically adopted by nursing (White, 2004). However, it still has a part to play in nursing knowledge because it demonstrates the nurse's ability to grasp and interpret the meaning of a situation, making use of the nurse's intuition and empathy (Peterson and Bredow, 2009). It also portrays the nurse's creative skill in imagining a desired outcome in an actual situation and how the nurse responds based on an interpretation of the whole situation, analyzing the interrelationships of its various aspects (Peterson and Bredow, 2009). This belief is inherent in my world view as far as caring is concerned, hence the interest in the phenomenon under study and the choice of the research topic.

According to White (2004, p.253), "*personal knowing is difficult to teach and master*" and information about one's self from others could be problematic in that it could be misperceived (Peterson and Bredow, 2009). However, personal knowing relates to the therapeutic use of self in the nurse-patient relationship, with reflection as the primary means by which personal knowing occurs (Peterson and Bredow, 2009). It comprises the nurse's individual self-reflection that could also be informed by the responses of others (Peterson and Bredow, 2009). Through reflection the nurse is able to manage the care environment and work towards a required beneficial outcome for the patients (Peterson and Bredow, 2009). I propose that undertaking this study will provide a forum for reflective practice by both the participants and myself, and the outcome of the study may add to specialist knowledge, increase awareness and inform service provision and

changes to the approach of caring for distressed people with communication difficulties and a learning disability (PCDL) in palliative care settings.

Ethical knowing involves knowledge of what is right or wrong in terms of judgements of moral value and the commitment to act on the basis of those judgements (Watson 2002). Nursing ethical codes and professional standards as well as different philosophical positions of what is considered good and what is identified as an obligation, remain important sources of ethical knowledge (Peterson and Bredow, 2009). All of the above are encompassed in my personal view of the world, which contributed to my interest in the phenomenon under study and also, complemented the critical review of literature, which subsequently informed the aim and objectives of this study.

Empirical knowledge holds a privileged position in nursing knowledge (Peterson and Bredow, 2009). However, I advocate the view that irrespective of the hierarchical importance of empirical knowledge, nursing knowledge should be perceived as an integrative framework (Fawcett, Watson, Neuman, Walker and Fitzpatrick, 2001). Moreover, the importance of ethical knowledge, and the significance of episodic, and procedural knowledge, as encompassed in aesthetic and personal knowing, should be recognised as complementary to empirical knowledge (Fawcett et al., 2001). I advocate this view because the fundamental nature of nursing knowledge is rooted in the understanding of human nature and our response to our environment, therefore making it imperative for nursing to embrace inclusive, rather than exclusive ways of knowing (Giuliano, Tyler-Viola and Lopez, 2005). Additionally, it has been acknowledged that diversity of philosophies of nursing theory may be seen as a more accurate representation of reality, which may have the potential of stimulating greater creativity and variety in the development of nursing models and theories (Landreneau, 2003). Hence, my personal view of the world.

3.2 Epistemology

Trochim (2001) explained that the term epistemology is derived from the Greek word *episteme*, which is a Greek term for knowledge. The theoretical assumption which has formed the epistemological basis of this study is the construction of meaning. It has been acknowledged that life experience generates and enriches meanings, while meanings provide explanation and guidance for the experience (Chen, 2001). The construction of meaning in this study is influenced on the one hand by my personal view of the world, which is based on my nursing knowledge as explained in Section 3.1 above and on the other hand by constructionism.

Young and Collin (2004) emphasized that social constructionism and constructivism separately, or considered under the generic and undifferentiated term 'constructivism', have developed substantially in social science including psychology since they were first mentioned in developmental and cognitive psychology by the main exponents including Bruner (1990), Piaget (1996), Von Glaserfeld (1993), and Vygotsky (1978). Furthermore, in an attempt to distinguish the two terms, Young and Collin (2004) explained that constructivism focuses on meaning making and constructing of the social and psychological worlds through individual cognitive processes, while constructionism stresses that social and psychological worlds are made real or constructed through social processes and interactions. However, there remains an ambiguity in the use of the terms constructivism and constructionism (Raskin, 2002) and some theorists have adopted the practice of referring to plural 'constructivisms' (Raskin, 2002), while others use the two terms interchangeably (Burr, 1995, 2003; Gergen, 1999). In this study the term constructionism has been used as a more befitting term taking into consideration the phenomenon under study, which will necessitate that participants construct meaning from their lived experiences of caring. This is in terms of how Registered Learning Disability Nurses (RNLDs) and palliative care professionals (PCPs) identify and respond to the distress of people with communication difficulties and a learning disability (PCDL) in palliative care settings.

Constructionism acknowledges that an individual's understanding of their life and situations are multiple and complex. It enables researchers to focus upon how meaning can be constructed through the study of interactions with participants (Guba and Lincoln, 1989; Holstein and Gubrium, 2008). Also, individuals construct meaning in the context in which they are situated in the world; therefore, meaning is negotiated through social interactions within a given culture (Crotty, 1996). Additionally, emphasis on the rhetorical and constructive aspects of knowledge could be perceived as the most significant aspects through which we come to understand and accept certain representations of reality as being true, legitimate, or acceptable (Silverman, 2010). In other words, the recognition that facts are socially constructed in particular contexts. This view forms the basis of the Constructionist model, which deals with the questions of 'what' and 'how', which also informs most qualitative research (Holstein and Gubrium, 2008).

Constructionism upholds the view that the only access we have to an individual's experience is through conscious interpretation, and the only means that one has to access a phenomenon is through the construction of meaning (Holstein and Gubrium, 2008). Conrad and Baker (2010) allude to Goffman's (1961, 1963) assertion that individuals are given to actively participating in the construction of their own social

worlds, including the construction of selfhood by ongoing social interaction. According to Bauman (1978), Plato was one of the earliest philosophers to describe the construction of meaning in his cave allegory. In the allegory, slaves constructed a process of meaning that resulted from naming the shadows on a wall that reflected from a fire although they were unable to see the items that created the shadows. Therefore, they created a new system of meaning. Within this new system of meaning the slaves earned status and respect by their ability to make sense of the shadows. A slave broke free and was able to see what cast the shadows and thus, he built a new construction of meaning or reality. When he returned to his previous position he tried to inform the other slaves about the origins of the shadows however, they had no reason to believe this slave's new construction of meaning or reality over their own. He lost the ability to see the shadows in the previous construction of meaning, which the other slaves still upheld and therefore, he lost status and respect in the group. Reality for the slaves in this case was arrived at through the shared construction of meaning within the context of the environment in which they found themselves. Subsequently, the role of naming in the construction of meaning has been widely discussed by philosophers. Plato advocates the existence of universal truths (Lemey and Pittes, 1994), and it has been asserted that men are condemned to meaning making and that *"to exist humanly is to name the world, to change it"* (Friere, 1972, p. 61).

Some philosophers like Immanuel Kant have also expressed the view that humans filter sensory information through the attribution of meaning and all humans have the same filters or ways to construct meaning, therefore, universal human knowledge or truths can be generated (Winfree, 1999). On the other hand, Friedrich Nietzsche questioned the existence of truth and concluded that no such entity existed as there is no universal truth waiting out there to be discovered (Winfree, 1999). In a similar vein, people are placed in a situated context without an element of consent or choice and they construct meaning through the cultural lens embedded within this context, which Heidegger described as 'thrown-ness' (Lemay and Pitts, 1994). It is anticipated that through interactions (interviews) with the participants in this study, the meaning of the fundamental nature of their experiences of caring for PCDLD experiencing distress in palliative care settings will be constructed.

3.3 Philosophical influences: The foundations of Phenomenology

This section provides the philosophical influences in relation to the foundations of phenomenology and how it evolved into a recognised philosophical tradition. This was deemed appropriate because phenomenology has been described as both a philosophy

and an approach because it is a methodology that has a strong orientation to philosophy (Dowling, 2007; Munhall, 2007; Van Manen, 1990). Also, phenomenology can refer to a research methodology, method, a philosophy, and an approach or a mixture of unique but related philosophies (Moran, 2000; Ray, 1994). It is commonly described as the study of phenomena or 'things' as perceived in human consciousness and it is increasingly being used to study the phenomena, which are central to health care and nursing, and it is also perceived as a "*credible display of living knowledge for nursing*" (Jones and Borbasi, 2004, p.99).

It has been recognized that a possible limitation of any phenomenological study is that the text could be repetitive and confusing due to the tendency of some researchers to adopt phenomenology as a research methodology without an adequate grasp or articulation of its underpinning philosophy (Koch, 1999; Munhall, 2007; Priest, 2004; Van Manen, 1990). Therefore, the goal of this section is to portray how the philosophical influences matched the selected methodology and methods, and thus, minimised the risk of misunderstanding and misrepresentations in the study (Koch, 1999; Munhall, 2004; Priest, 2004; Van Manen, 1990).

Phenomenology is a rather new philosophy. It was first observed in Germany before the First World War and has occupied a prominent place in modern philosophy (Gadamer, 1963, 1989). Moustakas (1994) explained that the word phenomenon is from the Greek word *phaenesthai*, which means to show itself, to flare up, to appear. This is closely linked to the motto of phenomenology "*Zu den sachen*", which means both "*to the things themselves*" and "*let's get down to what matters!*" (Van Manen, 1990, p.184). Also, it has been acknowledged that the term phenomenology was used in philosophy texts by Kant and later Hegel, who prominently used the term when it featured in the title of his 1807 work '*Phenomenology of Spirit*' (Moran, 2000).

There are many different and sometimes conflicting phenomenological perspectives, schools of thought or traditions. Although they all have some commonalities they also have distinct features (Moran, 2000). It is therefore necessary to locate the current study within one of the major traditions of phenomenological inquiry in order to avoid confusion. There is no right or wrong phenomenological tradition (King and Horrocks, 2010; Kleiman 2004). However, the choice of a methodological framework is usually dependent on the research content, the scholarly status of the researcher, the purpose of the research and the use to which the findings will be put (Silverman, 2010).

Racher and Robinson (2003), explained that the different perspectives of phenomenology locates its various forms in the positivist (Husserl), post-positivist (Merleau-Ponty), interpretivist (Heidegger) and constructivist (Gadamer) paradigms. On

the other hand, Cohen and Omery (1994) also declared that three different schools of phenomenological philosophy have given rise to approaches that have been used methodically in social science research. The schools of phenomenological philosophy are Eidetic or descriptive phenomenology championed by Husserl, Hermeneutics guided by Heidegger and Gadamer's philosophy, and the Dutch school of phenomenology (Cohen and Omery, 1994). Van Manen's approach is situated in the Dutch school.

I now provide a brief discussion of these three different schools of phenomenological philosophy commencing with Husserl's descriptive phenomenology, followed by Heidegger's and Gadamer's interpretive phenomenology and finally the Dutch school. The goal is to present an overview of how phenomenology evolved into a recognized philosophical tradition and also provide a rationale for locating the current study within Van Manen's (1990) hermeneutic phenomenology, which is discussed in Section 3.4 of this chapter. For purposes of clarity, these schools will be presented as distinct sections below.

3.3.1 Eidetic or descriptive Phenomenology

Descriptive phenomenology was championed by Husserl (1859-1938), who has been credited as being the founding father of phenomenology (Moran, 2005). Vandenberg (1997, p.11) also described Husserl as the "*fountainhead of phenomenology in the twentieth century*". Although the works of subsequent exponents have significant differences as far as interpretation and emphasis are concerned, they still have a relation to the work of Husserl (Langdrige, 2007). Husserl's inspiration for the development of phenomenology was Franz Brentano (1839-1917) who employed the phrase descriptive psychology or descriptive phenomenology to describe his work (Moran, 2000). From the outset, Husserl had envisaged phenomenology to be the study of universal eidetic structures or essences of phenomena. This is in line with Merleau-Ponty's (1962) assertion that phenomenology is the study of essences or finding definitions of essences in terms of the essence of an experience (Racher and Robinson, 2003). Husserl's goals are mainly epistemological and he considered experience to be the fundamental source of knowledge (Racher and Robinson, 2003).

Phenomenological reduction is a significant aspect of Husserl's phenomenology (Moran, 2000). Moran (2000) explained that for Husserl, the 'lifeworld' (*Lebenswelt*) is understood as what individuals experience pre-reflectively, without resorting to interpretations. Central to Husserl's theoretical perspective is the view that a phenomenon could be reached in a pre-reflective or predictive state, thus avowing that it

was possible to separate the subjective experience (the noesis) from the objective phenomena (the noema) (Moran, 2000). Husserl (1970) argued for the significance of the researcher describing phenomena as they appear to an individual, without the influence of prior knowledge. This is made possible through the process of phenomenological reduction, which Husserl described as bracketing (Husserl, 1980, 1983). Bracketing involves using imaginary brackets to highlight and suspend all preconceptions or everyday assumptions so that experiences are viewed in a new and unaltered manner (Beech, 1999), which will also facilitate the emergence of the essence of the phenomena (Racher and Robinson, 2003). This follows the discipline of transcendental phenomenology (King and Horrocks, 2010). Hence, Husserl's phenomenology is also called Husserlian phenomenology, transcendental phenomenology, or objective hermeneutics (King and Horrocks, 2010).

Husserl advocated the notion of intentionality (Racher and Robinson, 2003). Racher and Robinson (2003) described that Husserl saw experience as the fundamental source of knowledge. The process of turning towards or focusing attention upon an experience has been described by Husserl (1988) as intentionality. This process encapsulates attributing meaning to an experience or situation, which involves both reflection and recognition (Moran, 2000; Moustakas, 1994). Husserl adopted Brentano's account of intentionality as the fundamental concept for understanding and classifying conscious acts and experiential mental practices (Moustakas, 1994). Brentano (1838-1917) proposed the notion of intentionality as a way of describing how, in consciousness, the mind directs its thoughts to a specific object (Holloway and Wheeler, 1996). In addition, Husserl in his discussion of intentionality holds the view that all consciousness is consciousness of something (Moustakas, 1994) and he also acknowledged the role of consciousness in everyday experiences (Moran, 2000; Sawicki, 2006).

3.3.2 Hermeneutics

Husserl's successors in the phenomenological tradition questioned the researcher's ability to completely disengage themselves from what they were investigating, resulting in the move towards existentialism within phenomenology (King and Horrocks, 2010; Langdrige, 2007; Spinelli, 2005). Heidegger was amongst those to debate the work of Husserl, arguing that we are not able to view and describe another's experience from an objective point of view, due to our inter-connected relationship with the world around us (Moran, 2000). Heidegger argued that phenomena require interpretation and not just description (Moran, 2000). This resulted in interpretive methods of phenomenology championed by Heidegger, with subsequent developments by Merleau-Ponty (Moran,

2000), and Smith's (1996) development of the Interpretative Phenomenological Approach (IPA).

Heidegger agreed with Husserl's views to some extent. For example, Heidegger like Husserl is concerned with human experience as it is lived (Moran, 2000). Heidegger (1962) in line with Husserl, upholds the view that human consciousness is temporal and perspectival. He explained that potentially there is more than one universal (eidos) or essential nature of a phenomenon that can be accessed and also that a variety of interpretations are possible, which may all be valid (Langdrige, 2007).

However, the focus or emphasis of Heidegger's phenomenology was more on the process of gathering the subjective than seeking a universal essence (Langdrige 2007). Heidegger had as his aim the interpretation of phenomena to uncover hidden meaning (Holloway, 1996; Ray, 1994). Heidegger (1962) referred to phenomenology which seeks to uncover understanding of the meaning of Being as "*hermeneutic*"; designating it an interpretive rather than descriptive process (Heidegger, 1962, p.62). Heidegger saw the nature of existence (ontology) as the primary focus of philosophy, unlike Husserl, whose central focus was on the nature of knowledge (epistemology) (Cohen and Omrey, 1994; Moran, 2000). Thus, Heidegger's phenomenology is also called interpretive phenomenology, existential phenomenology or Heideggerian hermeneutics (Koch, 1995, 1996, 1999; Moran, 2000).

As far as phenomenological reduction is concerned, Heidegger advocates Husserl's notion of 'to the things themselves' but was however critical of Husserl's emphasis on description rather than understanding and of his use of bracketing (Cohen and Omery, 1994; Moran, 2000; Racher, 2003). Within hermeneutics, pre-existing personal experiences or prejudices are not suspended, but are acknowledged as having a profound influence on the understanding of a phenomenon and are also important to interpretation (Moran, 2000; Ray, 1994).

In discussing intentionality, Heidegger refined the notion of 'intentionality', which he perceived as a theory of *Being* rather than a theory of *Meaning*. 'Being' is viewed in terms of one's presence in the world (Cohen and Omrey, 1994). Heidegger also employs the phrase Being-in-the-world to describe the way human beings exist, act, or are involved in the world (Van Manen, 1990). Heidegger saw 'intentionality' as the constitution of consciousness (Kockelmans, 1993). He described consciousness as a projection from one's self rather than an interior thing (Heidegger, 1962, 1985). Kockelmans (1993) explained that consciousness is an opening of one's self to an issue, but not all things at once because a Being or 'Dasein' is limited by human shortcomings. Also the projection of one's self can only be done from a limited horizon, which is where

the individual or being finds themselves in the world (Kockelmans, 1993). Heidegger (1927, 1985) further elucidated that interpretation is not solely focused on acquisition of knowledge or information but also on working out the possibilities which are projected in understanding, and hermeneutics provides a horizon or place from which to project.

Additionally, Byrne (2001) emphasized that the focus of phenomenology is on an individual's lived experience and the obtaining of commonalities and shared meanings, whereas hermeneutics advocates two assumptions: that individuals experience the world through language, and that language provides them with both knowledge and understanding. However, within the context of hermeneutic phenomenology, hermeneutic still retains the meaning of the interpretation of meaning acquired through text (Annells, 1996). Interpretation has been described as a process through which a new and conceivable meaning is constructed, and it entails moving beyond a mere description of a phenomenon (Annells, 1996).

3.3.3 Philosophical Hermeneutics (Gadamer)

Gadamer's work *Truth and Method* followed the work of Heidegger (Moran, 2000; Ray, 1994) and it is credited with putting hermeneutics at the centre of contemporary philosophical debate (Bowie, 1998; Moran, 2000). Gadamer is also credited with helping to extend philosophical hermeneutics to critical hermeneutics by stressing the importance of tradition, background and history (Annells, 1999; Byrne, 2001). Gadamer (1989) advocated two central positions in his work. Firstly, prejudgement, which relates to a person's preconceptions or prejudices or horizon of meaning, which is part of our linguistic experience and makes understanding possible. Secondly, universality with the view that the persons who express themselves and the persons who understand are connected by a common human consciousness, which makes understanding possible (Ray, 1994).

Gadamer (1989) also explained that the process of understanding encapsulates the detachment of our fruitful prejudices, which facilitate understanding from our prejudices that obstruct understanding. Thus in Gadamer's phenomenology (philosophical hermeneutics), understanding is derived from the personal involvement of the researcher in a reciprocal process (Spence, 2001). The reciprocal process involves interpretations that are related to our being-in-the-world (Spence, 2001). It has been affirmed that in Gadamerian hermeneutics dialogue is essential and interpretation permeates every activity, with the researcher also considering socio-cultural and gender issues (Koch, 1999; Moran, 2000).

Gadamer (1985) explained that the interpretive account is the outcome of a fusion of horizons, which are the horizons of the text and the interpreter. Gadamer (1985, 1989) also described that a horizon is established by coming to an agreement about the issue being discussed through hermeneutical dialogues. Thus, the fusion of horizons is historically situated, as the horizon of the interpreter is formed within the traditions (horizons) and beliefs (horizons) of the time (Gadamer, 1989). Furthermore, in Gadamer's phenomenology (hermeneutic philosophy), the lifeworld or lived experience is the starting point from which all people come and it can never be fully eliminated as human life cannot be viewed from outside of its experience (Bruzina, 2000).

Although in hermeneutics the researcher is called upon to be aware of their current construction of meaning to allow the results of their interaction with the phenomenon under study to surprise them, it is not a process of 'bracketing' or phenomenological reduction as advocated by Husserl. Rather, it is a process of surrendering, which Gadamer describes as openness to the fusion of horizons and Heidegger describes as shining through (Moran, 2000). It has been emphasised that "*phenomenology without hermeneutics can become shallow*" because hermeneutics enhances the researcher's active interpretation through continuous dialogue with the text (Tordes and Wheeler, 2001, p.6). Fleming, Gaidys and Robb (2003) highlighted that to ensure credibility in the dialogical method of the hermeneutic process Gadamer added a further step to the concept of the hermeneutic circle with the need for feedback and further discussion with study participants.

3.3.4 The Dutch School

Van Manen is a Dutch scholar who migrated to Canada in 1967. The Dutch school, also referred to as 'Utrecht school' occupies an important place in the phenomenological movement (Van Manen, 1996). Bulytendijk was one of the first Dutch scholars to contribute to the field and he remained the central figure for many decades (Kockelmans, 1987). Other scholars included Van Lennep, Van den Berg, Strasser and Linschoten (Kockelmans, 1987). Some Dutch scholars like Kockelmans, migrated to America and his works, like those of Strasser had significant influence both in North America and internationally (Levering and Van Manen, 2002).

Before and after World War Two (WW2), Dutch psychologists attempted to create an understanding of psychology, which was based on Husserlian interpretations of phenomenological philosophy (Kockelmans, 1987). However, by the 1960s, their views had evolved to also include more experiential beliefs and the work of Dutch scholars like

Johannes Linschoten had cast considerable doubt on the possibilities of a pure psychology or transcendental subjectivity as explained by Husserl's theoretical perspective that a phenomenon could be reached in a pre-reflective or predictive state (Kockelmans 1987). Kockelmans (1987) described that the phenomenological tradition of Western Europe had undergone certain transformations away from Husserl's transcendental phenomenology towards an existential (experiential) approach as exemplified in the philosophical writings of Heidegger, Sartre and Merleau-Ponty. Kockelmans (1987, p.26) like other Dutch scholars argued that Husserl's transcendental phenomenology form of inquiry as the ultimate source of all meaning is "*without world*" because we cannot disconnect completely from the world, that is our experiences.

Also, Dutch scholars like Buytendijk, Van den Berg, and Linschoten suggested that Husserl's transcendental subjectivity and phenomenological reduction was a philosophical abstraction that prevented one from remaining connected with the world as we live it (Van Manen, 1996). As an emphasis on the significance of connecting with the world as we live it, Langeveld's (1983a) described the work of Dutch scholars as a 'home, kitchen, street' approach to phenomenological inquiry (Van Manen, 1996). Langeveld (1983b, pp.181-194) explained that bringing up and educating children must be brought to reflective awareness "*without becoming alienated from reality by making this bringing to consciousness too theoretically charged with abstract nonsense*", thus alienating us from the world we must all live in.

Van Manen (1996) explained that after WW2, much of the work of the Dutch and German phenomenologist was motivated by the general concern about examining values that would restore a sense of meaningfulness, personal relationship, and hope in a world that was felt to be lost on social currents of pessimism and alienation (Van Manen, 1996). The examination of such values involved descriptions and interpretation of the world as we live it (Van manen, 1996). After the exploration of the different phenomenological traditions and schools of thought, the current study was positioned within hermeneutic phenomenology following Van Manen (1990). This study investigates lived experiences or personal experiences of RNLDs and PCPs in terms of how they identify and respond to the distress of PCDLD in palliative care settings. Espousing Van Manen's (1990, p.28) hermeneutic phenomenology "*in pursuit of knowledge*" as the methodological approach facilitates this form of inquiry because it enabled me as the researcher to explore phenomena from another's perspective (Sadala and Adorna, 2002; Smith, 2008; Speziale and Carpenter, 2007; Spinelli, 2005).

3.4 Rationale for locating this study within Van Manen's (1990)

Hermeneutic Phenomenology

According to Van Manen (1990) hermeneutics originated from the Greek verb *hermeneuin*, 'to interpret'. Van Manen (1990) claimed that recorded hermeneutic tradition started with the interpretation of biblical texts in the seventeenth century. In addition, when applied within the context of hermeneutic phenomenology, hermeneutics maintains the meaning of the interpretation of meaning attained through text (Annells, 1996). Van Manen's (1990) hermeneutic phenomenology was chosen as the suitable methodology for this study for five main reasons:

1. Influence of European movement and North America tradition

Van Manen (1990) avows that his work was influenced by the spirit of European movements as well as certain North American developments. The North American phenomenological tradition does not seek pre-reflective experience but includes thoughts and interpretations of the experience in the data analysis (Dowling, 2007). Thus, Van Manen's, (1990) hermeneutic phenomenology is a combination of descriptive and interpretive phenomenology (Cohen and Omery, 1994). In the European phenomenological tradition, pre-reflective experience assumes a key role. However, the North American phenomenological tradition upholds the view that it is difficult for individuals to think aculturally (Caelli, 2000; Dowling, 2007). Hence, analysis of data focuses on describing and interpreting participants' lived experiences within the context of culture as opposed to searching for a universal meaning like the European phenomenological tradition, which had an impetus to eliminate traditional and cultural understanding through bracketing (Caelli, 2000; Dowling, 2007).

2. Preconceptions

Van Manen's (1990) works combine aspects of Husserl's descriptive phenomenology with an emphasis on the study of the pre-reflective world. However, Van Manen, (1990) does not advocate Husserl's partiality towards the life-world being limited to what individuals experience pre-reflectively, without resorting to interpretations. According to Van Manen, (1990), the term 'description' encompasses both interpretive (hermeneutic) as well as descriptive phenomenological elements. Van Manen (1990) argues that this combination is scientific and simultaneously involves interpretation. He utilizes the terms phenomenon and experience interchangeably (Van Manen, 1990) and declares that phenomena exist in the lifeworld and are reached through lived experience. However,

Van Manen (1990) does not embrace Husserl's notion of bracketing or phenomenological reduction, which emphasized that in describing phenomena, researchers had to hold back any pre-existing personal beliefs and experiences. Rather, in line with Heidegger, Van Manen (1990) advocates the importance of preconceptions or prejudices and the important role of the analyst in the interpretation of the phenomenological text. Van Manen (1990, p.47) acknowledges that "*if we simply try to ignore or forget what we already know, we might find that the presuppositions persistently creep back into our reflection*". I advocate this view as befitting the phenomenon under study, which is informed by a past clinical experience and also based on RNLDs and PCPs lived experiences.

3. Congruent with Nursing

Van Manen's (1990) hermeneutic phenomenology was selected as the chosen methodology for this study because Van Manen's (1990) work has contemporary popularity among nurses (Mak and Elwyn, 2003) as his four lifeworld existential provide guidance for researchers on phenomenological writing (Goodwin, Thurmeirer, and Gustafson, 2004). Van Manen's (1990) four existential are spatiality (lived space), corporeality (lived body), relationality (lived relation), and temporality (lived time). His four existential are illustrative of the fusion of the objective hermeneutic circle (part whole) and the alethic hermeneutic circle (pre-understanding) because they acknowledge the experience of a phenomenon in a whole experience and also the researcher's interpretive role in the research process (Dowling, 2007). In other words pre-understanding or preconception of an experience is considered important in the whole experience because it facilitates the researcher's interpretation and also allows for the emergence of new understanding and interpretations by the participants and the researcher. I advocate this precept of phenomenology by Van Manen (1990) especially because the phenomenon under study was informed by my past clinical experience. This is acknowledged in the study by the use of a reflective approach and also enhanced by the chosen method of data collection (semi-structured, audio-recorded interviews, demographic questionnaires and my fieldnotes). I also believed this approach would be suitable to gain an in-depth phenomenological understanding of the phenomenon under study. This is in terms of the participants' perspectives, gleaned from the participants who are engaged in reflection through hermeneutic dialogue (interviews) with the researcher, to tell their stories and construct meaning from their lived experiences about the phenomenon of caring for PCDLD experiencing distress in palliative care settings (Van Manen, 1990).

4. Framework

Furthermore, Van Manen's (1990) six research activities provided a framework to gain an in-depth understanding of the fundamental nature of the meaning the phenomenon of caring for distressed PCDLD have for the participants. Such a framework contributed to transparency as far as providing structure for the hermeneutic phenomenological writing is concerned (see Chapter Four, Table 4.3, pp.92-93).

5. Flexibility

Van Manen's (1990) hermeneutic phenomenology was selected as the chosen methodology because there is flexibility in the process by which data is generated. This is highlighted by Van Manen's (2002) emphasis on the significance of simultaneously incorporating description and interpretation when referring to a lived experience. Van Manen (2002) explained that one must experiment with a methodological informed inventiveness that combines the reflective and the pre-reflective life of consciousness. Also, he stressed that one needs to invent a flexible narrative rationality, a method for investigating and representing the phenomenon in question (Van Manen, 2002). This flexibility is also demonstrated by Van Manen's (1990, pp.92-93) initial approaches of isolating themes namely "*the wholistic or sententious approach, the selective or highlighting approach, the detailed or line-by-line approach*" and also, his four lifeworld existentials, which together, intentionally allow for active in-depth phenomenological interpretation of participants' transcripts. As far as intentionality is concerned, Van Manen (1990, p.182) stated that all thinking in terms of "*imagining, perceiving, remembering*" is always thinking about something. Moran (2000) emphasized that intentionality is the principle that every act is related to some object, thus implying that all perceptions have meaning (Owen, 1996). Van Manen (1990, p.79) described this flexibility and the important role of the analyst in the construction of meaning as the need to capture our desire to "*accept from the stars*", for understanding, bringing our full attention to the material at hand, and engaging in a "*free act of seeing*".

3.5 Phenomenology as a research methodology

As discussed, the phenomenological method of research developed from a philosophical movement that has different perspectives. As a research methodology, phenomenology relates to the study of phenomena in terms of their meaning and nature, with the goal of the phenomenological researcher being that of "*returning to the things themselves*" (Van Manen, 1990, p.184). The "*things*" refer to the elements of the lifeworld as experienced

or lived (Van, Manen, 1990, p.184). The lifeworld therefore, becomes the central focus of phenomenological inquiry. It encompasses everything concrete and meaningful to human beings as they understand and experience it, including an understanding of themselves, their bodies and relationships, their history and present experiences. Dahlberg, Dahlberg and Nystrom (2008) explained that the overall aim of lifeworld research is to describe and elucidate the lived world in a way that expands our understanding of human beings and human experiences.

Some phenomenological theorists have explained that there are some essential structures of the life-world encapsulating selfhood, embodiment, sociality, spatiality, temporality, project and discourse (Ashworth, 2003, 2006). Van Manen (1990) proposes four existential themes as guides for the reflective research process: lived space (spatiality) lived body (corporeality), lived time (temporality), and lived human relation (relationally or communality).

However, the interrelated segments of the lifeworld themes are not necessarily relevant to all accounts of phenomenology, taking into consideration the broad philosophical underpinnings of phenomenological research (Ashworth, 2003, 2006). Subsequently many phenomenological research methods and hermeneutic phenomenological alternates have developed. It has been affirmed that:

The flexibility of phenomenological research and the adaptability of its methods to ever widening arcs of inquiry is one of its greatest strengths (Garza, 2007 p. 338).

Therefore, it would seem that different approaches are needed and determined by the type of phenomenon under study, the type of knowledge the researcher aims to achieve, and the purpose for which the findings would be used (Munhall, 2007).

3.6 Ethnography methodology considered and rejected

Ethnography traced its roots back to anthropological studies of small, rural and remote societies that were conducted in the early 1900s with researchers like Malinowski and Alfred Redcliffe-Brown, who participated in these societies over an extended period of time and documented their social arrangements and beliefs systems (Reeves, Kuper and Hodges, 2008). Prior to the current methodology, ethnography was considered as a possible methodology for this study. This is because in addition to the current sample participants, I had also intended to include patient/client participants in the study. This would have necessitated conducting interviews with the RNLDs and PCPs to gain

understanding of how they identify and respond to the distress of PCDLD in palliative care settings and also, personally observe how PCDLD express distress in such settings. Ethnography was deemed suitable for this since the fundamental aim of ethnography is to provide rich holistic insight into people's views and actions, and the nature of the location they inhabit through a collection of detailed observations and interviews (Reeves, Kuper and Hodges, 2008).

However, apart from the difficulties I encountered in gaining access to client participants, using ethnography would have been problematic because of the relatively long periods of time ethnographers are expected to spend talking to participants and observing actions in the field. Also in relation to the length of time ethnographers spend in the field, a possible limitation of ethnographic studies is difficulties of securing repeated access, especially if institutional gatekeepers are concerned that the research may portray their organisation in a poor light (Hammersley, 1992; Hammersley and Atkinson, 2007; Reeves et al., 2008). Given the limited time frame of the PhD programme of study, I did not think it was feasible time-wise to undertake an ethnographic study. Hence, the choice of the current methodology.

3.7 Chapter Summary

This chapter has discussed the chosen methodology for this study as Van Manen's (1990, p.28) hermeneutic phenomenology "*in pursuit of knowledge*". It provided the methodology, which has underpinned the study guided by the research paradigm, epistemology, and philosophical influences. The theoretical assumption which formed the epistemological basis of this study was elucidated as the construction of meaning, which was influenced by my nursing knowledge, and by Constructionism. The chapter also provided an overview of the foundations of phenomenology and how phenomenology evolved into a recognized philosophical tradition and subsequently, became a research methodology. Ethnography was elucidated as a considered methodology for this study and a rationale for locating the current study within Van Manen's (1990) hermeneutic phenomenology was provided.

The subsequent chapter is Chapter Four, which provides the overall design in terms of the procedural methods selected to address the research question, and discuss the study's aim, and objectives. It also explains how Van Manen's (1990) six research activities are divided into related parts of this study to emphasize data synthesis and the structure of a phenomenological text.

Chapter Four: Methods

As discussed in Chapter Three, section 3.4 (see pp.66-73), I have taken the stance of hermeneutic phenomenology following Van Manen's (1990, p.28) "*in pursuit of knowledge*". This chapter provides a detailed explanation of the study's design encompassing the population, sample, and setting; sampling and recruitment of participants; data collection methods, procedures, and resources; data analysis process informed by Van Manen's (1990) six research activities and ethical considerations. The chapter concludes with the methodical framework which delineates how Van Manen's (1990) six research activities were used to guide the study.

4.1 Design

The study is qualitative in design, using a hermeneutic phenomenological approach. The data consists of thirteen face-to-face audio recorded interviews; one interview was conducted per participant.

4.1.1 Population, Sample and Setting

The study's population consisted of RNLD and PCPs who had or are still caring for PCDLD experiencing distress in palliative care settings.

The inclusion criteria for the sample were as follows:

Potential participants were required to:

- Be RNLDs and PCPs.
- Have experience of, or are working with distressed PCDLD in palliative care settings.
- Be willing to articulate their experiences.
- Be agreeable to consent by signing the written consent form.
- Be aware that they are free to withdraw from the study at any time by informing the researcher.
- Be over the age of 18 years.

RNLDs and PCPs were excluded from the study if they were still struggling with a past experience of working with PCDLD. Including them may have added another dimension to study's findings. However, the reason for their exclusion was that I could not ensure that I would be able to provide them with the counselling or therapeutic support they might require, which would have ethical implications related to the wellbeing of

participants and potentially create a sense of unease thus, affect the conduct of the investigation. Coyle and Wright (1996) and Dickson-Swift, James, Kippen and Liamputtong (2006) explained that some participants may have difficulties differentiating between research and therapy. Also, it has been agreed that individuals should participate in research only when the risks are justifiable and an individual's participation is voluntary and informed (Dickson-Swift et al., 2007; Ely, Anzul, Friedman, Garner and Steinmetz, 1991).

The intended sample size was fifteen. This is because it has been recognized that qualitative samples must be large enough to guarantee that most or all of the preconceptions that might be important are revealed, but at the same time if the sample is too large data becomes repetitive and, eventually, unnecessary (Mason, 2010). Thus, I was mindful of saturation when conducting interviews especially because the study aimed *to gain an in-depth phenomenological understanding of how RNLDs and PCPs identify and respond to the distress of PCDLD in palliative care settings*. Charmaz (2006) explained that the aims of qualitative studies are the definitive device in deciding the project's design and hence the sample size.

The settings consisted of learning disability nursing homes, hospices and community learning disability teams in the North of England.

4.1.2 Sampling and recruitment of participants

Participants were selected who were considered to possess a wealth of information, and who could potentially answer the research question and inform the aim and objectives of the study (Green and Thorogood, 2009; Oliver, 2004; Reed, Proctor and Murray, 1996; Silverman 2010), and they were also selected for the purpose of sharing their knowledge (Crotty 1996; Munhall 2007). Purposive sampling was used complemented by demographic questionnaires intended to capture a representation of diversity of age, gender, and experience of RNLDs and PCPs who care for PCDLD experiencing distress in palliative care settings.

The outcome of utilizing purposive sampling and demographic questionnaires was a sample which comprised of eight Registered Learning Disability Nurses (RNLDs) and five Palliative Care Professionals (PCPs) who met the inclusion criteria for the sample as detailed in section 4.4.1. All participants had experience of caring for distressed people with communication difficulties and a learning disability (PCDLD) in palliative care settings, trained to the required professional status of registered nurses or social worker and reported that they had attended various study days and workshops relating to

palliative care and learning disabilities. Participants completed a demographic questionnaire prior to the start of each interview session. Of the thirteen participants (see Table 4.1 overleaf), two were male, and eleven were female. All participants were Caucasian except for one who was of Black African origin. The sample reflected the rich diversity of age and experience. The participants were mature professionals. This was in terms of their chronological ages; their years of professional experiences and the years of experience in their current roles (see Table 4.1, overleaf).

Table 4.1 Demographical characteristics of the participants

Gender	Role	Professional experience (years)	Experience in current role (years)	Relevant specialist training and education	Age range
Female	RNLD (CM)	28	1 year and 8 months	LD Health Facilitation	50-55
Female	RNLD (CM)	14	2	BSc Health Studies	38-43
Female	RNLD (Lead Nurse Practice Development and health facilitation)	14	3	PLD, Older Adults and Dementia.	50-55
Female	RNLD (CM)	19	1 year and 9 months	BSc Combined Health Studies	30-43
Female	Senior PCSW	20	15	PCSW	50-55
Female	PCN (Nurse in-charge Palliative care Support and therapy)	1 year 6 months	1 year and 6 months	PCN, support and therapy	44-49
Female	CNS	6	1	CNS	50-55
Male	CNS	15	15	Palliative care	44-49
Female	CNS	8	8	BSc	50-55
Female	RNLD in CTLD	9	7	BSc	38-43
Female	RNLD	5	5	MSc (LD QoL), RGN and Diploma in Epilepsy	38-43
Female	RNLD (Nursing home manager)	21	8	MSc (LD QoL) and Diploma in Epilepsy.	44-49
Male	RNLD (Nursing home manager)	19	3	RNLD	38-43

Key to abbreviations:

Bachelor of Science degree: BSc, Community Matron: CM, Clinical Nurse Specialists: CNS, Community Team Learning Disabilities: CTLD, Learning Disability Quality of Life: QoL, Master of Science degree: MSc, Palliative Care Nurse: PCN, Palliative Care Social Worker: PCSW, People with Learning Disabilities: PLD, Registered General Nurse: RGN, and Registered Nurse Learning Disabilities: RNLD.

Participants were recruited from a hospice, learning disability nursing homes and community services, informed by a list provided by the learning disabilities complex needs matron, and chair of the regional network of learning disabilities and palliative care professionals. Recruitment was also achieved through word of mouth and by personal and local networks for learning disabilities and palliative care nurses.

Ethical issues related to recruitment

Initial approaches were made to managers or gatekeepers to clarify that the research numbers would be available. Following approval from the university based School Research Ethics Panel (SREP) and permission from the unit managers of the organisations where interested participants work, formal letters of invitation to take part in the study were sent to RNLDs and PCPs who had expressed an interest in taking part in the study (see Appendix 5, pp.274-275).

An informed consent form (see Appendix 6, pp.276-277), and an information sheet detailing the nature and purpose of the study were also enclosed (see Appendix 7, pp.278-282). The information sheet clearly stated that participation in the study would depend on meeting the inclusion criteria and giving informed consent by signing the written consent form. Participants were not compelled to sign and were free to withdraw from the study at any time by contacting me. Interested participants were contacted by phone or email to set a date, time and place for a meeting, during which participants could ask for any clarifications regarding the purpose of the study. Then a date, time and agreed convenient place was set for interviews.

Prior to applying for approval from the SREP for the current study, I had intended to include client/patient participants in the study. I had read about ethical dilemmas and issues about involving vulnerable adults in research, and due to the communication difficulties and learning disabilities of potential client participants, procedures which ensure and promote ethical and legal rights had to be carefully considered. Recruitment would have adhered to the guidance put forward by the Department of Health (2008b) 'Guidance on nominating a consultee for research involving adults who lack capacity to consent, issued by the Secretary of State and the Welsh Ministers in accordance with section 32 (3) of the Mental capacity Act 2005'. This is in relation to safeguards for the conduct of research involving those who may not be able to consent due to impairment such as a learning disability, and illness such as dementia, brain injury, or mental health problems. Subsequently the information sheet, letter of invitation and consent form had been written up to ensure that potential client participants would be supported to provide valid consent by an appointed or nominated consultee in cases where they could not consent for themselves. However due to the problems I faced in gaining access, the time constraints, and the seemingly limited awareness of the gatekeepers on the issue of involving vulnerable adults in research, that venture had to be abandoned in favour of the current study.

This had ethical implications because it has been argued that it would be unethical to exclude people with learning disabilities (PLDs) especially those with more severe

learning disabilities from studies that could give insight into their experiences and help to shape sensitive care in the future (Tuffrey-Wijne, Bernal, and Hollins, 2008). Although it is imperative to value the experiences of PLDs with the conduct of inclusive or participatory research (Cocks and Cockram, 1995), there are still substantial challenges (Kierman, 1999). Such challenges are reflected in the argument that research terms of engagement are negotiated between everyone involved and protocols have to focus on how rapport is established and boundaries maintained and monitored (Cameron and Murphy, 2007). Rapport-building between the researcher and participants requires skills which could be lacking for PLDs although, sometimes their professional carers and friends could provide this (Pockney, 2006). However, given that I was unable to gain access, I had to settle for the current study. Beresford, Tozer, Rabiee and Sloper (2004) explained that a challenge faced by researchers is to decide if the research is on or with PLDs.

4.1.3 Data collection methods, procedures and resources

Data were collected by semi-structured face-to-face audio-recorded interviews, field notes and demographic questionnaires. Interviews were deemed a suitable method of data generation for this study because it was perceived that the interviews would allow the participants the time and scope to talk about their opinions on the phenomenon under study. Interviews allow for the building of a rapport with the participants. It has also been identified that the one-to-one personal relationship that an interview provides is more effective in eliciting respondents' sincere participation in a research study (Thomas, 2003). The focus of the interviews was to understand the participant's point of view about the phenomenon of interest. Interviews can provide insights into a participant's private experiences and thoughts and provide first hand verbal and recorded information from a participant to answer the research question (Holland, 2001).

Prior to the actual collection of data as explained in the next paragraph, initial semi-structured questions were piloted with some RNLDs and PCPs who had no intention of participating in the study. The pilot was significant and successful because it enabled me to test the suitability of the questions and I was able to refine the questions before the commencement of the actual data collection.

The data collection procedure ensured that a convenient time for the interviews was negotiated with participants to avoid the risk of participants feeling coerced and to avoid possible risks of interruptions. Anonymity, confidentiality and privacy were assured.

Pseudonyms were used to enhance anonymity and confidentiality. All interviews were conducted in a quiet, private, convenient and safe location of the participants' choice.

After obtaining written informed consent from the participants, the number of interviews conducted was not fixed. The interviews were flexible and the duration of the interviews ranged from 25 to 90 minutes depending on the willingness of the participant to continue, and also to answer probing questions arising from experiences described. This had no physical risk to the participant and the participant had a choice to stop when he or she wanted.

Interviews were conducted and the data simultaneously analysed. The questions and prompts were adapted throughout the study to reflect emerging themes. I listened to the audio-recorded interviews and transcribed them verbatim. Therefore, the developing categories, clusters and themes determined the number of interviews needed. When no new theme could be identified from the data, saturation had been achieved. This occurred by the thirteenth interview.

The interview schedule for this study was divided into two sections. Section one consisted of a questionnaire used to collate demographical details of the participants, (see Appendix 8, p.283). This was to ensure that the data demonstrates diversity in terms of participants' age, gender and experience. These were planned to be completed prior to the start of each interview to minimise the chances of participants forgetting to complete the questionnaires. This allowed me to collect a substantial quantity of data in a relatively short period of time (Thomas, 2003a).

Section two consisted of a list of proposed semi-structured questions and prompts, which were formulated with a view of meeting the aim and objectives of the study (see Appendix 9, pp.284-285). They served as a checklist during the interview and ensured that basically the same information was obtained from a number of people, yet allowing for some degree of flexibility (Lindlof and Taylor, 2002). Lindlof and Taylor (2002, p.195) state that it is generally beneficial for the interviewer to have an interview guide, which is an informal "*grouping of topics and questions that the interviewer can ask in different ways for different participants*".

Non-verbal prompts such as head nods and silence were used to allow the participants to think, recall and tell their stories. At the end of the interview, I provided participants with the option to continue if they wanted.

Field-notes were used to complement the semi-structured interview questions and prompts and also, to enhance data collection as they included aspects of the study context like facial expressions and gestures that cannot be recorded on tape (Holloway,

1997, 2005; Morse and Field, 1996). The field-notes included a combination of raw data from the participants' interviews, my personal reflections, and detailed description that enhanced the remembrance of events in the setting. These were written during and immediately after each interview session and added to the transcripts of the interviews.

The resources used during the process of data collection and analysis included a digital audio recorder, a journal for field notes and personal reflections, a mobile phone to contact participants, a computer for transcribing data and the library for information.

4.1.4 Data analysis

The process of hermeneutic data analysis used in this study was an adaptation informed by Van Manen's (1990, pp.30-31) six research activities. First, I will state the six research activities. Second, a table will be provided to demonstrate how these activities have informed the data analysis process. It is worth-mentioning that the six research activities are also, fundamental in terms of the methodical framework of this thesis. To avoid repetition a brief description of each of the research activity will only be provided in (section 4.2: Study framework) of this chapter. The six research activities are:

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 essential themes which characterize the phenomenon.
4. Describing the phenomenon through the act of writing and re-writing.
5. Maintaining a strong and oriented pedagogical relation to the phenomenon.
6. Balancing the research context by considering parts and whole (Van Manen, 1990, pp.30-31).

The six research activities informed the data analysis process as demonstrated in Table 4.2 overleaf.

Table 4.2 How the Six Research Activities informed the Data Analysis Process

Six Research Activities	Data Analysis process
1. Turning to a phenomenon which seriously interests us and commits us to the world.	The activity of interest was the phenomenon under study: (RNLDs and PCPs experiences of how they identify and respond to the distress of PCDLD in palliative care settings. Also their perceptions about factors which determine how this population communicated distress in palliative care settings). Verbatim transcription of participants' interviews provided insight into to the phenomenon under study.
2. Investigating experience as we live it rather than as we conceptualize it.	An insight into the lived world of the participants was attained through the semi-structured audio-recorded interviews that was conducted with them. The audio-recorded interviews were listened to and transcribed verbatim. The transcripts were read several times to elicit the implicit or essential meaning of participants' experiences of caring for PCDLD experiencing distress in palliative care settings.
3. Reflecting on essential themes which characterize the phenomenon	Van Manen's (1990, pp.92-93) initial approaches of isolating themes comprising of the " <i>wholistic approach, the selective or highlighting approach and the detailed or line-by-line approach</i> " was used. The thematic categories from the initial approaches of isolating themes were scrutinized for meaning and clustered into main themes.
4. Describing the phenomenon through the act of writing and re-writing.	The thematic facets were further examined and grouped to identify similarities or differences pertaining to the meaning the phenomenon under study had for both the RNLDs and PCPs.
5. Maintaining a strong and oriented pedagogical relation to the phenomenon.	The existential approach was used. This took into consideration the wider significance of the emerging themes as essential structures of the participants lived experiences within the framework of Van Manen's (1990) life-world existential of spatiality (lived space), corporeality (lived body), temporality (lived time), and relationality (lived relationships or communality).
6. Balancing the research context by considering parts and whole (Van Manen, 1990, pp.30-31).	The essential thematic categories were further examined to identify the essence or fundamental nature of the phenomenon of caring for PCDLD experiencing distress in palliative care settings for the RNLDs and PCPs who have lived the experience.

Therefore, the process of hermeneutic data analysis was applied in this study as follows:

1. A verbatim transcription of participants' interviews immediately after the interview sessions was done.
2. The text was read several times to elicit the implicit or essential meanings of participants' experiences of caring for PCDLD experiencing distress in palliative care settings. Thematic categories were isolated using the "*wholistic approach, the selective or highlighting approach and the detailed or line-by-line approach*" (Van Manen, 1990, pp.92-93).
3. The thematic categories from the initial approaches of isolating themes were clustered into more concise themes and in terms of the different depth of understanding of the meaning of participants' lived experiences. This assisted the flow of the interpretive summaries of the analysed data.
4. The thematic facets were grouped to identify similarities or differences pertaining to the meaning the phenomenon under study had for both the RNLDs and PCPs.
5. The existential approach was used. This took into consideration the wider significance of the emerging themes as essential structures of the participants lived experiences within the framework of Van Manen's (1990) life-world existential of spatiality (lived space), corporeality (lived body), temporality (lived time), and relationality (lived relationships or communality).
6. The essential thematic categories were further examined to identify the essence or fundamental nature of the phenomenon of caring for PCDLD experiencing distress in palliative care settings for the RNLDs and PCPs who have lived the experience

See (Appendix 13, pp.293-341) for worked example of the data analysis process using a participant's transcript.

4.1.5 Ethical considerations

Stringent ethical practices were observed throughout the study as evidenced by Section 4.1.2 of this chapter. This is in terms of ethical guidelines around ethical approval, privacy, provision of participants' information in terms of confidentiality, anonymity and an opportunity to withdraw, obtaining informed consent, and correct and safe handling and storage of data. However, I am bound by the Nursing and Midwifery Council's (NMC, 2013) Standards of Conduct, Performance and Ethics to disclose information if a patient/client may be at risk of harm. Furthermore, approval was gained from the university based School Research Ethics Panel (SREP) and permission from the unit

managers of the organisations where interested participants work. I also ensured that during the conduct of this study, there were no physical risks involved for participants. However, in my case, there was the potential of risk to self (lone worker risk) when interviewing participants. To minimise this, the University of Huddersfield Risk Analysis Form was completed (see Appendix 10, pp.286-287).

It has been recognized that the detailed character of qualitative research can mean intimate engagement with the private and public lives of individuals (Munhall, 2007). In addition, the changing direction of interest and access during a qualitative study mean that new and unexpected ethical dilemmas are likely to arise during the course of the study (Manson, 2002). However, to minimise such ethical dilemmas the researcher should decide what the purpose of the research is, examine individuals or groups that might be affected or interested by the research topic, and consider the implications for these parties of framing the research topic (Mason, 2002; Silverman, 2010). In the writing of this thesis, I maintained a reflective approach with the acknowledgement of any previous personal experience, to minimise the potential for bias in terms of my experience as a RNLD. This study was a major undertaking lasting four years. The study maintained a well-planned approach throughout under academic supervision and scrutinized at intervals by progression monitoring requirements within the university.

4.2 Study framework

In expounding the methodical framework of the current study, the goal of this section is to explicate how the six activities (Van Manen, 1990) have been utilized or divided into related parts of my thesis as an emphasis on how data was synthesized and the structure of a hermeneutic phenomenological text. Firstly, I will state the six research activities and provide a brief description of each. Secondly, a table (Table 4.3) is provided to demonstrate how Van Manen's (1990) six research activities have been divided into related parts of this thesis. This will enhance clarity and allow the reader to gain a deeper and more profound understanding of the nature or meaning of the phenomenon of caring to the participants.

The six research activities are:

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 essential themes which characterize the phenomenon.
4. Describing the phenomenon through the act of writing and re-writing.

5. Maintaining a strong and oriented pedagogical relation to the phenomenon.
6. Balancing the research context by considering parts and whole (Van Manen, 1990, pp.30-31).

Research activity One: *"turning to a phenomenon which seriously interest us and commits us to the world"*, Van Manen stated that:

Every project of phenomenological inquiry is driven by a commitment of turning to an abiding concern... Phenomenological research does not start or proceed in a disembodied fashion. It is always a project of someone: a real person who in the context of particular individual, social, and historical life circumstances, sets out to make sense of a certain aspect of human existence (Van Manen, 1990, p.31).

In terms of research activity Two: *"investigating experience as we live it rather than as we conceptualize it"*, Van Manen stated that:

Phenomenological research aims at establishing a renewed contact with original experience. This turning to some abiding concern of lived experience has been called *"turning to the things themselves,"* Zu den Sachen (Husserl, 1911/80, p. 116).... it means that phenomenological research requires of the researcher to.....stand in.....the midst of the world of living relations and shared situations.....it means that the researcher actively explores the category of lived experience in all its modalities and aspects (Van Manen, 1990, pp.31-32).

In relation to research activity Three: *"reflecting on essential themes which characterized the phenomenon"*, Van Manen stated that *"a true reflection on lived experience is a thoughtful, reflective grasping of what it is that renders this or that particular experience its special significance"* (Van Manen, 1990, p.32).

In terms of research activity Four: *"describing the phenomenon through the act of writing and rewriting"*, Van Manen (1990, pp.32-33) explained that to undertake phenomenological research is *"bringing to speech of something".....and phenomenology is the application of logo (language and thoughtfulness) to a phenomenon (an aspect of lived experience)....."* to portray the fullness of that experience.

In relation to research activity Five: *"maintaining a strong and oriented pedagogical relation to the phenomenon"*, Van Manen (1990, p.33) explained that taken into consideration the demanding nature of an in-depth phenomenological inquiry, in order not to get unfocused, we must *"be strong in our orientation"* and not *"settle for superficialities and falsities"*.

In explicating research activity Six: *"balancing the research context by considering parts and whole"*, Van Manen (1990, p.33) stressed that to ensure a thorough phenomenological text or study, it is necessary to *"constantly measure the overall design of the study/text against the significance that the parts must play in the total*

textual structure". This also requires that the study answers the research question, aim, and objectives, and incorporates relevant research literature and theories to enhance understanding of the findings. This movement from parts and whole is fundamental in hermeneutic phenomenology (Van Manen, 1990).

Table 4.3 overleaf is an illustration of how these research activities have been divided into related parts of this thesis. The table also provides an explanation of the related research activity.

Table 4.3 Research activities, related thesis part and explanations

Research Activities	Related thesis part	Related research activity and outcome
1. Turning to a phenomenon which seriously interests us and commits us to the world.	Introduction	This included background to the study and the choice of the research or subject area.
2. Investigating experience as we live it rather than as we conceptualize it.	Literature review chapter and also, the methods chapter.	The literature review identified gaps in literature. It informed the research question, aim, and objectives of the study. The methods employed allowed for dialogue with participants (interviews).
3. Reflecting on essential themes which characterize the phenomenon.	This encompassed the data analysis: isolation of themes chapter, the interpretation of the findings chapter, and the discussion chapter.	Sub themes were isolated and clustered into main themes. The main themes were considered within Van Manen's (1990) four lifeworld existential themes. These were further examined to identify the essence or fundamental nature of participants' lived experiences. Relevant literature and theory were included throughout.
4. Describing the phenomenon through the act of writing and rewriting.	This consisted of the data analysis: isolation of themes chapter, the interpretation of findings chapter, and the discussion chapter. Relevant theory and literature were incorporated in these chapters as appropriate.	Utilizing a reflective approach within the analysis, interpretation and discussion chapters. Creating an animating, evocative text of participants' lived experiences. Create a better understanding of the research process and moment.
5. Maintaining a strong and oriented pedagogical relation to the phenomenon.	This included the following chapters: Data analysis chapter in terms of the isolation of sub and main themes, the interpretations of the findings chapter, and the discussion chapters	Remaining focused on the phenomenon under study, the research question, aim, and objectives in order to identify thematic categories, and any implications or recommendations for practice, education, policy and research.

6. Balancing the research context by considering parts and whole.	This encapsulated the research proposal, the plan and context of the study in terms of: the background to the research, the methodology and methods, interpretation, and discussions of the strengths and limitations of the thesis as an hermeneutic phenomenological research.	Creating a thesis that ensures that the findings are illustrative of the thematic analysis of the data and reflective of the circular movement between pre-understanding and interpretation which is imperative in hermeneutic phenomenology.
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4.3 Chapter Summary

In this chapter I have presented the methods used in planning and conducting the study. A detailed explication of the study's population, sample and setting; sampling and recruitment of participants; data collection methods, procedures and resources; data analysis and ethical considerations were provided. The chapter was completed with an illumination of how Van Manen's (1990) six research activities were divided into related parts of this study with the goal of emphasizing the structure of hermeneutic phenomenological writing and how data was synthesized.

The following chapter presents the findings relating generated from utilizing steps one to four of the six steps data analysis process.

Chapter Five: Findings

This chapter presents the findings of this study in terms of identifying the sub themes and main themes. It includes two sections. Firstly, the findings generated from utilizing steps one to four of the six steps data analysis process will be presented. Steps five and six, which are more related to the interpretive component of the data analysis process will be presented and discussed in Chapter Six: Interpretation of the findings. Lastly, a conclusion and chapter summary is provided.

5.1 The Interviews

This section presents the findings generated from utilizing steps one to four of the six steps data analysis process (see Figure 5.1, overleaf) in terms of illuminating how RNLDs and PCPs identified and responded to the distress of PCDLD in palliative care settings. In addition it identifies factors which determine how PCDLD communicate distress in palliative care settings from the RNLDs' and PCPs' perspectives. The findings from steps one to four of the data analysis process are presented as distinct sections in this chapter.

1. Verbatim transcriptions of participants' interviews immediately after the interview sessions were done.
2. The text was read several times to elicit the implicit or essential meanings of participants' experiences of caring for PCDLD experiencing distress in palliative care settings. Sub themes were isolated using the initial approaches of isolating themes comprising of the "*detailed or line-by-line approach, the selective or highlighting approach and the wholistic approach*" (Van Manen, 1990, pp.92-93).
3. The sub themes from the initial approaches of isolating themes were clustered into more concise themes and in terms of the different depth of understanding of the meaning of participants' lived experiences. This assisted the flow of the interpretive summaries of the analyzed data.
4. The themes were re-examined to identify similarities or differences pertaining to the meaning the phenomenon under study had for both the RNLDs and PCPs.
5. The existential approach was used. This took into consideration the wider significance of the emerging themes as essential structures of the participants lived experiences within the framework of Van Manen's (1990) life-world existentials of spatiality (lived space), corporeality (lived body), temporality (lived time), and relationality (lived relationships or communality).
6. The essential themes were further examined (hermeneutic circle) to identify the essence of the phenomenon of caring for PCDLD experiencing distress in palliative care settings for the RNLDs and PCPs who have lived the experience.

Figure 5.1 Six steps data analysis process

5.2.1 Step one: Verbatim transcriptions

The time and place for the conduct of the interviews were based on participants' preferences. The interviews were flexible because participants were free to stop at any given point if they chose. The duration ranged from between twenty-five to ninety minutes depending on the willingness of the participant to continue and answer further questions. The interviews were transcribed verbatim immediately after the interview sessions.

5.2.2 Step two: Isolating themes

Three approaches were initially used to isolate themes from the typed narrative transcripts. These included the “*detailed or line-by-line approach, the selective or highlighting approach, and the wholistic or sententious approach*” (Van Manen, 1990, pp. 92-93). For purposes of lucidity, these approaches will be elucidated as distinct sections.

The detailed or line-by-line approach

The detailed or line-by-line approach necessitated that participants’ transcripts were read line-by-line several times. Each sentence or sentence cluster was scrutinized with the view of developing an insight into the phenomenon under study and also, to gain an understanding of participants’ experiences (Van Manen, 1990). The outcome of this was the identification of words, statements, phrases, sentences and paragraphs that seemed to reflect important facets in terms of RNLDs and PCPs experiences of caring for distressed PCDLD in palliative care settings.

The selective or highlighting approach

The selective or highlighting approach involves “*reading a text several times and ask, What statement (s) or phrase (s) seem particularly essential or revealing about the phenomenon or experience being described? These statements we then circle, underline or highlight*” (Van Manen, 1990, pp.93). I meticulously ensured that all important words, phrases, or statements from each transcript that illustrated the participants’ experiences in terms of how they identify and respond to the distress of PCDLD in palliative care settings were highlighted. The highlighted texts were conceptualized according to meanings and later transformed into themes. Nineteen sub themes were identified: (1) Building relationships (2) Successful care (3) Pride and job satisfaction (4) Sincerity and sensitivity in care (5) Purposefully looking at the whole person (positive regard of personhood) (6) Empathy (7) Therapeutic touch (8) Training and providing a dignified end (9) Pain-free care (10) Comfort, safety and peace (11) Acknowledgement of shortcomings (12) Time and anxiety (13) Time and caring opportunities (14) Dying as part of living (15) Care environment and aesthetic knowing (16) Optimism (17) Proactive collaboration (18) Future improved access (19) Meeting expectations.

I provide examples of quotes from participants’ transcripts explicating the nineteen sub themes relating to how participants identified and responded to the distress of PCDLD, and also, the identified factors which determine how PCDLD communicate distress in

palliative care settings. It is worth mentioning that the participants were given fictitious names to maintain participants' anonymity and confidentiality.

Sub theme 1: Building relationships

Participants' transcripts illustrated that knowing by building relationships was an approach used to identify and respond to the distress of PCDLD in palliative care settings. Participants demonstrated that in order to meet the needs of distressed PCDLD in palliative care settings they had to build relationships at three levels namely: with the PCDLD, their family members and between the RNLDs and PCPs.

Building relationships with PCDLD

Participants' descriptions illuminated a commitment to developing an intuitive professional and personal relationship with the distressed PCDLD. Such relationships enhanced the development of a pattern of verbal and non-verbal communication, which was fundamental in anticipating the distress of PCDLD and also facilitated the response to their distress with the provision of optimum care. Laura said:

"...with time they were really good with the non-verbal communication and the sign language, showing do you want a drink so let's do that? There was a lot of non-verbal communication going on that was a mixture of some signing and.....I don't think that was from a traditional route. It was just what they developed to communicate with him, anticipate his feelings, identify when he was distressed and how to relief his distress and meet his needs you know, do you want to eat or a drink? Do you need to go to the have a wee? So a lot of non-verbal communication and he got really good at it and they got really good at it and the other day care patients got really good with him" (Laura, Ln.376-391, PCSW).

The commitment to building relationships was integral to the RNLDs' and PCPs' caring role; the depth of the relationships developed over time enabled the participants through observation of body language to anticipate the distress of PCDLD. The participants were able to respond by providing appropriate optimum care to relieve their suffering. Gary declared:

"...just knowing people over a period of time I think enables you to anticipate things and you pick up on things, body-language that in a hospital setting with the best will in the world staff wouldn't be able to do because they wouldn't just know clients well enough and I think it would be wrong to expect people to because if we had clients that were coming in for three or four days at a time we wouldn't know them like that you know, you just can't..." (Gary, Ln.488-496, RNLD).

Moira said:

"So absolutely I think for you to provide the optimum care for people with learning disabilities and to provide a quality service you as the health professional must be able to communicate with them and understand their communication. I think that is a cardinal point. I think that should be the cornerstone of care because without that nothing can go forward. That's they rely on you, their whole lives are in your hands. That's the way I feel and it's a scary thought" (Moira, Ln. 594-602, RNLD).

Sue reaffirmed this view with the expression:

"Right, getting to know him,it was quite endearing really because he had a standard phrase he would say 'you're sacked' if he didn't like what you were saying or if he was becoming distressed for whatever reason, he would say 'you're sacked, go away, you're sacked' and I think we soon learnt that the more he said that it indicated his level of distress" (Sue, Ln.43-49, CNS).

Building relationships with family members and carers

Participants' descriptions also revealed that building professional and interpersonal relationships with family members and carers of the PCDLD was fundamental to the attainment of foundational knowledge required to understand the distressed PCDLD. This was in terms of blending their past history and the present manifestations of their behaviour, physical and emotional state and over time utilizing that understanding or knowledge to identify and respond to their distress within palliative care settings. Jane stressed:

"I think it's probably because of the skills that I have and the experience that I have with people with learning disability although when he was allocated to me I had never met him before. Obviously you go through a process but I suppose it's just that I work so closely with him for such a long time as did the care providers that provided him with support in his own house. They had worked with him for about 5 years so they were a great source of err valid information and plus there are certain things, certain ways that you would approach somebody who is autistic so you adopt those strategies don't you?" (Jane, Ln.128-139, RNLD).

Gary stressed:

"I think being in a small home setting you get to know clients wider circle as well. You get to know the families well and they will share information with you from that client's childhood and it can be very significant and you don't always have that information in terms of written documentation so that can be hugely helpful but I think a learning disability nurse it's the inter-personal skills I think that we have that puts us at a real advantage and...., without them you can't provide good quality end of life care. So I think they are massively important" (Gary, Ln. 497-509, RNLD).

Viv affirmed this view with the expression:

"I think my relationships with family were quite good. They would call if they were worried, they were quite accepting about having me in the house," (Viv, Ln. 149-152, RNLD).

The knowledge acquired from family members and carers was not only significant in the development of an understanding of the PCDLD but subsequently, the knowledge became imperative in identifying and responding to their distress. This was by virtue of an acquired insight into the factors, which determine how PCDLD communicate distress such as being cared for by unfamiliar carers.

Lyn declared:

"Yes I am sure it does because obviously depending on the setting they are being cared for and how familiar the carers are, I found that in the past if they have got very familiar carers, those carers have been very good at picking up the non-verbal cues particularly around pain and distress and being able to very well identify what the problem is. That's been more of a problem if people who haven't been around or from any of our agency carers that maybe aren't as tuned in so that's made caring a little bit more difficult. Knowing their communication is key in care" (Lyn, Ln.39-49, RNLD).

Building mutual professional relationships

Knowing by developing mutual professional relationships portrayed the participants' experience with each other either as members in a team of professionals from the same field, or working in collaboration as members of a team encompassing health professionals from different fields who are directly involved in the care of the distressed PCDLD in a palliative care setting. Collaborative working was thus a vital method to facilitate the identification of the distress of this population in palliative care settings. To appropriately respond to the distress of PCDLD, participants recognised they also needed to develop honest professional relationships and support each other to ensure quality care. Tracy declared:

"I think it's absolutely crucial that learning disability professionals and palliative care professionals work together, joint working and collaboration in meeting somebody's needs....." (Tracy, Ln.420-423, RNLD).

In a similar line of thought Edith affirmed:

"...the more experience and the more knowledge you get of your different client groups the better. You know, working collaboratively with different professionals can only add to that experience. I think it benefits the patients and their journey using if you like, a multi-disciplinary approach," Edith, Ln.126-132. (CNS).

Adam said:

"I suppose my reassurance to them was that we would work together as a team, yes and we did and I visited him and they would say 'he's been showing signs of increasing pain this last few days, we have been giving him this medication, it does seem to work so what do you make of that?' and I would go from there" (Adam, Ln.144-150, CNS).

Sue affirmed this view:

".....we referred to the IMCA service and they came along.....that was obviously to get the syringe driver and to act in his best interests so in other words to do something that he didn't want us to do, that he wasn't consenting to do but we did it so I remember an IMCA became involved..... We just liaised quite closely with his team of key workers and.....he had lived out in the community and supported by his key workers.....so for quite a while I remember they would come along and help us to mediate between them because obviously David knew them and didn't know us....." (Sue, Ln.182-197, CNS).

Sub theme 2: Successful care

Participants' drew inspiration from past and current effective care interventions with distressed PCDLD to plan future care interventions. By reflecting on effective care interventions, participants were motivated to train and acquire more skills in end-of-life care (EoLC) and subsequently, utilize those skills to provide confident care to this population in palliative care settings. In line with the above view, Edith said:

"It was a really positive experience and I think for the staff as well and they didn't have that much experience of clients dying if you like. I think it helped them a great deal because they had looked after her for a long time and to be involved in that final stages where she was really comfortable and settled and you know it helped them deal with her death if you like" (Edith, Ln.98-102, CNS).

The ability to readily draw from past professional or personal experiences of caring, enabled the participants to provide appropriate confident care. This view was affirmed when at the end of an interview Paula, a CNS, had requested not to have the closing comments audio recorded but had consented for me to write down the comments verbatim in my fieldnotes of 6/12/11 and subsequently, use the comments as stated below after verification of the contents by the participant. Paula said:

"It was the frustration of the protectiveness of some carers and family members that really got to me...The social workers thought the client cannot cope with being told about his disease but I think if we had more or longer time with him in our care, we would have told him and we would have explained to his brother the need to do so...Well I hope his brother will be fine. This man died last week. You see, that's the second brother he has lost. I spoke to him and he said he was ok. I hope he comes back to us for bereavement and counselling. You see, I have personal experience with learning difficulties. My sister's son has autism err, and sometimes she can be very protective. I understand though. But things are

changing. It is a way forward and it was a wonderful and satisfying experience as a professional. It is that understanding of your own self as a person and a personal experience that sometimes gives you confidence to care,” (Fieldnotes, 06/12/11).

Sub theme 3: Pride and job satisfaction

Participants acknowledged that effective care interventions facilitated caring for this client group. This also created a sense of pride and job satisfaction when they efficiently utilized specialist skills to meet the needs of this population and their families within palliative care settings.

Paula echoed this view with the declaration:

“I personally found it a very positive experience. Because it was only this last week that he died. So we spoke and obviously reported to everybody and they gave us all a sort of pat on the back because I think we did a good job. I think in the short space of time we had we ended up with a good rapport with the carer and we managed to get him here, he died a comfortable dignified death. I think it would have been nicer to have a bit more time to explore other things but I think with what we had we did a good job and it was nice, it was umh you know, it wasn't something I'd normally do. He fitted in with everybody. Once he had settled everybody felt comfortable, the staff as well, it was just normal for him to come I think. It wouldn't be an issue” (Paula, Ln.338-351, CNS).

Viv confirmed:

“..... I was confident that working in collaboration with the staff who knew her very well and with other health professionals we were able to meet her needs,” (Viv, Ln.77-80, RNLD).

Lyn declared:

“It was how his family wanted it to be. It was at home.....We were satisfied that we were able to meet his needs as he wanted and the family were happy and he had a dignified dead” (Lyn, Ln.242-254, RNLD).

Edith affirmed this view:

“They absolutely excelled in looking after this lady. They took it in turns to stay with her. She was in her own room with her favourite music, dressed in all her favourite colours with everything familiar around it so it was a really positive experience....” (Edith, Ln.158-162, CNS).

Sub theme 4: Sincerity and sensitivity in care

Sincerity and sensitivity in care was portrayed as a keen attention to details. The participants were authentically present and observant hence, able to identify subtle changes in the facial expressions of the dying PCDLD. The changes might be indicative of pain or emotional distress. Participants responded to identified distress by purposely

offering themselves to be with not only the PCDLD who might be grieving due to a sense of loss and confusion at their disease trajectory, but also with their family members during the end of life stage and in the aftermath of the death of their relatives. Gary said:

"I mean obviously myself and the whole team we knew the lady was dying so as I say it wasn't a sudden death and her end of life probably in terms of specific end of life care where we withdraw any kind of life enhancing treatments went on for about two weeks which is quite a long period of time. We formed quite close links with the family, her sister in particular, so yes it had a big impact" (Gary, Ln. 159-166, RNLD).

Tracy said:

"I think it was at that stage that he knew and he accepted it and he had this look of resignation on his face and he accepted it. I believed him. He took a turn for the worse and within a few days he had passed away" (Tracy, Ln.140-144, RNLD).

"I supported mum to go there with him when he did pass away and he actually had a learning disabled brother whom we took over to the hospice as well and the brother went in and I felt that, that was very important for the brother to see that his brother had passed to help him have that understanding that he was no longer here," (Tracy, Ln.144-150, RNLD).

Viv reiterated the significance of being sensitive towards the distressed PCDLD by a readiness to provide the best possible care with the declaration:

"Yes I think that was more difficult and perhaps because the first person everything seemed to slip into place very easily.....whereas the second person was a bit messier because he had been discharged from hospital, he was supposed to die more quickly. He didn't,.....there just seemed to be a bit more crises.....and much more emotionally laden so that was more difficult definitely. But it was getting in there when we had to, being sensitive to what they were feeling and sincere really about the person's condition to family especially that this is just a phase of his life and they will eventually die" (Viv, Ln.127-142, RNLD).

Sub theme 5: Purposefully looking at the whole person (Positive regard of personhood)

Participants' transcripts indicated that purposefully identifying with the suffering of PCDLD and a positive regard of the whole person (personhood) was essential in identifying and responding to their distress with the provision of optimum care. Also participants demonstrated awareness that utilizing attributes attained from their own previous bodily experiences of suffering as human beings could enhance their ability, through observations and interactions with PCDLD, to notice different physical and behavioural changes and appropriately relate with and respond to such distress factors.

Lyn said:

"It was how his family wanted it to be. It was at home.....I think it was important that they got that and that's what happened so in the end it was a good outcome for him and for us you know. We were satisfied that we were able to meet his needs as he wanted and the family were happy and I can say he had a dignified dead. At the end of the day it is about the whole person really, and us trying to relief his pain and also consider the suffering of those who love him and trying to do what is best for the person and his loved ones too" (Lyn, Ln.242-258, RNLD).

Laura also said:

"But we have to provide, we have to be able to identify with their suffering as a person and we have to recognise that, that's as much an important aspect of caring for people as the other aspects that we have already identified. After all it's about being a person..... As a person or human being we all share some major similarities in our physical body and sometimes even in our emotions, feelings and beliefs that we have to consider when caring for these people with communication difficulties and learning disabilities in a palliative care setting" (Laura, Ln.156-167, PCSW).

Viv declared:

"One was a lady that lived in supported accommodation and was supported by a staff team who had been working with her for 10 years or so, so they had a really good knowledge about her.....I tended not to do so much direct work with her but more direct work with the carers about making sure that they were confident about what they were monitoring and what they were noticing about her behaviour and making sure they were confident about knowing who to call if they were worried about something whether it was the GP or the District Nurse or the Palliative Care team...." (Viv, Ln.63-77, RNLD).

Edith affirmed this view:

"I mean it must be about what eight years ago now and I think of it now and yes, yes it was just such a positive experience and that's what makes the job worthwhile no matter what you are doing. Whatever field you work in..... It is the whole person who matters. You only relieve their pain, suffering or distress if you look at the person really" (Edith, Ln.327-334, CNS).

Jade also declared:

"You know, it's about looking at the person as a whole and not just what's going on. It's about looking about everything around them you know. I think staff down here do take that more on board now. It's the little things that we do at the end of life for people to make their lives more comfortable at that point. It's the little things that matter and I think that makes a big difference to people. It's about knowing the person and perhaps knowing what they may like and we might not get it right all the time but at least we are trying" (Jade, Ln.209-219, RNLD).

The participants intentionally addressed the distress of PCDL by a positive regard of the whole person, which meant supporting the distressed or dying persons and also considering the feelings of their families. This ensured the provision of confident optimum care. This view was affirmed by Viv:

"Okay well obviously I think my relationships with family were quite good. They would call if they were worried, they were quite accepting about having me in the house.....I suppose you have to be very aware of what's going on in the family and there was another lady in the house, a sister of the guy who was dying who also had learning disabilities and I suppose trying to take into account how she might be feeling about things as well was quite different, difficult at times but then it was very necessary to consider the whole person and relate to their situation which meant I had to support not only the diagnosed person but consider the feelings of his family in order to provide the best possible care....." (Viv, Ln.143-161, RNLD).

Sub theme 6: Empathy

Empathy was employed by the participants as a method to identify and respond to the distress of PCDLD in palliative care settings. Participants acknowledged the significance of being receptive and empathetic if optimum care had to be provided to distress PCDLD in palliative care settings.

Laura stated:

"It is very dependent on the person that cares for the person with communication difficulties whoever they are to be responsive and sensitive to what they see but also to try and remember that if this was me, to try and think 'actually I know what I am like when I have got a cold. Actually I know this person. This is not, or it's much more serious than a cold and to be sensitive to that and to therefore facilitate regardless of what setting you are in.....that as long as we have ensured that there is nothing else the matter other than they just want a comfort day, that they get their comfort day" (Laura, Ln.137-150, PCSW).

Sue stated:

".....but if as time progressed and he became more poorly andhe used to want to eat and that was his major problem that he couldn't swallow so we had to say 'no' and he didn't understand.....He was never aggressive but his speech pattern would get a bit more quick and he would start sometimes when he was well enough he would pace around his room a little bit and just generally his body language would change and it would be obvious that he wasn't you know he was getting more distressed about what you were doing" (Sue, Ln.53-66, CNS).

Empathy was also demonstrated by the participants as compassion and insightful awareness of not just the verbal communication of the distressed PCDLD but also sensitivity to the physical deterioration of the dying PCDLD. Such sensitivity facilitated participants' recognition of distress cues through observation for certain signs or symptoms such as a change in behaviour, grimacing, breathlessness, restlessness, withdrawal, and vocalisation such as groaning, moaning and crying. The participants responded to the distress cues with the provision of optimum care.

Moira claimed:

"...it wasn't so much that he was able to say, it was just the deterioration that I found really difficult and I think that's what he was able to communicate to me you know he was able to communicate his distress just by virtue of the way that he deteriorated" (Moir, Ln.127-132, RNLD).

Jade explained:

.....it has been quite varied. There had been some people whose distress might be just from the way they are behaving, might be grimacing, facial expressions, things like that. For some it might be just the fact that they are moving round the bed and being quite unsettled, when we have determined that they need pain relief" (Jade, Ln.101-107, RNLD).

Edith reiterated this view by explaining that when the PCDLD were at the last phase of their disease trajectory the CNS would observe for any signs of discomfort or distress cues such as breathlessness to enable the provision of appropriate optimum care.

"Well verbally but as she got more poorly it was more non-verbal you know looking at any signs of discomfort when she was moved or any signs of breathlessness or distress umh which it would be with any person really" (Edith, Ln.48-52, CNS).

In a palliative care support and therapy environment, the PCPs would observe for any discomfort or distress cues such as restlessness. Paula said:

"To begin with he did have some, he had a rocking motion, and it seemed that was him expressing some anxiety, it seems quite obvious that was somehow anxiety because once if he was on a one to one and he seemed comfortable the rocking stopped. So it was you know learning, knowing his little ways and making all the team aware that you know that when they were observing him throughout the day, if he was sat doing this thing then he was anxious for some reason" (Paula, Ln.67-76, PCN).

Sub theme 7: Therapeutic touch

The findings portrayed touch as a strategy explored by the participants to identify and relieve the distress of PCDLD. Responding to identified distress with a touch was also perceived as an embodiment of loving care towards the dying PCDLD. Hence, helping them experience a good death in a palliative care setting.

Tracy avowed this view by stating:

"In a lot of cases they can understand verbal communication, they can understand when you are communicating with them even if they don't have verbal communication to answer back and a lot of it sometimes, it's just about touching, just a gentle touch relieves distress and communicates a thousand words, it really does, and it's so important for people with learning disabilities to help them experience what palliative care people call a good death" (Tracy, Ln. 404-413, RNLD).

This is confirmed by Jade:

".....he was very restless and he was groaning a lot, and moaning a lot in bed and that sort of indicated to us that he wasn't really settled and his breathing was quite erratic. But once the dose of pain relief had been increased, then he did seem to calm quite significantly. A comfort touch of hands also works" (Jade, Ln.134-140, RNLD).

Laura also reiterated that:

"As a person or human being we all share some major similarities in our physical body and sometimes even our emotions ...we have to consider when caring for these people with learning disabilities in a palliative care setting. At times a touch is therapeutic as it comforts" (Laura, Ln.161-164, PCSW).

Sub theme 8: Training and providing a dignified end

The participants' conscious commitment to improve their knowledge of palliative and end-of-life care (EoLC) for PCDLD was elucidated as an approach used to address the distress of PCDLD. They explained that this was in terms of obtaining training and clinical skills to meet the identified distress or palliative care needs and using an established palliative care framework such as the Gold Standard Framework (GSF, 2004) for EoLC to ensure appropriate advance care planning and EoLC for this population. Participants' descriptions demonstrated that given the appropriate specialist skills and training, it was their moral duty of care as healthcare professionals to provide optimal care and ensure a good death or dignified end for this client group in palliative care settings. Gary acknowledged this view by stating that death is part of life and it remains the moral duty of health professionals to ensure PCDLD in a palliative care setting have quality care at the dying phase and at the time of death. Gary declared:

"I think it's strengthened links definitely you know,.....So I think GSF (Gold Standard Framework) has changed us as a service really in terms of what we can provide and obviously our main focus is about people having quality of life, but you know,.....death is part of life and equally they should have quality at the end of life just as well as during their life. And more so in terms of our moral role to provide a dignified end at such time, we need a really focused time when you really need to have things in place and more so you really need to direct everything at that time to make sure they are comfortable and we have that now so that puts us at a huge advantage I would say" (Gary, Ln.375-388, RNLD).

Sub theme 9: Pain-free care

Dedication to providing care that was pain-free, comfortable and peaceful was perceived by the participants as a vital method of addressing the distress of PCDLD. Tracy declared:

"It was peaceful and it's what palliative care people would describe 'a good death' and they kept his pain under control and they cared for him and they came very

little at the end, the death if you like but it was a good death, it was, it was very peaceful, a good death" (Tracy, Ln.155-160, RNLD).

Jane said:

"It's really difficult because he wasn't for treatment, it was palliative care.....it was our duty of care. We had to manage his symptoms by controlling his pain or do away with whatever was causing him distress and manage his care" (Jane, Ln. 195-211, RNLD).

Jade stated:

"I think one of the gentlemen on one of the other bungalows when he was at end of life,as he did become more distressed he did go on syringe-driver during the process of his end of life. And we did have to increase the dose of his medication to relieve his distress. We could tell he did become distress because there was one day in particular, it was just the unsettled behaviour, he was very restless and he was groaning a lot, and moaning a lot in bed and that sort of indicated to us that he wasn't really settled and his breathing was quite erratic. But once the dose of pain relief had been increased, then he did seemed to calm quite significantly" (Jade, Ln.127-140, RNLD).

Sub theme 10: Comfort, safety and peace

Participants' narratives indicated that the participants had to make a conscious effort to provide a comfortable, peaceful and safe environment in order to identify and alleviate distress that was linked to the environment.

Paula said:

"I suppose as a team we decided to invite the gentleman on a day that we knew wasn't really over busy or because you know, he needed to feel safe in the environment" (Paula, Ln.58-64, PCN).

In line with the above Steph declared:

".....whether I'm a professional or not, it's a person, and therefore its harder and its more emotionally draining because we all want to think that people are pain free and comfortable and not in distress and have got somebody that can relate to that person and it might be one of the nurses and it might be one of the carers. It doesn't matter who it is, it's being sensitive" (Steph, Ln.115-122, RNLD).

Adam also stated:

"I think I visited at least once a week and as the man got worse it was twice a weekbut as he became frailer and as his symptoms changed, he was more isolated in the home..... The district nurses were involved as well because he did have a device called a syringe driver eventually and that needed changing by them. We had good support from the GP and out of hours GPs and so the best outcome for all of us involved with the patient foremost was that he died in that

home.....and he died where he was known and understood and loved and cared for and where he felt safe” (Adam, Ln.98-115, CNS).

Sub theme 11: Acknowledgement of shortcomings

Acknowledgement of shortcomings relates to the participants’ recognition and expression of prior caring experiences, knowledge, abilities, and confidence or the lack of these qualities as the case may be, in providing the best quality of care for PCDLD and their family members within palliative care settings. It also encompasses participants’ professional meticulousness as a fundamental approach in responding to the holistic distress of PCDLD in palliative care settings. Thus the participants were always mindful to recognize and overcome their shortcomings by training or drawing from past experiences to ensure good caring outcomes.

Moira confirmed this view:

“Whatever shortcoming that I had which sometimes I felt that I did but you know I was able, I had faith in myself to be able to overcome those shortcoming” (Moira, Ln.154-156, RNLD).

Adam confirmed this view with the description of his perceived shortcomings in caring for PCDLD in palliative care settings:

“I was very honest and I said ‘I have not looked after anyone before with a learning disability, this is my first time’ and they said ‘well it’s our first time looking after somebody with a cancer and needing palliative care’ so that again was really honest and open and good because we knew that we had some differences and some anxieties and yet we had lots of skills and experience between us that we could bring together and work really well for the patient” (Adam, Ln.84-96, CNS).

This view was confirmed by Laura with the description of shortcomings in the end-of-life care (EoLC) of dying PCDLD in a palliative care setting:

“There are some poorer examples of nursing home care.....I recognize that they have got difficulty with staffing numbers and qualified staff and they have large numbers of people with learning disabilities presenting complex problems, not just serious ill health problems, so.....it’s recognizing that they are struggling with all of those things but therefore they are not focused on the dying patient or.....prior to end of life, that bit before the end of life when they can be much more engaged in quality of life and treatments and pain symptom relief and engaging in activities that they still want to engage in, that gets lost a lot in the nursing home setting...” (Laura, Ln.497-514, PCSW).

Sub theme 12: Time and anxiety

The findings indicated participants' perspective of time as limited and yet a priority for the distressed PCDLD and their families. This was described by participants as being mindful to provide optimum care and meet the needs of the dying PCDLD, yet having to work within the constraints of available time and certain human limitations. Human limitations in this case encompassed the anxiety of delivering care outside professional expertise or familiar care settings and the dilemmas of where the health care professional fits in the bigger picture of palliative care and learning disability services. Additionally, participants' descriptions signified that time necessitated that these human limitations had to be overcome for participants to appropriately respond to the distress of PCDLD. The participants recognized that in order to do the best for the PCDLD and their families, they had to overcome professional barriers and stigma through training and sharing of professional knowledge and experiences. They also had to allow time to equip them with the essential experience and skills to meet the needs of distressed PCDLD within palliative care settings.

Adam declared:

"Certainly my anxieties were I suppose around would I understand this man and would I be able to fully comprehend any pain or distress that he was in and also taking into account that I was a stranger and he might be shy with me and you know there was his feelings to take into account as well as the fact that he has got a learning disability. So yes,.....my anxieties were about I suppose trying to help somebody with a condition that I didn't hand on heart really fully understand and I had no prior experience in sort of dealing with" (Adam, Ln.128-138, CNS).

This was affirmed by Sue:

"Quite frustrating speaking personally, quite frustrating.....I have had another one quite recently who had some mild learning difficulties and again I find it very frustrating because.....obviously you have to communicate on a level that the patient can understand.....I visited him at home on several occasions and.....I felt that I was in some way not getting through to him and I didn't know how to do it,.....because it seemed to me that he was distressed all the time" (Sue, Ln. 125-143, CNS).

Sub theme 13: Time and caring opportunities

The participants explained that accurate timing was a significant approach needed to address the distress of PCDLD and also facilitate the provision of appropriate palliative care from suitable services. This emphasized the importance of effective time management and early involvement in the care of distressed PCDLD in palliative care settings. Lyn stated:

"I think the referral came just two weeks into the new job.obviously I had worked as a Community Nurse before but never in this role. So when the referral came in there was a little bit of work to be done about whose role was what and that was a little bit frustrating because this young man, he was actually in transition, and he was just coming from a young adult service, well children's services into adult services, and although he had been very well monitored by the children's palliative care team there wasn't an automatic referral into the adult palliative care team and when I made some enquiries there was nothing, it was a very grey area it felt,..... it wasn't automatic in referral. There was a lot of umming and ahing about who should be doing what and I just felt frustrated that it did seem to sort of delay things a little bit and putting barriers that may be shouldn't have been there and because I was new in role as well it was like 'where do I fit into this picture?'" (Lyn, Ln.178-198, RNLD).

This view is reiterated by Tracy:

"I think..... for learning disabilities, it's important to get involved early because you need to build relationships with people and in this area in particular the palliative care people have been doing some good work in that respect, they do understand that. We have this elderly palliative care MDT group where we work together and we share information and experiences to ensure advance care. I do know that the End of Life project states that preparation and good planning for end of life care is probably twelve months..." (Tracy, Ln.387-397, RNLD).

Sub theme 14: Dying as part of living

The participants learned from their experiences and over time through training and collaborative working acquired the necessary skills, which enhanced their provision of continuous, consistent and confident optimal care to the distressed PCDLD. The expressed goal by the participants was a deliberate commitment to deliver care which took into consideration not only the distress of the PCDLD but the totality of their human experience, consequently perceiving dying and death as a part of living. Lyn confirmed this notion:

"...really that was a frustrating experience but it was a good learning curve...I am still learning about palliative care myself and I am coming across new things all the time and I am thinking 'if only I had known that before' and it's like, it's only with experience that you know that skill will come and each time, then next time I know what I might come across or what to ask and when. So I am building on that all the time but it's just a shame you know, that I didn't have that originally" (Lyn, Ln.203-213, RNLD).

Gary also stated:

"...obviously our main focus is about people having quality of life but you know..., death is part of life and equally they should have quality at the end of life just as well as during their life and more so in terms of our moral role to provide a dignified end. So at such time we need a really focused time when you really need to have things in place and more so you really need to direct everything at that time to make sure they are comfortable..." (Gary, Ln.378-387, RNLD).

Laura also declared:

"The learning disability staff worked with the hospital staff and with us and between us we managed to get this chap to have some proper diagnosis in place and it turned out to be benign tumour and we were quite pleased with our achievements.....But by then it was so well advanced that even surgery wasn't going to resolve the issue.So our mission then as well as the learning disability staff, GP and other professionals was to try and create opportunities for this man to be comfortable; continually providing him with holistic support he needed to relief his distress while helping mum to realise this diagnosis at this time is difficult but dying is another stage of his life, which she must embrace" (Laura, Ln.303-332, PCSW).

Sub theme 15: Care environment and Aesthetic knowing

Participants delivered palliative care in a variety of palliative care settings. Their descriptions reflected the structure of palliative care that included intensive care units, hospices and community-based palliative care settings. The community settings included nursing homes, residential care settings, an individual's private home or family home. Participants' narratives portrayed that aesthetic knowing was a method used by the participants to identify factors which contributed to how this population communicated distress and also, to identify and respond to the distress of PCDLD in palliative care settings. Aesthetic knowing meant the participants utilized sensitivity, insight and creativity to tailor the care environment according to an individual's specific needs. The participants were able to do so by consciously adjusting the care environment in order to plan care that was sensitive to the cultural and religious inclinations of the distressed or dying PCDLD within the limitations of the available care environment/space. Gary said:

"...we all wanted her to be very comfortable and not experience any pain because we wanted her to have a positive experience at that time you know and I would say overall she had that. I think she was pain free and comfortable and her family commented that she seemed extremely peaceful with herself and her surroundings at that time and they were very pleased about that" (Gary, Ln.290-303, RNLD).

The significance of utilizing aesthetic knowing to address the distress of PCDLD was reiterated by participants' descriptions which portrayed that the nature of dying and human suffering or distress was personal. Therefore, in order to identify and appropriately respond to any emotional, spiritual or psycho-social distress, planned care within the confines of the available care environment or space had to maintain the spiritual, cultural, and religious needs of the PCDLD so as to maximise their choices, rights and autonomy. Jade stated:

".....the involvement of family and what they needed from me in supporting of their daughter.....was you know, to do with them knowing me. It was certainly

them wanting certain people around at that point. It was all the things about end of life that were special to that person that I think had the impact you know.we have always been taught within the Gold Standards that end of life it's all about everything the person wants, which is spirituality. I mean we have always been big about that down here that if a person like a certain type of music then ensure that music was played..... I always remembered the parents saying to me one of the nicest things that they saw was when they came to the hospital that night, because I had taken my iPod with me and I was playing some music that this person particularly liked. And I had one ear in and she had one ear in, and they said that was the most poignant thing they had remembered that somebody took the trouble to try and ease that person's sort of stress levels" (Jade, Ln. 168-200, RNLD).

Gary reiterated:

The lady and her family had already expressed that this would be her choice for end of life, she didn't want to go into hospital, she didn't want to be in a hospice, she wanted to be in familiar surroundings. Her room even though it was small it did lend itself quite well to having regular visitors and for the last two weeks of her life she was bed bound so she remained in her bedroom at that time so she was able to have visitors in private which made things easier so family could have private time with her. She was religious so she was able to have a priest visiting..., we did have a member of staff there when the priest was there, but he was great. He read the sacraments of the sick in like a private dignified setting and then at the end he read the last rites to her. So I think because it was a small community home and a place that the lady had lived at for a long time, it lent itself quite well in terms of an environment. At the end of the day it was the whole person not only their pain or distress that we were thinking about (Gary, Ln.211-231, RNLD).

Participants emphasized that using sensitivity, insight, and creativity to adapt (aesthetic knowing) the care environment to meet individuals' needs also enhanced participants' understanding of the factors which determined how PCDLD communicated distress in palliative care settings. These factors comprised of: (1) Environmental factors relating to unfamiliar people, unfamiliar care setting and unfamiliar routine. (2) Physiological factors relating to pain. (3) Psychological factors relating to emotional stress. (4) Lack of understanding and communication difficulties.

Factor 1: Environmental factors

By ensuring that planned care within the confines of the available care environment maintained the spiritual, cultural, and religious inclinations of the PCDLD, participants were able to maximise their choices, rights and autonomy. Also, the participants were able to recognize that environmental factors specifically linked to unfamiliar people, unfamiliar care settings, and routines affected how this population expressed distress in palliative care settings. Participants explained that when exposed to these environmental factors the PCDLD became distressed and their distress was manifested in certain instances by becoming withdrawn. In reply to the interview question below:

Researcher:are there other factors that you can identify that will potentially affect the way they communicate distress? (Researcher, Ln.74-76).

Jade said:

".....Different bungalows have different circumstances going on. You know, we've got the circumstance from this morning. But we've got circumstance when we have new clients that have come in and we have some people that may become withdrawn" (Jade, Ln.78-82, RNLD).

To emphasize the impact of unfamiliar staff and routines on the communication of distress by PCDLD, Jade declared:

"....staff played a big part don't they? I mean changes of staff can really upset people. People not knowing a certain person's set routine can have a major impact on them on the day as it can on all other days" (Jade, Ln.147-151, RNLD).

Edith accentuated this view by explaining that unstimulating care environment affected PCDLD who then communicated distress by withdrawal. Edith said:

The environment. He was in a very protected environment at home and it's just stimulation you know, sometimes you have got to work with the family as much as you have with that person if not more sometimes because getting the family to trust you as well, and particularly if they have sort of been through other kinds of shall we say day care and it has not been a positive experience. It's getting them to trust you as well with their family" (Edith, Ln.264-272, CNS).

Factor 2: Physiological factors

By being sensitive, insightful, and creative to adapt the care environment (aesthetic knowing) to individual's specific needs, participants illustrated that they were able to realise that physiological factors, particularly pain, contributed to how PCDLD expressed distress in palliative care settings. Edith declared:

"Well when she was in pain it changed her behaviour but the staff where she lived actually knew her very well and they were able to you know interpret changes in behaviour or you know if she was in pain as she got more poorly that they were able to sort of interpret that really if you like but her behaviour changed and I mean she did complain of pain but also she did get emotionally distressed with it" (Edith, Ln.38-45, CNS).

Jade also said:

"I think one of the gentlemen on one of the other bungalows when he was at end of life,as he did become more distressed he did go on syringe-driver during the process of his end of life. And we did have to increase the dose of his medication to relieve his distress. We could tell he did become distress because there was one day in particular, it was just the unsettled behaviour, he was very restless and he was groaning a lot, and moaning a lot in bed and that sort of indicated to us that he wasn't really settled and his breathing was quite erratic. But once the dose of pain relief had been increased, then he did seemed to calm quite significantly" (Jade, Ln.127-140, RNLD).

Factor 3: Psychological factors

Also, by being sensitive, insightful, and creative to adapt the care environment (aesthetic knowing) to individual's specific needs, participants illustrated that they were able to identify that psychological factors relating to emotional stress may affect how PCDLD communicated distress in palliative care settings. Consequently, an individual experiencing emotional distress may display aggressive behaviour or become uncooperative with care interventions. Jade said:

"I've come across one client this morning who is displaying behaviours that haven't been seen for years. And it's probably one of the most unlikely person that we've at the moment to hit out but today he is declining his medications. I think it's more of an emotional distress.....with this person because another client in that bungalow who is currently not there has been in hospital and is very poorly. And it has kind of just dawned on us today that these behaviours have occurred.....So it's the whole situation because this gentleman sat very close to him all the time. So is his behaviour a reaction to the emotional distress he is feeling?" (Jade, Ln.51-66, RNLD).

This view is also emphasised by Paula:

"To begin with he did have some, he had a rocking motion, and it seemed that was him expressing some anxiety, it seems quite obvious that was somehow anxiety because once if he was on a one to one and he seemed comfortable the rocking stopped" (Paula, Ln.67-72, PCN).

Factor 4: Lack of understanding and communication difficulties

By being sensitive, insightful, and creative to adapt the care environment (aesthetic knowing) to individual's specific needs, participants illustrated that they were able to recognize that for some PCDLD the frustration of not being able to express their needs contributed to their distress, which was then manifested by withdrawal or a change in behaviour. This meant that their distress or state of health could only be identified by staff members who knew them well. Paula said:

"We have some people who can actually verbalise their needs, we have people who can show us what they need, we have some people who have some basic knowledge of Makaton and are able to sort of demonstrate by gestures, by certain hand movements. Erm, we have some other clients who really is a lot to do with how well the staff know them, and how the staff can pick up on what is it they are needing" (Paula, Ln.30-38, RNLD).

Adam demonstrated an awareness that communication difficulties of PCDLD may pose potential problems for PCDLD when describing their distress, symptoms or needs. Adam declared:

"Yes I had one I suppose one major case that I've worked with and it was a gentleman who had a cancer of the oesophagus and he was in his early 60s he had a mild learning disabilityhe was referred to me I think by his GP which is lovely because he obviously thought well you know there's potential here for some communication difficulties, some symptom problems so let's have a specialist nurse in palliative care involved so that was lovely" (Adam, Ln.57-69, CNS).

Through aesthetic knowing and prioritisation of collaborative working between the participants, PCDLD, and their family members, the participants were able to identify and respond to their distress. Participants explained that collaborative working enabled them to create an environment that emanated calmness and a sense of peace for both the PCDLD and their families. Nurturing such an environment constituted an appropriate caring response to the spiritual or psycho-social distress of the dying PCDLD.

Laura declared:

"...it was a good story about people working together really to create a caring environment to provide peaceful death and I don't think palliative care was any more important than psychology services were and no more important than the learning disability service nor any more important than the hospital once they were engaged. Each had a role to play at an appropriate time and played it well and I know the Learning Disability service, particularly the Learning Disability Nurse, that was heavily involved with this particular man and his brother continued to do some bereavement work afterwards with the Psychology Service, which was both beneficial to the mum and to the boy so that's an example of when things work well" (Laura, Ln.432-447, PCSW).

Sub theme 16: Optimism

Optimism was symbolic of a care strategy in terms of participants' obligation to ensure a planned future with appropriate services and care approaches that would address the distress of this client group in palliative care settings. This was affirmed by Moira:

"Umh I think it's definitely not bleak and I think there are great prospective out there" (Moira, Ln.342-343, RNLD).

In response to the interview question below Laura responded in a similar vein:

Researcher:

"Can you tell me about what you envisage about the future for learning disability and palliative care...?" (Researcher, Ln.589-591).

Laura replied:

"Well I have to say that I hope the future continues to be brighter because in learning disabilities, there have been lots of public campaigns not to say the least such as MENCAP...." Laura, Ln.597-600, PCSW).

Optimism was restated by participants as recognition of the need for a representative body comprising both palliative care and learning disability professionals at local organisational and governmental levels to promote the palliative care agenda for PCDLD. The palliative care agenda in this case relates to promoting service provision and development in several health-specific care areas for PCDLD who may be in need of any form of palliative care. For example, the need for health and social care professionals to develop a comprehensive ability in the use of learning disabilities specific assessment tools such as: the use of the disability distress assessment tool (DisDAT); non-verbal communication tools; and also in engaging families as a significant source of historical information about the PCDLD.

Laura affirmed this with the expression:

"...but if there are then going to be local initiatives and the regional initiative which you and I are both part of as well and a national initiative then you hope that, that has a political arm but it also has ... yes, a health related arm where they are working to continue to develop and to encourage the use of a DisDAT tool, to encourage use of non-verbal communication tools whatever that might be under that umbrella. We are encouraging all the time for people to step away, slow down, and spend time to work out what's happening. To engage and include families and also for professional carers to remember that they are your greatest source of information about those people historically" (Laura, Ln.613-629, PCSW).

Along a similar line of thought, Gary explained that with experience and increasing skills in the care of PCDLD at the end-of-life stage, the RNLDs could be at the forefront in contributing to practice development both at organisational and government levels. Gary stated:

"You know the Government is looking at people being cared for more in their own homes towards the end of life, there is a real push for that, and I can think we can really be at the forefront of that really. We have those skills and there is no reason why other learning disability homes can't do what we have done because you know we are not unique in any other way, we have just developed that so you know I could see other learning disability homes developing in the same way....." (Gary, Ln.422-431, RNLD).

Sub theme 17: Proactive Collaboration

Deliberately accentuating the essentiality of a more proactive collaboration between palliative care and learning disabilities professionals and services was perceived by the participants as important in the care of distressed PCDLD. The participants recognized that no one can be a specialist in every aspect of care and there was a need for health professionals directly involved in the care of PCDLD to be ready to share experiences and knowledge. Sharing specialist experiences and knowledge allowed no room for egos. It

also persuaded and inspired health professionals to work together and empowered them with the ability to identify and respond to the distress of PDCLD thus, providing improved palliative care. In agreement with the above, Laura declared:

"As part of the palliative care team and I guess the learning disability nurses and other professionals involved in the person's care we have to be more proactive in working together...wherever the person is based and that is really important because that's where the day to day twenty-four hour care is being met whether that's your own home, the small group home or the nursing home, its being met there" (Laura, Ln.676-684, PCSW).

This opinion is reiterated by Adam:

"I think the future is looking promising because already there's national collaboration with palliative care specialists and learning disability nurses and professionals,.....you know other experiences of teams being able to work collaboratively and help people with learning disabilities to have good peaceful deaths where they want to be then that's really encouraging and it can only grow,.....because you know, you've got to at the end of the day do what's absolutely best for the patients and there is no room for egos....." (Adam, Ln. 226-248, CNS).

Laura reiterated:

"I only go for an hour once a week because I have too many other people to see. The psychologist can only go for an hour once a week. We can only go and do a small part of what needs doing but if what we can do is to encourage, stimulate, educate, support, work alongside each other, we can do that. We empower others to do better and work better. We also empower us to become more proficient, to become clearer in what we do, to learn, and an example of that for us is the GSF, the Gold Standards Framework. We are trying to encourage in our own area the use of that in the nursing home setting, the residential home setting and the small group home setting" (Laura, Ln.684-698, PCSW).

Sub theme 18: Future improved access

Participants' narratives highlighted their commitment to promoting future improved access to palliative care for PCDLD. This was explored by the participants as an approach to identify and alleviate their distress. On the one hand, such commitment encompassed a timely intervention by PCPs, RNLDs and other health and social care professionals involved in the care of distressed PCDLD in palliative care settings. On the other hand, it ensured that consistency and continuity in the care provided to this population in palliative care settings was maintained. Accordingly, the participants acknowledged that better access to palliative care services included the need for a more consistent model of palliative care across children specialist palliative care, adult and community palliative care services and a more integrated palliative care that was accessible to all.

Steph affirmed this view by stating:

"Ideal, it's like M House, it's a children's hospice but they have people going there in their late 30s because the families don't want to lose that connection so the model that they have for M House, a consistent model, would be great if it could be extended across the children's service and other community services" (Steph, Ln.246-252, RNLD)

In advocating the need for a more integrated model of palliative care, which is accessible to both PCDLD and mainstream patients Lyn stated:

"I would hope that they could integrate well into the palliative care structure as it stands as other community members can use them....So yes I would hope that people with communication difficulties and learning disabilities with palliative care needs would be able to use perhaps the same palliative care services that you and I could....." (Lyn, Ln.263-271, RNLD).

To ensure future improved access to palliative care for PCDLD, the participants intentionally identified and proposed solutions to challenges that acted as hindrance to pertinent, timely and relevant care decisions for this client group. The expressed reasons for such challenges were a lack of autonomy, poor funding, poor EoLC and healthcare bureaucracy. Having more autonomy was perceived as a vehicle for improving palliative care service provision for this population. Participants emphasized the need for healthcare professionals directly involved in the care of PCDLD within a palliative care setting, to be allowed more opportunities for autonomy in certain palliative care decisions, and to be allowed more resources and funding.

Affirming the need for more autonomy as a vehicle for improving palliative care provision to PCDLD, Moira stated:

"Autonomy in care decision because we have the skills, we are capable, but again I think it's about us standing up and saying 'look we can do this as well and you need to give us the opportunity to do" (Moira, Ln.428-431, RNLD).

The participants stressed that future improved palliative care for PCDLD can only be planned with the availability of more resources and funding. Resources such as the Independent Living Fund (ILF) or direct payments for continuing health care into nursing home palliative care settings was needed to address issues related to independently funding additional staff with specific learning disability qualification, experience and knowledge to care for this population.

Laura declared that:

"I think one of the things that I would like to see that we in the learning disabilities and palliative care group would like to see is that maybe if there were some more resources through the direct payments approach or continuing health care approach ...the ILF. Maybe we need to be quicker at getting that kind of funding whether that's ILF or direct payments for continuing health care into those nursing homes.." (Laura, Ln.514-525, PCSW).

Healthcare bureaucracy was also identified as an issue that had to be addressed in order to ensure improved palliative care for PCDLD. Jane stated that:

"The health system is very bureaucratic isn't and everything is done that way and that's it and there's no flexibility and there's no, everything is a procedure isn't it. Things like when we eventually got him established at the hospice he would probably have been better at the hospice but there was never a bed at the hospice so sometimes he had to have an admission to hospital where I believe it would have been less distressing for him to being admitted to the hospice because once we got him going there the staff did get to know him,....." (Jane, Ln.97-108, RNLD).

Laura affirmed this view:

"There are some poorer examples of nursing home care...they have got difficulty with staffing numbers and qualified staff and they have large numbers of people with learning disabilities presenting complex problems, not just serious ill health problems, therefore they are not focused on the dying patient's prior to death, or prior to end of life..." (Laura, Ln.496-509, PCSW).

Sub theme 19: Meeting expectations

Meeting expectations was described by participants as advance care planning to meet the needs of distressed PCDLD in palliative care settings. Such expectations included making necessary plans to ensure the provision of optimum care to both the dying PCDLD and their family members. Hence, support and compassion towards the family members was explained by participants as the privilege of sharing in a personal moment (dying, death and funeral). Tracy declared:

"I felt...especially with mum and with the learning disabled brother, I felt as if I was sharing and participating in a very personal moment,.....a very personal part of their lives and mum was very, very, appreciative of my support... They were an eastern European family and so when they had the funeral they have like a funeral tea afterwards and its very similar to the Western world how we have weddings with like a top table and other tables and mum had asked me to be on the top table next to her and I felt very privileged to be there but under that kind of tension..... that way, she was expressing her thanks for my support throughout that process. So it's privileged and moving, very compassionate" (Tracy, Ln.171-188, RNLD).

Participants also acknowledged that the expectation for quality palliative care for this population can only be assured by a deliberate effort by professionals from both the palliative care and learning disability fields, to be actively involved in joined training initiatives. This would allow for breaking of professional barriers and stigma through innovative knowledge transfer or sharing, and also for more specific palliative care tailored to meet the needs of this population.

Gary described the effectiveness of training in terms of the acquired ability to provide more specific and effective palliative care such as dementia care for PCDLD:

"People with learning disabilities as we know, they're living much longer than previously and that's fantastic but along with that there are illnesses associated with old age that as learning disability nurses we possibly haven't come across as much in the past you know dementia is a big part of that, and all the associated illnesses around dementia. We can provide specific dementia care here so as our clients age we are going to meet their needs a lot more effectively than perhaps we would have previously...." (Gary, Ln.393-402, RNLD).

Edith affirmed the significance of training by stating:

"...I think it sort of helps remove the stigma if you like because people they do worry about things that they are not familiar with. They do worry 'oh God this patient has got this, I don't know how to deal with it' so I think it is about sharing and working together and particularly that lady she was an absolute, I don't know, it's just err,..." pauses (eyes tear up). (Edith, Ln.315-324, CNS).

Jane also affirmed this view with the expression:

"Myself and AM have done some training in general nursing so I know AM is involved in that and I went and we actually did a half day like a case study and a presentation on this gentleman in the case study. So that's a good way forward for LD and palliative care nursing staff, that could only be promoted can't it?" (Jane, Ln.225-231, RNLD).

The Wholistic approach

The 'wholistic' approach is part of the initial approaches of isolating themes (Van Manen, 1990). Van Manen (1990, p.93) stated that *"in the wholistic approach we attend to the text as a whole and ask, What sententious phrase may capture the fundamental meaning or main significance of the text as a whole?"* Therefore, to allow the readers to gain an understanding of the phenomenon under study, it was necessary to balance the research context by considering the parts and the whole (Van Manen, 1990). The rigour in the 'wholistic' approach of isolating themes utilized in this study was grounded in listening to the audio recordings and attending to typed transcripts to capture the main significance of the data as a whole. I achieved this throughout the analysis process by constantly reading and assessing the whole text in terms of the significance of the different parts or themes for the total structure or essence of participants lived experiences. Following the 'wholistic' approach, I re-examined all the components of general meanings gathered from the text comprising of the findings from the 'line-by-line' and 'highlighting approaches'. The aim was to ascertain a distinction between the incidental themes consisting of the sub themes and what will become the essential themes. I achieved this by constantly asking the question *"does the phenomenon without this theme lose its fundamental meaning?"* (Van Manen, 1990, p.107).

Subsequently, the sub themes were clustered into more concise main themes as demonstrated in Step three below. This was to ensure that subsequent analysis and explanations would appropriately reflect the progress in the process of arriving at the composite themes, which encapsulates the essential nature of participants' experiences of caring for distressed PCDLD.

5.2.3 Step three: The Clustering Process

The sub themes from Step Two were clustered into seven main themes according to the related meaning of participants' experiences of identifying and responding to the distress of PCDLD in palliative care settings (see Table 5.1, p.122).

Building relationships with PCDLD, their families, and amongst professionals as expressed by the participants were clustered under the first main theme of *Knowing by building relationships*.

Two sub themes specifically: Successful care, and Pride and job satisfaction, which related to caring outcomes, were clustered under the second main theme of *Positivity in successful caring outcomes*.

The succeeding four sub themes namely: Sincerity and sensitivity in care, Positive regard of personhood, Empathy, and Therapeutic touch, which could all be associated to compassion in care were grouped under the third main theme of *Humane care*.

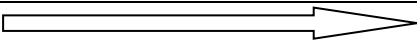
The next four sub themes: Training and providing dignified end, Pain free care, Comfort, safety and peace, and acknowledgement of shortcomings, which were linked to participants' obligation in providing the best possible care for this population, were clustered under the fourth main theme of *Moral duty of care*.

The ensuing three sub themes: Time and anxiety, Time and caring opportunities, and Dying as part of living, which portrayed relatedness to participants' conscious awareness of time during care interventions were grouped under the fifth main theme of *Time to care*.

The sub theme: Care environment and aesthetic knowing was re-titled as the sixth main theme, *Comfortable care environment/space*. This theme indicated a relatedness to participants' recognition of the significance of the care environment in identifying factors which determined how PCDLD communicated distress and also, in identifying and responding to the distress of this population in palliative care settings.

The next four sub themes specifically: Optimism, Proactive collaboration, Future improved access, and Meeting expectations elucidated participants awareness of the current limitations in the palliative care received by PCDLD and a commitment towards ensuring better palliative care and access in the future. These sub themes were grouped under the seventh main theme of *Future perspectives*.

Table 5.1 Clustering themes: retained sub themes into main themes

Sub themes 	Main themes
1. Building relationships: -with PCDLD. -Family members. -Between the PCPs and RNLDs.	Knowing by building relationships
2. Successful care. 3. Pride and job satisfaction.	Positivity in successful caring outcomes
4. Sincerity and sensitivity in care. 5. Positive regard of personhood. 6. Empathy. 7. Therapeutic touch.	Humane care
8 Training and providing dignified end. 9 Pain free care. 10 Comfort, safety and peace. 11 Acknowledgement of shortcomings.	Moral duty of care
12. Time and anxiety. 13. Time and caring opportunities. 14. Dying as part of living.	Time to care
15 Care environment and Aesthetic knowing.	Comfortable care environment/space
16 Optimism. 17 Proactive collaboration. 18 Future improved access. 19 Meeting expectations.	Future perspectives

5.2.4 Step four: Similarities or differences

Participants’ transcripts were re-examined to identify similarities or differences pertaining to the meaning the phenomenon under study had for both the RNLDs and PCPs. It is interesting to note that despite the professional differences of the participants, the participant interviews demonstrated a commonality in the approaches used by both the RNLDs and the PCPs in identifying and responding to the distress of PCDLD in palliative care settings. The major identified difference was in the area of professional expertise and experience, which consequently, accounted for the confidence or lack of confidence in providing care to this population.

In describing the recognition of differences in professional experiences and expertise, Adam declared:

"Oh yes absolutely..... There's no way that I could have just gone into his bedroom and communicated with him I think and found out what I really needed to know. If I had gone along there, I am the palliative professional, you can wait outside, that would have been a very very poor approach and very bad for the patient.....so as I said it was absolutely about collaboration and working together and acknowledging from the first time I met the staff that they knew things that I didn't know and I knew things that they didn't know and therefore for the good of the patient we would always be honest and you know we would support each other as much as we could and it was a pleasure really to work with them and to do that providing a dignified end" (Adam, Ln.164-179, CNS).

Edith said:

"It worked really well because what I lacked in skills about learning disabilities they were able to sort of advise me and we worked together really well" (Edith, Ln.67-69, CNS).

Lyn also declared:

"I think the referral came just two weeks into the new job. I had just done the induction for the new job so obviously I had worked as a Community Nurse before but never in this role so when the referral came in there was a little bit of work to be done" (Lyn, Ln.178-183, RNLD).

Laura reiterates the differences in professional experience and expertise with this declaration:

"That was a bizarre experience for the local hospice in their day care because they had not had anybody with quite such profound learning disabilities before and the gentleman wouldn't come into the building so his day care was conducted from the garden through a window and the manager of the day care was absolutely brilliant because she was able to say 'okay we have to show that we are lovely people, that we are nice and kind and he has to be able to look through the window and see what we do' and weeks fell into months, he came in a bit and went out a bit, came in a bit, went out a bid so eventually he was very definitely engaged in day care" (Laura, Ln.335-347, PCSW).

5.3 Chapter summary

Chapter five has presented the participants' data in terms of the sub themes and main themes. It consisted of the findings generated from utilizing steps one to four of the 'six steps data analysis process' (Figure 5.1, p.95).

Chapter six will comprise of the critical interpretative account of the findings generated in this study. It will include steps five and six of the 'six steps data analysis process' (Figure 5.1, p.95).

Chapter Six: Interpretation of Findings

Chapter six comprises of the critical interpretative account of the findings generated in this study. It includes steps five and six of the six steps data analysis process. The critical interpretative account integrates relevant prevailing research literature and theory. In particular, the theory of nursing as caring within the context of Watson's (1999, 2001) transpersonal caring relationships and Boykin and Schoenhofer's (2001) nursing situation and the imagery of the Dance of Caring Persons.

In step five I have examined the wider significance of the identified and presented main themes as essential structures of the participants' lived experiences within the framework of Van Manen's (1990) life-world existential themes of *spatiality* (lived space), *corporeality* (lived body), *temporality* (lived time), and *relationality* (lived relationships or communality). The main themes were identified as:

- Knowing by building relationships.
- Positivity in successful caring outcomes.
- Humane care.
- Moral duty of care.
- Time to care.
- Comfortable care environment.
- Future perspectives (see Table 5.1, p.122).

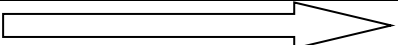
In step six the main themes were examined more closely. This was in respect to the essence of the phenomenon of caring for distressed people with communication difficulties and a learning disability (PCDL) in palliative care settings, from the perspective of the Registered Learning Disability Nurses (RNLs) and Palliative Care Professionals (PCPs) who have lived the experience. It is envisaged that the essence of the phenomenon of caring for this population may inform the creation of a new theoretical model for palliative and end-of-life care (EoLC) for this client group. In both steps five and six of the data analysis process, the examination of the findings includes relevant research literature and theory. Finally, a chapter summary is provided.

6.1 Step five: Van Manen's Existential themes as overarching themes

This section of the data analysis process explored the wider significance of the main themes as essential constructions of the participants' lived experiences within the framework of Van Manen's (1990) life-world existential themes of *spatiality* (lived space), *corporeality* (lived body), *temporality* (lived time), and *relationality* (lived relationships or communality). Van Manen's four existential are said to demonstrate a

fusion of the objective hermeneutic circle (part whole) and the alethic hermeneutic circle (pre-understanding) because together they recognize the experience of a phenomenon as the whole experience and also the researcher’s interpretive role in the research process (Dowling, 2007). Van Manen’s life-world existential were used here as overarching themes. The seven main themes were scrutinized for meaning related to the overarching themes, then mapped accordingly (Table 6.1).

Table 6.1 Main themes mapped unto Van Manen’s (1990) four existential themes as overarching themes

Main themes 	Overarching themes (Van Manen’s (1990) four life-world existential themes)
1. Knowing by building relationships	Relationality
2. Positivity in successful caring outcomes.	Corporeality
3. Humane care.	
4. Moral duty of care	
5. Time to care.	Temporality
6. Comfortable care environment	Spatiality
7. Future perspectives	Extended dimension of Temporality

The mapping of the main themes unto the overarching themes (Van Manen’s four life-world existential themes), are presented as distinct sections in this chapter.

6.2 Relationality (Lived relation)

Relationality is concerned with the lived relationships that individuals maintain with others in the interconnected space or environment that they share with them (Van Manen, 1990). The first main theme of this study titled ‘*Knowing by building relationships*’ demonstrates a significant similarity to relationality. This is because ‘*Knowing by building relationships*’ indicated how the participants sustained associations with lived others. In this case, lived others consisted of PCDLD, their family members and the participants themselves.

Participants had to build relationships with individuals as they became involved in the nursing situation of caring for them within palliative care settings. Participants recognized that the relationships they built and maintained with others (PCDLD, their families members and carers and amongst the professionals themselves) in the interpersonal environment that they shared with them was essential. This is because such relationships enhanced the interconnected nursing or caring interventions and also acted as a fundamental strategy to identify and appropriately respond to the distress of this population. I suggest that ‘*Knowing by building relationships*’ was an essential

aspect of the participants' lived experiences of caring for this population in palliative care settings. This is because participants' narratives indicated that the phenomenon of caring for distressed PCDLD in palliative care settings would be irrelevant without the existence of a committed, mutual, interpersonal and professional relationship between the participants, PCDLD, their family members and carers. The first main theme '*Knowing by building relationships*' was mapped under the overarching theme of Relationality to illustrate the different depths of participants' understanding of the meaning of the phenomenon of caring for this population in palliative care settings (see Figure 6.1, overleaf).

The 'unidirectional arrows' in Figure 6.1 overleaf emphasize and demonstrate the interconnected caring relationships between the participants and lived others (PCDLD; their family members and between the participants themselves). The 'unidirectional arrows' and the 'plus sign' also emphasize an absence of hierarchy and hence, the significance of the different relationships in terms of contribution to the care of the distressed PCDLD in palliative care settings. The 'down arrows' demonstrate how these relationships enabled the RNLDs and PCPs to identify the distress of this client group. The 'right braces' in Figure 6.1 point to how the interrelated relationships enhanced the provision of appropriate care to address the distress of this population. A detailed explanation of the components of Figure 6.1 is provided in the discussion of the theme '*Knowing by building relationships*' in section 6.2.1.

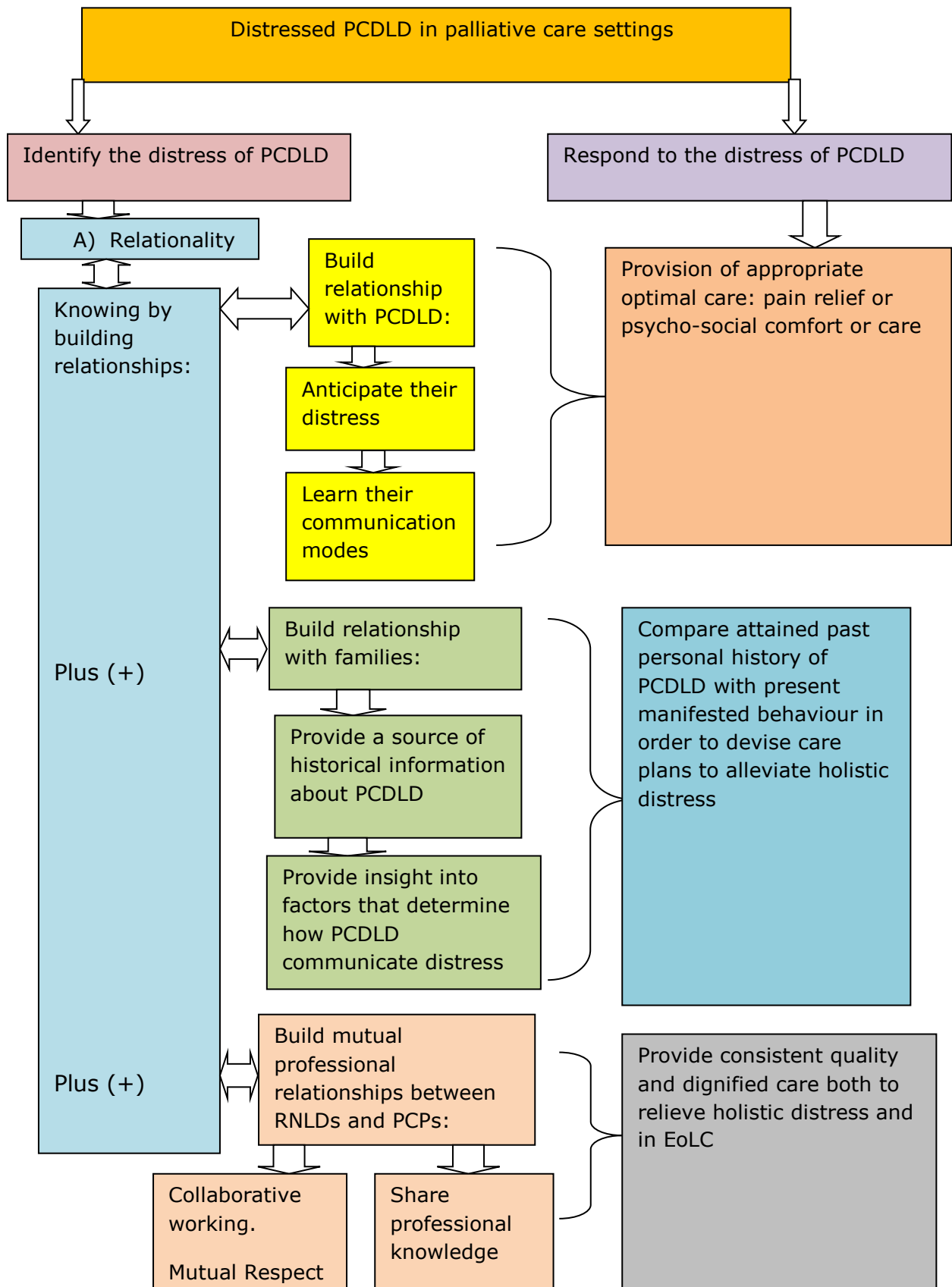


Figure 6.1 Relationality (lived relations)

6.2.1 Knowing by building relationships

Building relationships with PCLD

As demonstrated in participants' quotes in Chapter Five, see (pp.97-98), participants built relationships at three levels namely with the PCDLD, their families and carers, and amongst the professionals themselves. The profundity of the relationships developed with PCDLD, enhanced the development of a pattern of verbal or non-verbal communication, which was fundamental in anticipating their distress and also facilitated the response to their distress with the provision of optimum care. My growing understanding of the significance of professional and interpersonal relationships between the participants and PCDLD, which enhanced the development of a pattern of communication, was expressed with this entry in my field-note:

"During an interview session, as I sat listening to a certain participant and also in subsequent interviews, the vividness of participants' descriptions enlightened me with the realisation that when we take time to build meaningful and profound relationships with people in the environment where we find ourselves, there comes a point when the depth of the relationship is such that we could understand aspects of who they are and what they feel even without the benefit of words or the vitality of spirit associated with good health" (My Field-note, 21/11/11).

There is some evidence in a paper by Read (2005) to support the significance of communication to the care of people with learning disabilities (PLDs). Read's (2005) paper titled: '*Learning disabilities and palliative care: recognizing pitfalls and exploring potential*', portrayed the importance of communication as a key principle for all people receiving palliative care. In this paper, Read (2005) aimed to: (a) introduce the recognized challenges or pitfalls inherent in providing high quality palliative care to people with learning disabilities; and (b) explore the future potential and possibilities in delivering appropriate palliative care to this vulnerable population. Read's (2005) paper established that a recognized pitfall or challenge in providing palliative care to PLDs was around poor communication and a lack of interpersonal skills by service providers on the one hand and on the other hand, the difficulty in communication was often compounded by a lack of verbal communication proficiency in the PLDs themselves. Whilst Read's (2005) paper has provided evidence of the significance of communication to enable good palliative care for PLDs, my study emphasized that '*knowing by building relations*' with PCDLD, family members and amongst the RNLDs and PCPs would ensure appropriate communication, which would empower participants with the ability to anticipate individuals' distress, and also, facilitate addressing the distress with the provision of timely optimum care.

Furthermore, I suggest that a possible limitation to Read's (2005) paper was that it was a position paper and based on a review of literature. Thus in that aspect dissimilar to my study, which is a hermeneutic phenomenological study with a purposefully selected sample population and consequently, allowed for an in-depth exploration and interpretation of the participants' lived experiences by the participants themselves and with my active interpretive role as the researcher (Van Manen, 1990). I also argue that although position papers are not included in the hierarchy of evidence ladder, as an exception Read's (2005) paper was considered to have significance to the subject area and has contributed to knowledge associated to palliative care for PLDs, and specified the problem related to access to palliative care by this population. Read's (2005) paper is thus, indicative of the existing practice in terms of palliative care provided to PLDs. However, it remains important that more experimental studies are undertaken to address distress experienced by PCDLD in palliative care settings through an in-depth investigation of the lived experiences of RNLDs and PCPs. Hence, this emphasizes the significance of my study's findings, which have provided some substantial evidence relating to how RNLDs and PCPs identify and respond to the distress of this population in palliative care settings.

In an open dialogue on learning disability and palliative care, Cardy (2005) emphasized the significance of involving carers and key workers who understood the needs of an individual and can interpret their non-verbal communication. Cardy (2005) reported that there is little recognition among decision makers that the palliative care needs of PLDs merit specific attention and communication appears to be the fundamental issue. This is not only in relation to diagnosis but also in the assessment of symptoms, including physical pain and emotional distress. Cardy (2005) points out the focus of Macmillan Cancer Relief in alleviating barriers to access of any type, with palliative care as the yardstick of what all cancer care should be like. I propose that Cardy's (2005) paper demonstrated noteworthy knowledge associated with the importance of caring relationships and communication in the provision of optimal palliative care to PLDs who have cancer. It would seem that both Cardy's (2005) paper and this study's finding, specifically the theme '*Knowing by building relationships*' in terms of relationship with PCDLD, indicated that inappropriate communication is inevitably a frequent barrier for healthcare professionals who endeavour to improve access to care especially, palliative care for PLDs.

However, I suggest that the importance of understanding the communication modes of PLDs as established in Cardy's (2005) paper was not exactly arrived at based on the lived experiences of RNLDs and PCPs who had cared for or are still caring for distressed PCDLD in palliative care settings. Thus, this suggests that identifying and responding to

the distress of this population in palliative care settings remains problematic. This point to the need for more empirical studies purposely tailored to address the distress of PCDLD from the perspectives of RNLDs and PCPs. It also accentuates the relevance of my study in terms of specific contributions to knowledge by professionals from both the learning disability and palliative care fields. Moreover, unlike Cardy's (2005) paper, which recognized the move towards an all-inclusive palliative care in terms of cancer care, the focus of my study was not exclusively on cancer care but on palliative care that encompasses other life-limiting conditions such as dementia that PCDLD might be diagnosed with. I suggest that an in-depth exploration of palliative care that encompasses cancer care and other life-limiting conditions for this client group remains problematic. Therefore, the participants' experiences as highlighted in their narratives and the findings of this study might have further and far-reaching implications for practice as far as the provision of optimum palliative care to distressed PCDLD in palliative care settings is concerned.

Also, participants' obligation in '*knowing by building relationships*' with the goal of addressing the distress of PCDLD, to an extent, resonates with Watson's (1999, 2001) transpersonal caring relationships. Watson (2001) claimed that the nurse's caring consciousness and connection have the potential to heal since experience, perception, and intentional connection are taking place. Parker (2001) explained that Watson described the main elements of her theory as the carative factors, the transpersonal caring relationship, and the caring occasion or caring moment. Watson's (2001) carative factors were introduced in 1979, revised in 1985 and 1988. Watson (2001) viewed the carative factors as a guide for the core of nursing, and employed the term carative as a contrast to conventional medicine's curative factors. The carative factors were an attempt to "*honour the human dimension of nursing's work and the inner life world and subjective experiences of the people we serve*" (Watson, 1997 p.50). According to Watson (1999), the transpersonal caring relationship typifies a special kind of human care relationship that depends on the nurse's moral commitment to protecting and enhancing human dignity as well as the deeper/higher self or spirituality.

However, in my study, this intentional connection or relationship explicitly portrayed how the Registered Learning Disability Nurses (RNLDs) and Palliative Care Professionals (PCPs), go beyond an objective assessment, and show concerns towards the distressed person's subjective and deeper meaning regarding their own health situation. Consequently, participants' descriptions indicated that their caring consciousness as shown by their commitment to '*knowing by building relationships*' with PCDLD have become essential for the relationship and understanding of the other person's perspective. The commitment also emphasized the individuality or uniqueness of both

the PCDLD and the participants, and also the mutuality between them, which was essential to the relationship and also essential for acquisition of knowledge and understanding to address the distress of this population within palliative care settings.

Relationality in terms of the participants' obligation in '*knowing by building relationships*' with PCDLD, could also be likened to nursing situations as described in Boykin and Schoenhofer's (2001) 'Theory of Nursing as Caring'. The nursing situation is described as "*a shared lived experience in which the caring between the nurse and the nursed enhances personhood*" (Boykin and Schoenhofer, 2001, p.13). Boykin and Schoenhofer, (2001) described the nursing situation as encompassing the specific values, intentions and actions of two or more persons who choose to live a nursing relationship. Therefore, the nursed and the nurse (in the case of this study the PCDLD and the participants) are connected through a relationship and caring between the two transpires and is perceived as the foundation of nursing knowledge (Boykin and Schoenhofer, 2001). In this case especially, knowledge needed by the participants, to address the distress of this client group within palliative care settings.

Building relationships with family members and carers

Participants' emphasized that '*Knowing by building relationships*' in terms of professional and interpersonal relationships with family members and the wider circle of carers was fundamental because family members and carers, were a rich source of historical information about PCDLD. As elucidated in participants' quotes in Chapter Five, (pp.98-99) the acquired information enhanced understanding of the PCDLD. This was in terms of blending their past history and the present manifestations of their behaviour, physical and emotional state, and over time, utilize that understanding or knowledge to identify and alleviate their distress with the provision of optimum care (see Figure 6.1, p.127).

This view resonates with Boykin and Schoenhofer's (2001) imagery of the Dance of Caring Persons. Boykin and Schoenhofer's (2001) imagery of the Dance of Caring Persons illustrates the manner of relating to the cared-for and the persons who are involved in their care. The imagery of the Dance of Caring Person reflects a caring situation where there is no hierarchy to portray power. Nursing and healthcare as a whole has been described as hierarchical in nature with nurses and healthcare professionals having to respond to changes in their own management structure and also integrate into the leadership structures of different clinical disciplines to deliver optimal care to their patients. For example, recent changes in the hierarchical structure of a governing body like the NHS explicated how and who would manage decision making, service commissioning and funding on patients' care (NHS, 2013). Conversely, the participants' emphasis on the significance of '*knowing by building relationships*'

demonstrated that each dancer in my study (RNLDs, PCPs and family members of PCDLD), in the dance circle was acknowledged and valued by the participants for their distinctive contribution befitting their individual roles as they contributed to the care of PCDLD experiencing distress within palliative care settings.

To an extent, the theme '*knowing by building relationship*' in terms of building professional and interpersonal relationships with family members and the wider circle of carers is also, consistent with Tuffrey-Wijne and McEndhill's (2008) paper on '*Communication difficulties and intellectual disability in end-of-life care*'. Tuffrey-Wijne and McEndhill (2008) based their paper on previous research dealing with their personal professional experiences both in palliative care and learning disabilities service. Although Tuffrey-Wijne and McEndhill's (2008) paper is a critical review of literature and not an empirical study, it has relevance to palliative care for PLDs. They highlighted challenging issues in providing appropriate palliative and EOLC to this client group in particular inappropriate communication. However, I consider that the significance of understanding the communication modes of people with learning disabilities (PLDs) has been portrayed from different angles by my study and Tuffrey-Wijne and McEndhill's (2008) paper. This was in terms of the differences in the area of emphasis about the impact of appropriate communication in the care of this client group. In the case of Tuffrey-Wijne and McEndhill's (2008) paper, they mapped the communication difficulties experienced by people with intellectual disabilities within a palliative care setting. They established that communication problems resulting from two main sources can delay timely diagnosis and symptom assessment as well as the provision of psychological support to clients. The two main sources of communication problems highlighted by Tuffrey-Wijne and McEndhill (2008) are: 1) the failure of professionals to communicate accurately in order to be understood by the clients, and 2) the reluctance of carers to disclose the truth for fear of upsetting the client or fear that the client will be unable to cope with information about their condition.

In the case of my study, the first main theme '*Knowing by building relationships*' elicited that meaningful relationships was central to understanding the communication pattern of PCDLD and to addressing their distress in palliative care settings. It would seem that the discussion around the relevance of appropriate communication as deduced from both Tuffrey-Wijne and McEndhill's (2008) paper and my findings have not only added to emergent research relating to palliative care for this population but emphasizes the need for more experimental studies detailing evidence of good practice in the care of PCDLD. Such empirical studies could be used by health and social care professionals to address the distress of this population, and meet their increasing palliative and EoLC needs. I suggest that the findings from my study may have implications for practice especially

related to accessibility to timely and appropriate palliative care for PCDLD experiencing distress in palliative care settings.

Building mutual professional relationships

The dedication to '*knowing by building relationships*' was also accomplished by the participants through developing mutual professional relationships with each other. This was in terms of participants' experience with each other either as members in a team of professionals from the same field, or working in collaboration as members of a team encompassing health professionals from different fields who are directly involved in the care of distressed PCDLD in a palliative care setting. Collaborative working was therefore, a significant method to facilitate the identification of the distress of this population in palliative care settings. As demonstrated in Chapter Five (pp.99-100), in order to appropriately respond to the distress of this client group, participants recognized they also needed to develop honest professional relationships, show mutual respect for each other, and share knowledge in order to maintain quality, consistent and continuous care. They had to consciously utilize their varied skills or specialism in collaborative caring situations in order to effectively address the distress of PCDLD in palliative care settings. Mutual professional collaboration was especially imperative where the distressed individuals were dying and care had to be taken to ensure they had a dignified end.

The view is in line with Boykin and Scheoenhofer's (2001) assertion that individuals live caring and endings in the moment. Also nursing is described as a social process and consequently, does not occur in a vacuum; it is contextual, social, historical, dynamic and comparative (Keleher and McInerney, 1999). It remains an established fact that the sick, or nursed, have always been with us and in many cases someone assumes the caring role. In my study that role was assumed by the participants who related with significant others involved in the 'dance circle of caring' for PCDLD through mutual relationships, with the goal of alleviating their distress within palliative care settings.

There is some evidence to support the significance of professional relationships. This is in terms of the value placed on nurses' relationships with clients/patients and the role of the RNLDs in collaborating and negotiating with other health professionals. In a descriptive phenomenological study on RNLDs' experiences of being with clients who may be in pain but cannot communicate their feelings, Donovan (2002) highlighted that nurses valued highly their relationship with clients as these relationships can be therapeutic. Donovan (2002) emphasized that the role of the RNLDs as a source of information about their clients' personality and behaviour to other healthcare professionals was perceived as an essential aide to diagnosis. I suggest that Donovan's

(2002) study has contributed to the growing body of knowledge linked to the care of PLDs who might be in pain. However, Donovan's (2002) discussion on caring relationships focused exclusively on RNLDs' relationships with PLDs who might be in pain. Also, Donovan's (2002) portrayal of a caring relationship builds from the focus on the pain perspective, which was perceived in my study as one of the concepts encompassed within the holistic distress continuum. In my study distress was understood as holistic or a spectrum encompassing distinct concepts of physiological, spiritual, and psycho-social distress factors. Donovan's (2002) portrayal of a caring relationship and his focus on the pain perspective begs the question of how professionals address the distress related to other factors as experienced by this population. This points to the need for more experimental studies targeting the care of PCDLD experiencing distress in palliative care settings through investigation of the lived experiences of not just RNLDs but RNLDs and PCPs. Since the findings from my study indicate how RNLDs and PCPs identify and respond to the distress of PCDLD in palliative care settings, and also identified factors which determine how they communicate distress in palliative care settings, it is likely that the findings may have implications in terms of contribution to planned changes in care approaches for this client group in palliative care settings.

As far as *'Knowing by building relationships'* with families and carers of PCDLD is concerned, there is some similarity between my study and Tuffrey-Winje's (2011) study. This is in terms of the significance of involving family and professionals when providing care to people with learning disabilities (PLDs). Tuffrey-Wijne (2011) utilized focus groups and interviews, and applied grounded theory methods. The aim of Tuffrey-Wijne's (2011) study was to develop a model of breaking bad news to people with intellectual disabilities. Hence, the emphasis on building relationships with family and professionals was in terms of helping a person with learning disabilities understand and deal with bad news situations. I suggest that on the one hand, Tuffrey-Winje's (2011) study indicated the ever growing body of empirical studies related to the care of this population. On the other hand, the emphasis on good relationships and the impact on developing a model for breaking bad news to PLDs signified that other aspects associated to the palliative care of this population such as distress still warrants the attention of research and service communities. Therefore, there is need for more empirical studies specifically dealing with the care of PCDLD experiencing distress in palliative care settings in terms of how RNLDs and PCPs identify and respond to their distress. Arguably, collating RNLDs and PCPs' experiences as demonstrated in the participants' narratives will add to the growing body of knowledge needed to provide health and social care professionals with understanding about providing comfort and

optimal care to distressed PCDLD. I also suggest that such knowledge may inform the development of a model of palliative and EoLC for this client group.

Furthermore, there appears to be some correlation between the theme of '*knowing by building relationships*' with one of the findings identified in Foley and McCutcheon's (2004) paper on detecting pain in people with an intellectual disability. Foley and McCutcheon (2004) stressed that emergency department nurses must rely on the persons (learning disability professionals and carers) who know the person with an intellectual disability well in order to identify their pain. This view correlates with my study in terms of mutual professional relationships amongst RNLDs and PCPs as described by them in their commitment to addressing the distress of PCDLD in palliative care settings. Nevertheless, Foley and McCutcheon's (2004) emphasis was on how emergency department nurses detect pain in people with intellectual disabilities. This indicated a different thread in the contribution to knowledge as far as the care of people with learning disabilities is concerned. I suggest that this could mean that the care of this population by non-learning disabilities professionals remains problematic and points to the need for more evidence-based studies particularly dealing with an in-depth investigation of healthcare professionals' (especially, RNLDs' and PCPs') lived experiences of the phenomenon of caring for this population in palliative care settings. The findings from my study may prove fundamental to the potential contribution to practice and policy development particularly, relating to the care of PCDLD experiencing distress in palliative care settings.

6.3 Corporeality (lived body)

According to Van Manen (1990, p.103) "*we are always bodily in the world*". The lived world of corporeality relates to descriptions of bodily experiences between people in the environment in which they find themselves. This was in terms of individuals' use of both their physical bodies, skills, sentiments and senses (Van Manen, 1990). Three main themes identified in this study namely '*Positivity in successful caring outcomes*', '*Humane care*', and '*Moral duty of care*' showed some relevance to corporeality. These themes showed an association to corporeality because they indicated participants' awareness that being authentically present to provide care that encompassed sincerity, sensitivity, and kindness, placed them in the world of caring for distressed PCDLD in palliative care settings, shaped the care provided and consequently, affected the bodies of the persons being cared for. These themes also, demonstrated participants' understanding that the caring process entailed that nurses and other health professionals utilize their bodies to care for clients/patients often by executing physical

and emotional care throughout the person's illness and at time of death. Also, participants' descriptions as portrayed by the quotations in Chapter Five (pp.100-108), specified that the phenomenon of caring for distressed PCDLD will be irrelevant if devoid of the RNLDs' and PCPs' obligation in utilizing their bodies to provide physical and emotional care throughout an individual's illness and at time of death. Hence, the themes '*Positivity in successful caring outcomes*', '*Humane care*', and '*Moral duty of care*' were essential components in the care provided to PCDLD experiencing distress within palliative care settings. These themes were mapped under the overarching theme of Corporeality (lived body) to demonstrate another depth of participants' understanding of the meaning the phenomenon of caring for distressed PCDLD in palliative care settings (see Figure 6.2, overleaf).

In Figure 6.2 the 'unidirectional arrows' commencing from corporeality to the three themes show how these themes are related to the concept of corporeality. The 'unidirectional arrows' and the 'plus sign' also emphasize an absence of hierarchy and therefore, the relevance of each of these themes to the concept of corporeality in terms of identifying and responding to the distress of this population in palliative care settings. The 'right arrows' point to what each theme encapsulates. The 'right braces' point to how these themes were strategic to participants' ability to address the distress of PCDLD in palliative care settings. A discussion of corporeality encompassing these themes and in association with relevant theory and literature is discussed in sections 6.3.1; 6.3.2 and 6.3.3.

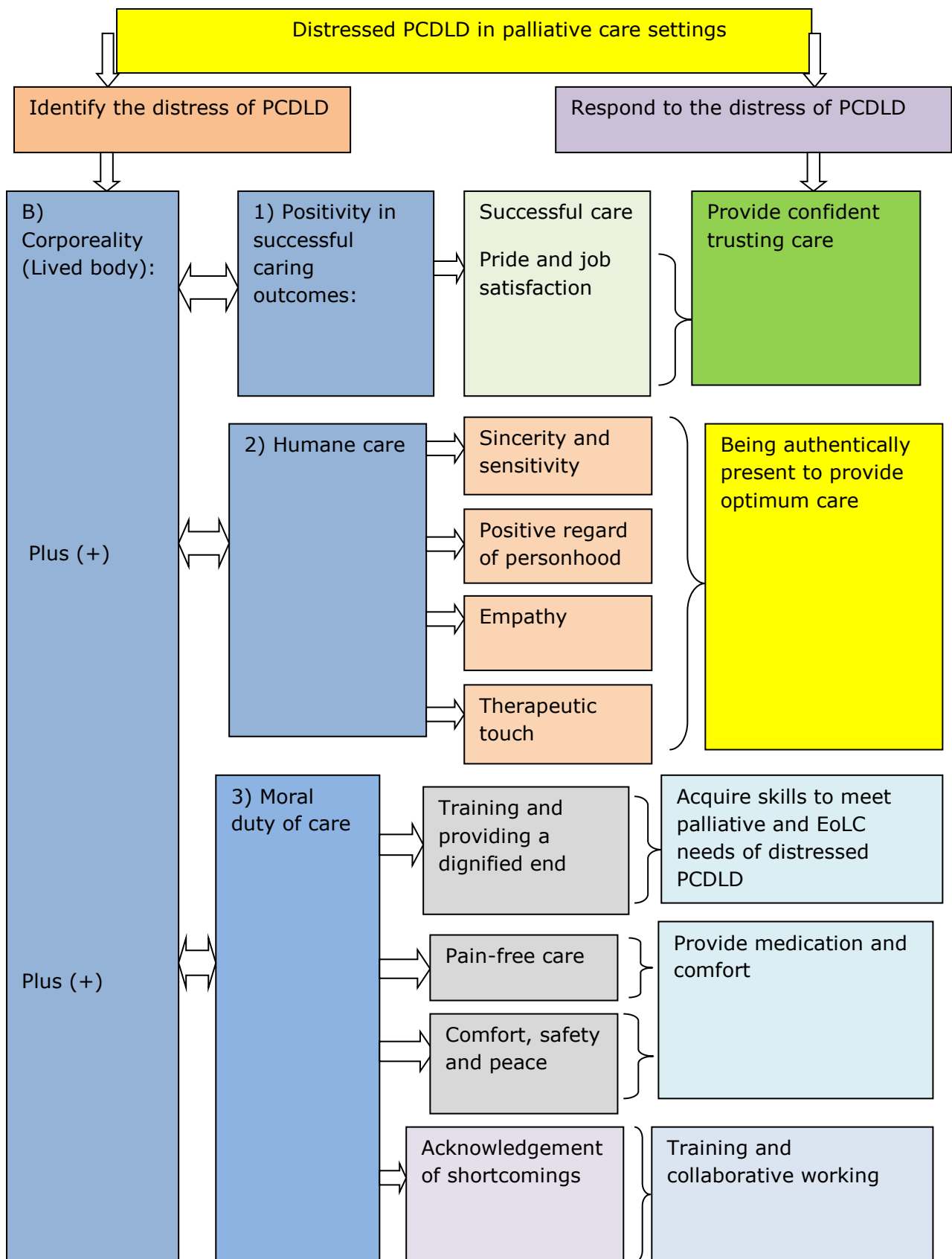


Figure 6.2 Corporeality (lived body)

6.3.1 Positivity in successful caring outcomes

The second main theme '*Positivity in successful caring outcomes*' (see Figure 6.2, p.137) had some relevance to the concept of corporeality "*we are always bodily in the world*" (Van Manen, 1990, p.103). Participants' narratives indicated that the conscious use of their bodies (physical and specialist skills) was essential to the phenomenon of caring for distressed PCDLD in palliative care settings. This was as a result of understanding one's self as a person and drawing from past experiences of care to deal with current or on-going issues. Participants drew inspiration from effective care interventions to plan future care interventions. Thus, they were motivated to train and acquire more skills in palliative and end-of-life care (EoLC) in order to meet the needs of this population in palliative care settings. As illuminated in participants quotes in Chapter Five (pp.100-101), the ability to readily draw from past professional or personal experiences of caring, enabled the participants to provide appropriate confident care. Participants also acknowledged that effective care interventions facilitated caring for this client group and also, created a sense of pride and job satisfaction when they efficiently utilized specialist skills to meet the needs of both this population and their families within palliative care settings.

6.3.2 Humane care

'*Humane care*', which is the third main theme identified in this study also has some relevance to Van Manen's (1990, p.103) explanation of corporeality: "*we are always bodily in the world*". '*Humane care*' as described by the participants encompassed sincerity and sensitivity, positive regard of the whole person (positive regard of personhood), empathy, and therapeutic touch as a beneficial response to distress (see Figure 6.2, p.137). '*Humane care*' required that the participants had to be bodily present in the world of the distressed PCDLD in order to address their distress.

Sincerity and sensitivity

The theme '*Humane care*' includes sincerity and sensitivity in care. This was portrayed by the participants as a keen attention to details, which was considered as essential to addressing the distress of PCDLD in palliative care settings. The participants quotes in Chapter Five (see pp.101-102), illustrated that they were authentically present and observant thus, they were able to identify subtle changes in the facial expressions of the dying PCDLD. Such changes might be indicative of pain or emotional distress. The participants were sensitive and responded to the identified distress by purposely offering themselves to support not only the PCDLD who might be grieving due to a sense of loss

and confusion at their disease trajectory, but also their family members during the end of life stage and in the aftermath of the death of their relatives.

I suggest that the association of '*humane care*' to corporeality, in particular, sincerity and sensitivity as described by the participants is congruent with Boykin and Schoenhofer's (2001) view about the concept of knowing the self as a caring person. Boykin and Schoenhofer, (2001, p.1) stated that, "*persons are caring by virtue of their humanness*". Knowing the self as a caring person requires a true awareness of the self by understanding the self from within as a caring person (Boykin and Schoenhofer, 2001). In this study, this understanding prepared the RNLDs and PCPs to become acquainted with the world of distressed PCDLD, and come to know them, and be authentically and intentionally present for them as caring professionals. Hence, the nurse (RNLDs and PCPs) utilizes sensitivity and expertise and attends to a call for nursing by being deliberately and genuinely present (Boykin and Schoenhofer 1997, 2001) to alleviate the distress of this client group within palliative care settings.

Purposefully looking at the whole person (Positive regard of personhood)

In this study, the theme '*humane care*' also encompassed a positive regard of personhood (purposefully identifying with the suffering of PCDLD), which was essential in identifying and responding to their distress. Participants demonstrated an awareness that utilizing attributes attained from their own previous bodily experiences of suffering as human beings could enhance their ability, through observations and interactions with PCDLD, to notice different physical and behavioural changes, and appropriately relate with and respond to such distress factors with confident optimum care.

I recommend that participants' purposefulness or commitment towards being bodily present to provide care that considered the whole person can be related to intentionality. This is because participants' intentionally addressed the distress of PCDLD by a positive regard of the whole person, which meant supporting the distressed or dying persons and also considering the feelings of their families. This ensured the provision of confident optimum care. According to Schoenhofer (2002, p.36) intentionality shares common characteristics with personhood and "*intentionality is consistently choosing personhood as a way of life and is the aim of nursing*". Accordingly, "*personhood is unity, the creative evolving of a unifying, consistent whole, awareness, wholeness, creative unfolding of recognisable self; and intention, blending desire and purpose*" (Boykin and Schoenhofer, 1997, p.61).

The benefits associated with '*humane care*' in terms of positive regard of personhood, which enhanced the provision of confident care to distress PCDLD as described by the participants, shares some similarity to the findings of Black and Hyde's (2004) study.

Black and Hyde (2004) employed case studies to explore nurses' or healthcare professionals' experiences of caring for PLDs with colorectal cancer and stoma. Their aim was to address issues of autonomy, consent, treatment, palliative care and death relating to the care of people with profound learning disabilities and challenging behaviour, who also have colorectal cancer and a stoma. Black and Hyde's (2004) study highlighted how nurses and healthcare professionals develop confidence in caring for people with profound learning disabilities who have cancer. Black and Hyde (2004) emphasized the necessity of meticulous and competent medical and nursing care to meet the needs of PLDs especially since the transition of PLDs from institutions to the community. The conclusion reached was that the fear experienced by nurses and healthcare professionals in caring for PLDs with cancer can be reduced by ensuring person-centred care protocols, which accommodated people with profound learning disabilities and also, by effective discussions and ongoing clinical support amongst the multidisciplinary teams (Black and Hyde, 2004).

It has been argued that the findings of cases studies may not be suitable for generalisation to a larger population because the focus is sometimes on a small sample, single individual or unit (Stake, 2005; Flyvbjerg, 2006). However, what we learn in a particular case can be transferrable to similar situations (Stake, 2005, p.455). Hence, I suggest that Black and Hyde's (2004) study has contributed to the growing body of empirical literature dealing with PLDs needing palliative care specifically cancer care. Both Black and Hyde's (2004) study and this study have demonstrated the importance of confident care in meeting the needs of individuals in palliative and EoLC. However, Black and Hyde's (2004) emphasis was on providing confident care to PLDs needing cancer care unlike this study wherein the distress experienced by PCDLD could stem from cancer or life-limiting conditions and neurodegenerative diseases such as dementia. Also my findings demonstrated another approach to ensure the provision of confident optimum care to this client group was by purposely addressing the distress of PCDLD through a positive regard of the whole person, which meant supporting the distressed or dying persons and also considering the feelings of their families.

On the one hand, I suggest that Black and Hyde's (2008) study points to the need for subsequent research to investigate cancer care provided to people with learning disabilities (PLDs). On the other hand, the emphasis on cancer care for PLDs portrays that caring for PCDLD experiencing distress or suffering from other life-limiting conditions that require palliative care still presents as a noteworthy and significant subject that has not been fully investigated by health and social care professionals. Therefore, there is a need for more experimental studies targeting the lived experiences of RNLDs and PCPs, which would evidence the significance of being sensitive and

receptive, and the essence of the phenomenon of caring for PCDLD experiencing distress in palliative care settings. I argue that the findings from my study as demonstrated by participants' quotes in Chapter Five of this thesis address these issues and may have implications for practice, and palliative care and learning disabilities service provision for this population.

Additionally, participants explanation of the relevance of '*humane care*' in terms of positive regard of personhood, which enhanced the provision of confident care to distressed PCDLD, concurs with a finding in Li and Ng 's (2008) study. Inherent in their study is the concept of how nurses develop confidence in caring for dying patients with profound learning disabilities. Li and Ng (2008) emphasized that the certainty of knowing the patients enabled the nurses to contrast their behavioural changes before and after the onset of their illness. Li and Ng's (2008) study provided a substantial discussion of confidence in providing End-of-Life Care (EoLC). They utilized a case study to identify areas of expertise and deficit in the specific knowledge employed in the care of dying patients with profound learning disabilities in an NHS Trust in the UK. The third main theme '*Humane care*' in terms of the positive regard of personhood as identified in my study stressed the essentiality of RNLDs and PCPs executing physical and emotional care throughout a person's illness and at time of death. A positive regard of the whole person was deemed imperative to the provision of appropriate and confident optimum care for this population. I suggest that it is an aspect of care which could be investigated by subsequent research in order to address the needs of distressed PCDLD in palliative care settings. I also propose that this increases the likelihood of the contribution of my study's findings to existing knowledge relating particularly to planned changes in care approaches for this client group in palliative care settings.

Empathy

Participants described experiences which upheld the view that the third main theme '*humane care*' also encompassed empathy (Figure 6.2, p.137). Empathy was employed by the participants as a method to identify and respond to the distress of PCDLD in palliative care settings. Participants acknowledged the significance of being receptive and empathetic if optimum care had to be provided to distress PCDLD in palliative care settings. Empathy was also demonstrated by the participants as compassion and insightful awareness of not just the verbal communication of the distressed individual but also sensitivity to the physical deterioration of the dying individual. As illustrated in participants' quotes (see Chapter Five, pp.104-105), such sensitivity facilitated participants' recognition of distress cues through observation for certain signs or symptoms such as a change in behaviour, grimacing, breathlessness, restlessness,

withdrawal, and vocalisation such as groaning, moaning and crying. Participants responded to the distress cues with the provision of optimum care.

To an extent, the participants' ability to identify distress cues such as change in behaviour, grimacing, breathlessness, restlessness, withdrawal and vocalisation such as groaning, moaning and crying through observation of the PCDLD, resonates with the findings in some of the prevailing literature. In a paper based on a systematic review of literature and aimed at assessing the reliability and validity of facial expressions as pain indicators in patients with severe dementia, Manfredi et al. (2003) established that facial expressions and vocalisation are methods for assessing the presence of pain but not its intensity in patients who are unable to communicate verbally because of advanced dementia. Additionally, Regnard et al. (2006) in a study using mixed methods aimed at piloting the Disability Distress Assessment Tool (DisDAT) identified a variety of distress cues, which were not specific to a particular cause and that distress did not have a common meaning amongst carers and was not only related to pain.

I suggest that Manfredi et al.'s (2003) paper and Regnard et al.'s (2006) study have provided a different thread to the identification of distress in people with learning disabilities. This points to the fact that despite previous attempts to research distress experienced by this client group, as well as people with dementia, distress has no generic meaning; it remains a valuable clinical construct that continually necessitates the need for more evidence-based knowledge to improve care approaches. In this case, care approaches that are specifically tailored to address the distress of PCDLD in palliative care settings. Hence, it is envisaged that my study's findings may have implications for practice and policy development relating to the care of this population.

Also, it is worth-mentioning that

"Participants' narratives increased my understanding of sensitive compassionate care. To be an effective healthcare professional these qualities are essential... Unless the healthcare professional utilizes a holistic approach that considers both professional skills (evidence-based knowledge and practical skills) and emotional sensitivity, delivering maximally effective and integrated care will be problematic" (My Fieldnotes, 19/1/2012).

Therapeutic touch

Participants' narratives indicated that the third main theme 'humane care' also consisted of therapeutic touch (see Figure 6.2, p.137). Participants portrayed touch as essential to the phenomenon of caring for distressed PCDLD in palliative care settings. Responding to identified distress with a touch was also considered as an embodiment of loving care towards the dying PCDLD. This also demonstrated the mutuality of the relationship between the PCDLD and the participants and the participants' commitment to be

authentically present for the distressed PCDLD thus, enabling them to experience a good death in a palliative care setting. See participants' quotes in (pp.105-106).

My increasing understanding of the importance of humane care in terms of participants' commitment to utilizing empathy and touch as a strategy to address the distress of PCDLD with the provision of confident care was expressed as:

"Delving into participants lived experiences throughout this inquiry I was left to marvel at the significance of words but even more so, the significance of an alternate form of communicating other than words. Communicating with words is something that at most times we all take for granted. Although words are spoken with different intonations and inflections it remains a fact that words are spoken in different parts of the world and used by people of different creed, colour and ethnicity. Taking into consideration the universality of words in comparison to an existence where there is no spoken word and where individuals are left to devise a medium of making their needs known and met, participants descriptions enlightened me to a deeper understanding that as human beings we are capable of training the self over time to utilize other methods (touch) to relate with each other even in the most awkward of situations" (My Field-notes 23/01/12).

Relieving distress or communicating caring through touch as described by the participants resonates with the terms 'comfort touch' and 'pathic touch'. Newson (2008, p.270) stressed that comfort touch is "*holding someone's hand and making eye contact at the same time to convey caring, understanding and willingness to be with the person*". 'Pathic touch' has been described as touching the self as a whole person (Kleiman 2005). In addition it has been asserted that 'pathic touch' is not limited to physical touch but is intended to increase understanding of the others' emotional feelings as human beings (Kleiman 2005).

6.3.3 Moral duty of care

Participants' demonstrated that their moral duty of care had some relevance to Van Manen's (1990, p.103) description of corporeality: "*we are always bodily in the world*". The fourth main theme '*Moral duty of care*' as portrayed in this study included: Training and providing a dignified end; Pain-free care; Comfort, safety and peace; and Acknowledgement of shortcomings (see Figure 6.2, p.137). These aspects could all be associated with participants' obligation in utilizing their physical bodies in terms of practical skills and specialism in providing the best possible care for distressed PCDLD. Participants' explanations denoted their understanding of the essentiality of maintaining moral standards while executing physical and emotional care throughout an individual's illness and at the time of death.

Training and providing a dignified end

Participants' '*Moral duty of care*' consisted of training and providing a dignified end to PCDLD in palliative care settings. The participants' conscious commitment to improve their knowledge of palliative and end-of-life care (EoLC) for PCDLD was elucidated as an approach used to address the distress of this population. This was in terms of obtaining training and clinical skills to meet the identified distress or palliative care needs and using an established palliative care framework such as the Gold Standard Framework (GSF, 2004) for EoLC to ensure appropriate advance care planning and EoLC for this population. Obtaining appropriate specialist skills and training was perceived as their moral duty of care as healthcare professionals to provide optimal care and ensure a good death or dignified end for PCDLD in palliative care settings.

The significance of training and the acquisition of specialist skills to address the distress of PCDLD substantiate the findings in existing literature by Ryan et al. (2005) and Catilidge and Read (2010). Ryan et al. (2005) made recommendations for training programmes to improve clinicians' communication techniques in order to obtain, recognize and respond to emotional distress of cancer patients.

However, Ryan et al.'s (2005) goals were specifically: to identify the barriers to cancer patients expressing their psychological concerns and also, to recommend strategies to assist oncologist to elicit, recognize, and manage psychological distress in their patients. I suggest that Ryan et al.'s (2005) paper has added knowledge to the care of cancer patients but not specifically to the care of PCDLD experiencing distress in palliative care settings from the perspectives of RNLDs and PCPs. However, Ryan et al. (2005) asserted that distress is common in cancer patients but it is often unrecognised and untreated. They claimed that anxiety and depression can mimic the physical symptoms of cancer treatments and consequently emotional distress may not be detected. The paper identified some barriers to cancer patients expressing their psychological concerns such as patients normalising or somatising their feelings, and recommended strategies such as basic communication techniques to enable oncologists to recognise and manage the psychological distress of their patients (Ryan et al., 2005).

I suggest that both my study and Ryan et al.'s (2005) paper highlight the significance of training healthcare professionals to ensure acquisition of relevant skills to meet the palliative and EoLC needs of patients. However, Ryan et al.'s (2005) paper is focused on cancer patients in the general population and not on psychological distress for PCDLD in palliative care settings. Thus, an indication of the need for more empirical research in the care of distressed patients other than cancer patients and in particular, distressed PCDLD in palliative care settings. I also propose that there is a need for more empirical

studies focusing on people with learning disabilities needing palliative care, which encompass cancer care and other life-limiting conditions such as dementia, which is a growing concern for this client group (Lakey et al., 2012; Mohan et al., 2009). There is also, a need for a model of palliative care for this population. This indicates the importance and the likely contribution of my study's findings to practice and policy especially, relating to the care of this population in palliative care settings. The findings from my study may contribute towards the creation of a model for palliative and EoLC for this population. A similar view is expressed in a study by Cartlidge and Read's (2010). The study demonstrated some similarity to the recognized significance of training and the acquisition of specialist skills to address the distress of PCDLD. Cartlidge and Read's (2010) study aimed to identify what educational preparation skills hospice staff felt were needed to enable them feel confident in providing specialist palliative care for people with intellectual disability. One of the findings in their study highlighted that appropriate education and training remain an essential preparation for hospice workers when caring for someone with an intellectual disability.

Pain-free care

The fourth main theme '*Moral duty of care*' also included pain-free care (see Figure 6.2, p.137). It was considered a '*moral duty of care*' by the participants to provide care that was pain-free, comfortable and peaceful to PCDLD experiencing distress in palliative care settings. Accordingly, being pain-free, comfortable and peaceful in one's self and surroundings constitutes a positive palliative care experience for both the PCDLD experiencing distress and their family members. This finding resonates with some of the issues raised by the Department of Health (DH, 2008a, p.12) end of life care strategy for adults which stated that

Although every individual may have a different idea about what would, for them, constitute a good death, for many this would involve: being treated as an individual, with dignity and respect; being without pain and other symptoms; being in familiar surroundings; and being in the company of close family and/or friends.

Comfort, safety and peace

As demonstrated in participants' quotes in Chapter Five (see pp.107-108), the participants' considered it their '*moral duty of care*' to make a conscious effort to provide a comfortable, peaceful and safe environment in order to identify and alleviate distress that was linked to the environment.

Acknowledgement of shortcomings

The fourth main theme '*Moral duty of care*' also, encompassed acknowledgement of short comings (see Figure 6.2, p.137). Acknowledgement of shortcomings relates to the

participants' recognition and expression of prior caring experiences, knowledge, physical and cognitive abilities, and confidence or the lack of these qualities as the case may be, in providing the best quality of care to PCDLD and their family members within palliative care settings. It also encompasses participants' professional meticulousness as a fundamental approach in responding to the distress of PCDLD in palliative care settings. Thus, participants felt it was their moral duty to be always mindful to recognize and overcome their shortcomings by training or drawing from past experiences to ensure good caring outcomes

The theme '*Moral duty of care*' demonstrated participants' desire to ensure that PCDLD are relieved from identified physiological, spiritual and psycho-social distress by providing them with optimum care whilst alive until the time of death. It is interesting to note that just as the participants could perceive the bodies of the PCDLD in their visually external or physical states, so too participants' descriptions indicated that their own bodies, in terms of their physical, cognitive, specialist or professional capabilities became an object of their own scrutiny. This scrutiny was in terms of participants' search to find ways to identify and respond to the distress of PCDLD within palliative care settings while acknowledging their own limitations such as the sense of time and the required skills to meet the needs of this population.

This view is in line with Van Manen's (1998) description of modalities of body experience in illness and health in which he explained that just as we can observe the bodies of others so too we can self-observe our own bodies. This occurs especially when the body is rebellious or unreliable. In other words when compromised, our bodies make it known to us if we are unable to perform due to drawbacks of any type. In such vulnerable situations, it remains our personal responsibility to seek ways to overcome those drawbacks (Van Manen, 1998). In my study, participants made a conscious effort to acknowledge and overcome their shortcomings by undertaking training in the pursuit of new knowledge and skills to meet the needs of PCDLD experiencing distress in palliative care settings. Thus acting in line with the assertion that being caring is being vulnerable and if we are not able to be vulnerable with ourselves and others, we become robotic, mechanical, detached and de-personal in our lives and work and relationships (Watson, 2000).

6.4 Temporality (lived time)

Van Manen (1990) described the lived world of temporality as relating to the subjective lived time as opposed to clock time or objective time. It also encapsulates our temporal

way of being in the world (Van Manen 1990). In this study it mirrors the RNLDs' and PCPs' perceptions of time while performing in the world and encompasses the temporal dimensions of past, present and future, which Van Manen (1990, p.105) describes as the horizons of a person's temporal landscape. In this study time was considered essential to the phenomenon of caring for distressed PCDLD in palliative care settings. Participants made a deliberate effort to be aware of time in order that timely and appropriate care was provided to address the distress of PCDLD. The fifth main theme identified in this study namely: '*Time to care*' shows some relevance to temporality. '*Time to care*' includes time and anxiety, time and caring opportunities, and dying as part of living (see Figure 6.3, overleaf).

In Figure 6.3 the 'unidirectional' arrow commencing from temporality to the theme '*Time to care*' show how this theme is related to the concept of temporality. The 'right arrows' point to what this theme encompasses, which contributed significantly to how participants identify the distress of PCDLD. The 'right brace' points to how this theme was strategic to participants' ability to identify and respond to the distress of PCDLD in palliative care settings. A discussion of this theme in association with relevant theory and literature is provided in section 6.4.1.

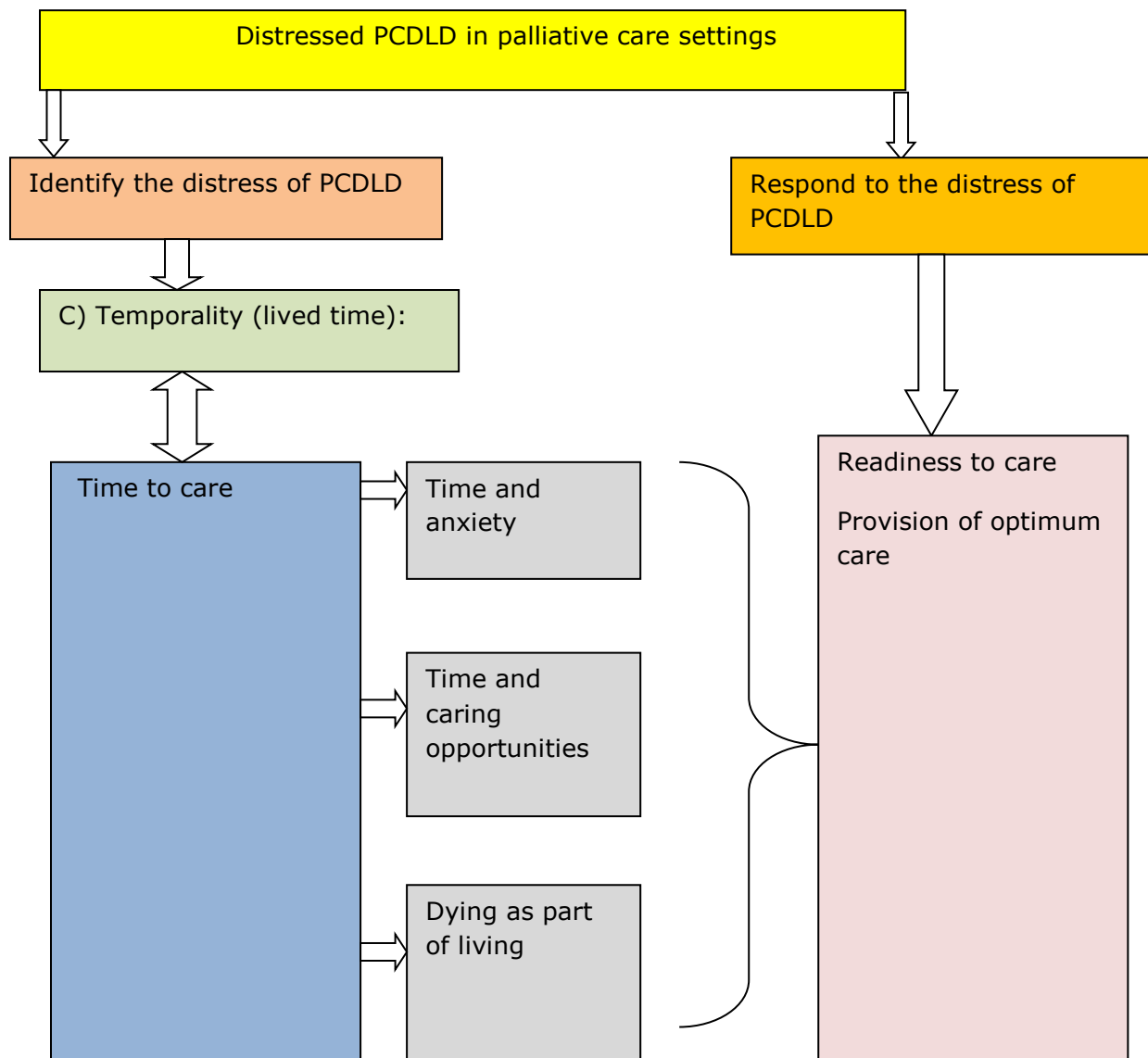


Figure 6.3 Temporality (lived time)

6.4.1 Time to care

Participants emphasized that 'time to care' was essential to the care of distressed PCDLD in palliative care settings. It comprised time and anxiety, time and caring opportunities, and dying as part of living (see Figure 6.3, above). Participants were aware of time and demonstrated patience by giving fully of themselves, in terms of being genuinely present; in order to provide optimum care to distressed PCDLD. Over time, participants were able to develop trusting relationships with the PCDLD. Thus, they could interact with them, observe them, and subsequently, provide timely and appropriate care to alleviate their distress. To an extent, the fifth main theme 'time to care' as elucidated in this study echoes the assumptions in the theory of *Nursing as Caring* (Boykin and

Schoenhofer, 2001). Boykin and Schoenhofer, (2001, p.1-2) stated that, "*persons live caring from moment to moment*" and that "*caring is unfolding constantly from moment to moment*". These postulations imply that the time employed in providing care is present time and continuing time. Additionally, Boykin and Schoenhofer (2000) also asserted that time to care is not reliant on how much time the nurse has to provide care for the patient/client; rather it is dependent on how much time the nurse can be genuinely present with the patient as a caring person.

Time and anxiety

The fifth main theme '*Time to care*' also encompassed time and anxiety (see Figure 6.3, p.148). Time and anxiety indicated participants' perspective of time as limited and yet a priority for the distressed PCDLD and their families. This was described by participants as being mindful to provide optimum care and meeting the needs of the dying PCDLD, yet having to work within the constraints of available time and certain human limitations. Human limitations in this case included the anxiety of delivering care outside professional expertise or familiar care settings and the dilemmas of where the health care professional fits in the bigger picture of palliative care and learning disability services. Additionally, participants' descriptions signified that time necessitated that these human limitations had to be overcome for participants to appropriately respond to the distress of PCDLD. Participants recognized that in order to do the best for the PCDLD and their families, they had to overcome professional barriers and stigma through training and sharing of professional knowledge and experiences. They also had to allow time to equip them with the essential experience and skills to meet the needs of distressed PCDLD within palliative care settings (see Chapter Five, p.109) for participants' quotations.

Time and caring opportunities

The theme '*Time to care*' also consisted of time and caring opportunities (see Figure 6.3, p.148). Being aware of time and caring opportunities was vital as far as the time to care was concerned. Participants explained that accurate timing was a significant approach needed to address the distress of PCDLD and also facilitated the provision of appropriate palliative care from suitable services. This emphasized the importance of effective time management and early involvement in the care of distressed PCDLD in palliative care settings. As illustrated in participants quotes in Chapter Five (pp.109-110), effective time management was important because healthcare bureaucracy made it difficult to identify how to liaise with appropriate services to meet the needs of this client group in palliative care settings. Participants expressed that this was especially challenging for newly appointed RNLDs or healthcare professionals who had to contend with both

healthcare bureaucracy while getting accustomed to their new roles, and the lack of information or standardised policies to do with the transition of young adults with learning disabilities from children's to adult palliative care services.

Problems related to healthcare bureaucracy and the need to incorporate accurate timing in terms of timely referral to palliative care services as illustrated in my study correlates to an extent, with Marsh et al.'s (2011) report on '*young people with life-limiting conditions: transition to adulthood*'. Their report highlighted that young people have a poor experience of transition, both in terms of services and in terms of having the control and the autonomy they wish. Marsh et al. (2011) also established that transition could be a shock for professionals as well, because they are still locked in detached and conflicting assumptions, structurally separated systems that are children's and adult services and that operate different practices or protocols for example, in pain relief. I suggest that this finding as well as Marsh et al.'s (2011) report have emphasized the significance of timely and appropriate palliative care and also that the transition of young people from children to adult palliative care services remains problematic. Even more so, it points to the need for further empirical studies investigating how RNLDs and PCPs address the palliative care needs of this client group including transition of individuals to appropriate palliative care services as required.

Dying as part of living

The fifth main theme '*Time to care*' also included the concept of dying as part of living (see Figure 6.3, p.148). Participants learned from their experiences and over time through training and collaborative working acquired the necessary skills, which enhanced their provision of continuous, consistent and confident optimal care to distressed PCDLD. The expressed goal by the participants was a deliberate commitment to deliver care, which took into consideration not only the distress of the PCDLD but the totality of their human experience, consequently perceiving dying and death as a part of living.

6.5 Spatiality (lived space)

According to Van Manen (1990, p.102) the "*lived space is felt space.....It is largely preverbal; we do not ordinarily reflect on it. And yet we know that the space in which we find ourselves affect the way we feel*". In this study, participants' narratives indicated that deliberately creating a comfortable care environment or space was fundamental to the care of distressed PCDLD in palliative care settings. The sixth main theme identified in this study namely '*Comfortable care environment*' could be applicable to spatiality. The theme consists of the care environment, and aesthetic knowing. Participants'

descriptions indicated that aesthetic knowledge of the care environment encompassed the use of sensitivity, insight, and creativity to adjust the care environment. This enhanced participants' ability to observe or identify subtle changes in the behaviour of PCDLD, which might be the presentation of distress directly related to the specific palliative care environment. Thus, participants were able to plan care that was sensitive to the spiritual, cultural and religious needs of the distressed or dying PCDLD within the limitations of the available care environment.

In this study, the palliative care settings where participants provided care to distressed PCDLD is an embodiment of their lived space. Ensuring an appropriate lived space or care environment was therefore an essential component which contributed to the care of distressed PCDLD. This theme was mapped under the overarching theme of spatiality (lived space) to exemplify the varied depth of understanding of the meaning the phenomenon of caring for distressed PCDLD in palliative care settings had for the participants (see Figure 6.4, overleaf).

In Figure 6.4 the 'unidirectional' arrow commencing from spatiality to the theme 'Comfortable care environment/space' show how this theme is related to the concept of spatiality. The 'right arrows' indicate what constitutes this theme. The 'right brace' points to how this theme enabled the participants to address the distress of PCDLD in palliative care settings. A discussion of spatiality, including the theme '*comfortable care environment*' with the incorporation of relevant theory and research literature, is provided in sections 6.5.1.

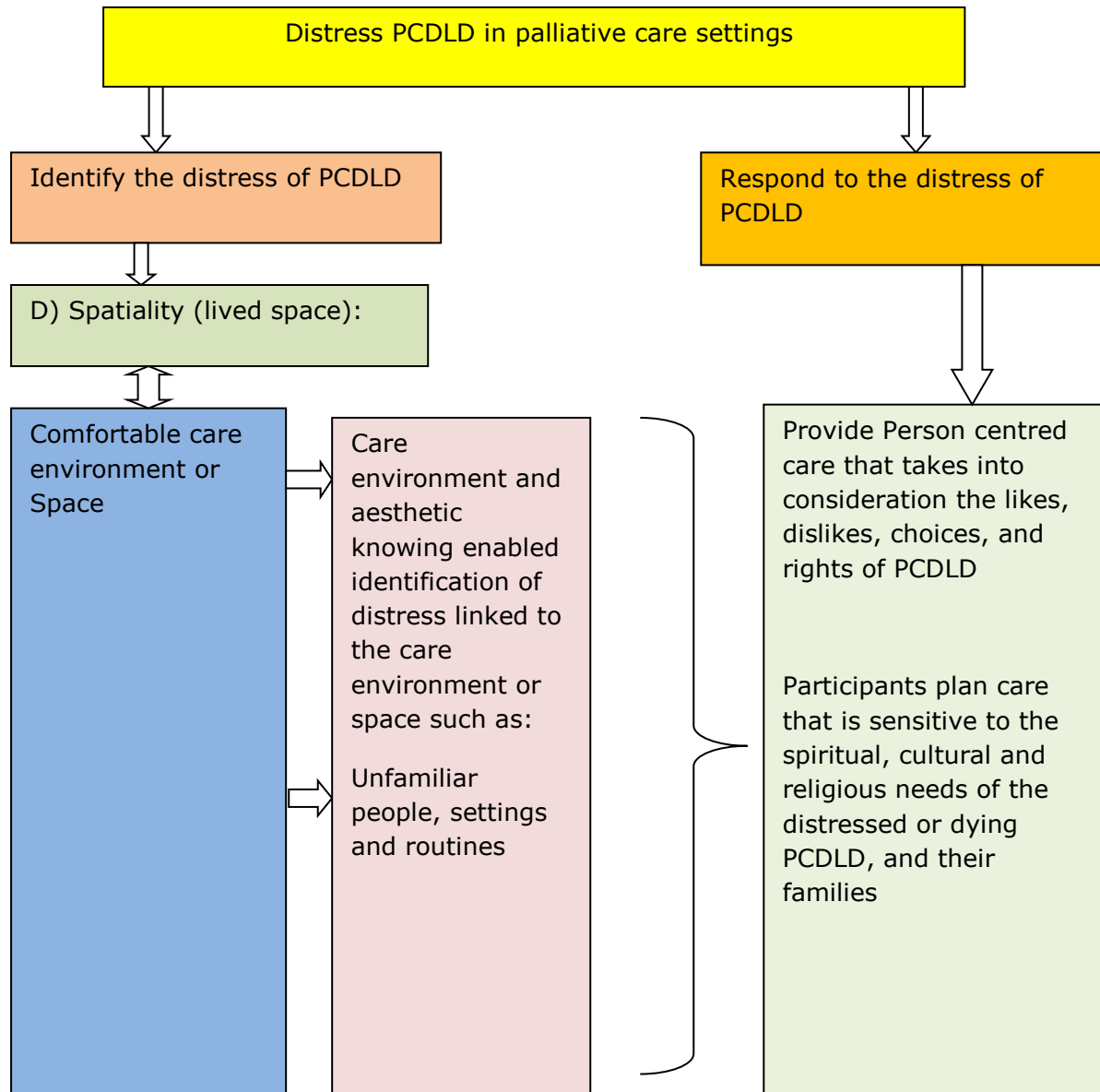


Figure 6.4 Spatiality (lived space)

6.5.1 Comfortable care environment

The participants delivered palliative care in a variety of palliative care settings. Their descriptions reflected the structure of palliative care that included intensive care units, hospices and community-based palliative care settings. Community settings included nursing homes, residential care settings, an individual's private home or family home. Participants' narrative portrayed that the sixth main theme '*Comfortable care environment*' encompassed aesthetic knowing. Participants described aesthetic knowing as a method used by the participants to identify and respond to the distress of PCDL in palliative care settings. Aesthetic knowing meant the participants utilized sensitivity,

insight and creativity to tailor the care environment according to an individual's specific needs. The participants were able to do so by consciously adjusting the care environment in order to plan care that was sensitive to the cultural and religious inclinations of the distressed or dying PCDLD within the limitations of the available care environment or space. The significance of utilizing aesthetic knowing to address the distress of PCDLD was reiterated by participants' descriptions, which portrayed that the nature of dying and human suffering or distress was personal. Participants emphasized that in order to identify and appropriately respond to any emotional, spiritual or psychosocial distress, planned care within the confines of the available care environment or space had to maintain the spiritual, cultural, and religious inclinations of the PCDLD so as to maximise their choices, rights and autonomy. It is noteworthy that

"Listening to participants' interviews deepened my understanding of the significance of person-centred care approach that considered every aspect of individuals' humanity. It deepened my understanding of the significance of care that ensured that even the smallest details were accounted for to ensure optimum care for people... Such details ensured that religious, cultural and spiritual needs of individuals, which could be easily overlooked, are met. I realised that although it is difficult to state what one person's spiritual experience is from another's, like love people know it when they experience it. It remains the duty of the healthcare professionals to ensure that level of self-satisfaction is attained by the people they care for" (My Fieldnote, 14/11/11).

To an extent, providing a comfortable palliative care environment that was sensitive to the cultural, spiritual and religious needs of PCDLD share some similarities with Tuffrey-Wijne's (1998) study in which she highlighted the significance of culture in the care of the terminally ill. In her case study entitled '*Care of the terminally ill*' Tuffrey-Wijne (1998, p.8) asked "*why are terminally ill people with learning disabilities often denied the chance to die in their own homes?*" She cited the case of a man with Down's syndrome and Alzheimer's and highlighted various reasons why residential care homes, for people with learning disabilities (PLDs), may feel unable to care for a terminally ill resident such as lack of resources in both staff and facilities. She also identified strategies which might assist PLDs to die at home, amongst which, was a consideration of cultural issues. Tuffrey-Wijne (1998) emphasized that staff may need to ask the PLDs and their families if any cultural or religious rites need to be executed towards the end-of-life. This is especially significant because there are considerable variations between cultures and it also depends on how involved the families are in the culture (Tuffrey-Wijne, 1998).

It would seem that the findings of both Tuffrey-Wijne's (1998) study and my study add to the growing body of empirical research relating to palliative care for PLDs. I also propose that the findings from both studies seem to emphasize that more still needs to be done in terms of practice and policy documents specifically illustrating that palliative

and EoLC should consider the spiritual and cultural needs of PLDs in general and PCDLD experiencing distress in particular. This is because both studies have portrayed different strands relating to culture in the care of this population with Tuffrey-Wijne's (1998) concentration on the place of care, (the home), of the terminally ill PLDs, and my study's theme '*Comfortable care environment*' emphasizing that in order to identify and appropriately respond to any emotional, spiritual or psycho-social distress, planned care within the confines of the available care environment had to maintain the spiritual, cultural, and religious needs of the PCDLD so as to maximise their choices, rights and autonomy.

In a similar vein, a paper by Flowers (2004), focused on the challenges in providing culturally competent nursing care in the 21st Century. Flowers's (2004) paper is a review of literature in which she also cited her own personal experience as an emergency room nurse in a small rural hospital in America, during which, she had witnessed an incident which led her to believe culturally competent care had not been provided by the healthcare professionals involved in a certain patient's care. Flowers's (2004) paper also described the current population trends in North America, the need for critical care nurses to develop cultural competence, a model for the development of cultural competence, and common pitfalls in the delivery of culturally competent care. The paper established that as patient advocates, critical care nurses are required to support decisions made by patients or patients' families that may reflect a cultural perspective that conflicts with mainstream healthcare practices. Flowers (2004) alludes to Ekbal et al's (2000) and Catalano's (2003) books to highlight the changing demographics of United States of America (USA), Sweden, and most societies of the world. The paper emphasized that due to the multi-cultural population in the USA and in most societies today, nurses must have a clear understanding of the diverse cultural background of their patients to be able to provide culturally competent care. Flowers (2004) cited Purnell and Paulanka's definition of cultural competence as:

developing an awareness of one's own existence, sensations, thoughts, and environment without letting it have an undue influence on those from other backgrounds; demonstrating knowledge and understanding of the client's culture; accepting and respecting cultural differences; adapting care to be congruent with the client's culture (Purnell and Paulanka, 1998, pp. 1-7).

The paper concluded that there is a direct relationship between a patient's culture and his or her health, and that of the many variables known to influence health beliefs and practices, culture is one of the most influential (Flowers, 2004).

Additionally, although viewed from a different perspective from my study, the significance of culture in care is further avowed with a focus on the elements and models

of EoLC in an educational project to develop a curriculum to educate physicians, (medical doctors), on EoLC (Emanuel, von Gunten, and Ferris, 1999). They provided a definition of palliative care, and highlighted conceptions of suffering, a framework of elements in EoLC, and a set of models and standards for the delivery of quality EoLC. Emanuel et al. (1998) identified that suffering, could be conceptualized as a fragmentation of personhood, a disturbed life story, as an opportunity for growth, or as total pain. They emphasized that elements of care could be divided into those that are fixed and those that could be modified. Those elements of care that are fixed, comprised of the patient's racial, ethnic, cultural, and socio-economic background, as well as the diagnosis and prognosis. Elements that could be modified included the symptoms suffered in the physical, mental, social and spiritual realms. They also recognized that suffering could best be addressed by utilizing a health system that acknowledges those characteristics that cannot be changed, and intervenes to influence those that can be changed to ensure the best possible outcome (Emanuel et al., 1999). They stressed that it is important for healthcare providers (medical doctors) to have a comprehensive framework from which to practice based on a broad perspective of human existence, if they were to relieve suffering at the end-of-life, and enhance quality of life.

To an extent, the above-mentioned literature resonates with my study's theme '*Comfortable care environment*'. Participants' emphasized that consideration must be made of the care environment and collaboration amongst the PCPs and RNLDs to ensure that the care environment is tailored according to individuals' needs. However, unlike Emanuel et al.'s (1999) educational project, my study did not focus on enhancing culturally competent nursing or developing a curriculum for educating physicians, (medical doctors) on EoLC. Rather, my study portrayed how the participants identified and responded to the distress of PCDLD through the provision of care that took into consideration aesthetic knowing, which allowed for the structuring of a care environment that was sensitive to the cultural and religious inclinations of PCDLD. Consequently, I could suggest that the similarities in the aforementioned literature to my study's finding, is an emphasis on the fact that despite the improvement in healthcare, and the reiteration on promoting equal access for people with learning disabilities (DH 2009), there is still a recognized need to improve effective interactions and the development of appropriate holistic care approaches for distressed PCDLD in palliative care settings and also people from diverse ethnic, cultural, and racial backgrounds.

The significance of care that was sensitive to the cultural and religious preferences of the PCDLD as portrayed in my study, is also in line with an existing finding of a strategy reform report, which acknowledges the links between race and cancer and emphasized how complex and varied the two are across different ethnic minority groups (Cancer

Reform Strategy, 2007). However, unlike the finding of my study that focuses on the notion that to appropriately respond to the distress of PCDLD, planned care within the palliative care settings where individuals are based had to be sensitive to their cultural and religious preferences, the focus of the strategy reform report is on cancer care. This is in terms of cancer care that takes into consideration user involvement from people such as people with learning disabilities or from ethnic minorities who may not usually join groups or attend meetings but have valuable experiences of services to share that may potentially contribute towards equality in cancer care (Cancer Reform Strategy, 2007).

I propose that the identified dissimilarity between the focus of the Cancer Reform Strategy (2007) and my study's finding restates the significance of my study in terms of the potential contribution to practice and policy dealing with the phenomenon of caring for PCDLD experiencing holistic distress in palliative care settings. Also, it is worth mentioning that

"throughout the inquiry, as I read, re-read, listened, questioned and reflected on participants' narratives with the goal of constructing meaning which was an authentic representation of participants' lived experiences, my understanding was transformed with the realisation that like the PCDLD and the participants in this study, we (as human beings) cannot be considered without our context or environment, which encapsulates our families, friends, beliefs, cultural and religious orientations. This is even more pertinent when a person is facing impending death as the people directly involved or related in their lives offer themselves in loving care, religious, cultural and professional inclinations as symbolic of a recognition of the person's pain or suffering and an attempt to relieve or respond to that suffering within the environmental context" (My Field-notes, 28/01/2012).

The theme 'Comfortable care environment' is also in line with Watson's (1988, 1999) nursing theory and Boykin and Schoenhofer's (2001) theory of nursing as caring. Watson (1988) described a person as a being-in-the-world who has three spheres of being including: mind, body and spirit. This description emphasized the interconnectedness between persons and their environment. Also, in the assumptions of the theory of nursing as caring, Boykin and Schoenhofer (2001) highlighted that all persons involved with the persons being cared for (in this case RNLs, PCPs and family members) must see themselves as caring persons and contribute towards creating a caring environment. More so, the concept of 'caring between' in the theory of nursing as caring can be related to Van Manen's (1990, p.102) spatiality: "lived space is felt space.....It is largely preverbal; we do not ordinarily reflect on it. And yet we know that the space in which we find ourselves affect the way we feel". This is because Boykin and Schoenhofer (2001) explained that caring between is the place where nursing is created.

Accordingly, in the current study the participants as caring persons deliberately create a relationship with the PCDLD within a palliative care setting, and caring between occurs. Creating a '*Comfortable care environment*' as illustrated by the participants also resonates with Watson's (1999, p.254) assertion about the concept of the environment or healing space, which can increase a person's "*awareness and consciousness*" and promote mind, body, and spirit wholeness and healing. Furthermore, the sixth main theme '*Comfortable care environment*' also echoes the views presented in the National Institute on Aging (NIA) (2009), which emphasized that comfort care at the end of life is an essential part of medical care, and the goal of EoLC is to relieve suffering as much as possible while respecting the dying person's wishes (NIA, 2009).

The participants' quotes, as illustrated in Chapter Five (pp.111-112), indicated that the participants utilized aesthetic knowing to adapt and create a comfortable care environment for the PCDLD, as a result, this enhanced participants' understanding of the factors that determined how PCDLD communicated distress in palliative care settings. These factors comprised of: (1) Environmental factors relating to unfamiliar people, unfamiliar care setting, and unfamiliar routine (2) Physiological factors relating to pain (3) Psychological factors relating to emotional stress and (4) Lack of understanding and communication difficulties. See quotes (pp.112-115).

The participants' narratives illustrated that environmental factors specifically linked to unfamiliar people, unfamiliar care settings, unfamiliar routines and un-stimulating environments affected how PCDLD expressed distress in palliative care settings. Consequently, participants explained that when exposed to these environmental factors the PCDLD became distressed and their distress was manifested in certain instances by becoming withdrawn or uncooperative with interventions.

Also, due to the interrelatedness of the relationships that the participants built with PCDLD within the space or environment that they shared with them (Van Manen 1990), the participants were able to observe and identify any physiological factors such as pain and any psychological factors such as emotional stress and anxiety, or the frustration at not being able to express their needs. This meant that their distress or state of health could only be identified by staff members who knew them well. Participants explained that when in pain or anxious, individuals became distressed and their distress was communicated by withdrawal, uncooperativeness during care interventions, changes in facial expressions or display of aggressive behaviours.

Participants' descriptions therefore stressed the importance of knowing the PCDLD which enabled them to observe and recognize physiological factors in particular pain or other factors, which affected how PCDLD in palliative care settings expressed their distress.

Hence, creating a *comfortable care environment* meant that the participants observed and ensured that the care environment was adapted to address the pain, environmental or psychological distress factors that individuals were faced with. To an extent, the significance of observation in the identification of pain has been mentioned in a paper by Hadjistavropoulous and Craig (2002). Hadjistavropoulous and Craig's (2002) paper aimed to provide a rationale for the use of self-report and observational strategies using a communication model and to examine factors that governs the utility and validity of such strategies. They highlighted that observational measures can be used and have clinical effectiveness as indices of pain when self-report is not available for example in infants, young children, people with intellectual disability or brain damage and seniors with dementia (Hadjistavropoulous and Craig's, 2002). They also stressed that both observational and self-report measures are essential in the assessment of pain because each type provided vital information (Hadjistavropoulous and Craig's, 2002).

I propose that my study extends the contribution to knowledge that was made by Hadjistavropoulous and Craig's (2002) paper in the subject area of pain identification and management. However, Hadjistavropoulous and Craig's (2002) paper has contributed knowledge in the subject area of pain identification and management especially in infants, young children, people with intellectual disability or brain damage and seniors with dementia. Whereas, my study's finding has indicated that creating a comfortable care environment through aesthetic knowing also enhanced participants' understanding of the factors which determined how PCDLD communicated distress in palliative care settings. I argue that there is an inference that, for palliative care to have a high impact on PCDLDs' experiences, there is still a need to continually identify areas of practice and policy that require improvement and plans for change should be made accordingly. Since my study is specifically related to the care of PCDLD experiencing distress in palliative care settings, in terms of how RNLDs and PCPs identify and respond to their distress, I suggest that my study's findings may contribute to the growing body of knowledge and policy documents relating to palliative care for this client group.

To an extent, participants' descriptions about creating a comfortable care environment that was adapted to address the pain, environmental or psychological distress factors that individuals' were challenged with resonates with a paper by Conboy-Hill (1992) titled '*Grief, Loss and People with Learning Disabilities*', (PLDs). This was in terms of the recognized impact of psychological distress on the behaviours of PLDs within the environments in which they are cared for. I suggest that both Conboy-Hill's (1992) paper and my study have contributed knowledge to the subject of psychological distress experienced by PLDs. However, unlike my study which is aimed at gaining an understanding of how RNLDs and PCPs identify and respond to the distress of PCDLD in

palliative care settings, particularly distress which was perceived as a continuum encompassing spiritual, physiological, and psycho-social distress, Conboy-Hill's (1992) focus was distress, in terms of grief experienced by PLDs as a result of death or loss. She suggested that a failure to identify the impact of loss on PLDs was as a result of the need to believe that PLDs did not grieve and consequently, rationalizing the approaches used to care for them. This also meant that when their behaviour was recognized as difficult, which was perhaps related to complicated grief, the PLDs were either sedated or 'trained out of it', often without reference to the possibility of an emotional cause. Conboy-Hill (1992) stressed that in reality many of the PLDs diagnosed as having behavioural issues had experienced multiple deaths in their ward, they had been told the deceased had 'gone away', and they had also been excluded from mourning rituals. Arguably, there is little or no emphasis on the view that the experience of grief might include more than just an understanding of death by the person with a learning disability as it could be related to distress (grief) at a lack of understanding of the changes taking place in an individual's body due to the progression of their disease trajectory and their difficulties with communication (Brown et al., 2005). Consequently, I suggest that this view emphasizes that understanding and identifying the psychological distress experienced by this population remains problematic. There is a need, therefore, for more empirical inquiry detailing examples of good practice by RNLs and PCPs in the care of PCDLD who are distressed in palliative care settings. Such examples of good practice may contribute to knowledge, planned changes in care, and may also inform palliative care service provision for PCDLD.

6.6 Future perspectives (Extended dimension of Temporality)

The seventh main theme: '*Future perspectives*' consists of Optimism, Proactive collaboration, Future improved access, and Meeting expectations. '*Future perspectives*' could be considered as extended dimensions of *temporality* (lived time). This is because this theme emulated participants' perceptions of time while engaged in the palliative care world and particularly encompassed the future as fundamental to the temporal dimensions of the past and present, which Van Manen (1990, p.105) described as the horizons of a person's temporal landscape.

In this study, the theme '*Future perspectives*' was considered as essential to the care of distressed PCDLD in palliative care settings. Participants' experiences indicated an understanding that appropriate and timely optimum palliative care for distressed PCDLD could be promoted if future perspectives relating to learning disabilities and palliative care service provisions were addressed. Therefore, a conscious commitment to time, in

terms of a planned future, was perceived by the participants as an essential approach to appropriately identify and respond to the distress of PCDLD in palliative care settings. The theme '*Future perspectives*' was mapped unto Van Manen's life-world existential of temporality (lived time) as an overarching theme (see Figure 6.5, overleaf).

In Figure 6.5, the 'unidirectional arrows' and the 'plus sign' from '*Future perspectives*' to the themes Optimism, Proactive collaboration, Future improved access and Meeting expectations show how these themes are related to the idea of Future perspectives. It is also an emphasis on the importance of each of these themes to this concept in terms of addressing the distress of PCDLD in palliative care settings. The 'right arrows' show what constitute a particular theme. The 'right braces' demonstrate how these themes enabled the participants to respond to the distress of this population. A discussion of the components of Figure 6.5 overleaf in terms of '*Future perspectives*' as an extended dimension of temporality, with the incorporation of relevant theory and research literature is discussed later in this chapter in sections 6.6.1, 6.6.2, 6.6.3 and 6.6.4.

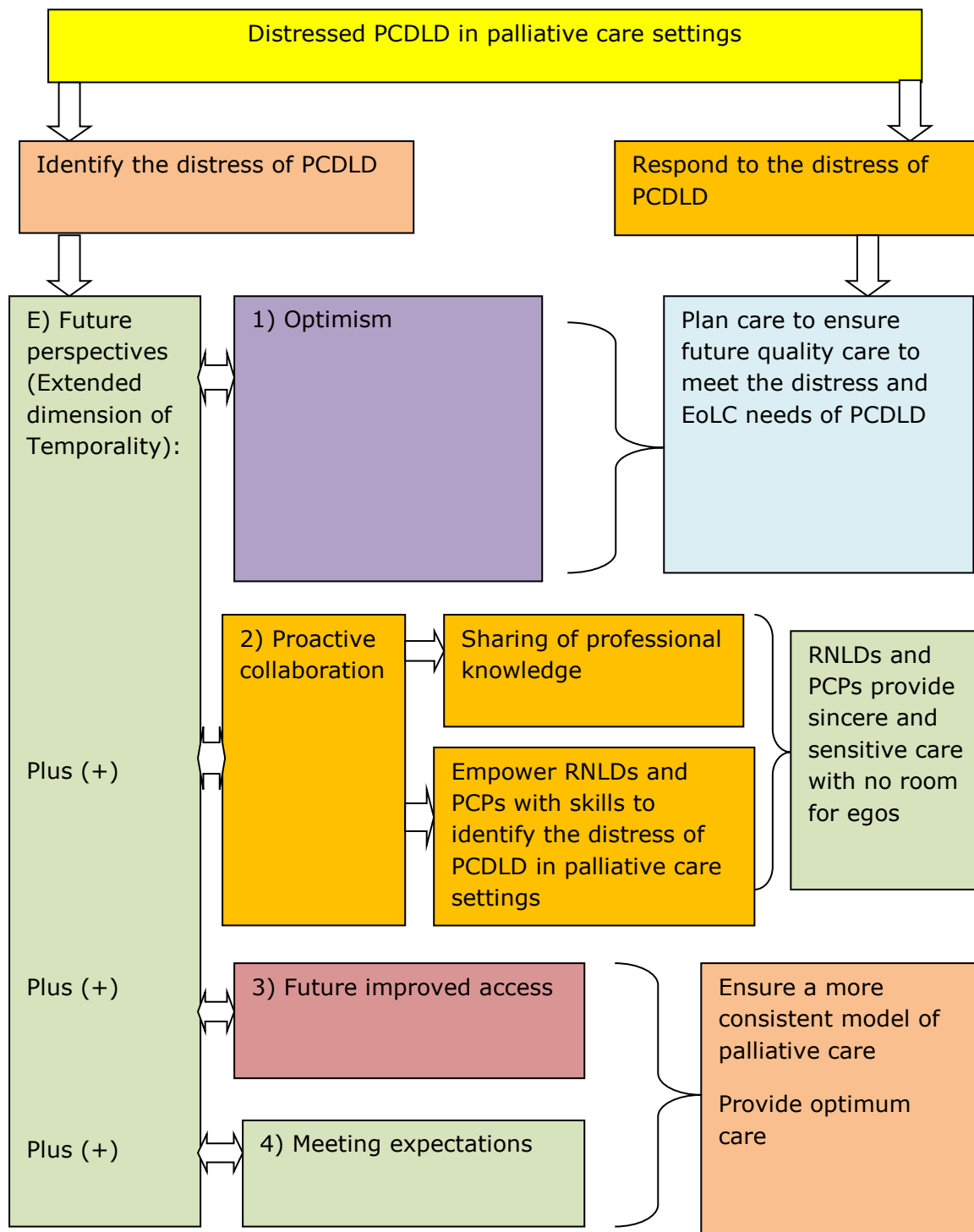


Figure 6.5 Future perspectives

6.6.1 Optimism

The seventh main theme '*Future perspectives*' included optimism (see Figure 6.5, above). This was symbolic of a care strategy in terms of participants' obligation to

ensure a planned future with appropriate services and care approaches that would address the distress of PCDLD in palliative care settings.

Optimism was restated by participants, as recognition of the need for a representative body comprising both palliative care and learning disability professionals, at local organisational and governmental levels to promote the palliative care agenda for PCDLD. The palliative care agenda, in this case, relates to promoting service provision and development in several health-specific care areas for PCDLD who may be in need of any form of palliative care. For example, as illustrated in participants quotes in Chapter five (see pp.115-116), the need for health and social care professionals to develop a comprehensive ability in the use of learning disabilities specific assessment tools such as: the use of the distress disability assessment tool (DisDAT); non-verbal communication tools; and also in engaging families as a significant source of historical information about the PCDLD. Also, participants explained that with experience and increasing skills in the care of PCDLD at the end-of-life stage, they could be at the forefront in contributing to practice development both at organisational and government levels.

6.6.2 Proactive collaboration

The theme '*Future perspectives*' also consisted of proactive collaboration (see Figure 6.5, p.161). Deliberately accentuating the essentiality of a more proactive collaboration between palliative care and learning disabilities professionals and services was perceived by the participants as important in the care of distressed PCDLD. Participants acknowledged that no one can be a specialist in every aspect of care and there was a need for health professionals directly involved in the care of this population to be ready to share experiences and knowledge. Participants' narratives indicated that sharing specialist experiences and knowledge allowed no room for egos. It also persuaded and inspired health professionals to work together and empowered them with the ability to identify and respond to the distress of PCDLD thus, providing improved palliative care.

6.6.3 Future improved access

The theme '*Future perspectives*' also encompassed future improved access. In describing '*Future perspectives*' as an extended dimension of temporality, participants' narratives indicated their commitment towards having the necessary resources in place to ensure that in the future, PCDLD have improved access to palliative care. The dedication to guarantee future improved access to palliative care for PCDLD was an approach explored

by the participants to identify and alleviate their distress now and probably in the future. Such dedication encompassed a timely intervention by PCPs, RNLDs and other health and social care professionals involved in their care and also entailed that consistency and continuity in the care provided to them was maintained. Accordingly, the participants recognized that better access to palliative care services for distressed PCDLD included the need for a more consistent model of palliative care across children specialist palliative care, adult and community palliative care services, and a more integrated palliative care that was accessible to all.

The need for a more integrated palliative care service as described by the participants in my study to an extent concurs with the Department of Health's (DH 2008c) vision for providing quality palliative care for young people with life-limiting condition in *Better Care Better Lives*, stated that:

Every child and young person with a life-limiting or life-threatening condition will have equitable access to high-quality, family-centred, sustainable care and support, with services provided in a setting of choice, according to the child and family's wishes.... To achieve this, the commissioning and delivery of services will be planned strategically... Services will be commissioned and delivered in line with identified local need and national policy, and driven by best practice. There will be full integration of services with a seamless transition of care between primary, secondary and tertiary healthcare settings, and close partnership working between healthcare, education, social services and voluntary sector organisations (DH, 2008c, p.11).

Furthermore, Addicott and Ross's (2010) paper also, explained that in order to meet patients' needs a whole-systems approach is needed that coordinates care across professional and organisational boundaries. They also stressed that it was important for end-of-life care to feature in any care pathway to ensure that focus is shifted beyond terminal cancer. However, I suggest that the similarity between the theme '*Future perspectives*' and the aforementioned literature, is an emphasis on the significance of the potential contribution of my study's findings to the existing body of knowledge relating to palliative care for distressed PCDLD. This is because despite previous emphasis on an integrated and whole system approach in palliative care services to promote equality of access by all in need of treatment (Addicott and Ross, 2010; DH, 2008c) my participants' descriptions portrayed that there is still need for more research and specific policy documents particularly relating to access and equality of palliative care for distressed PCDLD and people with learning disabilities in general.

To ensure future improved access to palliative care for PCDLD, the participants intentionally identified and proposed solutions to challenges that acted as hindrance to pertinent, timely and relevant care decisions for this client group. The expressed reasons

by the participants for such challenges were a lack of autonomy, poor funding, poor EoLC and healthcare bureaucracy. Having more autonomy was perceived as a vehicle for improving palliative care service provision for this population. Participants emphasized the need for healthcare professionals directly involved in the care of PCDLD within a palliative care setting, to be allowed more opportunities for autonomy in certain palliative care decisions, and to be allowed more resources and funding. The participants described that resources such as the Independent Living Fund (ILF) or direct payments for continuing health care into nursing home palliative care settings was needed to address issues related to independently funding additional staff with specific learning disability qualification, experience and knowledge to care for this population (see pp. 117-119).

To an extent, participants' vision about palliative care for PCDLD in terms of optimism, proactive collaboration, and future improved access correspond with some of the issues raised about providing quality EoLC in a report edited by Addicott and Ashton (2010) titled '*Delivering Better Care at End of Life: The next steps*'. The report was based on *The Sir Roger Bannister Summit*, held at Leeds Castle in November 2009, which was one of the many initiatives to ensure that EoLC remained at the centre of policy and practice, and that the implementation of the *End of Life Care Strategy for England* (DH, 2008a), and the Department of Health (2009) *End of life Care Strategy: Quality Markers and measures for end of life care*, was given attention and direction. The report also alluded to Gomes and Higginson's (2008) statistics about the predicted increase in annual number of deaths to a 17 per cent rise between 2012 and 2030. Furthermore, the report cited Gomes and Higginson's (2008) prediction that people will increasingly die at an older age, with the percentage of deaths among those aged 85 and over expected to rise from 32 per cent in 2003 to 44 per cent in 2030. People who are at an older age are likely to suffer from complex multiple morbidities thus, addressing related health issues would be a main challenge for commissioners and providers of care. In the report, Addicott and Ashton (2010) also established that another challenge which has to be addressed in order to implement quality EoLC is the significant and as yet unexplained geographical variation in the rates of deaths at home, but with the overall expectation that by 2030, less than 1 in 10 people will die at home. Hence, there is a vital need for planning to accommodate EoLC which is cost-effective, yet allows for a substantial increase in either inpatient facilities or community services.

I suggest that the similarity of the aforementioned policy documents and reports, to participants' description of what they consider as necessary for future improved palliative care for PCDLD, is an emphasis that more still has to be done to improve palliative and EoLC especially for this client group, as well as people in the general population.

Consequently, I contend that, this is an inference that, for EoLC to have a high impact on PCDLDs' experiences, their family members and even patients in the mainstream population, there is still need to continually identify and investigate areas of practice and policy that require improvement and plans for change should be made accordingly. It is envisaged that my study's findings may contribute to existing knowledge and policy document relating to palliative care and EoLC for PCDLD. Also the findings may contribute towards the creation of a model of palliative and EoLC for this client group.

6.6.4 Meeting expectations

The seventh main theme '*Future perspectives*' also consisted of meeting expectations. '*Future perspectives*' in relation to meeting expectations (see Figure 6.5, p.161) was described by participants as advance care planning to meet the needs of distressed PCDLD in palliative care settings. Participants' quotes, as elucidated in Chapter Five (see pp.119-120), indicated that meeting expectations included making necessary plans to ensure the provision of optimum care to both the dying individuals and their family members. Hence, support and compassion towards the family members was explained by participants as the privilege of sharing in a personal moment (dying, death and funeral). Participants' commitment towards ensuring a dignified end for PCDLD and also in ensuring that staff members and sometimes family are provided with the right kind of supportive and counselling services in the aftermath of the death of a client, to an extent echoes Dame Cicely Sanders's famous statement "*How people die remains in the memory of those who live on*" (DH, 2008a, p.2).

Also, the seventh main theme '*Future perspectives*' in terms of meeting expectations indicated that the expectation for quality palliative care for this population can only be assured by a deliberate effort by professionals from both the palliative care and learning disability fields, to be actively involved in joined initiatives. Such joined initiatives would allow for breaking of professional barriers and stigma through innovative knowledge transfer and also for more specific palliative care bespoke to address the needs of this population. The view about training, knowledge exchange and learning new skills as described by the participants in my study harmonizes with an existing study by Evans et al. (2010). In discussing the inequalities in cancer care, one of the recommendations made by Evans et al. (2010) is for healthcare staff to attend awareness sessions about making practical adjustments for people with learning disabilities when they are hospitalized. Although the purpose of Evans et al.'s (2010) study was on researching inequalities in cancer care, especially for people from ethnic minorities and people with learning disabilities, the emphasis on the significance of joined initiatives from healthcare

professionals points to the fact that more still has to be done by research and service communities to ensure optimal palliative and EoLC for those client groups. I propose that it also highlights that my study's findings may contribute to planned changes to care approaches for PCDLD experiencing distress in palliative care settings.

From this process of mapping the seven main themes (Table 6.1, p.125) unto Van Manen's (1990) life-world existential themes of relationality, corporeality, temporality and spatiality, it became apparent that (1) *Knowing by building relationships* (2) *Positivity in successful caring outcomes* (3) *Humane care* (4) *Moral duty of care* (5) *Time to care* (6) *Comfortable care environment* and (7) *Future perspectives* were essential to the phenomenon of caring for distressed PCDLD in palliative care settings for the RNLDs and PCPs who have lived the experience. However, taking into consideration that this study was structured following the framework of Van Manen's (1990) hermeneutic phenomenology, it was important to discuss the hermeneutic circle in terms of its contribution to the understanding of the essence or the fundamental nature of the phenomenon of caring for distressed PCDLD. This is explained in Section 6.7 below.

6.7 Step six: Essence statement and the development of a New Theoretical Model for Palliative and EoLC for PCDLD in Palliative Care Settings

This section presents the essence or the fundamental nature of the phenomenon of caring for distressed PCDLD in palliative care settings. At this stage it is vital to allude to the hermeneutic circle which is fundamental to hermeneutic phenomenology. Van Manen's (1990) four existential life-world themes are said to demonstrate a fusion of the objective hermeneutic circle (part whole) and the alethic hermeneutic circle (pre-understanding) because together they recognize the experience of a phenomenon as the whole experience and also, the researcher's interpretive role in the research process (Dowling, 2007). Furthermore, in describing the methodical framework of this study Van Manen's (1990) six research activities had been used and divided into the related parts of my thesis as explicated in Chapter Four (see Table 4.3, pp.92-93). The six research activities were also adapted to inform the data analysis process (see Table 4.2, p.87 and Figure 5.1, p.95). Number six of Van Manen's (1990) six research activities, which emphasized the significance of "*balancing the research context by considering parts and whole*" (Van Manen, 1990, p.31) in particular, depicted the hermeneutic circle. The hermeneutic circle, fundamental to hermeneutic phenomenology, has been described as the fusion of horizons, which is circular in process (Dowling, 2007; Gadamer 1989; Van Manen, 1990). It also consists of two arcs namely the forward arc and the return arc.

The forward arc or projection arc facilitates understanding or use of pre-understanding to interpret new experiences and understanding and the return arc allows for evaluation of the interpretive account (Dowling 2007; Gadamer 1989; Van Manen 1990).

Therefore, it was necessary to read back, and further examine the main themes. The goal was to construe from these main themes, a statement that intentionally captured and portrayed the understood meaning of the essence or fundamental nature of participants' experience of caring for this population. This was in terms of what was fundamental to effectively identify and respond to the distress of PCDLD in palliative care settings. The essence statement arrived at was:

Optimism, and a commitment in building personal, and professional relationships, and utilizing specialist, and physical skills to provide timely optimum humane care to distressed PCDLD within comfortable palliative care settings.

The essence statement demonstrated a correlation with Van Manen's (1990) life-world existential themes namely: relationality (lived relations), corporeality (lived body), and temporality (lived time) and spatiality (lived space) (see Section 6.1 p.124 and Table 6.1, p.125).

The essence statement also became symbolic of a response to the research question:

What is the experience of being a Registered Learning Disability Nurse (RNLD) or a Palliative Care Professional (PCP) caring for an individual with communication difficulties and a learning disability experiencing distress within a palliative care setting?

Consequently, the experience of being an RNLD or a PCP caring for PCDLD experiencing distress in palliative care settings involved: optimism, and a commitment in building personal, and professional relationships, and utilizing specialist, and physical skills to provide timely optimum humane care to distress PCDLD within comfortable palliative care settings. I suggest that the essence statement was indicative of the process of caring for distressed PCDLD in palliative care settings as experienced by the participants. This process was portrayed as a continuum and not as disparate approaches because the different components, which encapsulated the essence or fundamental nature of participants' experiences as demonstrated by the seven main themes, were interrelated and relevant. Hence, this allows for optimum care of this population in palliative care settings to be maximised (See Figures: 6.1; 6.2; 6.3; 6.4; and 6.5). By inference, on the one hand, the interrelated components of the essence statement reiterate Van Manen's (1990, p.93) emphasis on the examination of the whole text in order to identify the "...sententious phrase" that "...may capture the fundamental meaning or main significance of the text as a whole". On the other hand, the essence statement

substantiates and provides answer to the imperative question “*does the phenomenon without this theme (s) lose its fundamental meaning?*” (Van Manen, 1990, p.107). The probable answer in this case is yes. I also suggest that there is also the possibility that the components embedded within the essence or fundamental nature of participants’ experiences could become an embodiment of a new theoretical model for palliative and EoLC for PCDLD (see Figure 6.6, p.169).

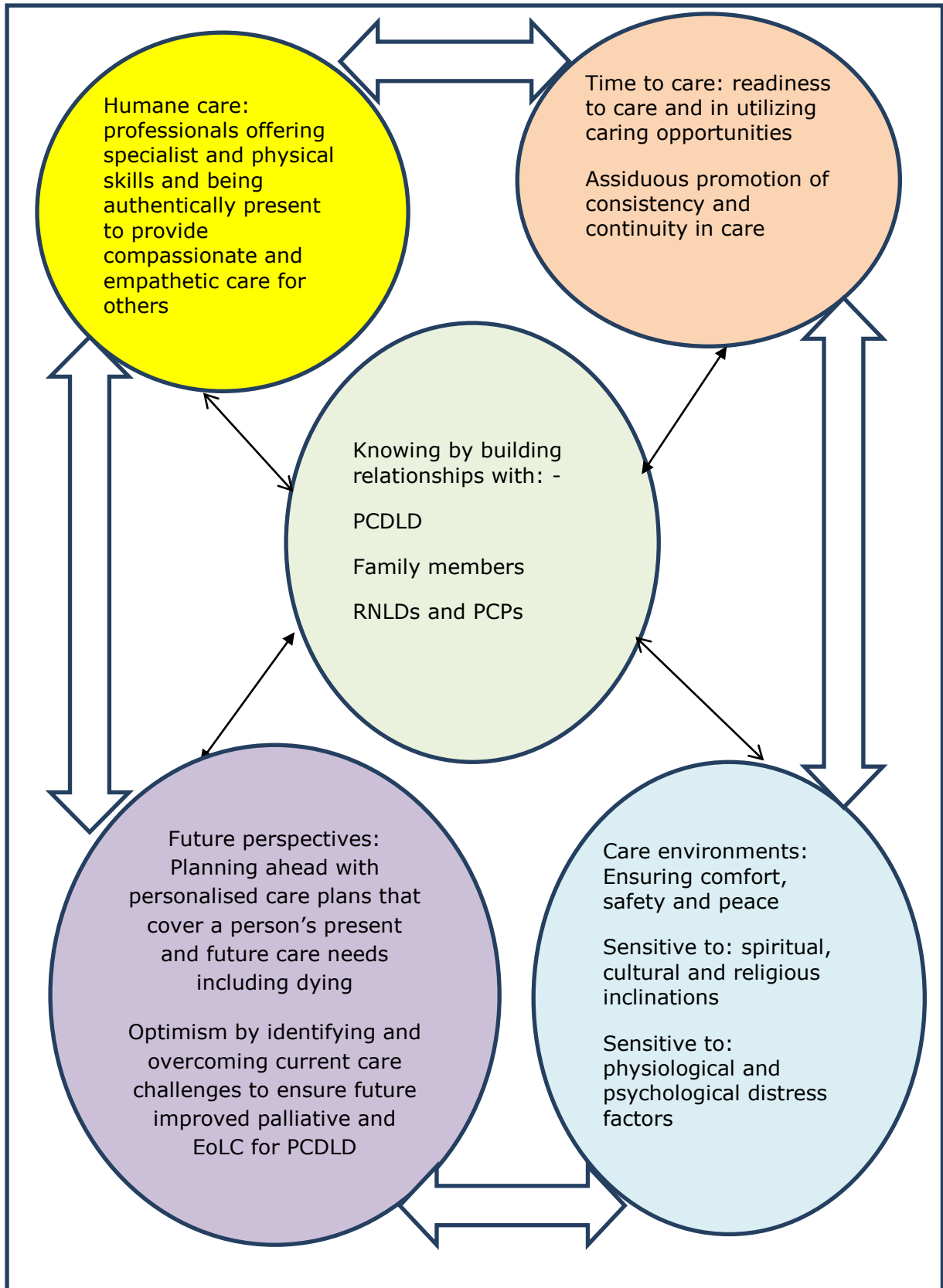


Figure 6.6 New Theoretical Model of Palliative and EoLC for Distressed PCDLD in Palliative Care Settings

The 'New Theoretical Model of Palliative and EoLC for Distressed PCDLD in Palliative Care Settings' provides insight into a process that could be utilized by RNLDs and PCPs in their daily practice when providing palliative and EoLC to distressed PCDLD in palliative care settings. It is important to note that central to the proposed model is the concept of 'knowing' in terms of 'building relations'. However, there is an inter-connectedness of 'humane care (specialist and physical skills), time, environment and the future' in terms of planning, implementing and evaluating care. This is demonstrated by the unidirectional arrows that connect the different components of the model (Figure 6.6, p.169). The inter-connectedness of 'humane care (specialist and physical skills), time, environment, and the future' to the central idea of 'knowing by building relationships' was also fundamental to participants' ability to identify the factors, which determined how PCDLD communicated distress in palliative care settings.

The proposed 'New Theoretical Model of Palliative and EoLC for Distressed PCDLD in Palliative Care Settings' would be complemented by a 'Checklist that will enable health and social care professionals to self-evaluate the holism of care provided to PCDLD in palliative care settings' (see Appendix 11). The checklist is complementary to the Model because the content is specifically tailored to enable professionals providing care to PCDLD in palliative care settings to self-evaluate the appropriate measures taken to ensure optimum care for this client group. For example with the checklist, the health and social care professional is encouraged to self-evaluate, reflect and act upon the following:

- If appropriate plans or measures have been taken to ensure a process of building relationship with individuals and their families, and also liaising with other professionals involved in individuals' care.
- If they have the required cognitive and physical skills to meet PCDLD palliative and EoLC needs.
- If the landscape of the care provided includes dimensions of past, present and future.
- If the care environment is suitable to meet the individual's specific palliative and EoLC needs including being compassionate and empathetic towards individuals by adapting the environment to be sensitive to individuals' dying, religious, cultural and spiritual needs.
- If future plans are in place to ensure possible improvement to care approaches, and continuity of care to other PCDLD within the particular palliative care setting, families, and staff, in the eventuality of the death of an individual (see Appendix 11).

Moreover, my vision for the possibility of change in practice is to ensure that a consistent use of the concepts embedded in the proposed 'Model of Palliative and EoLC', and the proposed 'checklist for self-evaluation of personal professional practice and the holism of care' provided to this population in palliative care settings, could be used for increasing health and social care professionals' capacity for care and compassion, and thus raising awareness to these significant concepts of care, which remain problematic. Given the recent concerns relating to poor care practices at the Staffordshire NHS foundation Trust and the recommendations for improving care as evidenced in the Francis Report (2013), I suggest that there is a fundamental need for more attention to be paid to humane care, and for health and social care professionals to have standardised tools to self-evaluate practice, and also evaluate the holism of care they provide to patients especially PCDLD.

As far as the fundamental nature or essence of participants' experience is concerned, the search of the essence of an experience has been likened to "*...peeling an onion so that as one slowly and heedfully...unravels the multiple layers of the participants' experiences the essences are revealed*" (Chapman, 1994 p.202). In addition, Van Manen (1990, p. 10) explained that if the search for an essence is effectively undertaken, the resulting description of the essence "*...reawakens or shows us the lived quality and significance of the experience in a fuller or deeper manner*".

Thus, I suggest that the identified fundamental nature or essence of the experience of caring for distressed PCDLD for the RNLDs and PCPs intentionally captured the underlying purpose of the process of participants' understanding. This was in terms of participants' individual values as far as professional skills and attributes are concerned. Also, their recognition of the need to build relationships, mutually share their professional skills in collaborative working environments, while being mindful about enhancing timely appropriate care, and enabling future effectiveness in palliative care, and learning disability service provision to meet the palliative care needs of this population.

It is notable that despite the weaving of the essential themes into a single essence statement, I was mindful of Van Manen's assertion that:

No conceptual formulation or single statement can possibly capture the full mystery of this experience. So a phenomenological theme is much less a singular statement than a fuller description of the structure of lived experience. As such, a so called thematic phrase does not do justice to the fullness of the life of a phenomenon. A thematic phrase only serves to point at, to allude to, or hint at ... the main significance of the text as a whole (Van Manen, 1990, p.92-93).

With this assertion, I could suggest that different research findings or studies are representative of alternative and varied interpretations and ways of understanding the lived experiences. Consequently this study seemed to have enabled participants to construct the meaning that the phenomenon of caring for PCDLD experiencing distress in palliative care settings had for them. It also provided a forum for participants' lived experiences to be heard.

The 'ah-ah' moment for me was in amalgamating the main themes. Subsequently, I understood the essence of what it was like being an RNLD or a PCP caring for an individual with communication difficulties and a learning disability experiencing distress within a palliative care setting. This was in terms of how the participants identified and responded to the distress of PCDLD in palliative care settings. I also understood the factors which determined how PCDLD communicated distress in palliative care settings. Although it is difficult to describe the thought process that resulted in the enunciation of these themes, however, having expressed them, I can describe their meaning. Ultimately, their understanding was induced by my persistent dwelling on the parts and whole of the text and the emerging thematic aspects. Their understanding was my epiphany in that the deeper meaning of the text effectively awoke an edifying effect in me such that it evoked a sudden perception of the lived meaning of the phenomenon of caring for PCDLD experiencing distress in a palliative care setting. It is anticipated that this same deep effect of understanding of the phenomenon under study may also profoundly stir the readers' understanding.

6.8 Chapter summary

Chapter six has provided a critical interpretive account of the findings generated in this study. It included steps five and six, which consisted of the interpretive component of the six steps data analysis process. Additionally, the critical interpretive account made use of relevant research literature and theory to substantiate the study's findings. In particular, the theory of nursing as caring within the context of Watson's (1999, 2001) transpersonal caring relationships and Boykin and Schoenhofer's, (2001) nursing situation and the imagery of the Dance of Caring Persons. In step five of the data analysis process, the main themes were examined as essential structures of participants lived experiences within the framework of Van Manen's (1990) life-world existential of spatiality (lived space), corporeality (lived body), temporality (lived time), and relationality (lived relationships or communality. In step six of the 'six steps data analysis process' the main themes were re-examined and the essence or fundamental nature of the phenomenon of caring for people with communication difficulties and a

learning disability (PCDL) experiencing distress in palliative care settings was identified. The essence statement was an embodiment of the main themes and it became symbolic of the process of caring for PCDLD experiencing distress in palliative care settings. Therefore, it informed the development of a 'New Theoretical Model of Palliative and EoLC for Distressed PCDLD in Palliative Care Settings', which encapsulated this process. The proposed model was also complemented by a prototype 'Checklist' to enable health and social care professionals to self-evaluate their personal professional practice and the care provided to this population in palliative care settings.

Chapter Seven discusses the strengths and limitations of this study in terms of the selected methodology and methods, and the breadth and depth of the general research process and how that contributed to the credibility of the study's findings. It includes the implications to practice, policy, education, and further research.

Chapter Seven: Discussion of the strengths and limitations of the study

Chapter seven presents the discussion of the strengths and limitations of this study. It consists of three sections. Section one provides the strengths and limitations of the study in terms of the selected methodology and methods, the breadth and depth of the general research process and how that contributed to the credibility of the findings. The discussion of the strengths and limitations will be simultaneously validated against trustworthiness in qualitative research in general, (Lincoln and Guba, 1985, 1986, pp.76-77) and in particular, Munhall's (1994) proposed 'One P, Ten Rs criteria' (Munhall, 2007, p.562-563) for evaluating rigour (trustworthiness) in phenomenological research. Section two presents the implications and recommendations of the findings to practice, policy, education, and further research. Section three explicate the plans for dissemination of the findings and section four is the chapter summary.

7.1 Strengths and limitations of the study

This section presents the strengths and limitations of this study. The criterion for assessing quantitative research is rigour, which takes into consideration the internal and external validity of the study, and its reliability and objectivity (Lincoln and Guba, 1986; Silverman, 2010; Ulin, Robinson and Tolley, 2004). On the other hand, evaluating a qualitative research study is about assessing its worth, taking into consideration theory and the research process and deciding if the methodology was appropriate (Holloway, 1997; Munhall, 2007; Silverman, 2010).

Rigour in qualitative research is referred to as trustworthiness (Lincoln and Guba, 1985; 1986). Lincoln and Guba's concept of trustworthiness comprises of four major criteria that may offer the phenomenologist an appropriate alternative to logical positivist terminology (Beck, Keddy and Cohen, 1994). These criteria are credibility, transferability, dependability and confirmability (Beck, Keddy and Cohen, 1994). In other words, in assessing the worth of a phenomenological or qualitative research in general, credibility replaces internal validity, transferability replaces external validity, dependability replaces reliability and confirmability replaces objectivity in quantitative research (Lincoln and Guba 1986, pp.76-77); (see Table 7.1) overleaf. Additionally, Munhall (1994, 2007) stated that the 'One P, Ten Rs criteria' consisting of phenomenological nod; resonancy; reasonableness; representativeness; recognisability; raised consciousness; readability; relevance; revelations; responsibility and richness' can

be used to evaluate the rigour (trustworthiness) of phenomenological research (Munhall 2007, pp.562-563), see Table 7.2 below.

To avoid repetition, this discussion simultaneously incorporates Munhall’s (1994, 2007) and Lincoln and Guba’s (1986) criteria as a focus to validate the strengths and limitations of this study in relation to the selected methodology and methods, the breadth and depth of the general research process and how these factors contributed to the trustworthiness of the study’s findings and the achievement or none achievement of the aim and objectives.

Table 7.1 Criteria for evaluating rigour (trustworthiness) in qualitative research

Rigour in Quantitative Research ↔	Trustworthiness in Qualitative Research
Internal validity	Credibility
External validity (Generalizability)	Transferability
Reliability	Dependability
Objectivity	Confirmability

Adapted from Lincoln and Guba (1986, pp.76-77).

Table 7.2 ‘One P and Ten Rs criteria’ for evaluating rigour (trustworthiness) in phenomenological research

Criteria	Explanation
Phenomenological nod	Indicates recognition of the findings and agreement that the researcher has captured at least partially, the meaning of the experience to the participants.
1. Resonancy	The interpretation of the meaning is familiar, sounds correct, and “resonates” with past experiences.
2. Reasonableness	All activities of the study, including the interpretation of the meaning of the experience, sound “reasonable”; the researcher presented carefully reasoned rationale for all aspects of the study.
3.Representativeness	The findings represent the many dimensions of the lived experience; this is evident because of the multiple data sources examined.
4. Recognisability	The reader becomes more aware of an experience by recognizing certain aspects of that experience, which leads to the next criterion.
5.Raised consciousness	The reader focuses on and gains understanding of an experience, a new insight not thought before.
6. Readability	Writing should be concrete, readable, interesting, and Understandable
Relevance	Research findings “should bring us close to our humanness, increase our consciousness, enable understanding, give us possible interpretations, offer us possible meaning, and guide us in our lives personally and professionally” p.192.
8. Revelations	As the reader gains a deeper understanding behind or underneath what is revealed to us, we have considered what is being concealed or what wishes to be concealed” (p.192).
9. Responsibility	Ethical considerations are evident, including process consent,

	sensitivity to content of conversations, and authentic representations of meanings.
10. Richness	"A full embodied , multifaceted, multilayered, thoughtful, sensitive impassioned description of a human experience" (p.193).

Adapted from Munhall (1994). In: (Munhall, 2007, pp.562-56).

7.1.1 Trustworthiness of the study's findings based on the chosen methodology

One of the criteria encompassed in evaluating the trustworthiness of qualitative research is dependability (Lincoln and Guba, 1985, 1986; Silverman, 2010). Dependability refers to the view that the methodology and methods of a study has been appropriately applied in such a way that the findings of a study are consistent and could be repeated (Lincoln and Guba, 1985; Silverman, 2010). The repeatability of qualitative approaches (phenomenology inclusive) has been questioned due to the subjective nature of these studies (Lincoln and Guba, 1985; Munhall, 2007; Sandelowski, 1993; Silverman, 2010). However it has been suggested that, although qualitative researchers should strive towards the achievement of repeatability of their study's findings, repeatability is not fundamental in qualitative studies and the creativity of qualitative research should not be lost in the pursuit of rigour; rather, it should provide a truthful account of the phenomenon under study (Lincoln and Guba, 1986; Sandelowski, 1993; Silverman, 2010). Silverman (2010, p.275) cites Hammersley's, (1990, p.57) explanation of the truth of a research study as "*the extent to which an account accurately represents the social phenomena to which it refers*". In a similar line of thought and in his attempt to clarify the term rigour as used in phenomenology and qualitative research, Van Manen, (1990) explained that "*In the quantitative sciences precision and exactness are usually seen to be indications of refinement of measurement and perfection of research design*" (1990, p.17). However, in contrast, phenomenology as well as other human science

...strives for precision and exactness by aiming for interpretative descriptions that exact fullness and completeness of detail and that explore to a degree of perfection the fundamental nature of the notion being addressed in the text (Van Manen, 1990, p.17).

Hermeneutic phenomenology has been described as both a philosophy and an approach because it is a methodology that has a strong orientation to philosophy (Dowling, 2007; Munhall, 2007; Van Manen, 1990). It has been recognized that a possible limitation of any phenomenological study is that the text could be repetitive and confusing due to the tendency of some researchers to adopt phenomenology as a research methodology

without an adequate grasp or articulation of its underpinning philosophy (Koch, 1999; Munhall, 2007; Priest, 2004; Van Manen, 1990).

However, to overcome this limitation and enhance dependability, I provided a brief but meticulous explanation of the philosophical influences in relation to the foundations of phenomenology, how it evolved into a recognized philosophical tradition and became applied to research, (see Chapter Three, section 3.3, pp.66-73). This was to ensure that it matched the selected methods and also minimized the risk of misunderstanding and misrepresentations in the study (Koch, 1999; Munhall, 2004; Priest, 2004; Van Manen, 1990). I contend that by making a deliberate attempt to remain transparent with the philosophical underpinnings to the hermeneutic phenomenological process, as applied in this study, dependability was attained (Van Manen, 1990). This is because I have discussed the philosophical underpinnings in terms of the foundations of phenomenology in such a way that I believe is accessible and open to examination (Munhall, 2007; Priest, 2004; Van Manen, 1990). Van Manen explained that:

Hermeneutics and phenomenology are human science approaches rooted in philosophy...therefore, it is important for the human science researcher...to know something of the philosophic traditions...enough to be able to articulate the epistemological or theoretical implications of doing phenomenology and hermeneutics (Van Manen, 1990, pp.7-8).

To enhance dependability, the methodology chapter (Chapter three) of this study incorporated explanations and discussions of 'my personal view of the world' based on my nursing knowledge (section 3.1.2). It also integrated the epistemological basis of the study based on the construction of meaning, which was influenced by my personal view of the world, and constructionism (section 3.2); and a rationale for the selected methodology was also incorporated (section 3.4). I subsequently, provided explanations for the general design and methods (Chapter four), which has informed the isolation and interpretation of themes in such a way that, the findings demonstrated the meaning the phenomenon under study had for the participants. This is in line with "*reasonableness*" which is one of Munhall's (1994) 'One P, Ten Rs criteria' for evaluating rigour (trustworthiness) in phenomenological studies (Munhall, 2007, p.562). See (Table 7.2, 'R' number two). Munhall emphasized that in a phenomenological study, the researcher should present "*...carefully reasoned rationale for all aspects of the study*" (Munhall, 2007, p.562).

Also, I was mindful to ensure that the isolation of themes (Chapter five) and in-depth interpretation and discussion of the findings (Chapter six) in this study were an appropriate portrayal of the participants' lived experiences of caring for distressed people with communication difficulties and a learning disability (PCDL) in palliative care

settings. I achieved this through the incorporation of direct quotes from participants' narratives (Van Manen, 1990). This view substantiates "resonancy", which is one of Munhall's (1994) criteria for evaluating rigour (trustworthiness) in phenomenological studies (Munhall, 2007, p.562), (see Table 7.2, 'R' number one). Munhall (1994) stated that "resonancy" in a phenomenological study is demonstrated when "*the interpretation of the meaning of the experience is familiar, sounds correct, "resonates" with past experiences*" (Munhall, 2007, p.562).

Another criterion encompassed in the rigour (trustworthiness) of qualitative research findings is credibility, which replaces internal validity in quantitative research (Lincoln and Guba, 1985, 1986; Silverman, 2010). It has been recognized that rather than the systematic test of the hypotheses of a study, (Agar, 1986; Silverman, 2001), credibility in qualitative research is attained when the findings are products of an intensive personal involvement of the researcher and the participants, which is made possible through good usage of the appropriate methodology and design (Silverman, 2001). I suggest that the strength of Van Manen's (1990) hermeneutic phenomenology in terms of its contribution to the credibility of the study's findings, is the flexibility that hermeneutic phenomenology offers to the researcher through the power of interpretation (Van Manen, 1990). Hence, in analysing participants' narratives, I was careful to demonstrate this flexibility by the use of a six steps hermeneutic data analysis process, which encompassed Van Manen's (1990, pp.92-93) initial approaches of isolating themes namely "*the detailed or line-by-line approach, the selective or highlighting approach, and the wholistic or sententious approach*" (see Chapter Five, Figure 5.1, p.95).

The use of these approaches of isolating themes intentionally allowed for my active in-depth phenomenological interpretation of participants' transcripts, which ensured that the findings fittingly portrayed what the phenomenon under study meant for the participants and also, the implications this understanding had for learning disability and palliative care practice, education, and further research. I suggest that this view resonates with "relevance", another of Munhall's (2007) criteria for evaluating rigour (trustworthiness) in phenomenological study, (see (Table 7.2, 'R' number seven). "Relevance" emphasized that rigour (trustworthiness) of phenomenological study is attained when the "*research findings ...enable understanding, give us possible interpretations, offer us possible meaning, and guide us...personally and professionally*" (Munhall, 2007, p.562).

Similarly, Van Manen (2002) has emphasized the significance of simultaneously incorporating description and interpretation when referring to a lived experience. Van Manen (2002) explained that one must experiment with a methodological informed

inventiveness that combines the reflective and the pre-reflective life of consciousness. Also, he stressed that one needs to invent a flexible narrative rationality, a method for investigating and representing the phenomenon in question, which will lead to the unravelling of the meaning of the phenomenon under study as experienced by the participants (Van Manen, 2002). Moreover, Van Manen (1990, p.21) stated that *"phenomenology...is the progress of humanising human life and humanising human institutions to help human beings to become increasingly thoughtful and thus better prepared to act tactfully in situations"*. It is envisaged that implications of the findings of this study may contribute to planned changes in care approaches and service provision for people with communication difficulties and a learning disability (PCDL) experiencing distress in palliative care settings.

In an attempt to ensure trustworthiness in terms of the credibility of the study's findings, I was mindful to explain how Van Manen's (1990, pp.30-31) six research activities shaped the methodical structure of this study as elucidated in Chapter Four, section 4.2 and Table 4.1. The methodical worth of qualitative methods depends on the ability of the researcher to communicate to others the appropriate approach of the study (Silverman, 2010). Additionally, Silverman emphasized that

If qualitative research is to be judged by whether it produces valid knowledge, then we should properly ask highly critical questions about any piece of research. And these questions should be no less probing and critical than we ask about any quantitative research study (Silverman, 2010, p.221).

I propose that the application of Van Manen's (1990, p.30-31) six research activities was a strength, in terms of its contribution to the credibility of this study because they provided a dependable but flexible framework, which was subsequently adapted as a guide in the development of the structure of the data analysis analytical process. The six research activities allowed me to critically question and reflect on the phenomenon of interest, and also, create a text that clearly revealed the meaning the phenomenon under study had for the participants (Van Manen, 1990) as demonstrated in the following:

- the sub themes and main themes (Chapter Five, Table 5.1);
- the mapping of the main themes under Van Manen's (1990) lifeworld existential as overarching themes (Chapter Six, Table 6.1);
- the fundamental nature of the participants' experience of caring for this population (Chapter six, section 6.7), which also informed the creation of a New Theoretical Model of Palliative and End-of-life care for Distressed PCDL in Palliative Care Settings (Chapter, Six, Figure 6.6).

Also, Van Manen's (1990) four lifeworld existential themes of spatiality (lived space), corporeality (lived body), relationality (lived relation), and temporality (lived time) as encompassed in the data analysis analytical process of this study, is a strength because it provided me with dependable guidance on phenomenological writing (Goodwin et al., 2004; Van Manen, 1990). The existentials also contributed to the credibility of the study's findings because they allowed for a critical discussion of the main themes with the incorporation of relevant theory and research literature (Van Manen, 1990). Consequently, this produced a text that encapsulated an in-depth phenomenological understanding of the phenomenon under study, in terms of a correct portrayal of the participants' perspectives, gleaned from the participants' narratives (Van Manen, 1990). Munhall (2007) has highlighted that a contributing factor to the rigour (trustworthiness) of a phenomenological research is that the "*writing should be concrete, readable, interesting, and understandable*" (Munhall, 2007, p.562), (see Table 2, 'R' number six, p.168). Van Manen (1990, p.2) also acknowledged that "*the method one chooses ought to maintain a certain harmony with the deep interest that makes one an educator*" or a specific professional. Additionally, a preferred method for research that deals with human beings should involve "*description, interpretation, and self-reflective or critical analysis*" (Van Manen, 1990, p.4).

Van Manen (1990, p.22) identified that a possible limitation to phenomenology like other qualitative studies is that "*phenomenology does not allow for empirical generalisations...*". However, rather than generalisation, trustworthiness in qualitative research also consists of transferability (Lincoln and Guba, 1986, p.76-77), (see Table 7.1, p.175). Although I cannot claim probabilistic generalization of the study's findings, I suggest that the findings could be transferable and incorporated in the care approaches provided to PCDLD experiencing distress in palliative care settings by Registered Learning Disability Nurses (RNLDs) and Palliative Care professionals (PCPs). This is because I ensured a meticulous application of the methodology and methods and the identified themes were substantiated with direct quotes from the participants' transcripts in an attempt to provide a text that was a true portrayal of the participants' experiences (Van Manen, 1990). Additionally, it has been stated that phenomenology always "*...takes its point of departure from lived experience or empirical data*" and the text should aim to describe and interpret meaning of lived experience such that it could be transferable to understanding and acting tactfully in similar lived experiences or situations (Van Manen, 1990, pp.22-23). Therefore, it was fitting to have stated as part of the rationale for this study, how my past personal experience contributed to my interest in the phenomenon under study. Also, when required, I maintained a reflective approach in the discussions of the findings because as Van Manen (1990, p.47)

explained, “if we simply try to forget or ignore what we already know, we may find that the presuppositions persistently creep back into our reflections”.

A likely limitation of Van Manen’s (1990) hermeneutic phenomenology is the argument that unlike quantitative studies, the nature of the phenomenological research question portrays “*phenomenology does not problem solve*” (Van Manen, 1990, p.23). The phenomenological research question for this study is: What is the experience of being an RNLD or a PCP caring for an individual with communication difficulties and a learning disability experiencing distress within a palliative care setting?

However, I argue that, although the phenomenological research question of this study was not designed to problem solve, it was aimed at providing in-depth knowledge about the phenomenon of caring for PCDLD experiencing distress in palliative care settings, from the perspective of RNLDs and PCPs who have lived the experience (Van Manen, 1990). Such knowledge may potentially contribute to planned changes in the care approaches for this population, and also, provide a new model of care for this client group. This was demonstrated by the development of a proposed New Theoretical Model of Palliative and End-of-life care for PCDLD, (see Figure 6.6, p.169.). This view substantiates “*raised consciousness*”, ‘R’ number five of Munhall’s (1994, 2007) ‘One P, Ten Rs criteria’ for evaluating rigour (trustworthiness) in phenomenological research. Munhall (2007, p.562) emphasized that rigour (trustworthiness) in phenomenological research is enhanced when the findings encompassed a richness in the interpretation and writing of the text so that, “*the reader...gains understanding of an experience, a new insight not thought of before*”. This view is in line with the assertion that phenomenological questions are meaning questions that aimed at asking a simple question “*what is like to have a certain experience?*” (Van Manen, 1990, pp.44-45). They ask for the meaning of an experience, which does provide insight into understanding of phenomena and also, increase the rationality of hermeneutic phenomenological research findings, in terms of ensuring that “*experience can be made intelligible*” (Van Manen, p.16) through the interpretation of the fundamental nature of a lived experience (Van Manen, 1990).

7.1.2 Trustworthiness of the study’s findings based on the selected Methods

Sampling method

It has been recognized that choosing an appropriate design for any research study is, ultimately, the most important decision researchers make (Higginson, 2006). Purposive

sampling was used in this study. This type of sampling may be considered as a limitation because there is the potential for bias with the use of purposive and/or other non-probability sampling based on the view that, every person was not given an equal opportunity to take part in the research (Gerrish and Lacey, 2006). Thus, this may also reduce the credibility of the research findings as far as the transferability of the study's findings to a population beyond the study sample is concerned (Polit and Beck, 2008; Silverman, 2010).

I argue that purposive sampling accounted for the suitability of the sample participants in terms of answering the research question and in meeting the aim and objectives of this study (Reed, Proctor and Murray, 1996; Oliver, 2004; Silverman, 2010). I recruited registered learning Disability Nurses (RNLDs) and Palliative Care Professionals (PCPs) who met the sample criteria and were willing to share their experiences (Crotty, 1996; Munhall, 2007). Munhall (2007, p.530) stated that in qualitative inquiry:

We deliberately select participants who may be considered experts in the same phenomenon that we are exploring...When we purposefully select according to the best example, the characteristics of whatever we are studying are easier to identify....

Population and Sample

The sample size for this study was thirteen participants. It could be said that the chosen sample size was small and thus limits the transferability of the study's findings (Munhall, 2007; Silverman, 2010). However, the small sample size allowed for the in-depth attention given to the lived experiences of RNLDs and PCPs who had or are still caring for PCDLD experiencing distress in palliative care settings (Van Manen, 1990). Similarly, it has been explained that a small sample size is more appropriate for qualitative studies due to the descriptive and detailed information collected through participants' observation and interviews (Miles and Huberman, 1994; Miles, Huberman and Saldana, 2013). Furthermore, this study lends itself to using a small sample because it is concerned with meaning and not in making generalized hypothesis statements, which belongs to a positivist tradition not congruent with my study (Crouch and McKenzie, 2006). It has been affirmed that samples for qualitative studies are often much smaller than those used in quantitative studies because as the inquiry progresses, more data does not necessarily result in more information (Ritchie, Lewis and Ellam, 2003). Also, Boyd (2001) considered two to ten participants as sufficient to reach saturation and Creswell (1998, pp.65) recommended "*long interviews with up to ten people*" for a phenomenological study. In the case of this study, the chosen sample size of thirteen was considered appropriate because saturation or completion of the interview and analysis process was achieved when no new themes could be identified and it was

believed that a continuation of the interviewing process would have been redundant (Bowen, 2008; Mason, 2010; Munhall, 2007; Silverman, 2010).

It is worth mentioning that apart from the current sample group of RNLDs and PCPS, I had initially intended to also include people with communication difficulties and a learning disability (PCDL) in the study's sample. However, despite the fact that existing policy imperatives promoting service user involvement has resulted to the involvement of people with mild and moderate learning disabilities in health and social care planning and research (Boxall, Carson and Docherty, 2004; Boxall, Warren and Chau, 2007), many people with learning disabilities (PLDs) struggle to have their voices heard and remain amongst the most disadvantaged members of our society (Emerson, Malam, Davies and Spencer, 2005; Emerson and Hatton, 2008). Also, violation of their human rights is "*a normal part of everyday lives*" for many (Joint Committee on Human Rights (JCHR), 2008, p.16; Equality and Human Right Commission, (EHRC), 2011).

Owing to the potential for limitations relating to informed consent and the challenges of collecting data from such a complex group, it was vital to incorporate a workable approach (DH, 2008b). It has been observed that good practice regarding consent to participate in research should apply to people with learning disabilities in the same way that it applies to other human subjects (Wiles, Crow, Heath and Charles, 2008). Therefore, I made plans with the goal of enabling professional participants to tell their stories and also allow for a greater depth of material to be collected through the observation of potential service user participants who are PCDLD (Munhall, 2007). I also had to study ethical dilemmas and issues around involving vulnerable adults in research. The aim was to enhance credibility and dependability in the subsequent inquiry because it provided a good argument about the basis of my work and why I wanted to include vulnerable adults as part of the participants' sample in the study. By explicating the exact methods of data collection and analysis, and the ethical considerations as would be applied in the study, it allowed for transparency of information as to how dependable the study's finding might be (Keilhofner, 1982; Munhall, 2007; Silverman 2010).

In an attempt to increase the credibility of the study, I had to carefully consider procedures which ensure and promote ethical and legal rights especially because of the communication difficulties and learning disabilities of the potential client participants (DH, 2008). Recruitment would have adhered to the guidance put forward in the Mental Capacity Act, 2005 in relation to safeguards for the conduct of research involving those who may not be able to consent due to an impairment such as a learning disability, and illnesses such as dementia, brain injury or mental health problems (Mental Capacity Act, 2005). I was mindful of the Act when I wrote the initial information sheet, letter of

invitation, and consent form. The contents of these forms were written to ensure that the potential client participants (PCDL) would be supported to provide valid consent by an appointed or nominated consultee in cases where they could not consent for themselves (DH, 2008b).

As a novice researcher, I had been initially naive in my conviction that once these forms were explicitly written and presented they would be accepted by the unit managers or gatekeepers of the settings where potential client participants were based. This was definitely not as simple as I had thought it would be. The replies or correspondence from the gatekeepers were few and far between and not regular, despite several attempts to contact them by email. Neuman (2000, p.352) described a gatekeeper as "*someone with the formal or informal authority to control access to a site*"; a person from whom permission is required (Neuman, 2000, 2003). The gatekeepers also seemed to have limited knowledge about involving vulnerable adults in research and were thus reluctant in granting access. It has been recognized that learning disabilities is a disputed category and decisions about which participants to include or not to include in a learning disability research may be complicated (Carlson, 2010; Rapley, 2004; Report of Ethics Workshop on Research Involving Adults who Lack the Capacity to Consent, no date). This is because:

Recruiting adults with learning disabilities as participants in a research project may also be hampered by a range of gatekeepers; parents/carers, social workers, health professionals and others, who may feel that participation in research is not a good idea for people with learning disabilities in question... (Special Research Ethics Guidance Paper (SREGP): Doing Research with People with Learning Disabilities, p.3, no date).

Owing to these problems faced in gaining access, the time constraints, and the seemingly limited awareness of the gatekeepers on the issue of involving vulnerable adults in research, I had to abandon that venture in favour of the current study and current sample participants because it would appear that gaining access for research with fully-consenting adult professionals was less problematic.

Ethical considerations in relation to the sample

One of the criterion of Munhall's (2007, p.563) 'One P, Ten Rs criteria' for evaluating the rigour (trustworthiness) of phenomenological research is "*responsibility*", (see Table 7.2, 'R' number nine). "*Responsibility*" is an emphasis on the view that rigour (trustworthiness) in phenomenological research is ensured when "*Ethical considerations are evident, including process consent, sensitivity to content of conversations, and authentic representation of meanings*" (Munhall, 2007, p.563). I suggest that trustworthiness of my study was enhanced by an adherence to stringent ethical

guidelines around ethical approval, privacy and protection of participants' information in terms of confidentiality, anonymity and an opportunity to withdraw, obtaining informed consent, correct and safe handling and storage of data (Holloway and Wheeler, 2009; Mason, 2002; Munhall, 2007; Silverman, 2010). Approval for the conduct of the research was gained from the School Research Ethics Panel (SREP) at the university, and from managers at the different research locations. The National Health Service (NHS) Local Research Ethic Committee was not used because the research locations had private organisational affiliations. An informed consent form and information sheet detailing the purpose of the study, inclusion criteria and that participation was dependent on written informed consent was used to avoid coercion and also ensure that the right people were recruited for the study (Holloway and Wheeler, 2009; Mason, 2002; Munhall, 2007; Silverman, 2010).

Demographical characteristics of the sample

A strength of my study was in the rich diversity of the sample participants in terms of experience, age, and relevant training and skills, which allowed for different views to be represented as illustrated in Table 4.1, p.82. However a limitation was imposed to an extent by the lack of participant diversity in terms of the gender and ethnicity representation in the study. There were just two male participants in the study and only one participant of Black African origin. All other participants were Caucasians. This could be considered as black minority ethnic (BME) and gender bias (Thompson, 1999). However, I argue that the small number of male participants, or participants of a different ethnicity other than Caucasians, was a reflection of those with the expertise in that area who were willing to participate in the study (Munhall, 2007; Silverman, 2010; Thompson, 1999). Also the small number of male participants or participants of a different ethnicity other than Caucasians could be as a result of the small sample size in general (Munhall, 2007, 2010; Thompson, 1999). However, issues of race and ethnicity are relevant to human existence and thus would warrant further research and understanding in the care of PCDLD experiencing distress in palliative care settings.

Data collection methods

The selected data collection methods applied in this study consisted of piloted interview guide for semi-structured probing interview, audio-recorded interviews, demographic questionnaires, and my field-notes. It has been acknowledged that the use of semi-structured interviews and audio-recorded interviews as data collection methods have some limitations as far as the researcher-participant relationship is concerned (Gerrish and Lacey, 2006). This is in terms of biases referred to as the Hawthorne effect (Gerrish and Lacey, 2006) whereby the research participants may tell the researcher what they

envisage the researcher wants to hear, and not necessarily the truth about the phenomenon under study. However, in an attempt to alleviate this problem, I made a conscious effort to ensure the interviews were conducted in places of the participants' choice where they were comfortable and willing to tell their stories in confidence, and I reminded them to be honest and to articulate their experiences in a way that expressed their true meaning (Ritchie and Lewis, 2006).

In addition, it could be suggested that, trustworthiness in terms of dependability of the study's findings was enhanced by the thoroughness with which the selected data collection methods were applied in the study, which duly resulted in the unveiling of hidden meanings in participants' experiences (Van Manen, 1990). To obtain meaning from semi-structured interviews is a serious undertaking and requires time and thoughtfulness. The interviews permitted and encouraged the participants in this study to tell a story (their experiences), which stimulated the production of rich data (Munhall, 2007; Silverman, 2010; Van Manen, 1990). This is because interview accounts are not simply representative of the world; they are part of the world they describe (Hammersley and Atkinson, 2007; Holloway and Wheeler, 2009; Silverman, 2001).

I engaged in hermeneutic dialogue with the participants through semi-structured audio-recorded interviews and ensured that the audio-recorded details of their narratives were transcribed verbatim. The interviews took place in settings chosen by the participants, which created a sense of comfort and thus facilitated the ease and flow of participants' narratives. The sense of comfort also enhanced my access to the participants' genuine accounts of relevant phenomena (Polit and Beck 2004; Van Manen, 1990). Munhall (2007, p.530) highlighted that the quality of a qualitative data is determined by "*willingness of the participants to talk, to reflect, and to describe his or her ability to share the experience with the researcher...*". Similarly, Van Manen (1990, p.7) stressed that *hermeneutic phenomenological research is fundamentally a writing exercise*; and the intensive dialogue involved in the exploration could provide dependable answers to what it meant to have a particular lived experience. To ensure the trustworthiness in terms of the dependability of the findings, participants were invited to read the verbatim transcribed transcripts to ascertain their agreement (Gadamer, 1988; Van Manen, 1990). This was to ensure that the text was a true representation of participants' experiences as described by them (Gadamer, 1989; Van Manen, 1990). This also allowed for a conversational relationship to be maintained with the participants throughout the research process (Gadamer, 1989; Van Manen, 1990). I suggest that this resonates with "*responsibility*", one of Munhall's (1994; 2007) 'One P, Ten Rs criteria' for evaluating rigour (trustworthiness) in phenomenological study, (see Table 7.2, 'R' number nine). "*Responsibility*" emphasized that trustworthiness of phenomenological study is attained

when the study demonstrated apparent ethical consideration including "...*sensitivity to content of conversations, and authentic representations of meanings*" (Munhall, 2007, p. 563).

The steps or process used in this study ensured that the gathering of data was a strength that augmented the credibility and the dependability of the findings (Silverman, 2010). This is because during the interviews, the participants' answers and comments were not seen as reality reports delivered from a fixed repository. Instead, they were recognized and judged for the ways that they constructed aspects of reality with my active collaboration as the interviewer (Van, Manen, 1990). It has been emphasized that to enhance the trustworthiness of qualitative research findings, when conducting interviews researchers should ensure that, "*the focus is as much on the assembly process as on what is assembled*" (Holstein and Gubrium, 1997, p.127).

The use of fieldnotes was a strength because it complemented the semi-structured audio-recorded interviews and allowed me to provide an account of what I heard, saw, experienced and thought during the interview process with the participants (Miles and Huberman, 1984; Miles et al., 2013). My accounts were dated and subsequently, when any excerpts from my fieldnotes were introduced to enhance the discussions of the findings of this study, I have clearly stated so. Miles and Huberman (1984) and Miles et al. (2013) highlighted that fieldnotes should be dated in order that the researcher can later correlate them with the data. Similarly, fieldnotes have been described as a secondary data storage method in qualitative research, which compels the researcher to further clarify each interview or interview setting (Caelli, 2001; Miles and Huberman, 1984).

Data analysis process

The hermeneutic phenomenological data analysis process used in this study was challenging and rigorous. It was done manually to maintain closeness to the text (Munhall, 2007; Van Manen, 1990). It was meticulous and time consuming due to the large volume of collected data. However, I suggest that the data analysis process in this study was a strength in terms of the contribution to the rigour (trustworthiness) of the study's findings. Watson and Girard (2007) explained that scientific adequacy means an expert and skilful technique is implemented with careful, systematic, and conscious intent of incorporating a reflective process during the interpretation of the text. Similarly, Van Manen (1990, p.11) stated that "*Phenomenology claims to be scientific in a broad sense, since it is a systematic, explicit, self-critical, and intersubjective study of its subject matter, our lived experience*". This is relevant in this study because the rigorous process of hermeneutic phenomenology and hermeneutic data analysis, guided

the interpretation of the data and allowed for the analysing of the data in either parts or as a whole, and at both micro and macro levels over the course of my PhD journey (Van Manen, 1990). The six steps data analysis process used in the study was an adaptation of Van Manen's (1990) hermeneutic phenomenology six research activities. By incorporating the constructs of hermeneutic phenomenological writing, I argue that the dependability of the study's findings was attained because I ensured that all the significant facets from participants' narratives were identified and the language of the text clearly portrayed an in-depth understanding of participants' meaning of the phenomenon under study (Van Manen, 1990). This view resonates with "readability" and "richness" two of the criteria of Munhall's (1994, 2007) criteria for evaluating rigour (trustworthiness) in phenomenological study (Munhall, 2007, p.562), (see Table 7.2, 'R' number six, and 'R' number ten, p.175-176). In terms of "readability" Munhall (2007, p.562) emphasized that the rigour (trustworthiness) of a phenomenological study is attained when the writing is "concrete, readable, interesting, and understandable". "Richness" ensures a "full embodied, multifaceted, multi-layered, thoughtful, sensitive, impassioned description of a human experience" (Munhall, 1994, p.193).

Trustworthiness of the study's findings in terms of credibility was enhanced in this study by my deliberate navigation away from wanting to provide an account of everything, and instead delve deeper into the text to unravel what seemed to be the most meaningful parts of the whole (Van Manen, 1990). The parts of the text (individual participant's transcripts) were related to the whole in order to allow the essential nature of the lived experience to be identified and shared with the readers (Van Manen, 1990). There is an emphasis on the significance of identifying and documenting recurrent features such as thematic categories in phenomenological research and qualitative research in general (Leninger, 1998; Munhall 2007; Silverman, 2010; Van Manen, 1990). This is because through intimate familiarity with participants' narratives and the subsequent unravelling of hidden meanings, the dependability of a study's findings are enhanced as elucidated by the themes (Kielhofner, 1982; Munhall, 2007; Silverman, 2010).

The seven main themes (Table 5.1, p.122) identified in this study using steps one to four of the six steps data analysis analytical process (Figure 5.1, p.95) were mapped onto Van Manen's lifeworld existential of relationality, corporeality, temporality and spatiality (Table 6.1, p.125). From these main themes, an essence statement was identified. This statement intentionally and holistically captured the fundamental nature or essence of the participants' lived experiences. This was in terms of participants' understanding and the meaning the phenomenon of caring for distressed PCDLD in palliative care settings had for them. By implication, I could argue that through the fusion of the horizons of the part and whole and the past and present within the hermeneutic circle, I created an

interpretation that was conceivable and satisfactory taking into consideration the complexities and diversities of participants' lived experiences (Van Manen, 1990). This is in line with Wertz's assertion that:

Phenomenology is a low-hovering, in-dwelling, meditative philosophy that glories in the concreteness of person-world relations and accords lived experience, with its determinacy and ambiguity, primacy over the known (Wertz, 2005, p.175).

I suggest that the findings of this study could be transferable because the findings demonstrated human understanding about the fundamental nature of care, which was obtained from human experience about caring for PCDLD experiencing distress in palliative care settings. It is recognized that phenomenological studies offer insightful perspectives (Van Manen, 1990). This is because human understanding facilitates human care and has direct care applications (Watson, 2001). Also, human understanding enables the provision of care that is fully informed, more sensitive, timely, and care that includes more appropriate responses from nurses and others involved with human care work (Watson, 2001; Van Manen, 1990). Additionally, other than care or practice, I anticipate that the meaning of the lived experience, as explained in the participants' narratives, might have wider implications in terms of service provision, healthcare education and even policy. This therefore establishes a sense of transferability and confidence in the truth of the research findings (Munhall, 2007; Polit and Beck, 2008; Van Manen, 1990). Van Manen (1990, p.62) acknowledged that in phenomenological inquiry, we want to understand what an experience is like for a certain individual as an aspect of their life and "*...therefore by extension, as an aspect of the possibilities of our being human*".

The trustworthiness of qualitative research includes confirmability. Confirmability replaces objectivity in quantitative research and it can be described as the criterion that upholds neutrality which means that the findings are shaped by the participants (Lincoln and Guba, 1985; 1986). An identified limitation of this study is the potential for bias linked to dual roles when conducting research. The potential for bias might exist where the researcher has the dual role of practitioner and researcher, as is the case of my role in this study (Goodwin et al., 2003; Mays and Pope, 2000). However, I used a reflective approach throughout the writing of this study. In research, reflection is recognized as a significant method in the substantiation of data (Ritchie and Lewis, 2006). It remains the responsibility of the researcher to be conscientious about personal biases and expertise linked to the phenomenon under study, which may potentially contribute to shaping the data (Ritchie and Lewis, 2006; Robson, 2002). The use of a reflective approach minimised bias and enhanced trustworthiness because I was able to deliberately

acknowledge my training as an RNLD, and a past personal experience of caring, which had the potential for biases that might influence the research process within the context of this study (Mays and Pope, 2000; Ritchie and Lewis, 2006). I was also mindful of this by being transparent with the methodology and methods and the process of hermeneutic phenomenological writing throughout the research process. This was done in order to elicit a text that demonstrates holism in terms of the similarity or multiplicity of participants' descriptions of the meaning of the phenomenon under study (Dahlberg, 2008; Van, Manen, 1990). Van Manen (1990) upholds the view that we cannot completely eliminate pre-conceptions when conducting research rather they should be acknowledged, where appropriate, in order to differentiate the researcher's interpretation from what is specifically related to participants' understanding of the phenomenon under study.

7.1.3 Trustworthiness of the study based on the breadth and depth of the study

To an extent, the breadth of the study could be seen as a limitation (Green and Thorogood, 2009). The stipulated time frame of the PhD programme of study did not allow for a more longitudinal study to be undertaken (Green and Thorogood, 2009). However, I suggest that, the incorporation of the relevant literature, theory and policies documents relating to the phenomenon under study emphasized the depth of this study because it allowed for a critical analytical discussion of the themes identified in participants' narratives (Munhall, 2007; Van Manen, 1990). Also, the innate strength of the study as an hermeneutic phenomenological study was revealed because the discussions of the findings provided rich data about the participants' experiences of caring for PCDLD in palliative care settings (Munhall, 2007; Van Manen, 1990).

Furthermore, I suggest that, the limitations, innate strengths, and quality of this study should be considered against the goal of hermeneutic phenomenology, which is "*always a bringing to speech of something*" (Van Manen, 1990, p.32). In other words, the strength of the presentation of the actual thesis should be considered as pertinent in achieving the goal of hermeneutic phenomenology. This will enable the reader to critique how well the document has been written as a phenomenological text especially, in terms of answering the research question, and achievement of the aim, and objectives of the study (Munhall, 2007; Van Manen, 1990).

The Research question for this study was:

What is the experience of being a RNLD or a PCP caring for an individual with communication difficulties and a learning disability experiencing distress within a palliative care setting?

The findings as indicated in participants' narratives portrayed that the experience of being an RNLD or a PCP caring for PCDLD experiencing distress in palliative care settings involved: Optimism and a commitment in building personal, and professional relationships, and utilizing specialist and physical skills to provide timely optimum humane care within comfortable palliative care settings.

The aim of the study was: to gain an in-depth phenomenological understanding of how RNLDs and PCPs identify and respond to the distress of PCDLD in palliative care settings.

The understanding attained from participants' narratives in relation to how they identified and responded to the distress of PCDLD in palliative care settings was demonstrated by the main themes. The participants' narratives designated that they were able to effectively identify and respond to the distress of this population with the provision of optimum care through (1) Knowing by building relationships; (2) Positivity in successful caring outcomes; (3) Humane care; (4) Moral duty of care; (5) Time to care; (6) Comfortable care environment; and (7) Future perspectives.

The objectives of this study were:

(a) To critically explore the lived experiences of RNLDs and PCPs who care for distressed PCDLD in palliative care settings.

(b) To critically explore the perceptions of RNLDs and PCPs about factors which determine how PCDLD express distress in palliative care settings.

In explicating how the objectives were met, participants' descriptions indicated that the participants delivered palliative care in a variety of palliative care settings. Their descriptions reflected the structure of palliative care that included intensive care units, hospices and community-based palliative care settings. The community settings included nursing homes, residential care settings, an individual's private home or family home. Participants' narratives portrayed that aesthetic knowing was a method used by the participants to identify factors which contributed to how this population communicated distress, and also, to identify and respond to the distress of PCDLD in palliative care settings. Aesthetic knowing meant the participants utilized sensitivity, insight and creativity to tailor the care environment according to an individual's specific needs. The participants were able to do so by consciously adjusting the care environment in order to plan care that was sensitive to the spiritual, cultural, and religious inclinations of the

distressed or dying PCDLD within the limitations of the available care environment or space. As illustrated in Chapter Five of this thesis, (see, pp.112-115), the participants indicated that the factors which determined how PCDLD communicated distress in palliative care settings consisted of: (1) Environmental factors relating to unfamiliar people, unfamiliar care setting, and unfamiliar routine; (2) Physiological factors relating to pain; (3) Psychological factors relating to emotional stress; and (4) Lack of understanding and communication difficulties.

7.2 Implications and Recommendations

The study's findings have implications for practice, education, policy and further research. Recommendations are also incorporated for these areas.

7.2.1 Implications and Recommendations for Practice

The proposals I have made in relation to the implications of participants' findings to practice, have not been proven to be statistically reflective or significant to a large cohort of participants, rather the proposals have been depicted from the perspective of the thirteen sample participants. However, the findings provided a unique and original insight about caring for distressed PCDLD in palliative care settings. This is in terms of the process involved in appropriately identifying and responding to their distress within palliative care settings and also in identifying the factors which affect how this population communicate distress in palliative care settings. I suggest that such a process could potentially provide significant evidence from which to tailor practitioner care and training, which could also be improved by further research. Therefore, my attempt at increasing the possibility of change in practice was made by proposing a 'New theoretical Model for Palliative and EoLC for Distressed PCDLD in Palliative Care Settings'. The proposed model was based on what was identified as the fundamental nature of the participants' experience of caring for this population (Chapter Six, Figure 6.6, p.169). The proposed 'New Theoretical Model for Palliative and EoLC' for this client group has been complemented by a prototype 'Checklist' document that will enable health and social care professionals to self-evaluate personal professional practice, and the holism of care they provide to PCDLD in palliative care settings (see Appendix 11). It is anticipated that the proposed new theoretical model would be adapted by health and social care professionals to ensure optimum palliative and EoLC for distress PCDLD in palliative care settings.

Also a consistent use of the proposed model and checklist, may reiterate the problematic issue of the fundamental need to pay more attention to humane, dignified, and compassionate care, and for health and social care professionals to have standardised tools to self-evaluate personal professional practice, and also, evaluate the holism of care provided to patients especially PCDLD (see Appendix 11).

The study's findings indicate the essentiality of knowledge and skills in providing good palliative care and ensuring a dignified and peaceful death for PCDLD experiencing distress in palliative care settings. The findings illuminated that, the participants readily acknowledged their own shortcomings in caring for PCDLD who are dying. However, the participants seemed more confident and had a sense of satisfaction in the care provided when they had successfully utilized skills acquired from collaborative working or training in End-of-Life care (EoLC) such as the Gold Standard Framework for EoLC (2004).

It could be suggested that this is also in accord with the Department of Health's (DH, 2008a) plans for adult EoLC. The UK government has established its commitment to funding and meeting quality outcomes for EoLC for all adults including people with learning disabilities (PLDs) in hospices and other palliative care settings (DH, 2008a). The first main theme in this study specifically '*knowing by building relationships*' emphasized that establishing relationship at various levels, namely with PCDLD, their family members, and among the professionals involved in their care is pertinent in promoting good quality palliative care for PCDLD in palliative care settings. Participants' narratives indicated that the strength of such relationships is based on the assumption that every person involved in caring for the PCDLD brings their personal skills and knowledge to achieve a common goal, the focus of which is quality care and a dignified end for the distressed PCDLD in palliative care settings. Such dignified endings will enable family members, and even professionals, to cope with the pain of losing someone. Appropriately, Dame Cicely Saunders asserted that '*how people die remains in the memory of those who live on*' (cited in DH, 2008, p.2).

Despite the National Institute for Health and Clinical Excellence's (NICE, 2011a; 2011b) emphasis on the introduction of clear quality standards to ensure that all adults receive optimal evidence-based quality EoLC, evidence still portray that this goal remains problematic for PCDLD. The Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD) demonstrated that:

in some cases NICE guidelines had not been adhered to, particularly those relating to the management of epilepsy (CG20) replaced by (CG137 in 2012), falls (CG21), venous thromboembolism prevention (QS3), and nutrition support in adults (CG32) (Heslop et al., 2013, p.59).

Therefore, I argue that the findings of this study in terms of '*knowing by building relationships*' is a reiteration of the view that it remains imperative that the government and private organisational policies should continue to promote the development of joint competency models developed by health and social care professionals, in this case RNLDs and PCPs (NICE, 2011a; 2011b). The competency models should be aimed at enabling these professionals to provide appropriate palliative and EoLC to PCDLD in palliative care settings. Participants narratives, as demonstrated in the theme, '*knowing by building relationships*' portrayed that, building on the varied skills of all involved could lead to the development of relevant policies that engage the client, the family and the professional at the point of admission into a palliative care setting or at the point of a palliative care diagnosis. Subsequently, this could enhance the quality and practice of palliative and EoLC for this client group.

The findings of this study indicated a vital necessity of creating a palliative care environment for the PCDLD that emanates comfort and peace. The findings also portrayed the significance of relationships between the participants and PCDLD, their families, and amongst the participants themselves in the context of meeting the individual's needs during their disease trajectory and during the dying phase in a palliative care setting. Such relationships facilitated the identification of individual's distress and allowed for timely and appropriate response to the distress with the provision of optimal palliative care. It is, therefore, recommended that all palliative care settings other than the hospice, in this case community-based settings such as learning disability nursing homes, must ensure that organisational policies are in place to implement a peaceful environment for the dying person. Hence, apart from the individual's room where they usually choose to spend their last moments as illustrated in the current study, organisations should allow for the provision of a quiet room where family members can take turns in waiting away from the rest of the clients and activities around the nursing home. This is especially lacking in community palliative care settings such as nursing homes. This is to respect the privacy of the other clients in the care setting where the dying PCDLD experiencing distress might be resident. Given the recent concerns relating to poor care practices at the Staffordshire NHS foundation Trust and the recommendations for improving care as evidenced in the Francis Report (2013), I suggest that there is a fundamental need for more attention to be paid to humane care especially PCDLD in palliative care settings.

7.2.2 Implications and Recommendations for Health Education

A problem identified from participants' narratives was the need for professionals from both fields to train and acquire necessary skills to meet the needs of this population in palliative care settings.

The findings of the current study indicated that positive caring experiences and outcomes served as a precedent from which participants planned future care. In other words, such positive caring experiences were recognized by the participants as sources of knowledge in caring for PCDLD in palliative care settings, and these also contributed towards their conscientious readiness to care. The findings indicated that more still needs to be done to ensure that stories and lived experiences are incorporated in the curriculum to enhance on the one hand, student nurses' learning on palliative and EoLC for PCDLD and on the other hand, continuing professional development courses for healthcare and social care professionals. Therefore, it is recommended that

- Stories of caring for the dying PCDLD experiencing holistic distress in palliative care settings from nurses, palliative care professionals and even nursing students could be developed as teaching scenarios and adapted by nurse educators to share and reflect on the experience of caring for this client group. Such scenarios could be further developed into short films of virtual palliative care settings, which students could access at their convenience or as part of clinical practice. This is especially important because nursing practice placements on end-of-life in real life situations are difficult to orchestrate for students.
- It is recommended that the findings of the essential themes may be considered as significant enough to be included in nursing education about palliative and EoLC for PCDLD in palliative care settings. At the undergraduate level, these essential themes could be dealt with as topics in palliative and EoLC in Learning disability and Adult nursing courses. At the Postgraduate and Masters levels, these themes could be included in health promotion courses, palliative care, critical and EoLC courses. Moreover, these themes could comprise continuing education programmes for nurses and palliative care professionals.

7.2.3 Implications and Recommendations for Policy

From a general perspective the significance of this study was underlined by concurrence to existing policy initiatives. The study's findings elucidated that the seventh main theme '*Future perspectives*' was as an extended dimension of lived time specifically in relation to participants' optimism for the prospective of palliative care and learning disabilities

services in meeting the needs of PCDLD. Participants also described '*Future perspectives*' as consisting of 'Optimism', 'Proactive collaboration', 'Future improved access' and 'Meeting expectations' (see Chapter Five, pp.115-120).

The theme '*Future perspectives*' have significance for certain key policies. For example the need for a more integrated palliative care service as described by the participants in my study to an extent concurs with the promotion of quality health for all (DH, 2008d) and also, with the Department of Health's (DH, 2008c) vision for providing quality palliative care for young people with life-limiting condition. Better Care, Better Lives, the Department of Health stated that:

Every child and young person with a life-limiting or life-threatening condition will have equitable access to high-quality, family-centred, sustainable care and support, with services provided in a setting of choice, according to the child and family's wishes.... To achieve this, the commissioning and delivery of services will be planned strategically... Services will be commissioned and delivered in line with identified local need and national policy, and driven by best practice. There will be full integration of services with a seamless transition of care between primary, secondary and tertiary healthcare settings, and close partnership working between healthcare, education, social services and voluntary sector organisations. (DH, 2008c, p.11).

I suggest that the comparison between my study and the aforementioned policy document emphasizes the significance of my study's findings, in terms of its contribution to the existing body of knowledge relating to palliative care for distressed PCDLD. This is because despite the emphasis of an integrated and whole system approach in palliative care services to promote equality of access by all in need of treatment as established in the document Better Care, Better lives (DH 2008c), my participants' descriptions portrayed that there is still a need for more research and specific policy documents. This is particularly, relating to access and equality of palliative care for PCDLD experiencing distress in palliative care settings, and people with learning disabilities in general.

Additionally, as illustrated in the theme '*Future perspectives*', participants' identified optimism for the future of learning disability and palliative care services, in terms of better improved access, and meeting expectations for the provision of improved palliative care to distressed PCDLD, resonates with the following policy or government documents: -

The Department of Health (2001b, 2006, 2010) has emphasized the significance of putting people with learning disabilities (PLDs) at the heart of all nursing and healthcare interventions, by incorporating person centred care approach. Hence, it empowers PLDs to make healthy choices about their lifestyles, and also enhances the involvement of

their voices in their care and treatment, to the degree that is reasonably possible, taking into consideration their learning disabilities.

In 2010, the Department of Health set up an organisation entitled: *Improving Health and Lives: Learning Disability Observatory (IHAL)*, aimed at providing knowledge and information to enable health and social care agencies to improve the health and general well-being of PLDs in England. IHAL was in response to recommendation 5 in *Healthcare for All: Report of the independent inquiry into access to healthcare for people with learning disabilities* (Michael, 2008). Recommendation 5 of the report stated that:

To raise awareness in the health service to the risk of premature avoidable death, and to promote sustainable good practice in local assessment, management and evaluation of services, the Department of Health should establish a learning disabilities Public Health Observatory. This should be supplemented by a time-limited Confidential Inquiry into premature deaths in people with learning disabilities to provide evidence for clinical and professional staff of the extent of the problem and guidance on prevention, (Michael, 2008, p.10).

The seventh main theme '*Future perspectives*' as described by the participants is also in line with the government White Paper, *Healthy lives, Healthy People: Our strategy for public health in England* (2010). The White Paper recognised the challenges in meeting patients' health needs, and also ways of empowering individuals to make healthy choices about their lifestyles, and incorporating of the patient's voice in their own care and treatment within their local communities.

I argue that the similarity of my study's finding (Future perspectives) to the identified policy documents and government papers is a reiteration of the need for more evidence-based research in the care of this population, especially, care related to palliative and EoLC. This necessitates professionals from both the fields of learning disabilities and palliative care to recognize current limitations and ensure that deliberate steps are taken to promote proactive collaboration through training, and research in good practice from which, health and social care professionals can draw from to meet the needs of this population now and in the future.

Moreover, the third main theme of this study '*Humane care*' (Figure 6.2, p.137) highlighted the need for humane care from RNLDs and PCPs in order to provide optimal care to PCDLD experiencing distress in palliative care settings. This strongly resonates with the most recent *Statutory Decree of Candour* passed by the Department of Health (DH, 2013) in response to the *Francis Report* about the failings at the Staffordshire NHS Foundation Trust. This decree establishes that a culture of zero harm and compassion will be a key marker of success in patient care, thus putting an end to the misleading

impact of targets expected from the health care service, which contributed to the failings at Stafford hospital. I suggest that there is still need to promote the concept of humane or compassionate care. It is usually assumed that every nurse or healthcare professional will deliver care that embeds this concept but that has not always been the case. Therefore, it is recommended that specific policy document and strategies by which health and social care professionals could assess themselves to ensure care that encompass this view is still needed.

7.2.4 Implications and recommendations for Research

The findings of the study have implication for research. Participants' narratives seem to reiterate that with the improvement in health care and increase in the life expectancy of people with learning disabilities, so will the demand for optimum palliative and end-of-life care for this population (DH, 2003, 2006; End of Life Care Programme, 2009). A lack of the necessary skills and confidence to provide optimum palliative and EoLC to people with learning disabilities was expressed by the participants as a pertinent concern. It is anticipated that with time, more health and social care professionals, especially, RNLDs and PCPs, will acquire the necessary training and skills to care for this population within palliative care settings. However, in the meantime, nurse researchers and health and social care researchers in general, should focus on undertaking empirical studies that would evidence good practice in the provision of palliative and EoLC to this client group, and which may potentially influence planned changes in care strategies and policies.

The findings of the current study has provided valuable information and knowledge for those involved in the care of PCDLD experiencing distress in palliative care settings. It is recommended that the findings could be more fully developed and studied through research, and may further contribute to the body of knowledge in learning disability nursing and palliative care related to palliative and EoLC. For example:

- A future longitudinal study could be undertaken utilizing phenomenology as the research methodology. The focus of the future study would be on gaining a broader understanding of care for this population within palliative care settings and at the end-of-life, and would incorporate issues of diversity, spirituality and culture based on the perspectives of health and social care professionals, family members, healthcare educators and the PCDLD themselves.
- A small sample population of RNLDs and PCPs took part in this study. Therefore, the recommended longitudinal study should consider a sample population that

includes RNLDs, PCPs, healthcare educators, PCDLD and their family members to get an even more varied perspective of the phenomenon under study.

- In addition, the current study did not include considerations of participants' spiritual, cultural and religious inclinations and how that influenced the care of PCDLD experiencing distress in palliative care settings in terms of identifying and responding to their distress. Consequently, a longitudinal study would consider the lived experiences of participants from different belief systems in caring for this client group in palliative care settings. This might be needed to gain a better understanding of diversity in terms of spirituality, culture and religion in palliative and EoLC of PCDLD.
- The study's findings indicate that there are many aspects of the care of PCDLD in palliative care settings that require further considerations. Therefore, empirical research ventures based on evidence-based practice that seek to increase understanding and awareness of the needs of PCDLD experiencing distress in palliative care settings would be of significance. It would be interesting to undertake a study that seeks to gain understanding and awareness of the lived experiences of RNLDs and PCPs caring for this client group in palliative care settings both within Britain and in countries outside Britain. This would allow for a comparison in models of care informed by the healthcare or socio-political systems governing nursing practice in the countries involved. Such comparison, it could be suggested would facilitate the Department of Health and other private healthcare organisations in the UK to undertake an in-depth validation of the palliative care provided to PCDLD in the UK in comparison to other countries.

7.3 Plans for dissemination of the Findings

The findings from this study will be disseminated in peer reviewed journals and conference presentations. Also it is anticipated that a research study will be undertaken to test the effectiveness of the New Theoretical Model for Palliative and EoLC and the checklist for professionals' self-evaluation of the holism of care provided to this population by RNLDs and PCPs in learning disabilities and palliative care settings.

7.4 Chapter summary

This chapter has provided the strengths and limitations of the study in terms of the selected methodology and methods, the breadth and depth of the general research

process and how that contributed to the credibility of the findings. The discussion of the strengths and limitations were simultaneously validated against trustworthiness in qualitative research in general, (Lincoln and Guba, 1986, pp.76-77) and in particular, Munhall's (1994) proposed 'One P, Ten Rs criteria' (Munhall, 2007, p.562-563) for evaluating rigour (trustworthiness) in phenomenological research. It also discussed the implications and recommendations of the findings to practice, policy, education, and research. Plans for dissemination of the study's findings were also explained.

Chapter eight is the final chapter of this study. It encompasses the final reflections and highlights the original contributions of the study to knowledge. It also provides a conclusion for the study.

Chapter Eight: Conclusion

The final chapter of this study consists of the final reflections and highlights the original contributions to knowledge. It also provides a conclusion for the study.

8.1 Reflections on the Aim and Objectives

The innate strength of the study as a hermeneutic phenomenological study was revealed because the discussions of the findings provided rich data, which answered the research question and met the aim and objectives of the study (Munhall, 2007; Van Manen, 1990). The findings portrayed the experience of being an RNLD or a PCP caring for PCDLD experiencing distress in palliative care settings involved: Optimism and a commitment in building personal, and professional relationships, and utilizing specialist and physical skills to provide timely optimum humane care within comfortable palliative care settings.

The findings identified seven main themes as fundamental strategies used by the participants to effectively identify and respond to the distress of this population with the provision of optimum care. These are:

(1) Knowing by building relationships

The Registered Learning Disability Nurses (RNLDs) and Palliative Care professionals (PCPs) recognized that the relationships they built and maintained with others: people with communication difficulties and a learning disability (PCDLD), their families and carers, and amongst the professionals themselves, in the interpersonal environment that they shared with them was essential because it enhanced the interconnected nursing or caring interventions, and also, acted as a fundamental strategy to identify and appropriately respond to the distress of PCDLD. Consequently, '*Knowing by building relationships*' was an essential aspect of the participants' lived experiences of caring for this population in palliative care settings. This was because the participants' descriptions indicated that the phenomenon of caring for distressed PCDLD in palliative care settings would be irrelevant without the existence of a committed, mutual, interpersonal and professional relationship between the participants, PCDLD, their family members and carers. Such relationships enabled the participants to learn the communication modes of PCDLD and thus enhanced participants' ability to anticipate their distress and provide optimum care.

(2) Positivity in successful caring outcomes

Participants' narratives indicated that the conscious use of their specialist and physical skills was essential to the phenomenon of caring for distressed PCDLD in palliative care settings. This was as a result of understanding one's self as a person and drawing from past experiences of care to deal with current or on-going issues. Participants drew inspiration from effective care interventions to plan future care interventions. Thus, they were motivated to train and acquire more skills in palliative and end-of-life care (EoLC) in order to meet the needs of this population in palliative care settings. The ability to readily draw from past professional or personal experiences of caring, enabled the participants to provide appropriate confident care. Participants also acknowledged that effective care interventions facilitated caring for this client group and also created a sense of pride and job satisfaction when they efficiently utilized specialist skills to meet the needs of this population and their families within palliative care settings.

(3) Humane care

'*Humane care*' encompassed sincerity and sensitivity, positive regard of the whole person (positive regard of personhood), empathy, and therapeutic touch as a beneficial response to distress. Humane care required that the participants had to be bodily present in the world of the distressed PCDLD in order to address their distress.

(4) Moral duty of care

For the participants, '*Moral duty of care*' encompassed training and providing a dignified end; pain-free care; comfort, safety and peace; and acknowledgement of shortcomings. These aspects could all be associated to participants' obligation in utilizing their physical skills and specialism in providing the best possible care for distressed PCDLD. Participants' explanations denoted their understanding of the essentiality of maintaining moral standards while executing physical and emotional care throughout an individual's illness and at time of death.

(5) Time to care

This reflected the RNLDs' and PCPs' perceptions of time while performing in the world and encompassed the temporal dimensions of past, present and future. Participants perceived that '*time to care*' was symbolic of an essential care strategy to address the distressed of PCDLD. They emphasised that a deliberate awareness of time will ensure that timely and appropriate care was provided to address the distress of PCDLD. '*Time to care*' encompassing the notions of time and anxiety, time and caring opportunities and dying as part of living was expressed by the participants as being mindful to provide

optimum care and meet the needs of the dying PCDLD, yet having to work within the constraints of available time and certain human limitations. Thus '*time to care*' necessitated effective time management in all care interventions for distressed PCDLD.

(6) Comfortable care environment

Participants expressed that deliberately creating a comfortable care environment or space was fundamental to the care of distressed PCDLD in palliative care settings. This required that aesthetic knowing consisting of sensitivity, insight, and creativity was utilized to adjust the care environment. This enhanced participants' ability to observe or identify subtle changes in the behaviour of PCDLD, which might be presentation of distress directly related to the specific palliative care environment. Participants also emphasized that adapting the care environment to suit individuals specific needs, enabled them to identify factors which determine how individuals expressed distress. Consequently, care was appropriately planned that was sensitive to the spiritual, cultural, and religious needs of the distressed or dying PCDLD within the limitations of the available care environment.

(7) Future perspectives

'*Future perspectives*' emulated participants' perceptions of time while engaged in the palliative care world and particularly encompassed optimism, proactive collaboration, future improve access and meeting expectations as fundamental to the care of distressed PCDLD in palliative care settings. Appropriate, timely and optimum palliative care for distressed PCDLD could be promoted if future perspectives, relating to learning disabilities and palliative care service provisions, were addressed. Consequently, a conscious commitment to time, in terms of a planned future, was perceived as an essential approach to appropriately identify and respond to the distress of PCDLD in palliative care settings.

The main themes were mapped under Van Manen's (1990) lifeworld existential themes of relationality; corporeality; temporality and spatiality as overarching themes (Table 6.1) and subsequently, the fundamental nature of the participants' experience of caring for this population was identified. This also informed the creation of a 'New Theoretical Model of Palliative and EoLC for Distressed PCDLD in Palliative Care Settings'. The proposed model was complemented with a prototype 'Checklist to enable nurses, health and social care professionals to self-evaluate their personal professional practice and the holism of care' provided to distressed PCDLD in palliative care settings.

RNLDs and PCPs established that being authentically present to provide care that encompassed sincerity, sensitivity, and kindness, placed them in the world of caring for

distressed PCDLD in palliative care settings, shaped the care provided and accordingly, affected the bodies of the persons being cared for. Participants emphasized that both the caring process and the practice of nursing entailed that nurses and other health professionals utilize their bodies to care for clients/patients often by executing physical and emotional care throughout the person's illness and at time of death. Therefore, it was deemed an obligation and an essential care strategy to provide care that necessitated engaging these qualities to appropriately address the distress of PCDLD in palliative care settings. The outcome of being physically present, receptive, and empathetic to the distressed PCDLD was the provision of pain-free, comfortable and optimum confident care.

Participants' indicated that they delivered palliative care in a variety of palliative care settings. Participants' descriptions reflected the structure of palliative care that included intensive care units, hospices and community-based palliative care settings. The community settings included nursing homes, residential care settings, an individual's private home or family home. Participants' narratives portrayed that aesthetic knowing was a method used by the participants to identify factors which contributed to how this population communicated distress in palliative care settings. Aesthetic knowing meant the participants utilized sensitivity, insight, and creativity to tailor the care environment according to an individual's specific needs. Participants were able to do so by deliberately adjusting the care environment in order to plan care that was sensitive to the spiritual, cultural and religious needs of the distressed or dying PCDLD within the limitations of the available care environment. The identified factors which determined how PCDLD communicated distress in palliative care settings as illustrated in participants' quotes in Chapter Five consisted of: (1) Environmental factors relating to unfamiliar people, unfamiliar care setting, and unfamiliar routine. (2) Physiological factors relating to pain. (3) Psychological factors relating to emotional stress. (4) Lack of understanding and communication difficulties.

(1) Environmental factor: The participants narratives illustrated that environmental factors specifically linked to unfamiliar people, unfamiliar care settings, and routines affected how PCDLD expressed distress in palliative care settings. Participants explained that when exposed to these environmental factors the PCDLD became distressed and their distress was manifested in certain instances by becoming withdrawn.

(2) Physiological factor: The findings indicated that physiological factors particularly pain contributed to how PCDLD expressed distress in palliative care settings. This could be manifested by a change in the behaviour of the PCDLD.

(3) Psychological factor: Participants' descriptions showed that psychological factors relating to emotional stress may affect how PCDLD communicated distress in palliative care settings. Hence, an individual experiencing emotional distress may display aggressive behaviour or become uncooperative with care interventions.

(4) Lack of understanding and communication difficulties: The findings indicated that for some PCDLD the frustration at not being able to express their needs contributed to their distress which was then manifested by withdrawal or a change in behaviour. This meant that their distress or state of health could only be identified by staff members who knew them well.

Original contribution to knowledge

The findings of this study have portrayed a rich ontological interpretation of RNLDs and PCPs' lived experiences of caring for PCDLD experiencing distress in palliative care settings. The study has made an original contribution to existing knowledge in the fields of learning disabilities and palliative care nursing in the following areas:

1. Insight into the essence or fundamental nature of the phenomenon of caring for PCDLD experiencing distress in palliative care settings

The study provided insight into the essence or fundamental nature of the phenomenon of caring for distressed PCDLD for the RNLDs and PCPs who have lived the experience. This was demonstrated by an essence statement that intentionally captured and portrayed the understood meaning of the essence or fundamental nature of participants' experience of caring for this population, in terms of what was essential to effectively identify and respond to their distress in palliative care settings. The essence statement arrived at was:

Optimism and a commitment in building personal and professional relationships, and utilizing specialist, and physical skills to provide timely optimum humane care to distressed PCDLD within comfortable palliative care settings.

On the one hand, the essence statement portrayed a correlation to the seven main themes as mapped within the framework of Van Manen's (1990) lifeworld existential of relationality (section 6.2 and Figure 6.1); corporeality (section 6.3 and Figure 6.2); temporality (section 6.4 and Figure 6.3); spatiality (section 6.5 and Figure 6.4) and future perspectives as an extended dimension of lived time (Figure 6.5).

On the other hand, the essence statement represents a response to my Research question:

What is the experience of being a RNLD or a PCP caring for an individual with communication difficulties and a learning disability experiencing distress within a palliative care setting?

Hence, by inference, the experience of being an RNLD or a PCP caring for PCDLD experiencing distress in palliative care settings involved: Optimism and a commitment in building personal and professional relationships, and utilizing specialist, and physical skills to provide timely optimum humane care within comfortable palliative care settings.

2. Identifies a process of caring for PCDLD in palliative care settings

A process of caring for PCDLD in palliative care settings was identified: The essence statement was also indicative of the process of caring for PCDLD experiencing distress in palliative care settings, as experienced by the participants. This process was portrayed as a continuum and not as disparate approaches because the different components which encapsulated the essence or fundamental nature of participants' experiences were interrelated and relevant hence, allowing for optimum care of this population in palliative care settings to be maximised.

I am aware that promoting effective working relationships and comfortable care environments have been identified in previous palliative care studies (Donovan, 2002; Foley and McCutcheon, 2004; Tuffrey-Wijne, 2011). However, I am unaware of any study that specifically identified a main essence of the phenomenon of caring for PCDLD experiencing distress in palliative care settings. I am also not aware of any study that related this essence to the process of caring for distressed PCDLD in palliative care settings as experienced by RNLDs and PCPs; or established that, the process should be considered as a continuum and not as disparate approaches.

3. Development of a New Theoretical model of Palliative and end of Life care for PCDLD experiencing distress in Palliative Care Settings

The development of a New Theoretical Model of Palliative and EoLC: The components embedded within the essence statement informed the development of a proposed 'New Theoretical Model of Palliative and EoLC for PCDLD in Palliative Care Settings' (Figure 6.6).

I am unaware of any existing study, which has highlighted the possibility that the components embedded within the essence or fundamental nature of participants' experiences as explicated in my study could become an embodiment of a 'New Theoretical Model of Palliative and EoLC for PCDLD'. (Figure 6.6, p.169). The components encompassed in the proposed model could be used for increasing health and social care professionals' capacity for care and compassion, and also raise awareness to these significant concepts of care, which still remain problematic. The significance of this contribution in my study is the anticipation that this will allow the reader to reflect and this might provoke further questioning and investigation into this phenomenon and other related human phenomena. It has been asserted that a phenomenological inquiry is never complete. It should only make people wonder (Van Manen, 1990).

4. Development of a prototype Checklist for self-evaluation of personal and professional practice

Development of an archetype 'Checklist for self-evaluation of personal professional practice and the holism of palliative and EoLC for PCDLD': The New Theoretical Model was complemented by a prototype checklist document that will enable RNLDs, PCPs, and potentially other health and social care professionals to self-evaluate their personal professional practice, and the holism of care they provided to PCDLD in palliative care settings (see Appendix 11). The checklist also enables nurses or health and social care professional to self-evaluate the following:

- If appropriate plans or measures have been taken to ensure a process of building relationship with individuals and their families, and also liaising with other professionals involved in individuals' care.
- If they have the required cognitive and physical skills to meet PCDLD palliative and EoLC needs.
- If the landscape of the care provided includes dimensions of past, present and future.
- If the care environment is suitable to meet the individual's specific palliative and EoLC needs including being compassionate and empathetic towards individuals by adapting the environment to be sensitive to individuals' dying, religious, cultural and spiritual needs.
- If future plans are in place to ensure possible improvement to care approaches, and continuity of care to other PCDLD within the particular palliative care setting, families, and staff, in the eventuality of the death of an individual, (see Appendix 11).

8.3 Conclusion

I suggest that the findings, implications and recommendations from this study have demonstrated that the compilation of a well-structured rigorous research design is clearly important to help give credibility and dependability to research results (Mays and Pope 2000; Munhall, 2007; Holloway and Wheeler, 2009; Silverman, 2010). I endeavoured to meet these criteria throughout this study by the utilization of a comprehensible theoretical framework in this case, Van Manen's (1990, p.28) hermeneutic phenomenology '*in pursuit of knowledge*'. This enriched the study with interrelated components existing between the epistemological basis of the study (constructionism), the methodology, methods, data collection and data analysis analytical process (Crotty, 1998, Holloway and Wheeler, 2009; Munhall 2007, Silverman, 2010).

Consequently, there was a clear explanation of all stages of the process of data collection and analysis in terms of isolating of sub-themes (Figure 5.1), which were then clustered into main themes (Table 5.2). These main themes were mapped unto Van Manen's (1990) life-world existential themes in order to glean the wider significance of the main themes as essential constructions of the participants' lived experiences (Table 6.1). These main themes sequentially evolved to form an essence statement that intentionally captured and portrayed the understood meaning of the essence or fundamental nature of participants' experience of caring for this population. This was in terms of what was fundamental to effectively identify and respond to the distress of PCDLD in palliative care settings. The essence statement also became symbolic of a response to my Research question and subsequently informed the creation of a 'New Theoretical Model of Palliative and EoLC for Distressed PCDLD in Palliative Care Settings' (Figure 6.6). The significance of a thorough research design to enhance the credibility of the researcher's interpretation of qualitative data is described by Mason, (2010, p.191-192) as:

....validity of interpretation in any form of qualitative research is contingent upon the 'end product' including a demonstration of how interpretation was reached. This means that you should be able to, and be prepared to, trace the route by which you came to your interpretations.

My persistent dwelling on the parts and whole of the text and the emerging thematic aspects enhanced my understanding of participants' experience of the phenomenon of caring for PCDLD experiencing distress in palliative care settings. I also understood the factors which determine how PCDLD communicated distress in palliative care settings as

described by the participants. I also conclude that this study has made specific contributions to knowledge in the fields of learning disability and palliative care nursing by highlighting the following:

- How RNLDs and PCPs identify and respond to the distress of PCDLD in palliative care settings.
- The essence or fundamental nature of the phenomenon of caring for PCDLD experiencing distress in palliative care settings from RNLDs and PCPs perspectives.
- The process of palliative and EoLC for this population in palliative care settings.
- The development of a proposed New Theoretical Model for Palliative and EoLC for PCDLD in Palliative Care Settings.
- The development of a prototype Checklist to enable RNLDs, PCPs, and potentially other health and social care professionals to self-evaluate personal professional practice, and the holism of care provided to PCDLD in palliative care settings (see Appendix 11).

Ultimately, I have learnt much about the value of utilizing a meticulous research process. I have grown as far as my competence in undertaking an in-depth hermeneutic phenomenological study following Van Manen's (1990, p.28) hermeneutic phenomenology '*in pursuit of knowledge*' is concerned. This enabled me to produce a rich text in terms of the detail descriptions and rationales provided for the selected methodology and design and the '*...bringing to speech of something*' (Van Manen, 1990, p.32) through the achievement of the aim and objectives of the study, and also in answering the research question. This is in line with notion that, in quantitative research "*... precision and exactness are usually seen to be indications of refinement of measurement and perfection of research design*" (Van Manen, 1990, p.17). In contrast, phenomenology "*strives for precision and exactness by aiming for interpretative descriptions that exact fullness and completeness on detail, and that explore to a degree of perfection the fundamental nature of the notion being addressed in the text*" (Van Manen, 1990, p.17).

It is anticipated that the proposed 'New Theoretical Model of Palliative and EoLC for Distressed PCDLD in Palliative Care Settings' and the concepts embedded in the model could be used as a process of palliative and EoLC for this population and also for increasing health and social care professionals' capacity for care and compassion, and thus, continue to raise awareness to these significant concepts of care, which remain problematic.

Ultimately, I have also, developed personally and professionally as the process of collecting data, analyzing data and the writing up of a hermeneutic phenomenological text provided me with a forum for an in-depth reflection and examination of my own understanding of optimum palliative and EOLC for distressed PCDLD. The participants' narratives and subsequent findings as elucidated in this study created a new awareness in me about the significance of interdisciplinary care that exhibits mutual professional acceptance, compassion, support and encouragement in order to maximise optimum patient/client outcomes. It is also anticipated that this thesis will evoke in the readers the same profound effect of understanding of the phenomenon under study that I had, and may also profoundly interest the readers', in particular, research and service communities to further question this phenomenon and other human phenomena.

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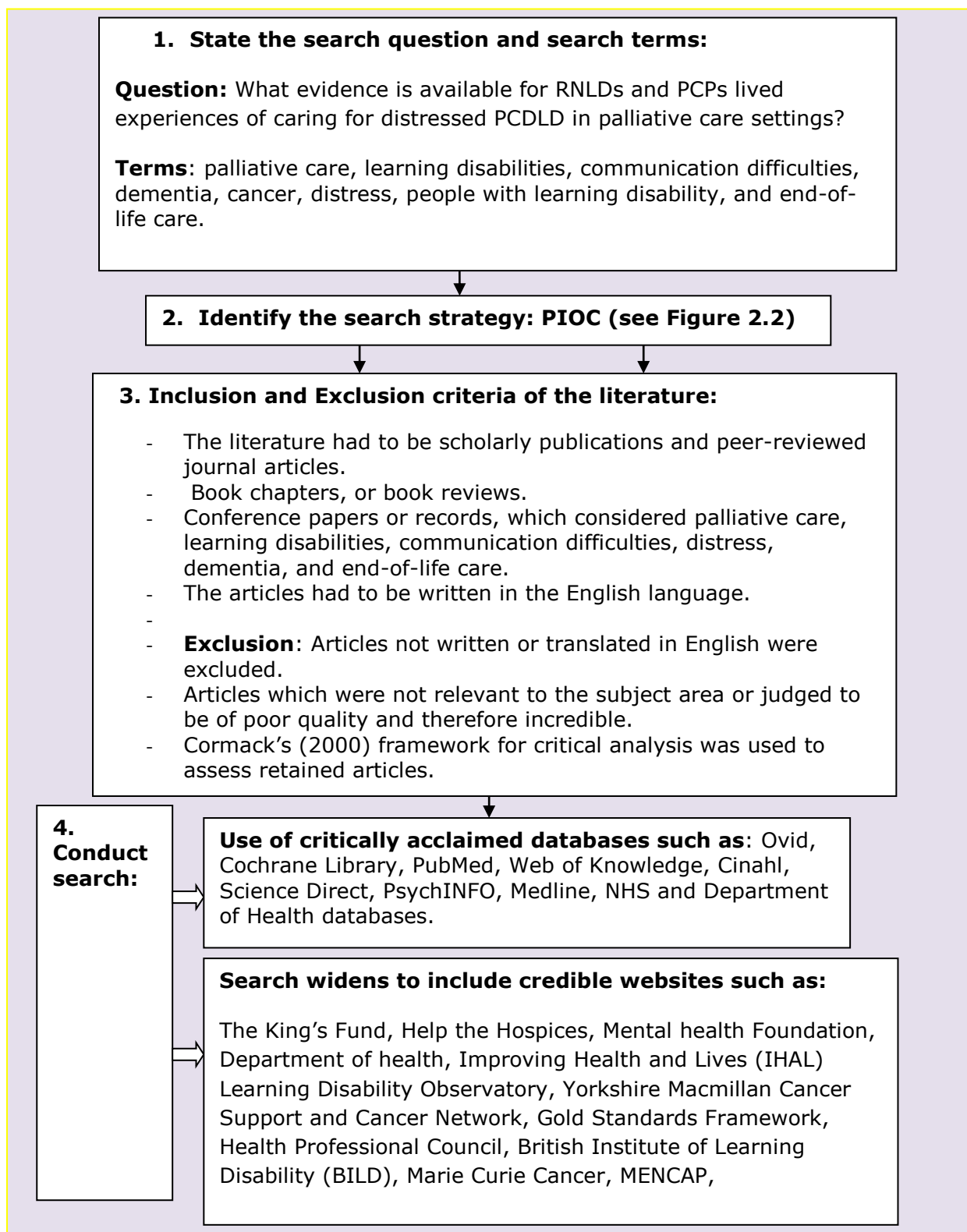
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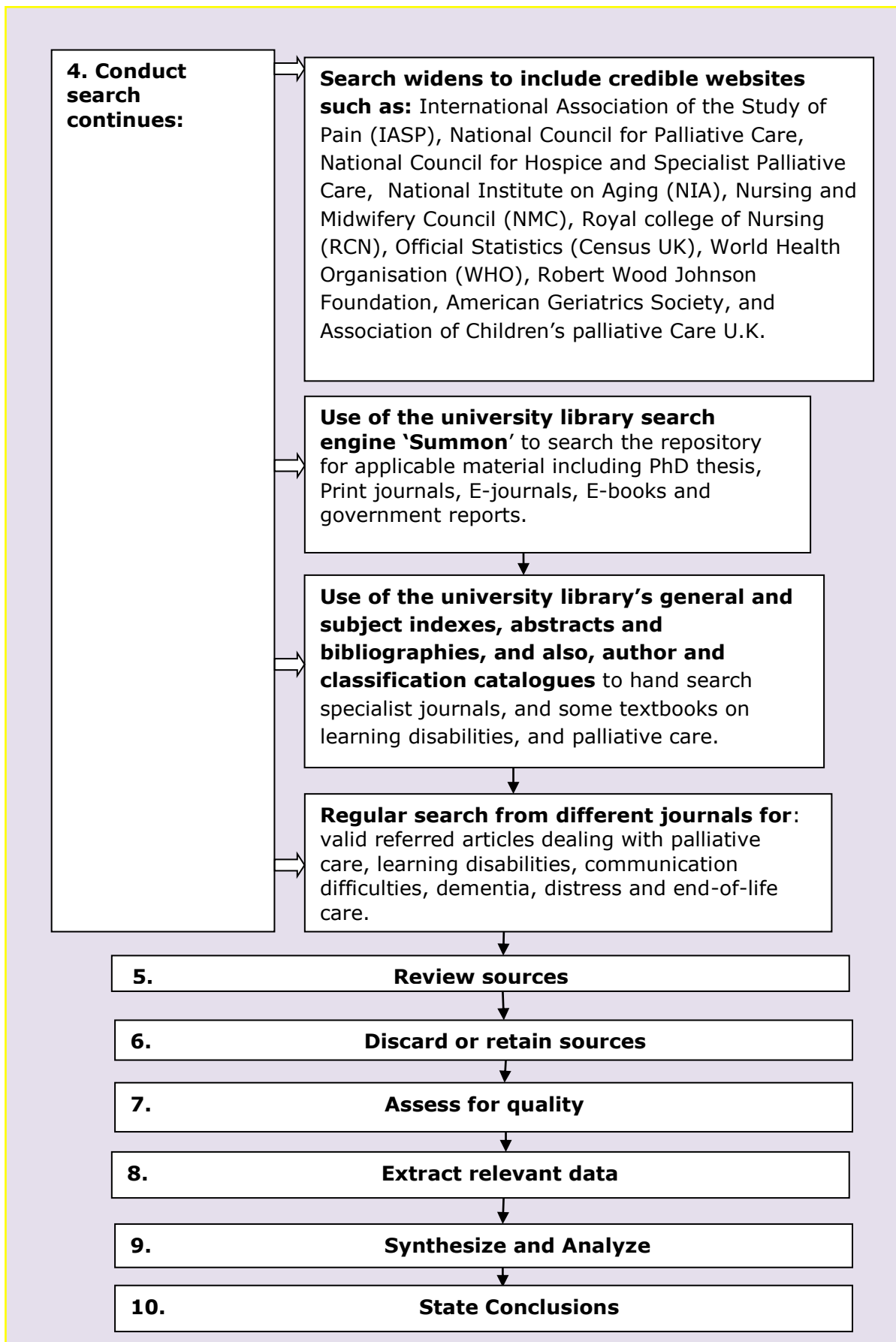
Appendices

Appendix 1 Overview of the critical review process

Overview of the critical review process



Appendix 1 Overview of the critical review process



Appendix 2 Cormack’s framework for critical analysis

Heading (Applicable to all studies)	Questions	Yes	No	Do not know
Title	<ul style="list-style-type: none"> - Is the title concise? - Is the title informative? - Does the title clearly indicate the content? - Does the title clearly indicate the research approach used? 	-	-	-
Author (s)	<ul style="list-style-type: none"> - Does the author(s) have appropriate academic qualifications? - Does the author(s) have appropriate professional qualifications and experience? 	-	-	-
Abstract	<ul style="list-style-type: none"> - Is there an abstract included? - Does the abstract identify the research problem? - Does the abstract state the hypotheses (if appropriate)? - Does the abstract outline the methodology? - Does the abstract give details of the sample subjects? - Does the abstract report major findings? 	-	-	-
Introduction	<ul style="list-style-type: none"> - Is the problem clearly identified? - Is the rationale for the study stated? - Are the limitations of the study clearly stated? 	-	-	-
Literature Review	<ul style="list-style-type: none"> - Is the literature review up-to-date? - Does the literature review identify the underlying theoretical framework(s)? - Does the literature review present a balanced evaluation of material both supporting and challenging the position being proposed? - Does the literature clearly identify the need for the research proposed? - Are important references omitted? 	-	-	-
The Hypothesis	<ul style="list-style-type: none"> - Does the study use an experimental approach? - Is the hypothesis capable of testing? - Is the hypothesis unambiguous? 	-	-	-

Operational definitions	<ul style="list-style-type: none"> - Are all terms used in the research question / problem clearly defined? 	-	-	-
Methodology	<ul style="list-style-type: none"> - Does the methodology section clearly state the research approach to be used? - Is the method appropriate to the research problem? - Are the strengths and weaknesses of the approach stated? 	-	-	-
Subjects	<ul style="list-style-type: none"> - Are the subjects clearly identified? 	-	-	-
Sample selection	<ul style="list-style-type: none"> - Is the sample selection approach congruent with the method to be used? - Is the approach to sample selection clearly stated? - Is the sample size clearly stated? 	-	-	-
Data collection	<ul style="list-style-type: none"> - Are any data collection procedures adequately described? - Has the validity and reliability of any instruments or questionnaires been clearly stated? 	-	-	-
Ethical considerations	<ul style="list-style-type: none"> - If the study involves human subjects has the study ethical committee approval? - Is informed consent sought? - Is confidentiality and anonymity assured? 	-	-	-
Results	<ul style="list-style-type: none"> - Are results presented clearly? - Are the results internally consistent? - Is sufficient detail given to enable the reader to judge how much confidence can be placed in the findings? - Does graphic material enhance clarity of the results being presented? 	-	-	-
Data Analysis	<ul style="list-style-type: none"> - Is the approach appropriate to the type of data collected? - Is any statistical analysis correctly performed? - Is there sufficient analysis to determine whether significant differences' are not attributable to variations in other relevant variables? 	-	-	-

	<ul style="list-style-type: none"> - Is complete information (test value, df, and p) reported? 			
Discussions	<ul style="list-style-type: none"> - Is the discussion balanced? - Does the discussion draw upon previous research? - Are the weaknesses of the study acknowledged? - Are clinical implications discussed? 	-	-	-
Conclusions	<ul style="list-style-type: none"> - Are conclusions supported by the results obtained? - Are implications of the study identified? 	-	-	-
Recommendations	<ul style="list-style-type: none"> - Do the recommendations suggest further areas for research? - Do the recommendations identify how any weaknesses in the study design could be avoided in the future? 	-	-	-

Appendix 3 List of Journals used for valid referred articles

1. British Journal of Learning Disability
2. British Journal of Nursing
3. Behaviour research and therapy
4. Creative Nursing
5. Death Studies
6. Dementia; PLOS (Peer Reviewed Journal on Line)
7. European Journal of Cancer care
8. Intellectual and Developmental Disabilities
9. International Journal of Palliative Nursing
10. Journal of Geriatric Psychology
11. Psychological Medicine
12. Journal of Accident and Emergency Nursing
13. Journal of Advanced Nursing
14. Journal of Comparative Social Work
15. Journal of Evidence-Based Social Work
16. Journal of Intellectual Disability
17. Journal of Gerontological Nursing
18. Journal of Learning Disability Nursing
19. of Medical Ethics;
20. Journal of Nursing Education
21. Journal of Paediatric Nursing
22. Journal of Pain and Symptom Management
23. Journal of Research in Nursing
24. Journal of Vocational Behaviour
25. Learning Disability Practice
26. Pain
27. Pain Management Nursing
28. Medicine
29. Qualitative Inquiry
30. Qualitative research
31. Research on Social Work Practice
32. The Clinical Journal of Pain
33. The Independent
34. The Irish Journal of Psychology
35. The Counselling Psychologist
36. Tizard Learning Disabilities Review

Appendix 4 Quality Assessment Matrix of review of retained articles

Authors & Title	Aim	Design	Sample Size	Main findings	Validity of the Findings and Relevance to the current study
Li, and Ng (2008) End-of-life care: nurses experiences in caring for dying patients with profound learning disabilities: a descriptive case study	To identify areas of expertise and deficits in the specific knowledge in the care of dying patients with profound learning disabilities in one NHS primary Care Trust in the UK	Case study	5 learning disability nurses: 2 males and 3 females	<p>Themes identified:</p> <p>Certainty of knowing the patients.</p> <p>Uncertainty and ambiguity in the following:</p> <p>Recognition of the cause or onset of patients' illness and the cause of death.</p> <p>Good working relationship viewed as important in promoting quality care.</p> <p>A checklist for identifying disease-related changes in patients with profound learning disabilities was imperative.</p>	<p>Factors enhancing the study's validity:</p> <p>The study incorporated some of the key search words of my study especially people with learning disabilities; palliative and EoLC.</p> <p>The title is concise and informative.</p> <p>The paper included an abstract and introduction which clearly identified the problem and aim.</p> <p>The authors identified limitation of the study in terms of the sample size and generalization of the findings.</p> <p>Data was collected and analyzed by both authors.</p> <p>The authors clearly stated</p>

					<p>how ethical approval was obtained. Other ethical considerations such as anonymity and confidentiality were stated.</p> <p>At the time when the paper was published the literature reviewed was up-to-date</p> <p>Both authors were trained counselors and had relevant professional, academic and research qualifications.</p> <p>Factors reducing the study's validity:</p> <p>Case studies are not high on the hierarchy of evidence ladder in terms of generalization of findings.</p>
Todd (2005) Surprised endings: the dying of people with learning disabilities in residential services.	Reflecting on the care of people with learning disabilities (PLD) at the end of their lives.	Comment piece taken from a wider study.		<p>Highlighted the challenges faced by those caring for PLD at the end-of-life as follows:-</p> <p>Learning disability and death in terms of the unheard perspectives of PLD when they are dying.</p>	<p>Factors enhancing the paper's validity:</p> <p>The author mentioned the method of data collection of the wider study as interviews.</p> <p>The literature</p>

				<p>Also the unheard bereavement experiences of those caring for them.</p> <p>Resistance of carers to outside help from other professionals.</p> <p>Unmet needs of the PLD.</p> <p>Communicating with clients in terms of whether they should be informed about dying.</p>	<p>review included in the Comment piece was current at the time it was written.</p> <p>The author proposed a recommendation: 'bringing learning disability services and specialist palliative care services together.</p> <p>The paper had relevance to my study in terms of end-of-life care provided to people with learning disabilities.</p> <p>Reducing the paper's validity</p> <p>The comment piece is linked to a wider study but the author did not mention the sample size, or data analysis method of the wider study.</p> <p>Comment pieces are not on the hierarchy of evidence ladder</p>
Hadjistavropoulos & Craig (2002). A theoretical framework	To provide a rationale for the use of self-report and	Critical review of literature	Not relevant	Automatic expressive behaviours are subject dependent upon higher	Factors enhancing the study's validity:

<p>for understanding self report and observational measures of pain: a communications model</p>	<p>observational strategies using a Communications Model.</p> <p>To examine factors that governs the utility and validity of such strategies in the measurement of pain.</p>			<p>mental processes.</p> <p>Observational measures can be used and have clinical utility as indices of pain when self-report is not available, for example in infants, young children, people with intellectual disabilities or brain damage, and seniors with dementia.</p> <p>Observational measures are also useful when self-report is questioned and even when credible self-report is available.</p> <p>The Model took into account the role of various human developmental stages of pain experience and expression.</p> <p>Both observational and self-report measures are essential in the assessment of pain because of the unique information that each type contributes.</p>	<p>The title is concise and informative.</p> <p>The paper included an abstract and introduction which clearly identified the problem and aims.</p> <p>Provided definition of the terms: self-report, unobtrusive observations, observational strategies</p> <p>A Conclusion was provided with the following points:-</p> <p>i) Acknowledged limitation of the paper: being that many of the propositions involved in the model are based on integration of findings from prevailing literature</p> <p>ii) A recommendation for future research which could help specify with greater precision the degree to which specific instruments rely on automatic versus higher</p>
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					mental processes.
Hadjistavropoulos et al. (2000) Measuring movement exacerbated pain in cognitively impaired frail elders.	To examine the utility of both self-report and nonverbal measures of pain in frail elders experiencing exacerbations of chronic musculoskeletal pain	Mixed methods: qualitative and quantitative	58 frail elders comprising 28 males and 30 females. 28 of the participants had significant cognitive impairments.	Supports the validity of self-report and behavioural measures of pain in frail elders with or without cognitive impairments. Investigation of pain in elders with cognitive impairments should use varying types of pain assessment tools.	<p>Factors enhancing the study's validity:</p> <p>The title is concise and informative.</p> <p>The paper included an abstract which clearly identified the objective and aim, main findings, and conclusion of the study.</p> <p>The authors identified as limitation that some of the methods they employed in the pain measurement may be unwieldy to use in clinical situations.</p> <p>Data collection and analysis methods were stated.</p> <p>At the time when the paper was published the literature review was up-to-date</p> <p>Factors reducing the study's validity:</p> <p>The authors did not clearly state how ethical</p>

					approval was obtained or other ethical considerations such as anonymity and confidentiality.
Manfredi, Breurer, Meier and Libow, (2003) Pain assessment in elderly patients with severe dementia.	To assess the reliability and validity of facial expressions as pain indicators in patients with severe dementia.	Systematic review of literature	Not relevant	Clinicians observations of facial expressions and vocalizations are accurate means for assessing the presence of pain, but not its intensity in patients unable to communicate verbally because of advanced dementia.	<p>Factors enhancing the study's validity:</p> <p>The title is concise and informative.</p> <p>The paper included an abstract which clearly identified the purpose, main findings, and conclusion of the study.</p> <p>Data collection and analysis methods were stated.</p> <p>At the time when the paper was published the literature review was up-to-date.</p>
Regnard, Reynolds, Watson, Mathews, et al. (2006) Understanding distress in people with severe communication difficulties: piloting and assessing	To pilot the Disability Distress Assessment Tool (DisDAT), which was developed by a palliative care team working with PLDs. DisDAT was used to record a range of signs and behaviours of	Mixed Methods	DisDAT was piloted with 16 carers and 8 clients DisDAT was assessed with 56 carers and 25 patients, most with severe communication difficulties.	<p>Distress did not have a common meaning amongst carers and was not only related to pain.</p> <p>Identified a variety of distress cues. The cues were not specific to a particular cause.</p> <p>No evidence that</p>	<p>Factors enhancing the study's validity:</p> <p>The title is informative.</p> <p>The paper included an abstract which clearly identified the purpose, methods,</p>

DisDat.	when a person is content or distressed.		Interviews with 10 carers of 10 of the patients, who were also observed for distress cues during different activities.	<p>pain had specific behaviours or signs.</p> <p>The pilot and assessment phases portrayed that distress was a valuable clinical construct</p> <p>DisDAT was easy to use by carers and it mirrored patients' distress communication recognized by carers, which provided them with evidence for their intuitive observations.</p>	<p>main findings, and conclusion of the study.</p> <p>Data collection and analysis methods were stated.</p> <p>At the time when the paper was published the literature review was current.</p> <p>Ethical considerations were stated</p> <p>Reducing the study's validity</p> <p>Limitations or recommendations for future study were not clearly stated.</p>
Whitehouse Chamberlain, and Tunna (2000). Dementia in people with learning disability: preliminary study into care staff knowledge and attributions.	<p>To assess the level of knowledge concerning aging and dementia of staff working with older adults with learning disability.</p> <p>To explore the likelihood of staff pursuing an appropriate referral through the identification of signs commonly associated with dementia.</p>	Pilot study	21 members of care staff (keyworkers) in residential homes for PLDs provided by Solihull healthcare NHS Trust, UK.	<p>Staff have knowledge of ageing at a comparable level to that of college students.</p> <p>Forgetfulness was a sign staff would most expect to see if they believed someone had dementia.</p> <p>Change in behaviour ascribed to dementia was perceived by staff as uncontrollable and staff were pessimistic about being unable to change behaviour.</p>	<p>Factors enhancing the study's validity:</p> <p>The title is informative and reflects the content. The paper included a summary and introduction, which identified the problem, and aims of the study.</p> <p>The Methods included: -Sample size and characteristic.</p>

	To assess the attributions staff give to behaviour changes commonly associated with dementia.			It was not just patients who have problem with communication but staff had problems communicating with them.	<p>-The settings were identified.</p> <p>-Data collection and analysis methods were stated.</p> <p>-Ethical considerations were identified.</p> <p>At the time when the paper was published the literature review was up-to-date.</p> <p>Limitations were acknowledged as the small sample size and issues around social desirability effect.</p> <p>Implications of the findings to staff training needs were recognized.</p> <p>Factors reducing the validity of the study: Pilot studies are not high on the hierarchy of evidence ladder.</p>
Black and Hyde (2004) Caring for People with Learning disability, Colorectal cancer and stoma.	To examine autonomy, consent, treatment, palliative care and death relating to people with profound	Case studies	2 Case studies. Each case study was based on the care of 1 patient.	The authors identified the need for plans to accommodate patients with profound learning disabilities. Anxieties in caring	<p>Enhancing the study's validity:</p> <p>The title is informative indicates the content.</p>

	<p>learning disabilities and challenging behaviour, who also have colorectal cancer and a stoma.</p>			<p>for PLD can be reduced in discussions with multidisciplinary teams (MDT) and ongoing clinical support team.</p> <p>The nature of learning disabilities is diverse. Therefore, MDT need focus attention to deal with a range of issues PLDs may have.</p> <p>Understanding how PLDs communicate was important.</p> <p>Understanding of consent issues and relevant material to help PLDs was fundamental.</p> <p>Established the lack of cancer information for PLDs especially relating to colorectal cancer and stoma.</p> <p>Emphasized the need for person-centred-care.</p>	<p>The paper included an abstract which stated the aim of the study.</p> <p>Awareness of ethical issues relating to consent and autonomy for PLDs were identified.</p> <p>At the time when the paper was published the literature review was current.</p> <p>Both authors are clinical nurse specialists in stoma/colorectal.</p> <p>The article was a runner-up in the Stoma Care category 2004, of the British journal of Clinical practice Awards.</p> <p>Reducing the study's validity: The Abstract did not clearly state the methodology or report of the main findings.</p> <p>Case studies are not high on the hierarchy of evidence ladder in terms of</p>
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					generalization of findings
Donovan (2002) Learning disability nurses' experiences of being with clients who may be in pain.	To describe the experiences of RNLDs when they are with clients who may be in pain but who cannot communicate their feelings verbally.	Descriptive phenomenology	8 RNLDs	<p>Five themes were highlighted:</p> <p>The importance of caring relationships with the clients.</p> <p>Recognizing changes in verbal and nonverbal behaviour.</p> <p>Identifying meaning in clients' behaviour.</p> <p>Negotiating with other health professionals</p> <p>Sharing in the clients feelings.</p>	<p>Enhancing the study's validity:</p> <p>The title is concise and informative.</p> <p>The aim of the study was provided.</p> <p>The Methods were clearly stated: Descriptive phenomenological approach</p> <p>Sampling and sample size were identified.</p> <p>Settings were identified.</p> <p>Data collection and analysis methods were stated.</p> <p>Ethical considerations were identified. At the time when the paper was published the literature review was up-to-date.</p> <p>Implications of the findings to practice/care were provided.</p> <p>Reducing the study's validity: limitation(s)</p>

					<p>are not clearly stated.</p> <p>Qualitative studies are not high on the hierarchy of evidence ladder.</p> <p>A conclusion is provided but no recommendation for future research.</p>
<p>Foley, & McCutcheon, (2004). Detecting pain in people with an intellectual disability.</p>	<p>To identify how emergency department nurses detect pain in people with intellectual disabilities (ID).</p>	<p>Review of literature</p>	<p>A review of literature comprising articles and case studies.</p>	<p>Some people with an ID may sometimes display predictable pain behaviour but cannot self-report</p> <p>They may display idiosyncratic pain behaviours, which may result to poor assessment by emergency department nurses.</p> <p>The authors established that there have been some attempts to categorize behavioural responses to pain by people with an ID, however, these have not been developed into a useful assessment tool.</p> <p>Emergency department nurses must rely on the person who knows the person with an ID well.</p>	<p>Factors enhancing the study's validity:</p> <p>The title is concise and informative.</p> <p>A summary and introduction are provided which highlights the problem of assessing pain in people with intellectual disability.</p> <p>At the time when the paper was published the literature review was current.</p> <p>A conclusion was provided recommending the conduct of research which would investigate what happens to people when they</p>

					<p>attend Emergency Departments. This will determine the most effective method of pain assessment for people with ID</p> <p>Reducing the study's validity:</p> <p>limitation(s) are not clearly stated.</p>
<p>Porter, Ouvry, Morgan and Downs (2001). Interpreting the communication of people with profound and multiple learning difficulties.</p>	<p>To explore the importance of validating communication, by working with family members and significant others, in the life of a person with profound and multiple learning disabilities (PMLDs) in order to build-up an accurate profile of how and what the person communicates</p>	<p>Case study</p>	<p>1 person with PMLD, the patient's parents, brother, nursery nurse assistant, teacher, escort and speech and language therapist.</p>	<p>Identified some of the issues involved in interpreting the communication and behaviours of people with PMLDs as: -</p> <p>Staff difficulties in understanding the person's communication and failure to prolong and sustain the conversation.</p> <p>Staff assume they know the meaning being expressed.</p> <p>Disagreement amongst the staff members about the interpreted meaning of the clients' communication.</p> <p>The authors concluded that: - reflections on practice were a vital aspect of validating communication</p>	<p>Factors enhancing the study's validity:</p> <p>The title is succinct and informative.</p> <p>A summary and introduction are provided, which highlighted some of the issues involved in interpreting the communication behaviours of people with PMLDs.</p> <p>The objective was stated in the introduction.</p> <p>A case report and discussion were provided.</p> <p>The method of data collection</p>

				<p>concerns.</p> <p>Validation of clients' communication can be done by sharing of information and views amongst family and staff. This will enable collating valid information on the subtleties of the client's behaviours and the context within which they occur. Also the client's records and observations should be used.</p>	<p>was identified as observations and interviews with the individual's parents, brother, teacher, nursery nurse assistant, escort and speech and language therapist.</p> <p>Analysis was thematic.</p> <p>At the time when the paper was published the literature included was relevant.</p> <p>Reducing the study's validity:</p> <p>No limitation(s) stated.</p> <p>Case studies are not high on the hierarchy of evidence ladder in terms of generalization.</p>
<p>Tuffrey-Wijne and McEndhill, (2008). Communication difficulties and intellectual disability in end-of-life care.</p>	<p>To address the failure by carers and professionals to communicate in a way that can be understood by people with intellectual disabilities (ID)</p>	<p>Critical review of relevant studies carried out by both authors.</p>	<p>Not relevant</p>	<p>Five themes emerged from the review:</p> <p>Communication difficulties, Comprehension, Disclosure, Taking time and Use of simple language.</p>	<p>Factors enhancing the study's validity:</p> <p>The title is concise and informative.</p> <p>An Abstract was included, which identified the</p>

	<p>To address carers' reluctance to disclose the truth for fear that the person with ID will become upset or unable to cope.</p>			<p>problem of communication difficulties as an obstacle in providing effective palliative care to people with ID.</p> <p>There is no introduction but the paper began with leading questions which clearly identified the problem of communication difficulties and IDs and could be inferred as a rationale for the paper.</p> <p>Design: Review of previous relevant research studies by both authors.</p> <p>At the time when the paper was published the literature reviewed was up-to-date.</p> <p>Operational definition of terms were provided.</p> <p>A conclusion was provided and implications to practice.</p> <p>Both authors are experienced</p>
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					<p>professionals and researchers.</p> <p>Reducing the study's validity: limitation(s) are not stated.</p> <p>The specific type of review (systematic or comprehensive critical review) was not clearly stated.</p>
<p>Ryan et al (2005) How to recognize and manage psychological distress in cancer patients</p>	<p>To identify the barriers to cancer patients expressing their psychological concerns.</p> <p>To recommend strategies to assist oncologist to elicit, recognize, and manage psychological distress in their patients</p>	<p>A Review of literature</p>	<p>Not relevant</p>	<p>Four main themes were identified:-</p> <p>Types of emotional cues that the patients have.</p> <p>Barriers to identifying patients emotional concerns were elucidated as relating to two categories of attributes namely, patient's attributes and the clinician's attributes.</p> <p>Strategies to recognize patient cues</p> <p>Strategies to increase frequency of patient cues</p>	<p>Enhancing the study's validity:</p> <p>The title is concise and informative.</p> <p>The paper included an overview and introduction, which identified the problem, aim and provided a conclusion.</p> <p>The method is clearly stated as review of valid literature.</p> <p>Data source and process of search was acknowledged</p> <p>The results from the literature review are clearly stated and consistent in terms of relevance to the aims.</p>

					<p>At the time when the paper was published the literature reviewed was up-to-date.</p> <p>A conclusion was provided and recommendations for training programmes to enhance clinicians' communication techniques to obtain, recognize, and respond to the emotional distress of patients.</p> <p>The conclusion included recommendation for a future randomized control trial practice.</p> <p>The authors are experienced professionals and researchers.</p> <p>Reducing the study's validity:</p> <p>The specific type of review (systematic or comprehensive critical review) was not clearly stated.</p>
Cooper (1997)	To ascertain rates of DCR	Mixed Methods:	134	Dementia occurred at a much higher	Factors enhancing

<p>High prevalence of dementia amongst people with learning disabilities not attributed to Down syndrome</p>	<p>defined dementia and associated factors in people with learning disabilities (PLDs)</p>	<p>Comprehensive psychiatric assessment and medical assessments undertaken with a whole population ascertained as far as was possible of PLDs in Leicester UK</p>		<p>rate among elderly PLDs than it does among the general population. This was independent of the association between dementia and Down's syndrome.</p> <p>Cooper could not establish whether this related etiologically to genetics, history of brain damage or a lack of brain 'reserve'.</p>	<p>the study's validity:</p> <p>The title is concise and informative.</p> <p>The paper included an abstract, which identified the problem, method, findings and included a conclusion.</p> <p>At the time when the paper was published the literature reviewed was up-to-date.</p> <p>A conclusion and recommendation was provided.</p> <p>The authors are experienced professionals and researchers.</p>
<p>Hogg, and Tuffrey-Wijne (2008). Cancer and intellectual disability: A review of some key contextual issues.</p>	<p>To gain information on the incidence and prevalence of cancer for PLDs in both institutional and community settings.</p>	<p>A review of the existing literature on the incidence and prevalence of cancer for PLDs in both institutional and community settings.</p>	<p>Not relevant</p>	<p>Hogg and Tuffrey-Wijne (2008) identified the following from the review: -</p> <p>The need for methodological sound studies to clarify the epidemiology of cancer in people with intellectual disabilities.</p> <p>The incidence, prevalence and trends in the population of PLDs showed a general</p>	<p>Factors enhancing the study's validity:</p> <p>The paper had relevance to the search terms and research question of my study.</p> <p>The title is concise, informative and clearly indicates the content.</p>

			<p>increase in cancer of all types in PLDs.</p> <p>Community studies indicated that the prevalence of cancer in PLDs is closer to that found in the general population.</p> <p>The studies indicated a general lack of information on survival rates in people with learning disabilities and cancer.</p> <p>Some studies listed the specific cancers identified in PLDs or provided a cause of death. The studies could not produce a tumor profile due to the diversity of PLDs with respect to ability level and associated characteristics, and the etiological heterogeneity of PLDs especially relating to chromosomal and genetic causations.</p> <p>The studies indicated that ageing had an impact in terms of lifespan influences on the development of cancer as individuals aged.</p> <p>Some studies in</p>	<p>A summary and introduction are provided which highlighted the issue to be research as: the increasing focus on cancer in learning disabilities research from different perspectives.</p> <p>The aim of the study was provided.</p> <p>Methods clearly stated the search strategy and identified the databases and range of literature reviewed.</p> <p>At the time when the paper was published the literature review was up-to-date.</p> <p>A conclusion is provided.</p> <p>A recommendation for future research into the ways in which appropriate screening can be made available to both men and women with LDs is also indicated.</p>
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				<p>the review identified environmental factors such as smoking, alcohol consumption. Also high prevalence of H. pylori which is linked to bowel cancer.</p> <p>The studies showed that little is known about the impact of transition from institution to the community in terms of the incidence of cancer among women with learning disabilities (LDs) either generally or in relation to breast or cervical cancer.</p> <p>Some studies indicated an increased risk of colorectal cancers but reduced risk of breast cancer in comparison to women in the general population.</p> <p>Limited data on the prevalence or incidence of breast cancer in women with LDs especially because screening for breast cancer for this population is lower than for the general population.</p> <p>Identified difficulties in undertaking cervical screening</p>	<p>The range of literature reviewed were stated as peer-reviewed studies and reports which had appeared in journals in the past twenty-five years and background documents from government departments.</p>
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				<p>for women with LDs. Also highlighted the need for both paid and family carers support to facilitate this.</p> <p>Incidence of stomach cancer as high in male with LDs and with those in the general population. Men with LDs had lower incidence of prostate cancer and increased testicular cancer in men with profound and sever LDs.</p> <p>Some deaths for PLD could be avoided.</p> <p>An emphasis on the key role of paid and family carers' and the need for awareness of the illness and the causative factors</p>	
<p>Hunt , Mastroiannopoulou, et al. (2002) <i>Not knowing- the problem of pain in children with severe neurological impairment</i></p>	<p>To gain an understanding of the context in which pain occurs and of issues that could affect pain assessment and management in this group</p> <p>To explore the diagnostic and clinical decision-making processes used by parents and healthcare</p>	<p>Grounded theory and symbolic interactionism</p>	<p>20 parents and 26 healthcare professionals</p>	<p>The main findings were that three forms of knowledge are needed for optimal pain assessment and management namely:-</p> <p>knowing the child</p> <p>familiarity with children with the same of similar conditions</p> <p>Knowing the science. The study concluded that pain relief can be compromised by</p>	<p>Factors enhancing the study's validity:</p> <p>The title is informative and clearly indicates the content.</p> <p>An Abstract and introduction are provided which highlighted the problem: pain assessment in children with neurological</p>

	<p>professionals in relation to pain in children with severe to profound neurological impairment.</p>			<p>systems of care that fragment rather than integrate care.</p> <p>The authors proposed a model which integrates population and science.</p>	<p>impairment.</p> <p>The aim of the study was provided.</p> <p>The methodology was provided</p> <p>Methods clearly stated as: guided conversations with parents of children and healthcare professionals.</p> <p>purposive sampling recruitment procedures by four centres</p> <p>Ethical considerations were identified.</p> <p>At the time when the paper was published the literature review incorporated in the study was up-to-date. A conclusion was provided</p> <p>The authors identified as limitation to the study as the inherently uncertain and ambiguous nature of the territory and the knowledge that a child's experience</p>
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					<p>can never be entirely captured.</p> <p>A model of pain assessment and management for children with severe and profound neurological impairment was proposed</p>
<p>Summers and Witt. (2003). <i>'Psychological intervention for people with learning disabilities who have experienced bereavement : a case study illustration'</i>.</p>	<p>To examined the experience of a young woman with learning disability after the death of her father</p>	<p>A case study illustration.</p>	<p>1 (based on a woman with learning disability)</p>	<p>Difficulties in ascertaining psychological distress (grieving). In the case of this woman, it was difficult to determine whether she was grieving.</p> <p>The woman was confused about the meaning of death.</p>	<p>Factor enhancing the study's validity:</p> <p>The title is concise and informative.</p> <p>A summary and introduction are provided, which highlighted some of the issues involved in psychological intervention for people with learning disabilities who have experienced bereavement.</p> <p>A case report and discussion were provided.</p> <p>At the time when the paper was published the literature included was relevant.</p> <p>A limitation is identified in</p>

					<p>terms of generalization of the findings especially because it was based on a single case study.</p> <p>Reducing the study's validity:</p> <p>Case studies are not high on the hierarchy of evidence ladder.</p>
<p>Llewellyn (2011) <i>'The needs of people with learning disabilities (PLD) who develop dementia: A literature review'</i>.</p>	<p>In the review of literature Llewellyn (2001) considered the following:-</p> <p>The challenges related to the increased number of older PLD together with the diagnosis and management of dementia.</p> <p>Reflects on the needs of PLD experiencing dementia in relation to the severity of their learning disability; their general health and underlying personality and the cause of their dementia.</p>	<p>A review of literature</p>	<p>Not relevant. The paper is a review of literature.</p>	<p>Llewellyn 's(2011) findings from the critical review of literature were classified under distinct sections :-</p> <p>Medical needs: This emphasized that the primary medical need for PLD who develop dementia as the need for timely and accurate detection and diagnosis of the disease. This was especially as a result of their varied degrees of learning disabilities and communication difficulties, which had an impact on the diagnosis of dementia and the tools needed to make a diagnosis</p> <p>Llewellyn (2011) identified from the literature 27 different tests related to diagnosis of dementia and that</p>	<p>The title is concise informative and indicates the content.</p> <p>An Abstract was included, which identified the approach as a review of literature, the type of specific data collected and the findings.</p> <p>The paper included an introduction which clearly stated the problem: as PLD living longer and increasingly developing age-related conditions including dementia and the challenges this poses to services. A rationale for the study was also provided.</p>

				<p>a number of tools have been used to aid diagnosis and assessment for PLD. Llewellyn (2011) pointed out that no single tool could accurately diagnose Dementia in PLD who were presenting with possible symptoms.</p> <p>Llewellyn (2011) also identified from the review of literature a problem with carers' diagnosis due to a culture of caring in which things are done for PLD rather than encourage them to be independent as such dementia symptoms may be unnoticed.</p> <p>Also high staff turnover can lead to failure of support staff to recognize changes which could be indicative of early dementia.</p> <p>From the literature Llewellyn (2011) highlighted that PLD experience other health problems such as thyroid malfunction, depression, and diabetes that could mimic or coexist with dementia.</p> <p>Llewellyn (2011) also illuminated</p>	<p>The search terms relating to learning disabilities and dementia and databases used were clearly identified.</p> <p>The inclusion criteria for the selected literature to be reviewed were also provided.</p> <p>The reviewing process was also indicated, which consisted of a small team of academic readers with an interest in the subject and a critical pro-forma was also designed for recording details of documents during the review.</p> <p>At the time when the paper was published the literature reviewed was current.</p> <p>The paper provided detailed findings from the reviewed literature.</p> <p>A conclusion was included.</p> <p>The author is</p>
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				<p>that both early and longitudinal assessments by carers are vitally important to the diagnosis and management of dementia.</p> <p>Also, PLDs in the terminal stages of dementia may need specialist care. It is recommended that specialist hospice type units are developed to meet their particular needs (Cosgrave et al, 2005)</p> <p>Social needs From the review of literature Llewellyn (2011) highlighted the following social needs:- Deficiencies of services to meet the complex needs of PLD who develop dementia.</p> <p>GPs see dementia as untreatable thus they may not refer PLD to specialist services.</p> <p>Family carers do not approach services until they are unable to cope. Some of the reviewed literature recommended the concept of 'ageing in place' (Kerr et al., 2006; Watchman, 2003) as ideal for PLD who develop dementia with the possibility of</p>	<p>both an experienced professional and researcher in the area being researched.</p> <p>Reducing the study's validity:</p> <p>Although it is apparent from reading Llewellyn's (2011) paper that it is a critical comprehensive review of literature, Llewellyn (2011) did not clearly state whether this was a critical comprehensive review or systematic review of literature.</p>
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				<p>adapting the environment to ensure this (Watchman, 2003).</p> <p>Other recommendations mentioned in the review of literature included better training for staff and creating an outreach model of care (Kerr et al, 2006).</p> <p>Needs of carers Llewellyn (2011) review of literature indicated that it was difficult to separate the needs of PLD from the needs of their carers because they both had impact on each other.</p> <p>Need for training on the normal processes of ageing and the indicators of changes, which signal a dementing process to workers, carers, peers and family (Wilkinson et al, 2005).</p> <p>Risk of staff burnout due to trying to meet the new challenges dementia poses in the care of the client (Wilkinson et al, 2005).</p> <p>Carers suggested the need for the development and use of widely flexible financial</p>	
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				<p>package.</p> <p>Development of a Dementia care pathway (Gwen Healthcare NHS Trust (2005)</p> <p>Needs of peer groups When changes occur in a person with dementia, this could have profound impact on others in the same care setting. -Dementia awareness for other clients and support as needed (Wilkinson et al, 2003).</p> <p>Models of support Llewellyn (2011) highlighted from the literature person centred approaches including cognitive work; reminiscence work and informal reality orientation. Early screening and Diagnostic Clinical Support; and Demantia Care Mapping</p> <p>Services. Llwellyn (2011) highlighted from the review that PLD and dementia should have the same access to specialist dementia services as those without dementia(Hatzidimitriadou and Milne, 2005; Watchman, 2003).</p>	
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				<p>Llewellyn (2011) also pointed out the recommendation for partnership working between learning disability services and Mental Health Trusts and Housing Agencies (Hatzidimitriadou and Milne, 2005).</p> <p>Conclusion Llewellyne (2011) indicated the needed for familiar services which can be adapted to meet the changing needs of PLD and develop dementia. -Need for better awareness and detection of early signs and symptoms of dementia.</p> <p>Needs of careers are closely intertwined with clients. Therefore both should be addressed e.g training and increasing number of staffing levels.</p>	
<p>Cartidge and Read (2010) <i>'Exploring the needs of hospice staff supporting people with an intellectual disability: a UK perspective'</i></p>	<p>Identify what educational and preparation skills hospice staff felt were needed to enable them to feel confident in providing specialist palliative care to people with intellectual disability (ID)</p>	<p>Methodology stated as qualitative approach (questionnaires and focus groups)</p>	<p>26 inpatient patients responded to the questionnaires Focus group: N=17</p>	<p>The findings included the following main themes:</p> <ul style="list-style-type: none"> a) Challenges relating to communication in terms of staff ability to determine if the person with ID 	<p>Factors enhancing validity were that:</p> <p>The title is informative and indicates the content.</p> <p>An Abstract was included, which identified the aim, methodology,</p>

				<p>understood their illness.</p> <p>b) Managing the health condition of the patient.</p> <p>c) Knowledge and understanding of ID required skills.</p> <p>d) Collusion.</p>	<p>sample and major findings.</p> <p>The search terms used were clearly identified.</p> <p>The inclusion criteria for the selected literature to be reviewed were also provided.</p> <p>The Methods were presented as:</p> <p>Focus group discussions and questionnaires</p> <p>Sample size was identified.</p> <p>The study's Conduct procedure and Ethical considerations were accounted for.</p> <p>At the time when the paper was published the literature reviewed was up-to-date.</p> <p>The paper included a discussion which provided the findings. The findings were categorized into emerging themes, sub themes and main themes.</p>
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					<p>The strengths and limitations of the study's use of focus groups were highlighted</p> <p>A conclusion and recommendation were stated.</p> <p>Reducing the study's validity: -The issue about generalization of findings in Qualitative studies.</p>
<p>Read (2005) Learning disabilities and palliative care: recognizing pitfalls and exploring potential.</p>	<p>To introduce the recognized challenges (or pitfalls) inherent in providing high quality palliative care to people with learning disabilities.</p> <p>To explore the future potential and possibilities in delivering appropriate palliative care to this vulnerable population.</p>	<p>A Position paper based on existing literature</p>	<p>A Position paper based on existing literature</p>	<p>The paper indicated four themes under Challenges to providing palliative care as:</p> <ul style="list-style-type: none"> -poor health status of PLDs -Ambivalence and discrimination. -Difficulties in proving holistic care -The challenge of the disability culture <p>5 themes were highlighted under Exploring the possibilities and potential:-</p> <ul style="list-style-type: none"> -Practice development. -Resources -Research, a route to good practice. -Collaborative working. Good practice 	<p>The title is informative and indicates the content.</p> <p>An Abstract was included, which identified the aim of the paper and mentioned a recommendation for practice development..</p> <p>An introduction is not stated under an identified heading . However, the opening paragraph served this purpose. It defined learning disabilities and palliative care and</p>

				initiatives	<p>indicated prevalence of learning disabilities in the UK and also the problems related to access to palliative care by PLDs.</p> <p>-At the time when the paper was published the literature included was up-to-date.</p> <p>Recommendations were provided as: -Need for more research to deal with baseline statistical information such as a national database of the numbers and types of palliative conditions of PLDs.</p> <p>-The inclusion of disadvantaged groups in the systems exploring existing palliative care services.</p> <p>-Regular audit and evaluation of good practice in palliative care services to accommodate the changes in palliative care</p>
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					<p>and develop appropriate approaches for all people in need of palliative care.</p> <p>-A conclusion was included in the paper.</p> <p>-The author is an experienced professional and researcher in the area under study.</p> <p>Reducing the study's validity:</p> <p>-It is a Position paper and thus does not include the search terms. However the author provided details of 'Websites and further Information' in Box 1 p 18 of the paper.</p> <p>-The Position paper did not state the inclusion criteria for the selected literature used.</p>

Appendix 5 Letter of Invitation



Letter of Invitation to potential participants

Dear Sir/Madam,

I am a postgraduate researcher based at the University of Huddersfield.

I am also a Registered Learning Disability Nurse. I work in a unit that provides care for adults with learning disabilities and complex health needs including palliative care needs.

I wish to invite you to take part in my research study titled: -

Caring for people with communication difficulties and a learning disability experiencing distress in palliative care settings

The research is being done for the purpose of gaining an understanding of how registered learning disability nurses and palliative care professionals identify and respond to the distress of people with communication difficulties and a learning disability in palliative care settings. Communication can be difficult especially when a person finds it difficult expressing their needs and choices and struggles to understand information. This may sometimes result in the person not getting the care or services they require to meet their needs.

For the purposes of this study, 'palliative care settings' will be perceived as any setting where individuals are receiving any form of supportive or specialist palliative care treatment. Therefore, the setting does not have to be a hospice or intensive care unit. It could be a community base nursing home, private home, day services, a residential or supported living care setting where there are nurses and other professionals in attendance to meet a person's holistic need in terms of supportive and specialist care.

This study is important because the findings will increase awareness and inform service provision and planned changes in the approach to care for people with communication difficulties experiencing distress.

Participation in the study will depend on giving informed written consent by signing the written consent form at the start of the interview.

Please see the enclosed information sheet.

It is also important that you complete a short questionnaire at the start of the interview in order to provide some brief information about who you are and the nature of your job.

Please do not hesitate to contact me for clarifications and discussion of any concerns you might have with taking part in the study. My contact details are stated below.

Thank you for reading this.

Researcher's signature:

Researcher's contact details:

Sally Ketchen Arrey

RNLD, PGDip Health Professional Ed, MSc Nursing

BA English Literature, PGDip English Literary Studies

PhD Research Student

University of Huddersfield

School of Human and Health Sciences

Centre for Health and Social Care Research

Queensgate, Huddersfield

HD1 3DH, UK.

TEL: 44 (0) 1484 471414

Mobile: 07727650348

Email: u1076211@hud.ac.uk

Appendix 6 Informed Consent



School of Human and Health Studies

Caring for people with communication difficulties and a learning disability experiencing distress in palliative care settings

Name of Researcher: Sally Ketchen Arrey,

CONSENT FORM FOR PARTICIPANTS

Please circle Yes or No as appropriate.

I have been fully informed of the purpose of this research.	Yes	No
I have been given opportunity to ask questions about the study.	Yes	No
I give my permission for my interview to be audio-recorded.	Yes	No
I understand that should anything be reported which contradicts NMC Code of practice it will be notified to the unit manager.	Yes	No
I understand that the audio recording will be kept in secure conditions at the University of Huddersfield.	Yes	No
I understand that after completion of the study, data will be retained in secure conditions in accordance with the University's policy for five years before it is destroyed.	Yes	No
I understand that no person other than the researcher and her supervisors will have access to the recording.	Yes	No
I understand that my identity will be protected by the use of pseudonym in the research report.	Yes	No
I understand no information that could lead to my being identified will be included in any report or publication resulting from this research.	Yes	No
I understand that I can withdraw from the study at any time.	Yes	No
I consent to take part in the research.	Yes	No

Participant name:
Date:

Signature:

Name of Researcher:
Date:

Signature of researcher:

Copy to participant and Copy to researcher

Appendix 7 Information sheet

UNIVERSITY OF HUDDERSFIELD SCHOOL OF HUMAN AND HEALTH SCIENCES

TITLE OF PROJECT:

Caring for people with communication difficulties and a learning disability experiencing distress in palliative care settings

Name of researcher: Sally Ketchen Arrey

Participant Information Sheet

You are being invited to take part in a research study for a PhD at the University of Huddersfield. Before you decide to participate, it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information carefully and discuss it with others if you wish. Take time to consider whether or not you wish to take part. Please contact me about anything that is not clear or if you would like more information.

Consumers for Ethics in Research (CERES) publish a leaflet entitled 'Medical Research and You'. This leaflet gives more information about medical research and looks at some questions you may want to ask. A copy may be obtained from CERES, PO Box 1365, London, N16 0BW. Email: info@ceres.org.uk Webpage: www.ceres.org.uk

Thank you for reading this information sheet.

Why is this research being conducted?

This research is being done for the purpose of gaining an understanding of how Registered Learning Disability Nurses and Palliative Care Professionals identify and respond to the distress of people with communication difficulties in palliative care settings. Communication can be difficult especially when a person finds it difficult to express their needs and choices and struggles to understand information. This may sometimes result in the person not getting the care or services they require to meet their needs.

For purposes of this study, 'palliative care settings' will be perceived as any setting where individuals are receiving any form of supportive or specialist palliative care treatment. Therefore, the setting does not have to be a hospice or intensive care unit. It could be a community base nursing home, private home, day services, a residential or supported living care setting where there are nurses and other professionals in attendance to meet a person's holistic need in terms of supportive and specialist care.

This study is important because the findings will increase awareness and inform planned changes in the approach to care for people with communication difficulties experiencing distress.

Why have I been chosen?

You have been asked to participate in this study because your views, either as a Registered Learning Disability Nurse (RNLD) or a Palliative Care Professional, are relevant to this study.

Do I have to take part?

No, it is entirely your decision whether to take part or not. If you do decide to participate in this study, after being given some time to think about your decision and to ask questions, you will be asked to sign a consent form. This information sheet is for you to keep should you want to read it through again. It is important that you realise that you will be free to change your mind and withdraw from the study at any time, without giving a reason.

What will happen to me if I take part?

If you agree to take part, you will be asked to sign a consent form. On the designated interview day(s) you will be asked to complete a short questionnaire in order to provide some information about who you are and the nature of your job. You will also be asked to discuss your perceptions of how the people with communication difficulties under your care communicate distress. The interviews will last for a maximum of 60 minutes and will be audio-recorded.

What do I have to do?

All that is required is that you attend the interview at the scheduled place and time and answer a few questions as part of an interview. There are no tests or treatments associated with this research.

What are the possible disadvantages and risks of taking part?

There are no hidden risks or particular disadvantages associated with this study, apart from giving up some of your time. If you do not feel able to attend the interview at the agreed scheduled time, please let me know (my contact details are at the end of this form). If during the interview session you become upset or do not feel well enough to continue, you can ask to stop to ensure your wellbeing. Some contact details will be provided for professional support/counselling should you require and specialised assistance. All discussions during the interviews will be confidential unless it

necessitates notifying the unit manager of conduct which contradicts the NMC Code of practice.

What are the possible benefits?

It is not anticipated that you will experience any direct benefit as a result of taking part in this study. However, you may find the interviews reflective and interesting. The information derived from the interview discussions will be carefully analysed and reported. It is likely that it will then be useful to develop further research that could contribute to planned changes in the care of people with communication difficulties in palliative care settings.

Will taking part in this study be kept confidential?

Yes. If you consent to take part in the study, this will be kept confidential. The only people who will know who has taken part will be the researcher and academic supervisors. Your name will not be disclosed in any report or publication. The interview data will be kept in a locked cabinet with only the researcher having access. The data consisting of the audio recordings will be destroyed after the thesis has been completed.

What will happen to the results of the study?

The results of the study will be written up in the form of a detailed research report/PhD thesis and later submitted for publications in relevant academic and professional journals. The results will be presented at conferences and seminars as posters and oral presentations

Who is organising and funding the research?

The study is being conducted in part fulfilment of PhD programme of study at the University of Huddersfield.

What if I have further questions?

Please feel free to contact me, if you have any further questions about the study. My details are listed below.

Researcher Contact Details:

SALLY KETCHEN ARREY

RNLD, PGDip Health Professional Ed, MSc Nursing

BA English Literature, PGDip English Literary Studies

Postgraduate Research Student

University of Huddersfield

School of Human and Health Sciences

Centre for Health and Social Care Research

Queensgate

Huddersfield

HD1 3DH

UK

Tel: 44 (0) 1484 471414

Mobile: 07727650348

Email: u1076211@hud.ac.uk

Making a Complaint:

If you choose to take part in the study and in the event of wanting to make a complaint about anything you are unhappy with in relation to your participation in the study please feel free to contact the student/researcher's academic supervisors.

Contact Details of Academic Supervisors:

DR. MARILYN KIRSHBAUM

RGN, BSc, MSc, PhD

Reader in Nursing,

Research Leader for Health and Rehabilitation,

University of Huddersfield

School of Human and Health Sciences

Queensgate

Huddersfield

HD1 3DH

UK

Tel: 44 (0) 1484 471277

Email: m.kirshbaum@hud.ac.uk

DR PHYL FLETCHER-COOK

MCSP, Med, EdD

Division of Health and Rehabilitation

University of Huddersfield

Queensgate

Huddersfield

HD1 3DH

Tel: 44 (0) 1484 472723

Email: p.fletcher-cook@hud.ac.uk

Appendix 8 Interview Schedule section 1: Demographic questionnaires



TITLE OF PROJECT:

Caring for people with communication difficulties and a learning disability experiencing distress in palliative care settings

NAME OF RESEARCHER: Sally Ketchen Arrey

Interview Schedule Section 1: Questionnaire for Collecting Demographical Data from Participants:

Please complete this short questionnaire to provide information about yourself and the nature of your job.

Age Range: 18-25 26-31 32-37 38-43 44-49 50-55
56-61 62-65 65+

Specialisation or further training: -----

Number of years you have worked for this Organisation or Trust: -----

Job title/Role: -----

Number of years you have worked in this position/role: -----

With which communication modes of the clients have you worked? -----

Thank you

Appendix 9 Interview Schedule section 2: Semi-structured questions and interview prompts



TITLE OF PROJECT:

Caring for people with communication difficulties and a learning disability experiencing distress in palliative care settings

NAME OF RESEARCHER: Sally Ketchen Arrey

Interview Schedule Section 2:

Proposed Semi-structured Questions and Prompts for Participants

1. Briefly tell me about the client/patient group you work with.
2. Please tell me if your clients experience distress.
For example physiological, psychological, social or spiritually related. (Prompt)
3. Tell me how your clients communicate their needs on a daily basis.
For example verbally or non verbally. (Prompt)
4. Since your clients have communication difficulties, please tell me how this has affected the way they communicate distress.
5. I will be interested in hearing about a particular case.
For example, what was it like to care for a distressed client with communication difficulties who is palliative or at the end of their life? (Prompt)
Also tell me if you worked closely with other professionals and how the affected the care provided (Prompt)
6. Tell me whether the manner in which they communicate distress can be linked to particular circumstances, environment or people.
For example during particular periods of their daily routine; during routine clinical procedures; special appointments to other health units or with other health professionals other than regular staff in this unit etc. (prompt).
7. Tell me about anything else that you have identified, which affects the way your clients express/communicate distress in the palliative care setting where they reside.
8. Tell me whether being able to identify these contributing factors affecting the way your clients communicate distress has helped you in their care.

For example what steps do you then put in place to plan their care? (prompt)

How did you feel about the outcome of the care you then provided? (Prompt)

9. Please tell me about a particular case.
10. Please tell me if you have used Disability Distress Assessment Tool (DisDAT) with your clients.
11. Tell me how effective you found the tool.
For example, tell me if you would change any aspect of this tool or would you prefer another distress assessment tool? (Prompt)
12. Please tell me: what do you envisage as the future for learning disability and palliative care services for people with communication difficulties and a learning disability in palliative care settings?
13. Is there anything else you would like to tell me?

This guide was used to ensure that basically the same information is obtained from a number of participants but at the same time allows for flexibility depending on the respondents views and subsequent probing questions (Holland, 2001)

Appendix 10 The University of Huddersfield Risk analysis and management Form

TITLE OF PROJECT:

Caring for people with communication difficulties and a learning disability experiencing distress in palliative care settings

NAME OF RESEARCHER: SALLY KETCHEN ARREY

ACTIVITY: Interviewing Research			Name: Sally Ketchen Arrey	
LOCATION:			Date:	Review Date:
Hazard(s) Identified	Details of Risk(s)	People at Risk	Risk management	Other comments
Discussing lived experiences.	There is the potential risk of becoming distressed while discussing experiences.	Participants	<p>The researcher will be sensitive to participants' changing mood and needs and react responsibly.</p> <p>If a participant becomes distressed, the participant will be asked if he/she wishes to stop the interviewing process and the interview will only continue at their expressed wishes.</p> <p>Information about professional counselling or support may be provided if required. Participants will be made aware</p>	There will be no set review dates. The review will be regular and ongoing during each scheduled interview session to ensure participants wellbeing.

<p>Safety</p>	<p>There is the potential of risk to self (lone worker risk) when interviewing participants.</p>	<p>Self</p>	<p>of bereavement counselling service such as work-life balance, which is available at no cost to healthcare professionals.</p> <p>Adhere to the lone worker policy within the care environment.</p> <p>Ensure that my supervisors and significant others know my whereabouts and movement.</p> <p>Have a mobile phone to contact supervisors if necessary.</p> <p>The university's student support services which offers professional counselling to students will be contacted as appropriate if need be.</p>	
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Appendix 11 Checklist

Developed by Sally .K. Arrey: as part of PhD Research Findings

Checklist for health and social care professionals to self-evaluate professional practice and the holism of care provided to PCDLD in palliative care settings

<p>Please tick as appropriate:</p> <p>Knowing: Building relationships with PCDLD:</p>	<p>Name of client/patient: -----</p> <p>D.O.B: -----</p> <p>Address:-----</p> <p>Type of learning disabilities: Mild <input type="checkbox"/> Severe <input type="checkbox"/> Profound <input type="checkbox"/></p> <p>Communication patterns: Verbal <input type="checkbox"/> Non-verbal <input type="checkbox"/></p> <p>Specify Non-verbal communication: Vocalisation <input type="checkbox"/></p> <p>Facial expression <input type="checkbox"/> Body language <input type="checkbox"/></p> <p>State any other modes of communication: -----</p> <p>Diagnosis: Cancer <input type="checkbox"/> Dementia <input type="checkbox"/> Respiratory <input type="checkbox"/></p> <p>Cardio Vascular Attacks <input type="checkbox"/> Aspiration problems <input type="checkbox"/></p> <p>State any other life-limiting condition the client/patient is diagnosed with:-----</p>
<p>Knowing: Building relationships with family members and/ or next of kin(s):</p>	<p>Have you identified Next of kin(s): Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>Names of next of kin(s): -----</p> <p>Address and contact details:-----</p> <p>Telephone:-----</p>
<p>Knowing: Building relationships between professionals involved in the client/patient's care</p>	<p>Are there other professionals involved in the client's care?</p> <p>Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>Have you identified them? Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>If no, do you have plans in place to contact other Multidisciplinary team (MDT) professionals involved in their care? Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>If yes, state the other professionals: 1) Name:-----</p> <p>Address and contact details: -----</p> <p>Telephone: -----</p> <p>2). Name: -----</p> <p>Address and contact details: -----</p> <p>Telephone: -----</p> <p>3). Name:-----</p> <p>Address and contact details: -----</p> <p>Telephone:-----</p> <p>4). Name:-----</p> <p>Address and contact details: -----</p> <p>Telephone: -----</p>

<p>Authentic presence (Body): Professionals utilizing specialist and physical skills to provide humane care.</p>	<p>Have you provided care to a person with a similar diagnosis before? Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>Do you need training or skills development to better meet their needs? Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>Is the client/patient's diagnosis managed or controlled with medication? Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>Does the client need support other than medication? Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>If so have you identified the support he/she might need? Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>Are you providing support or care that include the following: Empathy/compassion: Yes <input type="checkbox"/> No <input type="checkbox"/> Dignity: Yes <input type="checkbox"/> No <input type="checkbox"/> Therapeutic touch: Yes <input type="checkbox"/> No <input type="checkbox"/> Choice: Yes <input type="checkbox"/> No <input type="checkbox"/> Sincerity and sensitivity: Yes <input type="checkbox"/> No <input type="checkbox"/> Human rights: Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>If not identify a plan to improve on these aspects of care:----- Identify other support the client/patient might need:-----</p>
<p>Time to care (Temporality): The landscape of care includes the dimensions of past, present and future care.</p>	<p>Is palliative and/ or End-of-life-care (EoLC) provided within the setting where the client resides? Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>If yes do you have a palliative and/or EoLC tool or guidelines to inform care provided? Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>If yes have you a person centred future or advance care plan considering the following: Anticipatory prescribed medication: Yes <input type="checkbox"/> No <input type="checkbox"/> Rescue medication: Yes <input type="checkbox"/> No <input type="checkbox"/> Correct equipment. For example: Syringe driver <input type="checkbox"/> Oxygen machine <input type="checkbox"/> Nebuliser <input type="checkbox"/> Bereavement Support Plan: Yes <input type="checkbox"/> No <input type="checkbox"/> Identified Bereavement Support Services: Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>Have you assessed and reviewed your readiness to care in terms of the following: End-of-life-care training? Yes <input type="checkbox"/> No <input type="checkbox"/> Skills to use equipments? Yes <input type="checkbox"/> No <input type="checkbox"/> Cardiovascular Pulmonary Resuscitation (CPR) training? Yes <input type="checkbox"/> No <input type="checkbox"/> Do not attempt cardiovascular pulmonary resuscitation (DNACPR) training? Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>The use of any other assessment tool specific to people with learning disabilities such as DisDAT? Yes <input type="checkbox"/> No <input type="checkbox"/></p>

	<p>Do external health and social care professionals access the palliative care setting where the client/patient resides to provide care?</p> <p>Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>Do you have correct Person Centre Care Plans in place for such visits? Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>How regular are such visits? Daily basis <input type="checkbox"/> Monthly <input type="checkbox"/> Other <input type="checkbox"/></p> <p>Please specify: -----</p> <p>Do you have out of hours emergency contact details for such professionals? Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>Please specify: 1). Name: -----</p> <p>Address and contact details:-----</p> <p>Telephone:-----</p> <p>Add other contact details: -----</p>
<p>Comfortable Care Environment: Professionals utilising aesthetic knowing and collaborative working to provide compassionate, and empathetic care, and ensure that the care setting is sensitive to individual's socio-cultural, religious, and spiritual needs</p>	<p>Is the care setting where palliative and/or EoLC provided of the client/patient's choice? Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>Funeral plan: Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>Is the care setting comfortable and safe? Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>Do you have correct risk assessments in place to evidence the safety of the care setting? Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>Have you assessed and reviewed your knowledge on Mental Capacity Act and Deprivation of Liberty Safeguards to ensure the care provided and the care setting are safe? Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>Does the setting meet their comfort and specific choices and needs such as favourite: Colours <input type="checkbox"/> Photos <input type="checkbox"/> Music <input type="checkbox"/> Books <input type="checkbox"/> Furniture <input type="checkbox"/> Memorabilia <input type="checkbox"/> Others <input type="checkbox"/></p> <p>Has planned care identify how to meet the following needs in this care setting:</p> <p>Spirituality <input type="checkbox"/> Cultural beliefs <input type="checkbox"/> Religious beliefs <input type="checkbox"/></p> <p>Have you involved the family members? Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>If no, do you have plans in place to get family input to ensure a comfortable care setting for the client/patient? Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>Have you identified and plan changes to meet the client/patient's deteriorating health? Yes <input type="checkbox"/> No <input type="checkbox"/></p>
<p>Future perspectives (Extended dimension of time to care)</p>	<p>In the aftermath of the death of a client/patient do you have plans in place for the following:</p> <p>Funeral plan: Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>Burial rites: Yes <input type="checkbox"/> No <input type="checkbox"/></p>

	Have you identified evidence of good practice? Yes <input type="checkbox"/> No <input type="checkbox"/>
	Have you identified training needs? Yes <input type="checkbox"/> No <input type="checkbox"/>

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Appendix 12 Glossary of Abbreviations as first mentioned and as used throughout the thesis

LD: Learning Disability.....4

PCPs: Palliative Care Professionals.....4

PCDL: People with Communication Difficulties and a Learning Disability.....4

PLDs: People with learning disabilities.....4

RNLDs: Registered learning Disability Nurses.....4

UK: United Kingdom.....4

DH: Department of Health.....14

WHO: World Health organisation:.....15

AD: Alzheimer’s dementia.....16

EoLC: End of Life Care.....16

IHAL: Improving Health and Lives.....17

CRD: Centre for Research and Dissemination.....29

DisDAT: Disability Distress Assessment Tool.....33

ID: Intellectual Difficulties.....39

BSc.: Bachelor of Science Degree:.....82

CM: Community Matron.....82

CNS: Clinical Nurse Specialist.....82

CTLD: Community Team Learning Disabilities.....82

LD QoL: Learning Disability Quality of Life.....82

MSc: Master of Science Degree.....82

PCN: Palliative Care Nurse.....82

PCSW: Palliative Care Social Worker.....82

PLDs: People with learning disabilities.....82

RGN: Registered General Nurse.....82

Appendix 13 Worked example of the Data analysis process

Step One: Verbatim transcript of the interview of one of the participants, a Registered Learning Disability Nurse (RNLD) with the pseudonym Gary. The transcript includes Lines 1-552: commencing from the first line to the end of the transcript.

Note: I was unable to include the line numbers on the left corner of this transcript because of interference with the numberings in the rest of the thesis. Also, this because the font used for typing the transcripts was 'Arial 12'. The font has been changed here to 'Verdana 10' which is the font that has been used consistently throughout the thesis. Since changing the font has an implication for the line numbers in terms of direct quotations cited in the body of the thesis, I have also, provided an attached printed copy of the verbatim transcript in the initial typed font of 'Arial 12' and including the line numbers at the end of this thesis for transparency.

Sally: Okay thank you for agreeing to do this interview for my study. Now that you have read the communication sheet and have an idea of what this project is all about I have got some questions here just to guide us with the interview. So I am gonna start with asking you to tell me briefly about the patient group that you work for.

R: There are 8 clients at HS care setting. All have a learning disability, all have physical disabilities, and palliative care needs. None of the clients verbally communicate and they use a range of non verbal communication really from a client who have a picture board through to people who just pick up on prompts and through facial expressions and body language so a bit of a mix but nobody with perfect communication.

Sally: Okay and I mean on a daily basis not only those who have been identified with any supportive or palliative care needs do your clients communicate distress?

R: Yes all clients are able to communicate distress and we have like tools in place like Dis Dat and Pepsi Cola for measuring people's distress levels so.

Sally: Okay can you elaborate a bit more on the kind of distress they communicate?

R: Yes um I mean obviously it's quite individual and varies from client to client but in terms of vocal noises, facial expressions, gripping of clothing those kind of things really through to a client who can actually indicate by pointing whereabouts in the body they feel pain and things so .. that kind of thing.

Sally: Yes so basically they have physiological, psychological and other forms of distress.

R: Yes, yes

Sally: So you have already mentioned that on a daily basis your clients communicate non-verbally and use different tools as well to communicate so are you saying that they have communication difficulties? (Phone ringing)

R: Yes in the people that don't verbally communicate, so yes I think for all our clients you would need to know the clients reasonably well to understand their communication.

Sally: Okay so for the fact that our client group or the client group that you work with have communication difficulties, can you tell me from your perspective, do you think it has affected the way they express their distress?

R: Yes, I think because there would have been times when they would have been in distress or discomfort and people haven't picked up on it so that's probably led to more extreme expressions when people are in distress. So yes I think that will have had an impact because people will probably have had to go to greater lengths to make their needs known in terms of pain and other things. I mean hopefully not so much now but I think that probably has happened in the past.

Sally: Okay – do you have any particular case that you can elaborate on just as an example?

R: In terms of not picking up on somebody's distress and things?

Sally: Yes

R: Umh yes we had a client who had sustained an injury, quite a serious injury, they ended up having a fracture, and we still don't know what the cause was but it appears to have been a while before we picked up on it and that maybe because they went into shock and they weren't really showing any signs. They certainly weren't verbalising any distress so yes that's one extreme example I suppose you know, that somebody was clearly in a lot of distress and pain and on that occasion we think it must have happened during the night but it was the following morning when it was picked up and it was later in the morning as well because they hadn't really shown any signs but as I say, we think they had probably gone into shock. So they weren't really either they weren't feeling any pain because of the shock or they just weren't able to express that pain because of the shock.

Sally: Yes it could be. Let's look at it now from a general basis, would you say I mean apart from any of those specific things that you have said about being able to use like the tools and the different ways that you can identify that people communicate distress, are there any other determining factors that you think as a professional you could identify or link it to the way that people communicate their distress? What I mean is things like the environment, people, is there any other thing that you think affects this?

R: In terms of clients expressing distress?

Sally: Yes

R: Other than the things that I have said?

Sally: Yes

R: Umh

Sally: You know, that affects them, that distresses them

R: Yes there are certainly lots of other things that can have an impact. I mean it's a very individual thing isn't it

Sally: Yes

R: So we have people here that we know very well if they are in a busy group situation they will be distressed, they will get very hot.

Sally: Yes

R: that you know they will become more vocal and they will express distress in that way so yes there are definitely other indicators, other external things that happen that have an impact without a doubt yes but as I say it's very individual isn't it you know for the client. But one lady in particular that was here we regularly have parties so that relatives visit and we always ended up doing something separate with her because she finds that environment extremely distressing and gets herself very upset. So you know we make sure that she does something else on those occasions.

Sally: Yes okay umh if we take it back now because I am very interested in the palliative care and I know you have had some experience in that area. Is there any particular case that you can tell me about?

R: In terms of palliative or end of life?

Sally: All. It's inclusive. I am using palliative care now as inclusive from the supportive right to the end of life.

R: Well in the time I have been a manager we've had

one client who we supported with their end of life care and we used the Gold Standards Framework so that was the tool we used in terms of ensuring everything was in place and we provided the right support so we did a lot of very detailed work with that client and the family at the time and they had an advanced care plan which was really useful because we put that into place before they became very ill and before they were at the end of life so that set up in some detail the kind of things they wanted at the end of their life. Symptom control, things like anticipating prescribing so we already had medication in place before it was required. The kind of things that family wanted and the lady herself wanted at that time. So I think having that in place was hugely helpful really and I think for us as practitioners and for me in particular because I had not had a great deal of experience in palliative care. It gave us the skills to do what we needed to do and provide a really good quality end of life care which I don't think we are the best one in the world but we would not have been able to provide to that standard without having Gold standards and so I think it was extremely helpful. And with all our clients, with all our clients with palliative care needs, we evaluate their palliative care needs, what part of the register they are on in terms of whether they have got years to live, months, days, weeks. Their needs in terms of symptom control and pain management we regularly evaluate. Everyone has an advance care plan in place, dignity care plan, so lots of things around that really. It is very useful.

Sally: Okay. So this specific client that you cared for towards end of life can you tell me if it had any particular impact on you as a professional?

R: Yes very much. I mean obviously myself and the whole team we knew the lady was dying so as I say

it wasn't a sudden death and her end of life probably in terms of specific end of life care where we withdraw any kind of life enhancing treatments went on for about two weeks which is quite a long period of time. We formed quite close links with the family, her sister in particular, so yes it had a big impact. I mean the lady had lived at the home for 8 years, she was a big personality within the home, so yes I would say it had a big impact at lots of levels on all of us really and it affected us a lot you know. The family were very keen that we weren't morbid around that time. They wanted her to be surrounded by laughter. They wanted people to be cheerful and they wanted everything to carry on as normal. They didn't want us tip-toeing around and having a very down atmosphere because they wanted even though it was a very difficult time they wanted to have some happy memories from that time as well but yes it did have a big impact in terms of the loss of that lady and the impact that had on the service, the impact that had on the family. Err, the family maintained quite close links afterwards and the impact it has on the team and you are having to support members of the team because we had staff who had never dealt with a death and we have quite a big age group within our staff team at that time. I think we had people in their late teens through to people that would have retired so people in their 60s, so people with very different experiences. And also one of the things we found was people that had personally experienced a loss or a bereavement recently it really hit home for them because I think it brought a lot of sensitive issues back so managing that and supporting people was a big part of the process really in ensuring that staff got the right kind of support. So yes it had a massive impact definitely. Sincerity and sensitivity was vital.

Sally: And from this particular experience as well could you describe what you think. You have already mentioned it had a good impact, and some maybe concern for the staff team and for this lady and her family definitely it had a massive impact as well. Can you describe how you felt that you had to offer some kind of palliative care service in a different setting that is not a hospice?

R: Yes in a non hospice setting.

Sally: Yes

R: Because we did have the Goal standards and we had everything in place that made things much easier. I mean we are very lucky here in that it's a small home so we know all the clients really well. We tend to know families very well. The lady and her family had already expressed that this would be her choice for end of life, she didn't want to go into hospital, she didn't want to be a hospice, she wanted to be in familiar surroundings. Her room even though it was small it did lend itself quite well to having regular visitors and for the last two weeks of her life she was bed bound so she remained in her bedroom at that time so she was able to have visitors in private which made things easier so family could have private time with her. She was religious so she was able to have a priest visiting and he was able to have, we did have a member of staff there when the priest was there, but he was great. He read the sacraments of the sick in like a private dignified setting and then at the end he read the last rites to her so I think because it was a small community home and a place that the lady had lived at for a long time, it lent itself quite well in terms of an environment. At the end of the day it was the whole person not only their pain or distress that we were thinking about. I would say the only aspects that

possibly were a little bit more tricky for us were things like her having pain relief by a syringe driver so we had to have additional training in place. So there were things that we had to set up which ordinarily we wouldn't have had in the home setting. The technical clinical things we needed to provide specific training and do things because we had not done those things before but I think in terms of the kind of inter-personal skills we were very well set up because you know we knew the lady well, a lot of us had quite close relationships with her and her family. So, it was more on the clinical side that we had to really step things up a gear but we did have a lot of support from the palliative care teams so that helped and the district nurses. It was our moral duty to train.

Sally: Okay so there was some kind of collaborative work involved

R: There was a lot, I would say that was a big part of the success was the GP was on board with it. He attended the advance care plan meeting so he already knew what we were hoping. He put anticipatory medication in place so we had all the meds we needed and for the last two weeks he visited perhaps not on a daily basis but very regularly. When the lady went into distress he was there immediately and got the syringe driver set up and everything and then he would visit on a regular basis just to check how she was and evaluate how things were going and he worked very closely with the district nurses because they were coming in at that time to help. So yes I would say an MDT approach was essential really, we couldn't have done it on our own you know so having other professionals there helped with that end of life care quality really.

Sally: Yes and because you knew this lady I mean you have known her for quite some time, would you say that when she was in this palliative state the way she communicated her distress changed over time?

R: Yes very much I mean originally even though I have only worked here for 3 years I had previously worked here in a different role so I had known her the lady on and off for over the entire time she had been here. When she first moved to the home she was a lady with Down's Syndrome but she was very outgoing, she was quite skilled at that time. She spoke, and she walked at that time. So knowing her at a time when she could express herself well I think was quite a big help because obviously we were able to get information directly from her at that time so that was helpful but gradually she lost a lot of her skills because she had dementia. So she lost her ability to verbalise and to express herself verbally but she was still quite a good communicator in that she did express well in other ways and she was a very people person and she did maintain that even when she had dementia she liked people. She would still laugh at things in response to people and she would respond, she would make eye contact so she kept that to the end really but yes it changed an awful lot in terms of the way she expressed her needs in terms of distress and especially towards the end she was on anti-meta medications, sedative medication, she was on strong pain killers so beyond her own abilities and personality that had a massive impact you know because a lot of the time she was in a semi conscious state at that time because she was in pain. Obviously our wish was for her to be comfortable and not in any pain and not have any distress. So I would say the medication would have masked her ability to express herself towards the end of her life definitely but we were all fully aware of that and knew that would be the case so planned

care and we all wanted her to be very comfortable and not experience any pain because we wanted her to have a positive experience at that time you know and I would say overall she had that. I think she was pain free and comfortable and her family commented that she seemed extremely peaceful with herself and her surroundings at that time and they were very pleased about that. We provided care sensitive to her pain.

Sally: Yes so would you say working with, having a structure I don't know like having a structured procedure in place to help you with this lady's needs as she deteriorated and working in collaboration with the MDT like you've already mentioned helped you in some ways in identifying and responding to her distress?

R: I think it helped enormously yes. I think having GOLD Standards and working with the GP, the district nurses, the palliative care team and with the lady's family as well because in a non professional role they were as involved as anyone else and led the care in a lot of ways because they knew the lady really well. So yes I think that made a massive difference for the lady herself and for everybody else involved. Yes so that was key to success and having the tools that the GOLD standards provides. As a learning disability nurse, I myself and I think most of my colleagues wouldn't have had the knowledge of what to do and we would have been far more reliant on outside agencies and we have a policy in place to reduce hospital admissions. So I think that lady would have been in and out of hospital and possibly ended up dying in hospital and that would have been very sad because that wasn't what she wanted so things like that made an enormous difference. We probably wouldn't have had a policy our own service specific policy on reducing hospital admissions

because I think as a learning disability nurse you don't necessarily think in those ways you know. You are looking at the social side of things and you are looking at people's independence and the choices and the communication but you are not necessarily trained to look at other aspects in terms of medical care and things.

Sally: Yes so do you think can you tell me whether that case has broadened your perspective of your role?

R: Enormously

Sally: Can you tell me a bit more about how you see your role and from this experience?

R: I think in terms of my own role and what we as a service provide we can provide much more than a standard learning disability home now you know. We can provide palliative care, we can provide end of life care and I think equal to a hospice setting really and obviously a massive bonus because as a rule people with learning disabilities find hospitals and other settings quite distressing in themselves because they are away from their familiar surroundings, they are not surrounded by people who know them well so I think we are in an enormous advantage in terms of that. I think clinically we have skills that we didn't previously have and that's because of our GOLD Standards status and because we support our clients with end of life care so yes I think it's made a huge difference and I also think because we have the GOLD standards other professionals treat us differently because they realise we are professionals in that area and they deal with things in that way. So I think we have respect from the GP and the District Nurse and the palliative care team which perhaps previously we wouldn't have had and I think because it's clear to them that we really know what we are

talking about in that area. I think its strengthened links definitely you know its strengthened links and that's helped hugely. So I think GSF has changed us as a service really in terms of what we can provide and obviously our main focus is about people having quality of life but you know part of your life, death is part of life and equally they should have quality at the end of life just as well as during their life and more so in terms of our moral role to provide a dignified end. So at such time we need a really focused time when you really need to have things in place and more so you really need to direct everything at that time to make sure they are comfortable and we have that now so that puts us at a huge advantage I would say.

Sally: So can you tell me what you think is the future especially from this massive experience, can you talk about the future of learning disability in relationship to palliative care?

R: People with learning disabilities as we know they're living much longer than previously and that's fantastic but along with that there are illnesses associated with old age. As learning disability nurses we possibly haven't come across as much in the past you know dementia is a big part of that, all the associated illnesses around dementia. We can provide specific dementia care here so as our clients age we are going to meet the needs a lot more effectively than perhaps we would have previously. Obviously we work with our clients very closely at the time evaluating the care so we can anticipate a lot of things. We are not waiting for things to happen you know on a monthly basis we are reviewing people's life expectancy and obviously when there are changes if people change on the Coding Register so their life expectancy reduces then anything kicks in, in terms of providing the right

support and things at those times. So I think the way we are evolving and for the future we can provide everything we have previously supplied in terms of people's quality of life and having a person centred approach but we can then extend that throughout the life and provide the right approaches you know in end of life as well. So I think that puts us at an advantage and I think learning disability homes that are quite static in terms of the client group that they have people who live there throughout their life need to evolve in that way because that's the kind of care we need to provide really. You know the Government is looking at people being cared for more in their own homes towards the end of life, there is a real push for that, and I think we can really be at the forefront of that really. We have those skills and there is no reason why other learning disability homes can't do what we have done because you know we are not unique in any other way, we have just developed that. So you know, I could see other learning disability homes developing in the same way and having in terms of the inter-personal skills they have already got the kind of basic stuff there. So it's just building on that really in terms of the clinical skills and things around that. All these will ensure future improved access.

Sally: And then if we go back to the ... are you okay?

R: Yes fine I am just thinking I need a drink.

Sally: If we go back to the Dis DAT tool that you mentioned before, obviously you have used that before?

R: Yes, yes we use that it is effective

Sally: Can you tell me about it, how you find using it and if there is anything that you think could be added on

to it or if there is another tool?

R: Well we use Pepsi cola as well which is a similar tool but I think the advantage of Dis Dat is if you know somebody well you know when they are expressing pain and things but the big advantage is in terms of continuity. A newer member of staff or an agency member of staff or a bank member of staff can come on and use that tool and you know when to give PRN pain relief so that's the big advantage of that and in terms of the way we look at pain here we do try and look at all aspects so the physiological side, spiritual side, the emotional side, we do try and look at it holistically and supporting people in that way. I mean also because of similar client palliative care needs we use the analgesic ladder so a lot of our clients are already on regular pain relief and perhaps in another setting they might not be so they are not getting break through pain and things so we do not really get instances where people are massively distressed and screaming because the pain is very well managed prior to that stage. So I think as well that's part of us having GSF we are much more in tune in terms of symptom management and pain relief than I think we all know there would be as learning disability nurses and the analgesic ladder in particular is really useful You know, knowing what level of pain relief to give at what times and things .

Sally: So to sum it all up would you say as a learning disability nurse your ability to identify or maybe not put words into your mouth, can you tell me like on a summary basis as a learning disability nurse what you think has helped or you think improved your ability to identify and respond to the distress of people with communication difficulties with palliative care needs in this sort of palliative care setting?

R: I think just purely looking at it from a learning

disability point of view the big advantage is that we are very person centred so we tend to know our clients because we look after clients over a period of time so we get to know them really well. Obviously we are trained to respond to people's body language and facial expressions and gestures and ways of communicating other than non verbal and it's something that we are comfortable with and familiar with, it's not something that is new to us so I think that puts us at an enormous advantage and just knowing people over a period of time I think enables you to anticipate things and you pick up on things that in a hospital setting with the best will in the world the staff wouldn't be able to do because they wouldn't just know clients well enough and I think it would be wrong to expect people to because if we had clients that were coming in for 3 or 4 days at a time we wouldn't know them like that you know you just can't and the other advantage I think of being in a small home setting is you get to know clients wider circle as well. You get to know the families well and they will share information with you from that client's childhood and it can be very significant and you don't always have that information in terms of written documentation so that can be hugely helpful but I think a learning disability nurse it's the interpersonal skills I think that we have that puts us at a real advantage and the interpersonal skills in end of life care are just without them you can't provide good quality end of life care so I think they are massively important. Relationships facilities communication.

Sally: Thank you so much. Is there anything that you think you want to say.

R: No sorry I'd just say that GOLD Standards in particular has been a massive boost to us here and I would recommend anyone looking at it. I think even

in non nursing settings now they are looking at the uptake, it's a lot of work but it just makes so much difference it really does. It's an excellent tool and also say for people in learning disability settings the document Routes to Success is a great starting point because it's quite simplistic and it's very easy to read so I would say pre-GOLD Standards is a good starting points because GOLD Standards is quite detailed and can be its a lot of work basically but the Routes to Success is a fantastic starting point and we had quite a lot of input into that document here and I would recommend that to anyone really.

Sally: Thank you so much. Thank you. Interestingly enough when I spoke to other professionals who are not learning disability background what I got from them was like they are beginning to see learning disability nurses especially as apart from the liaison between the two somebody actually described learning disability nurses as a tool to enhance you know their being able to work with.

R: Yes, yes

Sally: People with learning disability and I was really fascinated.

R: Yes I think Amanda working with the Trust has probably helped out enormously as well because I think people are seeing you know what a learning disability nurse can do and the massive impact she has had in terms of improving client's experience of when in hospital and across acute services but also improving professional's knowledge of what to do when clients come in and us and Miss B as well on the mental side she has done some similar work and I think having key people like that in an acute place has just made a massive difference. In the past some people have had some bad experiences of acute settings and hopefully that is going to lessen

now and people are gonna be more people proactive.

Sally: Okay thank you very much. Thanks.

Step Two: Isolating themes using Van Manen's (1990, pp.92-93) initial approaches of isolating themes comprising of the "*detailed or line-by-line approach, the selective or highlighting approach, and the wholistic or sententious approach*".

Note: The line numbers used for direct quote references in this section are as used in the Verbatim Transcript of the version typed in Arial font (see the attached printed copy of Gary's transcript at the end of this thesis).

The detailed or line-by-line approach and the Selective or highlighting approach

The two approaches were incorporated in the analysis as follows: First, the transcript was read in detail (line-by-line). Each sentence or sentence cluster was scrutinized with the view of developing an insight into the phenomenon under study and also, to gain an understanding of the participants experiences. Words, phrases, sentences or paragraphs were identified that seemed to reflect important facets in terms of RNLDs and PCPs experiences of caring for distressed PCDLD in palliative care settings. This was in terms of how RNLDs and PCPs identified and responded to the distress of PCDLD in palliative care settings and also, in terms of RNLDs and PCPs perceptions about the factors which determined how this population communicated distress in a palliative care setting.

Second, the selective or highlighting approach involved "*reading a text several times and ask, what statement (s) or phrase (s) seems particularly essential or revealing about the phenomenon or experience being described? These statements we then circle, underline or highlight*" (Van Manen, 1990, p.93).

See below for the highlighted text of all the important words, phrases, sentences, statements from the exemplar transcript (Gary's transcript) that illustrated Gary's experiences in terms of identifying and responding to the distress of PCDLD in a palliative care setting. The highlighted text were conceptualized according to mean and later transformed into themes (see below for the initial explanatory notes, which will subsequently develop into thematic categories or sub themes).

Sally: Okay thank you for agreeing to do this interview for my study. Now that you have read the communication sheet and have an idea of what this project is all about I have got some questions here just to guide us with the interview. So I am gonna

start with asking you to tell me briefly about the patient group that you work for.

R: There are 8 clients at HS care setting. All have a learning disability, all have physical disabilities, and palliative care needs. None of the clients verbally communicate and they use a range of non verbal communication really from a client who have a picture board through to people who just pick up on prompts and through facial expressions and body language so a bit of a mix but nobody with perfect communication.

Note: Client Group: All have LD and palliative care needs (Gary, Ln 8-10, RNLD).

Note: Communication mode : Non verbal (Gary, Ln. 9-16, RNLD).

Sally: Okay and I mean on a daily basis not only those who have been identified with any supportive or palliative care needs do your clients communicate distress?

R: Yes all clients are able to communicate distress and we have like tools in place like Dis Dat and Pepsi Cola for measuring people's distress levels so .

Note : Dis DAT and PEPSI COLA tools: Methods used by the RNLD to identify and measure the distress of PCDLD in a palliative care setting (Gary, Ln.20-22, RNLD)

Sally: Okay can you elaborate a bit more on the kind of distress they communicate?

R: Yes um I mean obviously it's quite individual and varies from client to client but in terms of vocal noises, facial expressions, gripping of clothing those kind of things really through to a client who can actually indicate by pointing whereabouts in the body they feel pain and things so .. that kind of thing.

Note: (Distress cues): Distress cues for pain identified by the RNLD were: vocalisation, facial expressions, gripping of clothing (Gary, Ln, 25-30, RNLD)

Note: (How RNLD identify the distress of PCDLD):

Distress cues: Observation of distress cues such as vocalisation, facial expressions, gripping of clothing, was used by the RNLD as an approach to identify the distress (pain) of PCDLD in a palliative care setting. (Gary, Ln, 25-30, RNLD).

Sally: Yes so basically they have physiological, psychological and other forms of distress.

R: Yes, yes.

Sally: So you have already mentioned that on a daily basis your clients communicate non-verbally and use different tools as well to communicate so are you saying that they have communication difficulties? (phone ringing)

R: Yes in the people that don't verbally communicate, so yes I think for all our clients you would need to know the clients reasonably well to understand their communication.

Note: (Knowing/relationship): Knowing the client well puts the RNLD in a better position to understand their communication. (Gary, Ln. 39-42, RNLD).

Sally: Okay so for the fact that our client group or the client group that you work with have communication difficulties, can you tell me from your perspective, do you think it has affected the way they express their distress?

R: Yes, I think because there would have been times when they would have been in distress or discomfort and people haven't picked up on it so that's probably led to more extreme expressions when people are in distress. So yes I think that will have had an impact because people will probably have had to go to greater lengths to make their needs known in terms of pain and other things. I mean hopefully not so much now but I think that probably has happened in the past.

Note (Communication difficulties): For the RNLD Communication difficulties is a factor that impacts on the way PCDLD express distress in a palliative care setting. (Gary, Ln.48-55, RNLD).

Sally: Okay – do you have any particular case that you can elaborate on just as an example?

R: In terms of not picking up on somebody's distress and things?

Sally: Yes

R: Umh yes we had a client who had sustained an injury, quite a serious injury, they ended up having a fracture, and we still don't know what the cause was but it appears to have been a while before we picked up on it and that maybe because they went into shock and they weren't really showing any signs. They certainly weren't verbalising any distress so yes that's one extreme example I suppose you know that somebody was clearly in a lot of distress and pain and on that occasion we think it must have happened during the night but it was the following morning when it was picked up and it was later in the morning as well because they hadn't really shown any signs but as I say, we think they had probably gone into shock. So they weren't really either they weren't feeling any pain because of the shock or they just weren't able to express that pain because of the shock.

Sally: Yes it could be. Let's look at it now from a general basis, would you say I mean apart from any of those specific things that you have said about being able to use like the tools and the different ways that you can identify that people communicate distress, **are there any other determining factors that you think as a professional you could identify or link it to the way that people communicate their distress?** What I mean is things like the environment, people, is there any other thing that you think affects this?

R: In terms of clients expressing distress?

Sally: Yes

R: Other than the things that I have said?

Sally: Yes

R: Umh

Sally: You know, that affects them, that distresses them

R: Yes there are certainly lots of other things that can have an impact. I mean it's a very individual thing isn't it

Sally: Yes

R: So we have people here that we know very well if they are in a busy group situation they will be distressed, they will get very hot.

Sally: Yes

R: That you know they will become more vocal and they will express distress in that way. So yes there are definitely other indicators, other external things that happen that have an impact without a doubt yes but as I say it's very individual isn't it you know for the client. But one lady in particular that was here we regularly have parties so that relatives visit and we always ended up doing something separate with her because she finds that environment extremely distressing and gets herself very upset. So you know we make sure that she does something else on those occasions.

**Note: (Unfamiliar environment and unfamiliar people):
A factor which determines how PCDLD express distress in a palliative care setting is the unfamiliar environment and unfamiliar people, which may cause upset. (Gary, Ln.101-108, RNLD)**

Note: How the RNLD responded to the identified environmental factor that contributes to the distress of PCDLD in a palliative care setting was by removing the individual from the environment (Gary, Ln.101-108, RNLD)

Sally: Yes okay umh if we take it back now because I am

very interested in the palliative care and I know you have had some experience in that area. Is there any particular case that you can tell me about?

R: In terms of palliative or end of life?

Sally: All. It's inclusive. I am using palliative care now as inclusive from the supportive right to the end of life.

R: Well in the time I have been a manager we've had one client who we supported with their end of life care and we used the Gold Standards Framework so that was the tool we used in terms of ensuring everything was in place and we provided the right support so we did a lot of very detailed work with that client and the family at the time and they had an advanced care plan which was really useful because we put that into place before they became very ill and before they were at the end of life so that set up in some detail the kind of things they wanted at the end of their life. Symptom control, things like anticipating prescribing so we already had medication in place before it was required. The kind of things that family wanted and the lady herself wanted at that time. So I think having that in place was hugely helpful really and I think for us as practitioners and for me in particular because I had not had a great deal of experience in palliative care. It gave us the skills to do what we needed to do and provide a really good quality end of life care which I don't think we are the best one in the world but we would not have been able to provide to that standard without having Gold standards and so I think it was extremely helpful.

Note: (Training and skill development): Training and skill development in the use of the appropriate EoLC framework (GSF) was an approach used by the RNLD to identify the distress of PCDLD and respond with the provision of optimum dignified care in a palliative care setting. (Gary, Ln. 124-147, RNLD).

Note: Acknowledgement of shortcomings: RNLD identified own limitation and the need to train to better meet the PCDLD needs in palliative care settings. (Gary, Ln. 141-144, RNLD).

And with all our clients, with all our clients with palliative care needs, we evaluate their palliative care needs, what part of the register they are on in terms of whether they have got years to live, months, days, weeks. Their needs in terms of symptom control and pain management we regularly evaluate. Everyone has an advance care plan in place, dignity care plan, so lots of things around that really. It is very useful.

Sally: Okay. So this specific client that you cared for towards end of life can you tell me if it had any particular impact on you as a professional?

R: Yes very much. I mean obviously myself and the whole team we knew the lady was dying so as I say it wasn't a sudden death and her end of life probably in terms of specific end of life care where we withdraw any kind of life enhancing treatments went on for about two weeks which is quite a long period of time. We formed quite close links with the family, her sister in particular, so yes it had a big impact.

Note: (Knowing/Building relationships with family):

Mutual understanding and relationships was a method used by the RNLD to identify and respond to the distress of PCDLD in order to ease their suffering and promote a dignified end. (Gary, Ln.159-166, RNLD).

I mean the lady had lived at the home for 8 years, she was a big personality within the home, so yes I would say it had a big impact at lots of levels on all of us really and it affected us a lot you know. The family were very keen that we weren't morbid around that time. They wanted her to be surrounded by laughter. They wanted people to be

cheerful and they wanted everything to carry on as normal. They didn't want us tip-toeing around and having a very down atmosphere because they wanted even though it was a very difficult time, they wanted to have some happy memories from that time as well but yes it did have a big impact in terms of the loss of that lady and the impact that had on the service, the impact that had on the family.

Note: Sincerity and sensitivity in care: was a strategy used by the RNLD to identify the distress of PCDLD. This enabled the RNLD to respond with Care that was sincere but sensitive to needs of the dying PCDLD and the wishes of their family. (Gary, Ln. 166-181, RNLD).

Err, the family maintained quite close links afterwards and the impact it has on the team and you are having to support members of the team because we had staff who had never dealt with a death and we have quite a big age group within our staff team at that time. I think we had people in their late teens through to people that would have retired so people in their 60s, so people with very different experiences. And also one of the things we found was people that had personally experienced a loss or a bereavement recently it really hit home for them because I think it brought a lot of sensitive issues back so managing that and supporting people was a big part of the process really in ensuring that staff got the right kind of support so yes it had a massive impact definitely. Sincerity and sensitivity was vital.

Note: (Building Personal and professional relationships (Relationality): Reinforcing personal and professional relationships as essential to the care of PCDLD in a palliative care setting. (Gary, Ln 166-182, RNLD).

Note: Sincerity and sensitivity in care: Being sincere

that an individual was dying and being sensitive to their needs and the needs of their support circle was essential to address their distress with optimum care. (Gary, Ln, 170-181, RNLD)

Note: Sincerity and sensitivity in care also included the aftermath of the death of PCDLD: This necessitated that the RNLD ensured that staff members are provided with the right kind of supportive and counselling services to enable them cope at two levels: The distress of losing a client and distressing memories of past personal experiences. (Gary, Ln. 182-196, RNLD)

Sally: And from this particular experience as well could you describe what you think. You have already mentioned it had a good impact, and some maybe concern for the staff team and for this lady and her family definitely had a massive impact as well. Can you describe how you felt that you had to offer some kind of palliative care service in a different setting that is not a hospice?

R: Yes in a non-hospice setting.

Sally: Yes

R: Because we did have the Goal standards and we had everything in place that made things much easier.

Note: The experience of caring for PCDLD was made easier for the RNLD with the use of the GOLD Standard Framework for End of Life Care (Gary, Ln.207-208, RNLD).

I mean we are very lucky here in that it's a small home so we know all the clients really well. We tend to know families very well. The lady and her family had already expressed that this would be her choice for end of life, she didn't want to go into hospital, she didn't want to be in a hospice, she wanted to be in familiar surroundings. Her room even though it was small it did lend itself quite well to having

regular visitors and for the last two weeks of her life she was bed bound so she remained in her bedroom at that time so she was able to have visitors in private which made things easier so family could have private time with her.

Note: Knowing the family and Mutual caring relationships enhanced care provided (Gary, Ln. 207-211)

Note: (Comfort and peaceful care setting): Ensuring that the care setting was comfortable and peaceful was essential to identify and respond with optimum care to the distress of the dying PCDLD. (Gary, 209-221, RNLD).

She was religious so she was able to have a priest visiting and he was able to have, we did have a member of staff there when the priest was there, but he was great. He read the sacraments of the sick in like a private dignified setting and then at the end he read the last rites to her. So I think because it was a small community home and a place that the lady had lived at for a long time, it lent itself quite well in terms of an environment. At the end of the day it was the whole person not only their pain or distress that we were thinking about. **Note: A method used by the RNLD to identify and respond to the distress of PCDLD was by being sensitive to the whole person and not just their disease. (Positive Regard of Personhood) (Humane care). (Gary, Ln.221-231, RNLD).**

I would say the only aspects that possibly were a little bit more tricky for us were things like her having pain relief by a syringe driver so we had to have additional training in place. **Note: Acknowledgement of shortcomings: The RNLD acknowledged their own shortcomings and the need to train in order to provide certain aspects of palliative care. (Gary, Ln.231-234, RNLD).**

Note: Training: Over time, training and skills development enabled the RNLD to identify and respond to the identified needs of the distressed PCDLD with optimal care (Gary, Ln.231-234, RNLD).

So there were things that we had to set up which ordinarily we wouldn't have had in the home setting. The technical clinical things we needed to provide specific training and do things because we had not done those things before but I think in terms of the kind of inter-personal skills we were very well set up because you know we knew the lady well, a lot of us had quite close relationships with her and her family. So, it was more on the clinical side that we had to really step things up a gear but we did have a lot of support from the palliative care teams so that helped and the district nurses. It was our moral duty to train.

Note: Moral duty of care: (Training): The RNLD perceived that it was their moral duty to acquire necessary training to ensure that the RNLD develop necessary skills to respond to the identified distress and need of the PCDLD in a palliative care setting with the provision of optimum care. (Gary, Ln.233-246, RNLD).

Note: Collaborative working: This was used as a strategy to identify and respond to the distress of PCDLD. Collaborative working ensured continuity of care . (Gary, Ln.233-246, RNLD).

Sally: Okay so there was some kind of collaborative work involved

R: There was a lot, I would say that was a big part of the success was the GP was on board with it. He attended the advance care plan meeting so he already knew what we were hoping. He put anticipatory medication in place so we had all the meds we needed and for the last two weeks. He visited perhaps not on a daily basis but very

regularly. When the lady went into distress he was there immediately and got the syringe driver set up and everything and then he would visit on a regular basis just to check how she was and evaluate how things were going and he worked very closely with the district nurses because they were coming in at that time to help. So yes I would say an MDT approach was essential really, we couldn't have done it on our own you know so having other professionals there helped with that end of life care quality really. **Note: Collaboration and MDT working: This was used by the RNLD as method to identify and respond to the distress of PCDLD with optimum care. (Gary, Ln. 249-265, RNLD).**

Sally: Yes and because you knew this lady I mean you have known her for quite some time, would you say that when she was in this palliative state the way she communicated her distress changed over time?

R: Yes very much I mean originally even though I have only worked here for 3 years I had previously worked here in a different role so I had known the lady on and off for over the entire time she had been here. When she first moved to the home she was a lady with Down's syndrome but she was very outgoing, she was quite skilled at that time. She spoke, and she walked at that time. So knowing her at a time when she could express herself well I think was quite a big help because obviously we were able to get information directly from her at that time so that was helpful but gradually she lost a lot of her skills because she had dementia. So she lost her ability to verbalise and to express herself verbally but she was still quite a good communicator in that she did express well in other ways and she was a very people person and she did maintain that even when she had dementia she liked people. She would still laugh at things in response to people and she

would respond, she would make eye contact so she kept that to the end really but yes it changed an awful lot in terms of the way she expressed her needs in terms of distress and especially towards the end she was on anti-meta medications, sedative medication, she was on strong pain killers so beyond her own abilities and personality that had a massive impact you know because a lot of the time she was in a semi-conscious state at that time because she was in pain. Obviously our wish was for her to be comfortable and not in any pain and not have any distress so I would say the medication would have masked her ability to express herself towards the end of her life definitely but we were all fully aware of that and knew that would be the case so planned care

Note: Knowing the person well: This enabled the RNLD identify and relief their distress by providing continuity of care through the different stages of the person's life from being well, diagnosed, the disease trajectory and death. (Gary, Ln. 270-303, RNLD).

Note: Pain-free and comfortable environment: How the RNLD responded to the identified distress of the PCDLD was by ensuring a pain-free and comfortable environment. (Gary, Ln.290-303, RNLD)

Note: RNLD's Wish/duty to provide Pain-free care (Gary, Ln.290-303, RNLD).

and we all wanted her to be very comfortable and not experience any pain because we wanted her to have a positive experience at that time you know and I would say overall she had that. I think she was pain free and comfortable and her family commented that she seemed extremely peaceful with herself and her surroundings at that time and they were very pleased about that. We provided care sensitive to her pain.

Note: Pride and job satisfaction: An experience of

pride and satisfaction in a job well done knowing that the provision of care that was sensitive to the pain and /or distress of PCDLD would ensure that they are supported to be pain free and peaceful in a comfortable environment. (Gary, Ln.303-311, RNLD).

Note: Successful care: The RNLD was able to respond to the distress of PCDLD in a palliative care setting with the provision of care that was pain-free in a comfortable environment and family were pleased with the outcome. (Gary, Ln.307-311, RNLD).

Sally: Yes so would you say working with, having a structure I don't know like having a structured procedure in place to help you with this lady's needs as she deteriorated and working in collaboration with the MDT like you've already mentioned helped you in some ways in identifying and responding to her distress?

R: I think it helped enormously yes. I think having GOLD Standards and working with the GP, the district nurses, the palliative care team and with the lady's family as well because in a non professional role they were as involved as anyone else and led the care in a lot of ways because they knew the lady really well. So yes I think that made a massive difference for the lady herself and for everybody else involved yes so that was key to success and having the tools that the GOLD standards provides. **Note: (Collaborative and MDT working): Collaborative and MDT working with other professionals, family members and utilizing the tools that the GOLD Standard Framework provided enabled the RNLD to identify the distress of PCDLD and responded by planning care in advance to meet the persons needs. (Gary, Ln.319-328, RNLD).**

As a learning disability nurse, I myself and I think most of my colleagues wouldn't have had the

knowledge of what to do and we would have been far more reliant on outside agencies and we have a policy in place to reduce hospital admissions so I think that lady would have been in and out of hospital and possibly ended up dying in hospital and that would have been very sad because that wasn't what she wanted. So things like that made an enormous difference. We probably wouldn't have had a policy, our own service specific policy on reducing hospital admissions because I think as a learning disability nurse you don't necessarily think in those ways you know you are looking at the social side of things and you are looking at people's independence and the choices and the communication but you are not necessarily trained to look at other aspects in terms of medical care and things.

Sally: Yes so do you think, can you tell me whether that case has broadened your perspective of your role?

R: Enormously

Sally: Can you tell me a bit more about how you see your role and from this experience?

R: **I think in terms of my own role and what we as a service provide we can provide much more than a standard learning disability home now you know. We can provide palliative care, we can provide end of life care and I think equal to a hospice setting really and obviously a massive bonus because as a rule people with learning disabilities find hospitals and other settings quite distressing in themselves because they are away from their familiar surroundings, they are not surrounded by people who know them well so I think we are in an enormous advantage in terms of that. **Note: Training and acquisition of new skills: These were used by the RNLD as an approach to identify and respond to the distress of PCDLD in a palliative care setting with the provision of****

optimum holistic care in the familiar surroundings of their homes. (Gary, Ln. 352-362, RNLD).

I think clinically we have skills that we didn't previously have and that's because of our GOLD Standards status and because we support our clients with end of life care. So yes I think it's made a huge difference and I also think because we have the GOLD standards other professionals treat us differently because they realise we are professionals in that area and they deal with things in that way. So I think we have respect from the GP and the District Nurse and the palliative care team which perhaps previously we wouldn't have had and I think because it's clear to them that we really know what we are talking about in that area. **Note:**

(Successful caring outcomes): Successful caring outcomes and the use of new skills created a sense of pride and job satisfaction which enabled the RNLD to respond to the distress of PCDLD in a palliative care setting with the provision of Confident care. (Gary, Ln.363-375, RNLD) (especially Ln.367-375)

I think its strengthened links definitely you know its strengthened links and that's helped hugely. So I think GSF has changed us as a service really in terms of what we can provide and obviously our main focus is about people having quality of life but you know part of your life, death is part of life and equally they should have quality at the end of life just as well as during their life and more so in terms of our moral role to provide a dignified end. So at such time we need a really focused time when you really need to have things in place and more so you really need to direct everything at that time to make sure they are comfortable and we have that now so that puts us at a huge advantage I would say. **Note:**

Moral Duty of Care: The RNLD's commitment to

respond to the distress of the PCDLD by providing holistic care which promoted quality and dignity both in life and at the end of life for PCDLD. (Gary, Ln. 375-388, RNLD).

Note: Time- (Dying as part of living): The RNLD was aware of time and responded to identified distress of PCDLD by ensuring optimum holistic care, which aims to provide the best for the individual whilst they are alive, dying and at death (Gary, Ln.375-388, RNLD) (especially, Ln.379-388)

Sally: So can you tell me what you think is the future especially from this massive experience, can you talk about the future of learning disability in relationship to palliative care?

R: **People with learning disabilities as we know they're living much longer than previously and that's fantastic but along with that there are illnesses associated with old age. As learning disability nurses we possibly haven't come across as much in the past you know dementia is a big part of that, all the associated illnesses around dementia. We can provide specific dementia care here so as our clients age we are going to meet the needs a lot more effectively than perhaps we would have previously.**

Note: Future Perspectives: Optimism of being able to provide specific and more effective palliative care for PCDLD such as dementia care. (Gary, Ln. 393-402, RNLD). Obviously we work with our clients very closely at the time evaluating the care so we can anticipate a lot of things. We are not waiting for things to happen you know on a monthly basis we are reviewing people's life expectancy and obviously when there are changes if people change on the Coding Register so their life expectancy reduces then anything kicks in, in terms of providing the right support and things at those times. **So I think the way we are evolving and**

for the future we can provide everything we have previously supplied in terms of people's quality of life and having a person centred approach; but we can then extend that throughout the life and provide the right approaches you know in end of life as well. So I think that puts us at an advantage and I think learning disability homes that are quite static in terms of the client group that they have people, who live there throughout their life need to evolve in that way because that's the kind of care we need to provide really. **Note: Future Perspectives: (Optimism): Hopefulness in being able to extend person centred approach throughout the life span of PCDLD, to also encompass end-of-life care. (Gary, Ln. 411-422, RNLD). You know the Government is looking at people being cared for more in their own homes towards the end of life, there is a real push for that, and I think we can really be at the forefront of that really. We have those skills and there is no reason why other learning disability homes can't do what we have done because you know we are not unique in any other way, we have just developed that. So you know, I could see other learning disability homes developing in the same way** **Note: Future perspectives: (Future improved palliative care): This will necessitate the RNLD to contribute to practice development both at organisational and governmental levels to enhance future improved access. (Gary. Ln.422-431 and Ln.435, RNLD).**

and having in terms of the inter-personal skills, they have already got the kind of basic stuff there. So it's just building on that really in terms of the clinical skills and things around that. **All these will ensure future improved access.**

Sally: And then if we go back to the ... are you okay?

R: Yes fine I am just thinking I need a drink.

Sally: If we go back to the Dis DAT tool that you mentioned before, obviously you have used that before?

R: Yes, yes we use that it is effective.

Sally: Can you tell me about it, how you find using it and if there is anything that you think could be added on to it or if there is another tool?

R: Well we use Pepsi cola as well which is a similar tool but I think the advantage of Dis DAT is if you know somebody well you know when they are expressing pain and things but the big advantage is in terms of continuity. A newer member of staff or an agency member of staff or a bank member of staff can come on and use that tool and you know when to give PRN pain relief so that's the big advantage of that and in terms of the way we look at pain here we do try and look at all aspects so the physiological side, spiritual side, the emotional side, we do try and look at it holistically and supporting people in that way. I mean also because of similar client palliative care needs we use the analgesic ladder. So a lot of our clients are already on regular pain relief and perhaps in another setting they might not be. So they are not getting break through pain and things so we do not really get instances where people are massively distressed and screaming because the pain is very well managed prior to that stage. So I think as well that's part of us having GSF we are much more in tune in terms of symptom management and pain relief than I think we all know there would be as learning disability nurses and the analgesic ladder in particular is really useful you know knowing what level of pain relief to give at what times and things.

Note: Assessment tools (Dis DAT and the GSF PEPSI COLA tool and the analgesic ladder) were used by the RNLD to identify the distress of PCDLD in a palliative care settings. (Gary, Ln. 444-451 and 455-457, RNLD).

Sally: So to sum it all up would you say as a learning disability nurse your ability to identify or maybe not put words into your mouth, can you tell me like on a summary basis as a learning disability nurse what you think has helped or you think improved your ability to identify and respond to the distress of people with communication difficulties with palliative care needs in this sort of palliative care setting?

R: I think just purely looking at it from a learning disability point of view the big advantage is that we are very person centred so we tend to know our clients because we look after clients over a period of time so we get to know them really well. **Note: Knowing/ (Relationship): Building relationship with the PCDLD was used as an approach to identify and respond to their distress. (Gary, Ln.478-482, RNLD)**

Obviously we are trained to respond to people's body language and facial expressions and gestures and ways of communicating other than non verbal and it's something that we are comfortable with and familiar with, it's not something that is new to us so I think that puts us at an enormous advantage **Note: Knowing/relationship with PCDLD: This enabled the RNLD to identify their distress in a palliative care setting through the method of observing for nonverbal cues such as facial expressions and gestures (Gary, Ln.482-488, RNLD).**

and just knowing people over a period of time I think enables you to anticipate things and you pick up on things that in a hospital setting with the best will in the world the staff wouldn't be able to do because they wouldn't just know clients well enough and I think it would be wrong to expect people to because if we had clients that were coming in for 3 or 4 days at a time we wouldn't know them like that you know you just can't **Note: Knowing/ (building**

relationship (Relationality): Knowing the PCDLD enabled the RNLD to anticipate their distress and respond with appropriate care. (Gary, Ln. 488-496, RNLD).

and the other advantage I think of being in a small home setting is you get to know clients wider circle as well. You get to know the families well and they will share information with you from that client's childhood and it can be very significant and you don't always have that information in terms of written documentation so that can be hugely helpful but I think a learning disability nurse it's the inter-personal skills I think that we have that puts us at a real advantage and the inter-personal skills in end of life care are just without them you can't provide good quality end of life care so I think they are massively important.

Note: Knowing: (Building Mutual relationships with family (Relationality): An approach used by the RNLD to identify and respond to the distress of PCDLD in a palliative care setting was by being able to build relationships with the wider family circles of the PCDLD.

The RNLD then used interpersonal skills to acquire relevant information from family and wider circle of the person experiencing distress that contributed to the quality of care provided. (Gary, Ln. 497-509, RNLD).

Sally: Thank you so much. Is there anything that you think you want to say.

R: No sorry I'd just say that GOLD Standards in particular has been a massive boost to us here and I would recommend anyone looking at it. I think even in non nursing settings now they are looking at the uptake, it's a lot of work but it just makes so much difference it really does. It's an excellent tool and also say for people in learning disability settings the document Routes to Success is a great starting point

because it's quite simplistic and it's very easy to read so I would say pre- GOLD standards is a good starting points because GOLD standards is quite detailed and can be a lot of work basically but the Routes to Success is a fantastic starting point and we had quite a lot of input into that document here and I would recommend that to anyone really.

Sally: Thank you so much. Thank you. Interestingly enough when I spoke to other professionals who are not of learning disability background what I got from them was like they are beginning to see learning disability nurses especially, as apart from the liaison between the two, somebody actually described learning disability nurses as a tool to enhance you know their being able to work with

R: Yes, yes

Sally: People with learning disability and I was really fascinated.

R: Yes I think Amanda working with the Trust has probably helped out enormously as well because I think people are seeing you know what a learning disability nurse can do and the massive impact she has had in terms of improving client's experience of when in hospital and across acute services but also improving professional's knowledge of what to do when clients come in and us and Miss B as well on the mental side she has done some similar work and I think having key people like that in an acute place has just made a massive difference. In the past some people have had some bad experiences of acute settings and hopefully that is going to lessen now and people are gonna be more people proactive.

Sally: Okay thank you very much. Thanks.

Wholistic approach:

Following the 'wholistic' approach, I re-examined all the components of general meaning gathered from the text as highlighted above. The aim was to ascertain a distinction between

the incidental themes or what will become the essential themes. This was achieved by constantly questioning “*does the phenomenon without this theme lose its fundamental meaning?*” (Van Manen, 1990, p.107).

General meanings highlighted in Gary’s transcript above:

- **Note 1:** Client/patient group: PCDLD (see Gary, Ln.8-10, RNLD).
- **Note 2 :** Client/patient communication mode: non-verbal (see Gary, Ln.9-16, RNLD).
- **Note 3:** Tools used by RNLD in a palliative care setting to identify the distress of PCDLD in this palliative care setting: DisDAT (see Gary, Ln.20-22, RNLD); PEPSI COLA and Analgesic ladder (see Gary, Ln.444-451 and Ln.455-457, RNLD).
- **Note 4:** Factors determining how PCDLD communicated distress in a palliative care setting:
 - The communication difficulties of PCDLD: (see Gary, Ln.48-55, RNLD).
 - Unfamiliar environment and people (see Gary, Ln.101-103, RNLD) and (Gary, Ln.105-116, RNLD).
- **Note 5:** The RNLD identified the distress of PCDLD in a palliative care setting by observing for distress cues such as vocalisation; facial expressions and gripping of clothing, which sometimes indicated pain (see Gary, Ln.25-30, RNLD).
- **Note 6:** Knowing the PCDLD
 - Relationship with PCDLD – knowing the individual with communication difficulty and a learning disability well enabled the RNLD to understand their communication (see Gary, Ln.39-42, RNLD).
 - Such relationship (Knowing the PCDLD well) enabled the RNLD to respond to their distress with the provision of continuing care throughout their disease trajectory and death (Gary, Ln.270-303, RNLD).
 - Person centred approach to care enhances getting to know the PCDLD well and enabled the RNLD to identify their distress and respond with the provision of optimum care (see Gary, Ln.478-482, RNLD).
 - Such relationship (Knowing the PCDLD well) also enabled the RNLD to identify non-verbal distress cues (see Gary, Ln.482-488, RNLD)
 - It also enabled the RNLD to anticipate their distress and respond with appropriate optimum care (see Gary, Ln.488-496, RNLD).
- **Note 7:** Knowing the family members of the PCDLD
 - Relationship with family – enabled the RNLD to obtain vital information about the PCDLD history (social, health and/ or medical) which was incorporated in the care plan to identify and address their distress in a palliative care setting (see Gary, Ln. 159-166 RNLD); (see Gary, Ln.207-211, RNLD); and (Gary, Ln. 497-509, RNLD).

- **Note 8:** Knowing other professionals
 - Relationship with other professionals – Collaborative and Multidisciplinary Team (MDT) working between the RNLD enhanced their ability to identify and respond to the distress of PCDLD in a palliative care setting (see Gary, Ln.319-328, RNLD).
- **Note 9:** Successful care:
 - Training, new skills, all contributed to identifying and responding to distress of PCDLD in a palliative care settings with successful care intervention (see Gary, Ln.307-311, RNLD).
- **Note 10:** Pride and job satisfaction:
 - RNLD had an experience of pride and job satisfaction when the distress of PCDLD was successfully identified and appropriate care provided to alleviate it (see Gary, Ln.363-375, RNLD).
- **Note 11:** Sincerity and sensitivity in care:
 - The RNLD addressed the distress of PCDLD in a palliative care setting by being sincere about their condition and being sensitive to their distress and the needs of their support circle (family and carers) (see Gary, Ln.166-181, RNLD) and (especially, Ln.170-181).
 - Sensitive to the needs of staff in the aftermath of the death of PCDLD (see Gary, Ln.182-196, RNLD).
- **Note 12:** Positive regard of personhood (looking at the whole person and not just their disease:
 - Looking at the whole person (family, environment, religion etc. And not just their disease) (see Gary, Ln.221-231, RNLD).
- **Note 13:** Training and skill development and providing a dignified end:
 - Training and skill development (see Gary, Ln.124-147, RNLD).
 - Training over time enabled RNLD to address distress with optimal care (see Gary, Ln.231-234, RNLD).
 - Training as a moral duty (that is in terms of acquisition of necessary skills to meet the needs of the distressed PCDLD in a palliative care setting (see Gary, Ln.233-246, RNLD).
 - Moral role to provide a dignified end (see, Gary, Ln.383, RNLD).
- **Note 14:** Acknowledgement of shortcomings (see Gary, Ln.141-144, RNLD). Also (see Gary, Ln.231-234, RNLD).
- **Note 15:** Pain-free care:
 - RNLD's wish/duty to respond to the distress of PCDLD in a palliative care setting with the provision of pain-free care (see Gary, Ln.290-303, RNLD)

- RNLD's ensured the PCDLD experiencing distress received care that was pain-free and also, ensured the person was comfortable (see Gary, Ln.303-311, RNLD).
- **Note 16:** Comfort, safety and peaceful care setting:
 - The RNLD identified and responded to the distress of PCDLD by ensuring the person was safe, at peace and in a comfortable palliative care setting (Gary, Ln.208-221, RNLD)
- **Note 17:** Dying as a part of living (The main heading for clustering in this section will be Time to care):
 - See Gary, Ln.379-388, RNLD.
- **Note 18:** Comfortable Care environment:
 - RNLD ensured care was provided in a comfortable setting (see Gary, Ln.209-221, RNLD) especially Ln.215-221.
- **Note 19:** Optimism:
 - Optimism – In the future, being able to provide more effective palliative care including dementia care (see Gary, Ln.393-402; Ln.411-422, RNLD).
- **Note 20:**
 - Future improved access (see Gary, Ln.422-431 and Ln.435, RNLD).

The above initial notes from Gary's transcript were transformed into sub themes with quotations as illustrated below:

Note: The line numbers used for direct quote references in this section are as used in the Verbatim Transcript of the version typed in Arial font (see the attached printed copy of Gary's transcript at the end of this thesis).

Sub themes from Note 4:

Sub theme: Communication difficulties

(As a factor which determined or affected how PCDLD communicated distress)

"Yes, I think because there would have been times when they would have been in distress or discomfort and people haven't picked up on it so that's probably led to more extreme expressions when people are in distress. So yes I think that will have had an impact because people will probably have had to go to greater lengths to make their needs known in terms of pain and other things" (Gary, Ln.48-55, RNLD).

Sub theme: Unfamiliar environment and people

(As a factor which determined or affected how PCDLD communicated distress in a palliative care setting)

"So we have people here that we know very well if they are in a busy group situation they will be distressed, they will get very hot" (Gary, Ln.101-103, RNLD).

".....that you know they will become more vocal and they will express distress in that way so yes there are definitely other indicators, other external things that happen that have an impact without a doubt yes but as I say it's very individual isn't it you know for the client. But one lady in particular that was here we regularly have parties so that relatives visit and we always ended up doing something separate with her because she finds that environment extremely distressing and gets herself very upset. So you know we make sure that she does something else on those occasions" (Gary, Ln.105-116, RNLD).

Sub theme from Note 5:

Sub theme: Distress cues

"Yes um I mean obviously it's quite individual and varies from client to client but in terms of vocal noises, facial expressions, gripping of clothing those kind of things really through to a client who can actually indicate by pointing whereabouts in the body they feel pain and things so .. that kind of thing" (Gary, Ln.25-30, RNLD).

Sub theme from Note 6:

Sub theme: Building relationships with PCDLD:

"Yes in the people that don't verbally communicate, so yes I think for all our clients you would need to know the clients reasonably well to understand their communication" (Gary, Ln.39-42, RNLD).

"Yes very much I mean originally even though I have only worked here for 3 years I had previously worked here in a different role so I had known her the lady on and off for over the entire time she had been here. When she first moved to the home she was a lady with Down's Syndrome but she was very outgoing, she was quite skilled at that time. She spoke, and she walked at that time. So knowing her at a time when she could express herself well I think was quite a big help because obviously we were able to get information directly from her at that timegradually she lost a lot of her skills because she had dementia.....yes it changed an awful lot in terms of the way she expressed her needs in terms of distress and especially towards the end she was on anti-meta medications, sedative medication, she was on strong pain killers so beyond her own abilities and personality that had a massive impact you know because a lot of the time she was in a semi conscious state at that time because she was in pain. Obviously our wish was for her to be comfortable and not in any pain and not have any distress so I would say the medication would have masked her ability to express herself towards the end of her life definitely but we were all fully aware of that and knew that would be the case so planned care" (Gary, Ln.270-303, RNLD).

"I think just purely looking at it from a learning disability point of view the big advantage is that we are very person centred so we tend to know our clients because we look after clients over a period of time so we get to know them really well" (Gary, Ln.478-482, RNLD).

"Just knowing people over a period of time I think enables you to anticipate things and you pick up on things that in a hospital setting with the best will in the world the staff wouldn't be able to do because they wouldn't just know clients well enough and I think it would be wrong to expect people to because if we had clients that were coming in for 3 or 4 days at a time we wouldn't know them like that you know you just can't" (Gary, Ln.488-496, RNLD).

Sub theme from Note 7:

Sub theme: Building relationship with family members

"I mean obviously myself and the whole team we knew the lady was dying so as I say it wasn't a sudden death and her end of life probably in terms of specific end of life care where we withdraw any kind of life enhancing treatments went on for about two weeks which is quite a long period of time. We formed quite close links with the family, her sister in particular, so yes it had a big impact" (Gary, Ln.159-166, RNLD).

"Because we did have the Goal standards and we had everything in place that made things much easier. I mean we are very lucky here in that it's a small home so we know all the clients really well. We tend to know families very well" (Gary, Ln.207-211, RNLD).

"I think of being in a small home setting is you get to know clients wider circle as well. You get to know the families well and they will share information with you from that client's childhood and it can be very significant and you don't always have that information in terms of written documentation so that can be hugely helpful but I think a learning disability nurse it's the inter-personal skills I think that we have that puts us at a real advantage and the inter-personal skills in end of life care are just without them you can't provide good quality end of life care so I think they are massively important. Relationships facilities communication" (Gary, Ln.497-509, RNLD).

Sub theme from Note 8:

Sub theme: Building relationships with other professionals

"I think having GOLD Standards and working with the GP, the district nurses, the palliative care team and with the lady's family as well because in a non professional role they were as involved as anyone else and led the care in a lot of ways because they knew the lady really well. So yes I think that made a massive difference for the lady herself and for everybody else involved. Yes so that was key to success and having the tools that the GOLD standards provides" (Gary, Ln.319-328, RNLD).

Sub theme from Note 9

Sub theme: Successful care

"I think she was pain free and comfortable and her family commented that she seemed extremely peaceful with herself and her surroundings at that time and they were very pleased about that. We provided care sensitive to her pain" (Gary, Ln.307-311, RNLD).

Sub theme from Note 10:

Sub theme: Pride and job satisfaction

"I think clinically we have skills that we didn't previously have and that's because of our GOLD Standards status and because we support our clients with end of life care so yes I think it's made a huge difference and I also think because we have the GOLD standards other professionals treat us differently because they realise we are professionals in that area and they deal with things in that way. So I think we have respect from the GP and the District Nurse and the palliative care team which perhaps previously we wouldn't have had and I think because it's clear to them that we really know what we are talking about in that area" (Gary, Ln.363-375, RNLD).

Sub theme from Note 11:

Sub theme: Sincerity and sensitivity in care

"I mean the lady had lived at the home for 8 years, she was a big personality within the home, so yes I would say it had a big impact at lots of levels on all of us really and it affected us a lot you know. The family were very keen that we weren't morbid around that time. They wanted her to be surrounded by laughter. They wanted people to be cheerful and they wanted everything to carry on as normal. They didn't want us tip-toeing around and having a very down atmosphere because they wanted even though it was a very difficult time they wanted to have some happy memories from that time as well but yes it did have a big impact in terms of the loss of that lady and the impact that had on the service, the impact that had on the family" (Gary, Ln.166-181, RNLD)

".....the impact it has on the team and you are having to support members of the team because we had staff who had never dealt with a death and we have quite a big age group within our staff team at that time..... people with very different experiences. And also one of the things we found was people that had personally experienced a loss or a bereavement recently it really hit home for them because I think it brought a lot of sensitive issues back so managing that and supporting people was a big part of the process really in ensuring that staff got the right kind of support. So yes it had a massive impact definitely. Sincerity and sensitivity was vital" (Gary, Ln.182-196, RNLD).

Sub theme from Note 12:

Sub theme: Looking at the whole person (Positive regard of personhood)

"She was religious so she was able to have a priest visiting and he was able to have, we did have a member of staff there when the priest was there, but he was great. He read the sacraments of the sick in like a private dignified setting and then at the end he read the last rites to her so I think because it was a small community home and a place that the lady had lived at for a long time, it lent itself quite well in terms of an environment. At the end of the day it was the whole person not only their pain or distress that we were thinking about" (Gary, Ln.221-231, RNLD).

Sub themes from Note 13:

Sub theme: Training and skill development

"Well in the time I have been a manager we've had one client who we supported with their end of life care and we used the Gold Standards Framework so that was the tool we used in terms of ensuring everything was in place and we provided the right support so we did a lot of very detailed work with that client and the family at the time..... It gave us the skills to do what we needed to do and provide a really good quality end of life care which I don't think we are the best one in the world but we would not have been able to provide to that standard without having Gold standards and so I think it was extremely helpful" (Gary, Ln.124-147, RNLD).

Sub theme: Training as a moral duty

"So there were things that we had to set up which ordinarily we wouldn't have had in the home setting. The technical clinical things we needed to provide specific training and do things because we had not done those things before but I think in terms of the kind of inter-personal skills we were very well set up because you know we knew the lady well, a lot of us had quite close relationships with her and her family. So, it was more on the clinical side that we had to really step things up a gear but we did have a lot of support from the palliative care teams so that helped and the district nurses. It was our moral duty to train" (Gary, Ln.234-246, RNLD).

Sub theme from Note 14:

Sub theme: Acknowledgement of shortcomings

"I had not had a great deal of experience in palliative care. It gave us the skills to do what we needed to do and provide a really good quality end of life care" (Gary, Ln.141-144, RNLD).

"I would say the only aspects that possibly were a little bit more tricky for us were things like her having pain relief by a syringe driver so we had to have additional training in place" (Gary, Ln.231-234, RNLD).

Sub theme from Note 15:

Sub theme: Pain-free care

"...yes it changed an awful lot in terms of the way she expressed her....distress and especially towards the end she was on anti-meta medications, sedative medication, she was on strong pain killers so beyond her own abilities and personality that had a massive impact you know because a lot of the time she was in a semi conscious state at that time because she was in pain. Obviously our wish was for her to be comfortable and not in any pain and not have any distress. So I would say the medication would have masked her ability to express herself towards the end of her life definitely but we were all fully aware of that and knew that would be the case so planned care" (Gary, Ln.290-303, RNLD).

"we all wanted her to be very comfortable and not experience any pain because we wanted her to have a positive experience at that time you know and I would say overall she had that. I think she was pain free and comfortable and her family commented that she seemed extremely peaceful with herself and her surroundings at that time and they were very pleased about that. We provided care sensitive to her pain" (Gary, Ln.303-311, RNLD)

Sub theme from Note 16:

Sub theme: Dying as part of living

".....obviously our main focus is about people having quality of life but you know part of your life, death is part of life and equally they should have quality at the end of life just as well as during their life and more so in terms of our moral role to provide a dignified end. So at such time we need a really focused time when you really need to have things in place and more so you really need to direct everything at that time to make sure they are comfortable and we have that now so that puts us at a huge advantage I would say" (Gary, Ln.379-388, RNLD).

Sub theme from Note 17:

Sub theme: Comfortable care environment

"Her room even though it was small it did lend itself quite well to having regular visitors and for the last two weeks of her life she was bed bound so she remained in her bedroom at that time so she was able to have visitors in private which made things easier so family could have private time with her" (Gary, Ln.215-221, RNLD).

Sub theme from Note 18:

Sub theme: Optimism

"People with learning disabilities as we know they're living much longer than previously and that's fantastic but along with that there are illnesses associated with old age. As learning disability nurses we possibly haven't come across as much in the past you know dementia is a big part of that, all the associated

illnesses around dementia. We can provide specific dementia care here so as our clients age we are going to meet the needs a lot more effectively than perhaps we would have previously" (Gary, Ln.393-402, RNLD).

"So I think the way we are evolving and for the future we can provide everything we have previously supplied in terms of people's quality of live and having a person centred approach but we can then extend that throughout the life and provide the right approaches you know in end of life as well. So I think that puts us at an advantage and I think learning disability homes that are quite static in terms of the client group that they have people who live there throughout their life need to evolve in that way because that's the kind of care we need to provide really" (Gary, Ln.411-422, RNLD).

Sub theme from Note 19:

Sub theme: Future improved access

"You know the Government is looking at people being cared for more in their own homes towards the end of life, there is a real push for that, and I think we can really be at the forefront of that really. We have those skills and there is no reason why other learning disability homes can't do what we have done because you know we are not unique in any other way, we have just developed that. So you know, I could see other learning disability homes developing in the same way..... So it's just building on that really in terms of the clinical skills and things around that. All these will ensure future improved access" (Gary, Ln.422-435, RNLD)

Step Three: The Clustering process:

This example of the clustering process has been based on just a single transcript for purposes of clarity in terms of the data analysis process. The sub themes and main themes as elucidated here are drawn exclusively from Gary's (a single participant's transcript). See the body of the thesis for details of sub themes from the thirteen participants' transcripts and how they were clustered into main themes and for examples detailing quotations from all participants' transcripts.

The sub themes building relationships with PCDLD, their families, and amongst professionals as expressed by Gary were clustered under the first main theme of *Knowing by building relationships*.

Two sub themes specifically: Successful care, and Pride and job satisfaction, which related to caring outcomes, were clustered under the second main theme of *Positivity in successful caring outcomes*.

The succeeding two sub themes namely: Sincerity and sensitivity in care, Positive regard of personhood, which could all be associated to compassion in care were grouped under the third main theme of *Humane care*.

The next four sub themes: Training and skill development, Training and moral duty, Pain free care, and Acknowledgement of shortcomings, which were linked to RNLDs' obligation in providing the best possible care for this population as explained by Gary, were clustered under the fourth main theme of *Moral duty of care*.

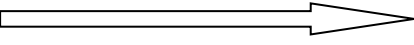
The ensuing sub theme: Dying as part of living, which portrayed relatedness to this participant's conscious awareness of time during care interventions was grouped under the fifth main theme of *Time to care*.

The sub theme: Comfortable care environment was maintained as the sixth main theme. This theme indicated a relatedness to this participant's recognition of the significance of the care environment in identifying factors which determined how PCDLD communicated distress and also, in identifying and responding to the distress of this population in palliative care settings.

The next two sub themes precisely: Optimism, and Future improved access elucidated this participant's awareness of the current limitations in the palliative care received by PCDLD and a commitment towards ensuring better palliative care and access in the future. These sub themes were grouped under the seventh main theme of *Future perspectives*.

The Clustering process: The identified sub themes from Gary's transcripts were clustered into main themes as follows:

Table: 1 Clustering themes: Sub themes into main themes

Sub themes 	Main themes
Building relationships with: -PCDLD. -Family members. -Between the PCPs and RNLDs. }	Knowing by building relationships
Successful care. Pride and job satisfaction. }	Positivity in successful caring outcomes
Sincerity and sensitivity in care. Positive regard of personhood. }	Humane care
Training and skill development. Training and moral duty. Pain free care. Acknowledgement of shortcomings. }	Moral duty of care
Dying as part of living. }	Time to care
Comfortable care environment }	Comfortable care environment/space
Optimism. Future improved access. }	Future perspectives

Step Four of the data analysis process

The transcripts and identified sub themes from all the thirteen participants transcripts were scrutinized. This was to ascertain the similarities or differences the phenomenon under study had for both the RNLDs and PCPs. I will be unable to provide examples here because Appendix 13 (worked example of the data analysis process) is based on a single transcript. See (Chapter Five, Section 5.2.4) for details of such comparisons.

Step Five: The Existential approach

This took into consideration the wider significance of the emerging themes as essential structures of the participants lived experiences within the framework of Van Manen's (1990) life-world existential themes of spatiality (lived space), corporeality (lived body), temporality (lived time), and relationality (lived relationships or communality). These existential themes were used as overarching themes.

Using Gary's transcript as an example, the seven main themes identified in his narrative were scrutinized for meaning related to the overarching themes, then mapped accordingly (see Table 2, below).

Table 2: Main themes (from Gary's transcript) mapped unto Van Manen's (1990) four existential themes as overarching themes

Main themes	Overarching themes (Van Manen's (1990) four life-world existential themes)
- Knowing by building relationships	Relationality
- Positivity in successful caring outcomes. - Humane care. - Moral duty of care	Corporeality
- Time to care.	Temporality
- Comfortable care environment	Spatiality
- Future perspectives	Extended dimension of Temporality

Step Six: The essence statement (or fundamental nature of the phenomenon of caring for PCDLD experiencing distress in palliative care settings).

This section presents the essence or the fundamental nature of the phenomenon of caring for distressed PCDLD in palliative care settings. The seven main themes identified in Gary's transcript (see Table 1 above) which had been subsequently mapped under Van Manen's (1990) life-world existential themes (see Table 2 above) were again scrutinized to identify any seamless interrelatedness of meaning.

From these themes (see quotations above) it was apparent that there was an interconnection between the RNLD's professional obligation to develop mutual

relationships with PCDLD, their family members and other professionals and also, an imperative commitment to develop new skills through training and collaborative working. This was to ensure optimum care to distressed PCDLD in comfortable palliative care settings.

However, it would be premature and misleading to arrive at an essence statement from a single transcript. Therefore, it was necessary to read back, and further examine the main themes which are a correlation of the clustering process of the sub themes from the thirteen participants' transcripts (see Chapter Six, section 6.7, pp.166-168) for a detailed explication of Step six of the data analysis process and the final essence statement that was arrived at. The goal was to construe from these main themes, a statement that intentionally captured and portrayed the understood meaning of the essence or fundamental nature of participants' experience of caring for this population. This was in terms of what was fundamental to effectively identify and respond to the distress of PCDLD in palliative care settings.

