In search of Care-strategies for Distressed People with Communication Difficulties and a Learning Disability in Palliative Care Settings: The Lived Experiences of Registered Learning Disability Nurses and Palliative Care Professionals.

ABSTRACT

Aim

The study aimed to gain an in-depth phenomenological understanding of the care strategies used by registered learning disability nurses (RNLDs) and palliative care professionals (PCPs) to identify and respond to the distress of people with communication difficulties and a learning disability (PCDLD) in palliative care settings.

Objective

The objective was to critically explore the lived experiences of RNLDs and PCPs who care for distressed PCDLD in palliative care settings

Design

A single phase hermeneutic phenomenological study following Van Manen provided the framework for synthesising and the structuring of the hermeneutic phenomenological text

Settings

Participants were drawn from learning disabilities nursing homes, community learning disabilities teams and hospices.

Sample

Purposive sampling was used and thirteen participants consisting of eight RNLDs and five PCPs were interviewed.

Methods

Data were collected by semi-structured, audio recorded interviews, fieldnotes, and demographic questionnaire. Hermeneutic data analysis was used. Ethical approval was gained from the University Research Ethics Panel and from individual research locations.

Findings

The primary strategies used by the participants to identify and respond to the distress of PCDLD were encapsulated by seven main themes: knowing by building relationships; positivity in successful caring outcomes; humane care; moral duty of care; time to care; comfortable care environment; and future-perspectives.

Conclusion

Effective care-strategies based on the above-mentioned findings can reduce the dilemma professionals encounter in addressing the distress of PCDLD and enhance their confidence to care.

Keywords

Distress, communication, palliative care, learning disabilities, hermeneutic phenomenology, Van Manen.

BACKGROUND

In the United Kingdom (UK), the term learning disability is synonymous to intellectual disability. My interest in caring for distressed People with Communication Difficulties and a Learning Disability (PCDLD) in palliative care settings was developed from working with adults with learning disabilities with complex health needs and life limiting conditions (LLCs) and the realisation that providing optimum palliative care to distressed PCDLD was inadequately addressed. I realised that this inadequacy was sometimes exacerbated when these individuals were unable to communicate their distress in a way that carers and staff could interpret. This impacted upon the care provided and accessibility to appropriate services including palliative care.

A personal experience of caring for a man with bowel cancer and pneumonia who died suddenly and the difficulties encountered in understanding and addressing his distress, by the learning disability nurses and palliative care professionals involved in his care, emphasized this inadequacy. This personal experience of providing care alongside the critical review of existing literature, revealed scarcity of applicable and dependable research that could contribute knowledge to the care strategies used by registered learning disability nurses (RNLDs) and palliative care professionals (PCPs) to identify and respond to the distress of PCDLD in palliative care settings.

It is worth-mentioning that in the context of this study, PCPs encompassed clinical nurse specialists, a palliative care nurse, and palliative care social worker. RNLDs included community learning disability matrons, nursing home managers, staff nurses and learning disability nurses with specialist training in older adults with dementia, epilepsy, and health facilitation (See Table 1). Both the RNLDs and PCPs were directly involved in the care of distressed PCDLD in a palliative care setting

Table 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)	I year 6 months	1year 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.

INTRODUCTION

Using the findings of a research study, this paper will illustrate the care-strategies used by registered learning disability nurses (RNLDs) and palliative care professionals (PCPs) to identify and respond to the distress of people with communication difficulties and a learning disability (PCDLD) within palliative care settings.

As with the general population, people with learning disabilities experience a range of life-limiting-conditions (LLCs) and need palliative care (Evans et al., 2012). For the RNLDs and PCPs, being able to provide palliative care to distressed PCDLD especially, when these individuals are faced with LLCs and death can be problematic and requires certain proficiencies. First, proficiencies needed to identify and alleviate distressing symptoms. Second, an understanding of distress, given that distress is a complex construct (Regnard et al., 2006).

In terms of proficiencies needed to alleviate distressing symptoms, this can be problematic for the RNLDs and PCPs due to the different categories of learning disabilities that effect a person's cognitive, psycho-social, and communication abilities and thus, impacts on how they communicate distress (Regnard, et al., 2006; Brown, et al., 2005; Evans, et al., 2012). In the UK, learning disabilities encapsulates significant limitation in intellectual functioning with intelligence quotient that is below 70 and significant limitations in adaptive behaviour as portrayed in conceptual, practical, and social skills, which begins before the age of 18, (Schalock et al., 2010). It affects about 2.5% of the population in the UK, with numbers likely to increase every year (Emerson and Hatton, 2008; Emerson et al., 2012). In England 1, 087,100 people who are known to the services are living with learning disabilities (Hatton et al, 2016)

and there are four categories of learning disabilities namely: mild, moderate, severe and profound learning disabilities (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, 2001).

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, 2001). 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, 2001).

In terms of the complexity of the concept distress, the predominant challenges that professionals encounter as reflected in the literature are associated with defining and differentiating the physiological, psycho-social, and spiritual components inherent in distress (Abelloff, 2004; Ridner, 2004). Furthermore, it is clear within the literature that distress does not have a common meaning among carers, it is not only related to pain, and is rarely portrayed from a holistic perspective (Regnard et al., 2006). Distress is often presented from physiological perspective with most papers focusing on the experience of pain, (Donovan, 2002; Hunt et al., 2003; Manfredi et al., 2003; Foley and McCutcheon, 2004). Papers reflecting psychological perspectives relate to

emotional issues and grief (Summers and Witts, 2003; Ryan et al, 2005). Other literature on distress tends to focus on communication difficulties (Black and Hyde, 2004; Todd, 2005; Tuffrey-Wijne and McEndhill, 2008; Cartlidege and Read, 2010).

Additionally, healthcare professionals often assume that assessing or detecting pain by observing behaviour or using self-report measures can provide accurate measures of distress or pain (Foley and McCutcheon, 2004). However, evidence suggests that these assessments are insufficient to address the needs of people with learning disabilities especially, when they are unable to communicate verbally their discomfort and when utilised by healthcare professionals who lack the necessary communication and care-skills (Foley and McCutcheon, 2004). Therefore, when accepting the complex nature of distress and the complexity of the care of this population, it becomes clear that distressed people with communication difficulties and a learning disability in palliative care settings, should be cared for by RNLDs and PCPs who are familiar with or have progressively developed a holistic understanding of this diverse population. This is important because intended care interventions and strategies are based on procedures for consent to treatment, which necessitates providing individuals with relevant information utilising appropriate communication methods and support (General Medical Council, 2008). However, there is a paucity of literature specifically focused on the care-strategies used by RNLDs and PCPs in identifying and responding to the distress of PCDLD within palliative care settings. To address this gap, a study set out to develop a better understanding of the issues by delving into the experiences of RNLDs and PCPs who routinely care for these individuals.

The underpinning research question was: What is the experience of caring for a distressed individual with communication difficulties and learning disability in a palliative care setting?

THE STUDY

Methods

The aim of the study was to gain an in-depth phenomenological understanding of the care strategies used by registered learning disability nurses and palliative care professionals to identify and respond to the distress of people with communication difficulties and a learning disability in palliative care settings.

The objective was to critically explore the lived experiences of RNLDs and PCPs who care for distressed PCDLD in palliative care settings.

A single phase hermeneutic phenomenological study following Van Manen provided the framework for synthesising and the structuring of the hermeneutic phenomenological text

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

The settings encompassed learning disability nursing-homes, hospices, and community learning disability teams in the North of England. Within the context of the study, palliative care settings are defined as any setting where individuals are receiving any form of supportive or specialist palliative care treatment. This included not only hospices and intensive-care units but also community based nursing homes, private homes, day-services, respite, residential or supported-living settings where there are nurses and other professionals in attendance to meet a person's holistic needs.

Participants were purposefully selected based on their position and experience to capture a diverse representation of age, gender, and experience of RNLDs and PCPs

in palliative care settings. Participants were included in the study if they were: RNLDs and PCPs and have experience of, or are working with distressed PCDLD in palliative care settings, willing to articulate their experiences, and over the age of 18 years. Participants who did not meet the above criteria were excluded.

To recruit participants, 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.

An informed consent form and an information sheet detailing the nature and purpose of the study were also enclosed. 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 the researcher. 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 the interviews.

Data collection methods and procedures

In a short piloting phase, 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 allowed for the suitability of the questions to be

tested and for the questions to be refined before the commencement of the actual data collection.

Data were collected by in-depth, semi-structured, face to face, audio-recorded interviews, fieldnotes, and a demographic questionnaire. The period of data collection was from 2011-2014

The interviews followed a phenomenological approach by being purposefully directed to participants lived experiences encapsulating their beliefs, feelings, and convictions about the phenomenon of caring for PCDLD within palliative care. Participants were asked about their experiences of caring for an individual with communication difficulties and a learning disability who experiences distress within palliative care settings. Prompts were used to develop their responses to this central phenomenon in order to gain an understanding of the care strategies they used to identify and respond to the distress of PCDLD within palliative care settings. The time and place for the conduct of the interviews were based on participants' preferences, which could be a quiet room in their work-setting or one in the university campus. The interviews lasted between twenty-five to ninety minutes, and were flexible because participants were free to stop at any given point if they chose. This allowed the participants the time and scope to talk about their opinions and helped to build vital rapport and trust.

The fieldnotes included a combination of raw data from participants' interviews, personal reflections, and detailed descriptions that enhanced the remembrance of events in the setting. These were written during and immediately after each interview session. The interviews were transcribed verbatim as soon as possible after the interview session and the field-notes were added to the transcripts of the interviews.

Analysis

The data analysis for the study was undertaken by the researcher. It was done on paper using Microsoft Word in order to maintain hermeneutic closeness with the text. The transcripts were given to participants to check that they accurately reflected their interviews and the academic supervisors assure rigour of the data analysis throughout by ensuring that the emergent themes truly reflected the transcripts. Maintaining rigour in the analysis of qualitative research data can be challenging, therefore a research mentor (academic supervisor) especially with more experience in the specific methods or topics in which one is interested, can be instrumental (Corbin and Strauss, 2015; Marshall and Rossman, 2016).
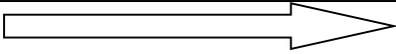
The hermeneutic data analysis process used in the study was framed by Van Manen's (1990) precept of hermeneutic data analysis. This process comprises the initial approaches of isolating themes: the "*wholistic*" approach, the selective or highlighting approach and the detailed or line by line approach, and considers the four life-world existential-themes: corporeality, relationality, temporality, spatiality, and six research activities. Key to a phenomenological study is the need to identify an essence statement that represents the main themes and provides a symbolic response to the research question. Following the verbatim transcription of participants' transcripts, subthemes were identified using the "*wholistic*" approach, selective or highlighting approach, and the detailed or line-by-line approach. Nineteen subthemes were clustered into seven main-themes to determine the essence statement **(See Table 2).**

Table 2 Clustering themes: sub themes into main themes
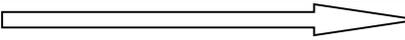
Sub themes	Main themes
1. Building relationships: -with PCDLD. -Family members. -Between the PCPs and RNLDs.	Knowing by building relationships
2. Successful care. 3. Pride and job satisfaction.	Positivity in successful caring outcomes
4. Sincerity and sensitivity in care. 5. Positive regard of personhood. 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

Each of the seven main-themes is presented in more details with supporting quotes in the findings section. The seven main-themes are then mapped unto the overarching framework of Van Manen's existential-themes **(See Table 3)** to establish their wider significance as essential structures of the participants' lived-experiences. The data are then examined to arrive at the essence statement. These will be presented in the Findings section.

Table 3: Main-themes mapped onto 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

FINDINGS

Thirteen interviews were conducted lasting from between twenty-five to ninety minutes. Quotes from the participants using pseudonyms have been used to maintain participants' anonymity. It is important to note that although there was commonality in the approaches used by both professional groups (the RNLDs and PCPs), the major difference identified was around professional expertise and experience, which consequently, accounted for the confidence or lack of confidence in providing care to this population. Edith, a clinical nurse specialist explained that:

> "…*What I lacked in skills about learning-disabilities they (the RNLDS) were able to sort of advice me and we worked together really well*" *(*Edith, Ln, 67-69, CNS).

Jane stated:

> "*Learning disabilities and palliative care we share some similar person-centred care-approaches but have different skills…*" (Jane, RNLD).

The seven main-themes identified were as follows:

Theme 1: Knowing by building-relationships

Participants explained that Knowing by building-relationships was an approach used to care for PCDLD who are distressed within palliative care. Knowledge to care was developed by building 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 facilitated the response to their distress with the

provision of optimum care. Sue, a Clinical nurse specialist (CNS) confirmed the importance of knowing by building relationship:

> *"Right, getting to know him...he had a standard phrase…and I think we soon learnt that the more he said that it indicated his level of distress" (*Sue, Ln. 43-49, CNS).

The professional relationships with family members and carers, allowed for the attainment of foundational and historic knowledge required to understand the distressed PCDLD as Jane explained:

> "*They had worked with him for about 5 years so they were a great source of err valid information*" (Jane, Ln.128-139, RNLD).

Gary talked of the significance of knowing the family and the deficits of relying on written documentation:

> "…*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"* (Gary, Ln.497-509, RNLD).

Collaborative-working, honest, mutual professional-relationships, and support for each other was a strand of Knowing by building relationships that ensured quality care for the PCDLD in palliative-care settings as Edith said:

> "*"...working collaboratively with different professionals...I think it benefits the patients and their journey using if you like, a multi-disciplinary approach,"* (*Edith, Ln.126-132, CNS).

Theme 2: Positivity in Successful Caring-Outcomes

The participants described Positivity in successful caring-outcomes as another strategy to care for distressed PCDLD within palliative care settings. The participants explained that this encompassed being conscientiously reflective in terms of drawing from positive and successful past professional and personal experiences of caring for this population, to plan current and future care.

Paula a palliative care nurse (PCN) explained how reflecting on and utilising skills from positive and successful past professional and personal experiences of caring for this population, can enhanced the provision of appropriate confident care:

"*…I have personal experience with learning difficulties. My sister's son has autism err, and sometimes she can be very protective. I understand though. …It is that understanding of your own self as a person and a personal experience that sometimes gives you confidence to care,*" (Fieldnotes, 6/12/11: Paula, PCN).

Ultimately, such thorough reflection in terms of utilising skills from past positive experiences of care allows for confident care to alleviate the distress of PCDLD and creates a sense of pride and job satisfaction. Lynn said:

"*It was how his family wanted it to be…we were satisfied that we were able to meet his need as he wanted and the family were happy and he had a dignified dead*" (Lynn, Ln.242-254, RNLD).

Theme three: Humane-Care

Participants considered humane-care as another approach to care for distressed PCDLD in a palliative care setting. Humane-care as described by the participants included: making a deliberate effort to ensure that sincerity and sensitivity, positive

regard of the whole person, empathy, and the use of therapeutic touch were embodiment of the care provided to distress PCDLD. Participants explained that humane-care allowed them to be sensitive, to be physically and authentically present in the world of the distressed individuals, and to alleviate their distress.

Lyn talked of the importance of seeing the whole person:

"...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..." (Lyn, Ln.242-258, RNLD).

Jade explained that touch could be an authentic means of being present and for relieving distress:

"…..he was very restless and he was groaning a lot…that sort of indicated to us that he wasn't really settled…. 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).

Tracy reiterated:

"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...a good death" (Tracy, Ln.404-413, RNLD).

Theme 4: Moral-duty of care

Moral-duty of-care was described by participants as another strategy employed to care for distressed PCDLD in palliative care settings. Participants' explanations portrayed Moral-duty of care first, as an obligation in maintaining moral standards of care by acknowledging any personal shortcomings related to the care of distressed PCDLD.

Second, training to overcome the shortcomings and subsequently, utilising their newly enhanced specialism to provide the best possible care that includes alleviating distress throughout the individual's disease trajectory.

 Moira declared:

"Whatever shortcoming that I had…you know…I had faith in myself to be able to overcome those shortcoming" (Moira, Ln.154-156, RNLD).

Gary explained how training had helped shift the focus of their service and highlight the importance of dignity:

"*I think GSF (Gold Standard Framework) training has changed us as a service…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…"* (Gary, Ln.375-388, RNLD).

Theme 5: Time-to-care

For the participants, time-to-care was fundamental to the care of distressed PCDLD within palliative care settings. Participants described this as effective time management, which must take into consideration anxiety, caring opportunities, and dying as part of living. Participants explained that time was limited and yet a priority for these individuals and their families. Therefore, participants had to be mindful to provide optimum care, yet having to work within the constraints of available time and certain human limitations. Human limitations in this case included healthcare bureaucracy and the anxiety of delivering care outside professional expertise or

familiar care settings, and the dilemmas of where they fit in the bigger picture of palliative care and learning disability services.

To emphasise the significance of effective time management, Lyn talked of the frustrations of dealing with bureaucratic delays:

> *".... this young man, he was actually in transition, and he was just coming from... children's services into adult services, ...and there wasn't an automatic referral into the adult palliative care team...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…"* (Lyn, Ln.178-198, RNLD).

Tracy reiterated:

> *"I think.... for learning disabilities, it's important to get involved early… 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).

Theme 6: Comfortable care-environment

Purposely ensuring a comfortable care-environment was deemed as another strategy to care for distressed PCDLD within palliative care settings. Participants' narratives portrayed that 'Comfortable care-environment' encompassed aesthetic-knowing, which meant that to identify and alleviate any cultural distress related issues, participants knowingly adjusted the available care-environment to plan care that was sensitive to the spiritual, cultural and religious inclinations of the distressed and dying person. Gary explained:

> *"...She didn't want to be in a hospice, she wanted to be in familiar surroundings. ...for the last two weeks of her life she was bed-bound so she remained in her*

bedroom, …which made things easier so family could have private time with her. She was religious so she was able to have a priest visiting...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…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).

Theme 7: Future-Perspectives:

Participants explained that taking into consideration 'Future-perspectives' was fundamental to the care of distressed PCDLD in palliative care settings. Participants explained that this comprised: being proactive in anticipating potential drawbacks to learning disability and palliative care service provision in order to ensure future quality care for distressed PCDLD in palliative care settings. Participants highlighted that present and future hindrances to care such as poor funding, lack of autonomy, and poor access must be proactively identified and addressed. Laura talked of the issue related to funding and explained:

> "*I think one of the things that ... we in the learning disabilities and palliative care group would like to see is that 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).

Linking the main-themes to the overarching lifeworld existential-themes

The seven main-themes were mapped onto Van Manen's four existential-themes as overarching themes (See Table 4). This was to emphasise how these main-themes resonated with the existential-themes and their wider significance as crucial constructions of the participants' lived-experiences of caring for this population. Brief explanations are provided followed by, the essence statement.

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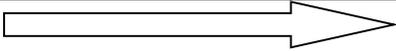
Main-themes	Overarching-themes (Van Manen's (1990) four life-world existential-themes
1. Knowing by building relationships	Relationality
2. Positivity in successful caring outcomes. 3. Humane-care. 4. Moral duty of care	Corporeality
5. Time to care.	Temporality
6. Comfortable care-environment	Spatiality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

Relationality resonated through the finding *'knowing by building-relationships'* as it reflected how the participants sustained relationships with lived others consisting of PCDLD, their family members and the participants themselves.

Corporeality was evident within three themes: 'positivity in successful caring-outcomes', 'humane-care', and 'moral-duty of care' as these themes incorporated participants' awareness of the need to be authentically present to be able to provide palliative care that encompassed sincerity and sensitivity.

Temporality encapsulates our temporal way of being in the world (Van Manen, 1990). Temporality echoed through the themes 'time to care' and 'future-perspectives' as

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.

Spatiality relates to 'lived-space' (Van Manen 1990). Spatiality resonated through the theme of 'comfortable care-environment', which encompassed the participants' discussion on planning care that was sensitive to the spiritual, cultural and religious needs of the distressed and dying PCDLD within the limitations of the actual care environments.

The essence-statement

The goal of the continual examination of the totality of the text was to construe a statement that portrayed the meaning of the fundamental-nature of participants' experience of caring for distressed PCDLD. The essence-statement arrived at was:

> Optimism and commitment in building personal and professional relationships, and utilising specialist and physical skills, to provide timely optimum humane-care to distressed people with communication difficulties and a learning disability within comfortable palliative care settings.

The essence-statement representational of the seven main-themes, resonated with Van Manen's lifeworld existential-themes, and was symbolic of a response to the research question. The essence-statement was indicative of the process of caring for distressed PCDLD in palliative care settings as experienced by the participants and had implications for a proposed theoretical model of caring for this population. This will be discussed in a subsequent paper.

DISCUSSION

Caring for distressed PCDLD receiving palliative care is complex and challenging. The findings of the exemplar study are unique but to some extent, resonate with existing literature. The finding '*Knowing by building relationships*' addressed the issue of communication from a holistic perspective. This theme emphasised that comprehensive knowledge is required to care for distressed PCDLD within palliative care settings, and can only be achieved realistically by building relationships with the PCDLD, family members, and amongst the professionals themselves. Such knowledge would ensure appropriate communication and empower participants with the ability to anticipate and address individuals' distress. This view to an extent, echoed the significance of communication identified by Read (2005) and Tuffrey-Wijne and McEndhill (2008). Read (2005) emphasised the significance of communication to enable quality palliative care for people with learning disabilities (PLDs). Concurrently, Tuffrey-Winje and McEndhill (2008) established that communication problems in palliative care result from the failure of professionals to communicate accurately in order to be understood by the clients, and 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.

Purposefully addressing the distress of PCDLD through a humane and positive regard of the whole person was seen by the participants to be fundamental to ensuring confident and high-quality care. To an extent, this concurred with Black and Hyde's (2004) findings that relate to assuring confident care. Black and Hyde noted that person centred care protocols, which accommodate people with profound learning disabilities, effective discussions and on-going clinical support amongst the multidisciplinary teams help reduce the fear experienced by nurses and healthcare

professionals in caring for PLDs. Despite Black and Hyde's (2004) contribution about the factors that can support the confident care of PLDs, the focus of their work was on cancer care, while this study considered the wider context of LLCs and associative distress.

The concept of adjusting the care-environment to reduce the distress of the PCDLD by ensuring that it was as supportive and culturally and aesthetically appropriate as possible was central to the findings of this study. Participants emphasised the importance of identifying and responding appropriately to any emotional, spiritual, or psycho-social distress experienced by the PCDLD and to ensure that care was planned as optimally as possible within the constraints of the care-environment. Personalising care helped professionals to meet the spiritual, cultural, and religious needs of the PCDLD and to maximise their rights, autonomy and their choices such as where they wanted to be cared for. This is contrary to Tuffrey-Wijne's (1998) findings that demonstrated that many PLDs are denied the chance of dying in their own homes. The cultural relevance of care is also seen to be important in Flower's (2004) work; she argues that of the many variables known to influence health beliefs and practices, culture is one of the most influential.

Time was identified as a key issue in terms of delivering optimal care, not just in terms of considering the care that needed to be delivered now and in the short-term future but also considering the longer-term care needs and issues such as transition. Better access to a more accessible, consistent, and integrated model of palliative care across children's specialist palliative care, adult and community palliative care services. These findings align with existing literature that argues the need for more seamless, flexible, and accessible services (Addicott and Ashton, 2010) and that end-of-life care should feature in the other care pathways not just cancer. The participants in this study

identified the benefits of training and education and this is echoed in the work by Evans et al., (2012) who recommend that to improve inequality in cancer care healthcare staff must attend awareness sessions about making practical adjustments for PLDs when they are hospitalized.

A limitation of the study was the small sample size and therefore generalisation is not possible although generalisation is rarely a consideration of a phenomenological study. After completing 13 interviews and undertaking analysis, it appeared that saturation had been achieved as 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).

This study has highlighted the need for training, and the recognition that positive caring outcomes and experiences were sources of knowledge, which served as a precedent to plan future care. The implication for nursing research, and nurse education is the need for longitudinal studies on RNLDs and PCPs lived experiences of caring for PCDLD within palliative care, and the need to embed such lived-experience concepts within nursing curriculum. This will enhance learning for pre-registration students and continuing professional development of social and healthcare professionals. This is especially important because nursing practice placements on palliative and end-of-life in real life situations are difficult to orchestrate for students.

CONCLUSION

Identifying and addressing the distress of PCDLD within palliative care can be a complex issue. In an attempt to describe more adequately how to care for PCDLD experiencing distress within palliative-care, reduce the dilemma professionals encounter in addressing the distress of PCDLD within palliative care, and enhance

their confidence to care, an essence statement was developed within a hermeneutic framework. The statement reads: 'Optimism and commitment in building personal and professional relationships, and utilising specialist and physical skills, to provide timely optimum humane-care to distressed people with communication difficulties and a learning disability within comfortable palliative care settings.

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