An Interpretative Phenomenological Analysis of Community Nurses

Experiences of Providing end of life dementia care

(Preliminary thesis findings)

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This is a presentation of preliminary findings for my professional doctorate thesis.

Abstract:

Aim:

The aim of the research study is to explore community nurse's first-hand experience of providing end of life dementia care and the meaning they attribute to their experience.

Methodology and Methods:

The study utilised a qualitative research approach, specifically interpretative phenomenological analysis (IPA). A purposive sample of six qualified community nurses with experience nursing terminally ill people with dementia was recruited. Data was collected using face-to-face semi-structured interviews. Interview themes, rather than an interview schedule, were utilised. The interviews were audio taped and transcribed for analysis. Data was analysed in line with IPA, in which transcripts were read and re-read. Emergent themes are clustered into sub-ordinate themes. Sub-ordinate themes for individual participant transcripts are clustered into super-ordinate themes.

Preliminary findings:

Preliminary findings from this study highlight the following superordinate themes:1. Pride and pleasure 2. It's Overwhelming, 3. Objectification, 4 Up skilling

Discussion:

Community nurses experienced a paradoxical interplay of joy and despair. Furthermore, nurses seem to have a contrasted desire to provide compassionate care for the dying patient but also wanting to distance from death. Nurses identified the impact of repeated exposure to grief but felt they did not have permission to grieve. Some participants have developed self-care strategies to cope with the stressors and on-going exposure to death associated with providing end of life dementia care.

Key words: IPA, end of life, dementia, community nurses

Problem Statement:

Nurses providing end of life dementia care are routinely exposed to patient deaths. In the United Kingdom approximately 850 000 individuals are diagnosed with dementia, this figure is projected to rise to one million by 2025 (Alzheimer's society, 2018). Approximately one third of those age over 60 years, that is about 100 000 people die with dementia each year, the majority of these cases receive nursing care (Sampson, Burns and Richards, 2018; Birch and Draper, 2008). Furthermore, there is poor appreciation of the pathophysiology of dementia among nurses and other clinicians that may lead to poor end of life dementia care as they are not perceived to have a terminal illness (Sampson, Burns and Richards, 2011). Demands of an ageing population suggest that the need for end of life nursing care will increase (Crowther, 2013).Even though there is an increase in end of life dementia research (van der Steen, 2014), there is a dearth of research focusing on the experiences of nurses providing end of life dementia care.

Caring for individuals with end stage dementia is considered stressful, emotionally draining and exposes nurses to vicarious trauma (Meller et al. 2019, Costello, 2001; McCreight, 2004; Age UK, 2013). Moreover, the NHS staff and learners mental wellbeing commission (2019) acknowledges that, nurses carry with them a lifetime of bereavement by exposure. Yet there is limited studies exploring nuanced psychological and sociological facets of grief from a nurses perspective (Meller et al. 2019). Notwithstanding this, some nurses are reluctant to talk about their experiences or receive formal support (Wilson and Kirshbaum, 2011). This is hardly surprising as nurses have a reputation for 'coping' and tend to put other's

needs before their own (Burnard and Chapman, 2004). Death education and social support in professional education has been identified as an area for further development (Bailey, Murphy & Porock, 2011). Notwithstanding, that training on end-of-life care for nursing staff are effective in improving knowledge and increasing satisfaction with end-of-life care in bereaved family members (Arcand et al. 2009).

Nursing is associated with stress, burnout and compassion fatigue (Hegney et al 2014; Harrad and Sulla, 2018), resulting in absenteeism, staff sickness, poor moral and high staff turnover (Maben et al 2012; Gartner et al 2010). Stress and burnout significantly increases nurses' frustration and intention to leave the profession (Flinkman et al 2010). Studies suggest that about 10% of the nursing workforce intend to leave the profession prematurely (Flinkman et al, 2013; Health Education England, 2018). It is not surprising that in a recent survey two thirds of nurses identified staffing shortage as the main barrier to providing good care to dying patients (Marie Curie, 2019). Additionally, an inquiry by the UK Equality and Human Rights Commission (2011) concluded that time constraints and high levels of staff turnover pose a challenge to providing even a basic standard of end of life dementia care.

There is a huge amount of literature exploring patient and carer experience of dementia care (Sims-Gould et al. 2010; Livingston et al 2013; Lee, et al 2017). However, there are limited studies that explore the experiences of nurses providing end of life dementia care.. In light of the background there is need to explore further, the lived experience of nurses giving end of life dementia care because this presents a high risk of burn out for nurses (Rizo-Baeza, et al. 2018).

Purpose of this study:

This study explores how community nurses caring for end of life dementia patients make sense of their experience. The question the present study is seeking to answer is: How do community nurses make sense of their experience of providing end of life care for people with dementia? Where earlier research focused on carers and barriers to good end of life care for people with dementia, this study focus on the individual nurses' experience using Interpretative Phenomenological Analysis (IPA).

The following section builds on the central issues discussed here, the concept of stress and resilience is discussed, followed by the transitional model of stress and coping.

Conceptualisation of stress and Resilience in nursing care:

The relationship between occupational stress in nursing and the adverse impact on quality of life as well as its negative impact on patient outcomes is well documented in scholarly literature (Mark and Smith, 2012; Sarafis et al, 2016). It is widely accepted that nurses need to be more resilient in order to be more effective in their role of caring for the infirm (Sarafis et al, 2016). However, one of the big challenges for nursing, researchers and nurse educators is how to train nurses with an ability to bounce back from stressful situations and from adverse events (Chamorro-Premuzic and Lusk, 2017). This conception of stress and resilience is not a linear, bi-directional psychological process. A more helpful conception is from Lazarus and Folkman (1984) who in their seminal work depict stress and coping as existing in a continuum for the individual. At one end of the spectrum is the primary appraisal or assessment of threats and challenges. Whilst the other end of the spectrum is secondary appraisal or coping options

This dynamic model seems to fit well with end of life dementia care because it considers cognitive approaches as opposed to fight-flight approach to stress. Furthermore, it accommodates individual differences in how we appraise and cope with stress. However, one has to acknowledge that further work needs to be done to establish empirical evidence on the application of this model to end of life dementia care and if it helps nurse develop resilience and thrive in stressful caring situations.

Research Design:

This is a qualitative study utilising IPA methodology. The present study sought to understand how nurses make sense of their experience of providing end of life dementia care, therefore, IPA which, focuses on meaning and sense-making of people's experiences and their relationship of the world was more appropriate methodology (Larkin and Thompson 2012, Smith, Flower and Larkin, 2009). Moreover, the study focuses on the meanings of the participants' experiences, and the idiographic emphasis of IPA which stresses on the particular rather than the general (Larkin and Thompson, 2012) was more appealing. What's more, the hermeneutic ideals of IPA which, stresses on interpretation as well as an opportunity to develop an explicit critique of narratives using metaphors in the context of the participants' narratives (Larkin and Thompson, 2012) was equally attractive. Taken together, the reflexivity embedded in IPA will provides a leverage for me as a nurse, a researcher, and a nurse educator to analyse the data in an open-minded and transparent manner.

Method:

The target population of this study is qualified nurses undertaking post-registration study at the University of Wolverhampton. A purposive sample of six community nurses with experience of end of life dementia care was recruited.

Data collection:

Data was collected using semi structured interviews. This interview approach has been adopted to allow participants to include as much information, including emotions, meaning and sense making, of their experience nursing people with end stage dementia.

Interview themes rather than a schedule with specific questions was used. Face-to-face interviews were audio taped with consent from participants. The recordings were transcribed verbatim. Semi-structured interviews are appropriate for my research question as they collate descriptions of the life-world of the participants (Kvale, 2013). Face-to-face interviewing is advantageous as it is synchronous in time and place, which allows me as the researcher to respond to social cues such as voice, intonation and body language. I made note of the cues and add them to the audio answers of the participants. Furthermore, face to face interviewing gave me an opportunity to create a good interview ambience (Opdenakker, 2006). Interviews lasted a maximum of 60 minutes; however, this time was flexible.

Table 1: Characteristics of participants

Pseudonym	Gender	Ethnicity	NMC Registration	Length of Experience of ELDC	Area of Practice
Pam	Female	Asian British	Registered General Nurse (RGN)	6 years	Community
Grace	Female	White British	RGN	3 years	Community
Olivia	Female	White British	RGN	8 years	Community
Tracey	Female	White British	RGN	5 years	Community
Yvonne	Female	White British	RGN	6 years	Community
Theresa	Female	White British	RGN	10 years	Community

Data Analysis:

Data was analysed using Interpretative Phenomenological Analysis (IPA) (Smith et al. 2009). This consisted of immersion in the original data by listening to recordings numerous times (for tone and rhythm of voice). The recordings were transcribed including notes on how things were said (tone, rhythm, rate, pauses and hesitations as these can reveal underlying emotions or irony). Transcribed text was analysed to identify emerging themes. Emergent themes were clustered into sub-ordinate themes. Sub-ordinate themes for individual participant transcripts were clustered into super-ordinate themes.

Preliminary Results:

Four preliminary superordinate themes with subordinate themes emerged from the data analysis (Table 2).

Table 2: List of superordinate and subordinate themes

Superordinate themes	Subordinate themes
Pride and pleasure	• It's gratifying to be a nurse • No Better feeling
It's Overwhelming	• It's Stressful • Grief and Depression
Objectification	• Syringe driver
Upskilling	• Before it was just cancer • A little more training

Discussion:

This section locates the findings in the context of existing literature. The results of community nurses' experience of providing end of life dementia care highlights ambiguity of feelings due to the interplay between satisfaction and despair (Popova, 2018). End of life dementia care seems to generate psychological dissonance in nurses resulting in feelings of stress. Chronic stress can result in nurses developing depression and compassion fatigue (Costello, 2001; McCreight, 2004). There seems to be a paradox between satisfaction and despair, this is depicted in the superordinate themes; 'pride and pleasure' and it's overwhelming'. This shows the complex emotions nurses feel when providing end of life dementia care. Preliminary findings from this study seem to indicate that community nurses experienced a paradoxical interplay of joy and despair, this ambiguity of feelings seems consistent with nurses' experiences of providing end of life dementia care. End of life dementia care seems to generate psychological dissonance in nurses resulting in feelings of stress. Chronic stress can result in nurses developing depression and compassion fatigue. The results however, seem to demonstrate that this is not clear-cut. There seems to be a paradox between satisfaction and despair, satisfaction when care provided is deemed of good quality and despair when nurses feel ill equipped to provide care that patients need.

Pride and pleasure:

Findings from this study demonstrated that participants ascribed feelings of pride and pleasure when providing end of life dementia care. Cottrell (2018) has written comprehensively about the notion of joy in end of life care. However, her study focuses on joy in relation to patient receiving end of life care rather than the joy and pleasure that nurses may experience when providing end of life care. The notion of joy and pleasure in end of life nursing care seems counter intuitive. This is

because of the complex nature of the paradoxical interplay of joy and despair in end of life dementia care. This is aptly captured in a paper by Popova (2018) in which she discusses the paradox of joy and despair, this ambiguity of feelings seems consistent with nurses' experiences of providing end of life dementia care. End of life dementia care seems to generate psychological dissonance in nurses resulting in feelings of stress. Chronic stress can result in nurses developing depression and compassion fatigue. The results however, seem to demonstrate that this is not clear-cut. There seems to be a paradox between satisfaction and despair, satisfaction when care provided is deemed of good quality and despair when nurses feel ill equipped to provide care that patients need.

It is prudent to exercise some caution with this analysis great pride and pleasure as its easy for nurses to express what is expected of a good nurse. Williams (1954) notion of 'structure of feeling' which he defines as a dominant cultural character or thought with a value system of behaviour and attitudes, therefore, structure of feeling can dictate how members of a group behave in response with public expectation of their lived lapses and consequences. Williams discussed structure of feeling in the context of social acceptability of certain conversations; even though this had nothing to do with nursing this is applicable to the dominant culture of end of life dementia care.

It's Overwhelming:

The analysis has demonstrated that end of life care is emotional work, which carries a risk of stress, and burnout (McQueen, 2004). From this analysis end of life dementia care emerges as emotional labour that can evoke complex feelings of stress and grief. Although the themes and points raised by this analysis may seem

obvious and humdrum this shines a spotlight issues that are important for end of life dementia care nurses. Consistent with the thesis finding a study by Roger and Atwal (2018) noted that health organisations advocate a good death. However, there seems to be lack of recognition and active acknowledgement of the emotional impact regular exposure to patient deaths can have on nurses.

This lack of recognition of seems to be taking place in a context where there is an ongoing societal discourse on how best to deal with complex end of life dementia care issues. The study by Seale et al. (2015) argues that it is important to look closely at the circumstances in which the debates are taking place because this has a bearing on the nurses' attitudes. Johnstone, (2011) highlights that end of life dementia care is within the nursing profession one of the least glamorous of nursing roles, resulting in significant staff shortages which lead to nurses over working and suffering from burn out. Lee, et al., (2017) further argues that nurses working in community dementia care are predominantly lone workers which can create perceptions of being alone which predisposes them to feeling overwhelmed.

In an attempting to contextualise end of life dementia care within a wider societal discourse Johnstone, (2015) introduces the notion of alzheimerisation; which he defines as a process of placing less value on individuals with Alzheimer's disease or dementia in general. This in essence leads to a subtle acceptance by society that individuals with advanced dementia are unredeemable resulting in inferior end of life care due to poor government funding policy. It is important to note, that this feeds into a discourse of dementia as a burden on society; resulting in the acceptability of underfunding & suboptimal end of life dementia care. This has a direct impact on nurses who provide the bulk of end of life dementia care which can manifest as work related stress and poor mental health (Johnstone, 2015, Lee, et al., 2017).

Consistent with the above assertions a study by van den Block et al., (2014) exploring the burden of caring for nursing staff, identified the benefits of nurses' intense contact with dying patient, however this resulted in emotional burden among nursing staff which affected decision making. Nurses' role consists of advocating and promoting the interest of individual patients, this raises the question of how far nurses can immerse themselves in each patient's predicament before it has an impact on the nurse (Paulsen, 2011). There is no doubt that emotional presence enhances nursing care however 'feeling patient's pain' can be emotionally taxing on the nurse especially in end of life dementia care.

Furthermore, there is depth of literature supporting this; a study by Meller et al (2019) argues that caring for individuals with end stage dementia is considered stressful, emotionally draining and exposes nurses to vicarious trauma (Age UK, 2013). Moreover, the NHS staff and learners mental wellbeing commission (2019) acknowledges that, nurses carry with them a lifetime of bereavement by exposure. Yet, there is limited studies exploring nuanced psychological and sociological facets of work related stress and grief from a nurses' perspective (Meller et al. 2019). Notwithstanding this, a study by Wilson and Kirshbaum, (2011) found that some nurses are reluctant to talk about their experiences or receive formal support This is further supported by Burnard and Chapman, (2004) who argue that this is hardly surprising as nurses have a reputation for 'coping' and tend to put other's needs before their own. Furthermore, the ambivalence of not seeking help is supported with a quote by Nussbaum (2016):

"The society that incorporates the perspective of tragic compassion into its basic design thus begins with a general insight: people are dignified agents, but they

are also, frequently, victims. Agency and victimhood are not incompatible: indeed, only the capacity for agency makes victimhood tragic".

At a basic level the analysis seems to show a conflicted picture, of caring professionals and wounded healers. This is consistent with the work of Nussbaum (2016) on trauma & tragedy and agency & victimhood. She argues that a victim of misfortune shows us our own vulnerability to misfortune and we have reason to fear similar adversity. She further argues that the conditions that produce basic framework of victimhood highlight the dual nature of the human experience; 'we are at once agents of and vulnerable to the whims of larger systems over much of which we have no control'. Traditional research into nurses' experience of providing end of life care seems to provide a superficial exploration of their experiences without dealing with the psychological nuances of their experience. This analysis seems to highlight the emotional dissonance between providing good end of life dementia care and the emotional toll on the nurses.

Moreover, Nurses value therapeutic alliance with their patience. This is a challenge when caring for people with end stage dementia due to cognitive decline. This can cause angst among nurses caring for this client group because when patients present as agitated, nurses' resort to provide predictive care. This seems to generate stress among nurses because the patients unable to articulate their care needs.

The thesis finding where staff expressed grief hidden from others is consistent with findings form a study by Wilson and Kirshbaum (2011) that found patient death can result in disenfranchised grief. Disenfranchised grief is a term that was coined by Ken Doka in which he defined disenfranchised grief as grief individuals experience

following a loss that is not openly acknowledged, publicly mourned or socially supported. (Doka 1989, Meyers 2019). This notion of disenfranchised grief is consistent with professional and societal expectation of nurses' following patient death. Society has constructed rules and norms that govern the losses individual can grieve. However, study has shown that it is plausible for nurses to suffer bereavement emanating from end of life dementia care which is consistent with the work by Meyers (2019).

This study has found that nurses working in end of life care are exposed to death of patients on a regular basis. The emotional and psychological consequences of patient deaths is not fully recognised nor acknowledged. Nurses seem to feel they have no permission to openly mourn for the loss of a patient and it is professionally frowned upon as poor professional boundaries and over involvement (NMC, 2018). The accumulation of such experiences can result in the nurse feeling a persistent sense of sadness, compassion fatigue and depression. This is consistent with findings by Sheehan-Zeidler (2018) who assert that unacknowledged and unsupported losses that are not fully processed can alter ones 'weltanschauung' a German word for worldview due to the emotional burden. This can in turn affect the individual's self-confidence in their job, leading to poor self-esteem and feelings of worthlessness and not able to do the job. Lang (2016) in the quote below seems to capture the context in which nurse deal with emotional toil:

"There is a gentrification that is happening to cities, and there is a gentrification that is happening to the emotions too, with a similarly homogenising, whitening, deadening effect. Amidst the glossiness of late capitalism, we are fed the

notion that all difficult feelings — depression, anxiety, loneliness, rage — are simply a consequence of unsettled chemistry, a problem to be fixed, rather than a response to structural injustice or, on the other hand, to the native texture of embodiment, of doing time, as David Wojnarowicz memorably put it, in a rented body, with all the attendant grief and frustration that entails" (Laing, 2016).

This is consistent with the work by Ufema (2010) where she highlights that nurses working with dying patients can become seriously damaged and may require specialist psychological support and treatment.

Objectification:

Some participants alluded to using patient objectification as a way of emotionally distancing themselves from a dying patient. Further analysis has demonstrated the polemic notion of objectification; this was unexpected outcome of the analysis. On its most basic level objectification problematic because commodifies patients. This can be viewed as dehumanising and contrary to patient centred care. Timmermans and Almeling (2009) support this by arguing that objectification is dehumanising because it involves an alienation of patient identities and silencing of the self.

However, an in depth analysis demonstrates when nurses referred to patients in terms of the task they were going to perform such as 'syringe driver'; it worked as an aid memoir of the jobs they need to complete on their busy schedule; there was no evidence of dehumanisation nor commodification of patients. This was used as a strategy to emotionally distance from a dying patient. It seems emotional distancing as a way of coping with what would otherwise a stressful situation. However, could

be indicative of compassion fatigue highlighted by avoidance of forming a therapeutic relationship with its associated emotional toll.

Upskilling:

The study by Bailey, Murphy & Porock (2011) advocating further development in death education and social support in nurse education is needed; is supported by work by Arcand et al. (2009) which argue that training on end-of-life care for nursing staff is effective in improving knowledge provides context for this thesis findings. Participants in this study this study identified further specialist end of life dementia training as presently lacking. Consistent with these findings is an article by Harris (2007) that found that educational programmes for nurses improved knowledge and attitudes on end of life dementia care. The need for training is further supported by Kumar and Kuriakose (2013) who agree that palliative care training in end of life dementia care needs to be widely available as it is associated with improved nurses' competence.

Conclusion:

This study explored how nurses make sense of their experience of caring for people with end of life dementia from a qualitative and phenomenological viewpoint using Interpretative Phenomenological Analysis. The IPA approach used has meant that the key epistemological claim is for how the phenomenon of providing end of life dementia care appeared to community nurses, rather than how it actually was.

This study found that nurses working in end of life care are exposed to death of patients on a regular basis. The emotional and psychological consequences of patient deaths is not fully recognised nor acknowledged. Nurses seem to feel they

have no permission to openly mourn for the loss of a patient and it is professionally frowned upon as poor professional boundaries and over involvement (NMC, 2018). The accumulation of such experiences can result in the nurse feeling a persistent sense of sadness, compassion fatigue and depression. This is consistent with findings by Sheehan-Zeidler (2018) who assert that unacknowledged and unsupported losses that are not fully processed can alter ones 'weltanschauung' a German word for worldview due to the emotional burden. This can in turn affect the individual's self-confidence in their job, leading to poor self-esteem and feelings of worthlessness and not able to do the job.

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