End of Life Care: The Psychological Impact on Community Support Workers

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CONTENTS

ABSTRACT

Research studies with nurses and health care staff in residential settings have demonstrated a range of adverse psychological symptoms and protective factors when delivering end of life care. However, little research has been undertaken with community support workers, and none has been undertaken with those working with mixed caseloads.

Five community support workers working with mixed caseloads of health, social, and end of life care clients undertook semi-structured interviews. Data was analysed using Interpretative Phenomenological Analysis.

The current study aims to gain an understanding of the lived experience of delivering end of life care in the community, the psychological impact, and the effect of patient death. Superordinate themes relating to “Forming Bonds”, “Working in the Terminal Space”, “After a Death” and “Caring for The Carer” emerged.

Participants formed attachment bonds with some clients, experienced disenfranchised grief, and lacked systems of support. Some experienced post-traumatic growth while others were left traumatized by their experiences. Findings suggest community support workers would benefit from better training, education, and a working environment in which they can express grief within a supportive team and create a meaningful context within which to place their grief. Further research is required into providing these more supportive conditions.

INTRODUCTION

1. Background:

1a. End of Life Care in the Community

There is strong evidence to suggest that people prefer to be cared for, and die, in their own homes (Gomes et al, 2013). Research evidence supports the view that the majority of people would prefer to die at home so long as they were assured of receiving good quality care and support (Higginson & Sen Gupta, 2000; Herber & Johnson, 2013). It is estimated that 70% of the U.K. population would choose to die at home (NICE, 2014). In the UK there has been a reversal in the trend of institutionalised dying (Gomes et al, 2012). From 1974 to 2003 the number of home deaths almost halved (Gomes et al 2012; Gomes & Higginson, 2008). However, this trend was reversed from 2003 to 2010 with home deaths increasing steadily from 18.3 % of deaths in 2004 to 20.8% in 2010 (Gomes et al, 2012).

There are major challenges for end of life care, and palliative home care, posed by a rapidly ageing population with increasing complexity in their care needs (Gomes et al, 2013; Gomes et al, 2012; Gomes & Higginson, 2008). Couple this with an increase in the prevalence of long-term chronic conditions and it results in the need for a dramatically expanded health and social care workforce (Ingelton et al, 2011). This workforce will need to combine registered professionals with unqualified support staff to ensure that care in the community can be provide to all those that require it (Ingleton & Seymour, 2008; Ingelton et al, 2011).

In the UK, regardless of setting, patient centred multidisciplinary care provides the means to compile suitable care plans for dying people. Individualised care plans encompass physical symptoms (e.g. pain, breathlessness, and fatigue), psychological symptoms (e.g. anxiety, depression), social needs, and spiritual needs (for some people). It is acknowledged that good communication is required to ensure that people feel involved in the decision making process around their care provision. If done successfully, this contributes to their perceptions of being treated with care, dignity, and respect (NICE, 2014).

In 2002 The Liverpool Care Pathway was designed as a clinical tool to improve care for dying patients and was subsequently recommended as best practice in the UK national end of life care strategy (DH, 2008; Ramasamy Venkatatsalu et al, 2015). The Liverpool Care Pathway was seen as a way of transferring the model of "excellence" in care from hospices to other healthcare settings (NICE, 2014). However, following media criticisms, Baroness Neuberger's review of the Liverpool Care Pathway entitled, *"More care less pathway",* highlighted numerous concerns. These included a lack of strong evidence for the Liverpool

Care Pathway improving the quality of end of life care (Neuberger et al, 2013; Ramasamy Venkatatsalu et al, 2015). Consequently, the UK government decided to phase out The Liverpool Care Pathway by July 2014 (Chan & Webster, 2013). This has left a challenge for the NHS, and other health service providers, to ensure that the care delivered to people in the last days of their life is evidence based, of high quality, and based on the needs of the dying individual (NICE, 2014). The Neurberger et al (2013) recommendations included:

(i) The CQC undertake a thematic review of how dying patients were treated across various settings, including in the community;

(ii) Research into the experience of dying should be undertaken as there, "are critical and legitimate social and health objectives and benefits that must be understood, in how patients, their relatives or carers experience care at the end of life." (p.18, Neuberger et al, 2013).

(iii) There is a pressing need for, "more evidence based education and care in all settings that care for the dying." (p.46, Neuberger et al, 2013).

In response to Neuberger et al (2013) The Leadership Alliance for the Care of Dying People (LACDP) (DH, 2014) set out their priorities for the care of a dying person. This is a collective and individual commitment to ensuring all care given to people in the last days of their life in England:

"Is compassionate;

Is based on and tailored to the needs, wishes and preferences of the dying person and, as appropriate, their family and those identified as important to them;

Includes regular and effective communication between the dying person and their family and health and care staff and between health and care staff themselves;

Involves assessment of the person's condition whenever that condition changes and timely and appropriate responses to those changes;

Is led by a senior responsible doctor and a lead responsible nurse, who can access support from specialist palliative care services when needed; and

Is delivered by doctors, nurses, carers and others who have high professional standards and the skills, knowledge and experience needed to care for dying people and their families properly." (p. 7 - 8, DH, 2014).

Canadian research by Mistry et al (2014) undertook an in-depth phenomenological study of 107 community based palliative care providers and administrators to discern the essential considerations of end of life care in the community. Nine main themes emerged, with the most prominent being: That the patient's wishes were fulfilled. This theme was then followed by: Attending to non-physical needs; Healthcare teams' nature of care delivery; Ensuring that patient wishes were honoured; Attending to physical needs; Preparation for and acceptance of death; Communication and relationship development; and finally, Involving the family and supporting them. It was concluded that tailoring the provision of end of life care to these elements plays an important role in ensuring a positive experience of end of life care for both family and patient. These themes provide valuable guidance as to what matters most for end of life home care. The themes also correspond to a patient-centred approach, in which care goes beyond symptom management to supporting people to die in a way that they desire (Mistry et al, 2014).

1b. The role of community support workers

It is widely recognised that health care assistants provide a key role in the provision of community palliative care, and end of life care in the UK (Lovatt et al, 2015). Community support workers involved in the provision palliative and end of life care operate as part of patient centred multi-disciplinary teams (Herber & Johnston, 2013). In the UK their role was introduced as part of the 1990 NHS and Community Care Act (Department of Health, 1990; Lovatt et al, 2015). In order, to perform this role no formal training or mandatory qualifications are required, and specific duties can vary according to the individual settings and services (Lovatt et al, 2015; Mc Kenna et al, 2004).

Research has shown that emotional labour performed by health care assistants when working in the community is a large part of their role (Lovatt et al, 2015). Emotional labour includes listening to the patient, their family, and informal carers. It constitutes offering advice on what to expect during their patient’s illness and being a reassuring presence right up to the death of the patient (Clark et al, 2000; Denham et al, 2006).

A systematic review of the literature carried out by Herber & Johnston (2013) examined the role and tasks of community support workers providing end of life and palliative care. They also studied the challenges and supporting factors associated with their ability to provide this care. Their findings demonstrated that community support workers undertook numerous tasks. These included the provision of emotional and personal care, domestic support for families, and respite care. The challenges for support workers included the ambiguity of their role, the paucity of their training, and the degree to which they became emotionally attached to their clients. The supporting factors included peer support, a sense of cohesiveness amongst colleagues, and task orientation (Herber & Johnston, 2013). It was recommended that future research:

(i) Identify caring situations in which challenges occur.

(ii) Deduce interventions tailored specifically to support workers requirements.

(iii) Investigate how to improve support workers performance in order to reassure patients. (Herber & Johnston, 2013).

It should be noted that no research has been undertaken with a population of community support workers who have a mixed caseload of healthcare, social, and end of life clients. The current study aims to address this gap in the literature. Furthermore, the current study aims to explore: (a) The effect of patient death on community care workers, and, (b) The impact that delivering end of life care work as part of a mixed caseload of clients has on their psychological functioning more generally.

LITERATURE REVIEW

2. The effect of patient death on community care workers:

Let us begin the literature review by considering the issues of attachment and loss, theories of grief, and previous literature into healthcare workers experiences of grief:

2a. Attachment and Loss

When delivering end of life care in the community, support workers can become close to their clients due to the amount of time they spend with them and the high degree of emotional labour involved in the job (Lovatt et al, 2015). This suggests that support workers might form an attachment bond with the people that they care for. This would be in line with attachment theory (Bowlby,1980).

Bowlby (1980) developed attachment theory and the notion of separation anxiety when a loved one dies (Wilson & Kirshbaum, 2011). According to attachment theory children develop an attachment to their primary caregivers, despite individual differences in the quality of this attachment bond (Field et al, 2005). Attachment bonds in adults are considered different from child to parent bonds because both adults can serve as an attachment figure to each other (Hazan & Ziefman, 1999). This suggests a greater reciprocity than a child to adult bond, however, adult to adult bonds are understood to a serve similar function for those involved. These functions distinguish attachment relationships from other types of relationships (Field et al, 2005).

Such an adult attachment bond could be expected to form between a support worker and a client as they become close over the time they work together. One of the traits of community care work is that a support worker will often work with a client for a long-time, providing healthcare and social support, before the client becomes terminally ill. At this point they will become involved in providing palliative and end of life care before the client passes away. This allows for an extended period of time for an adult attachment bond to form as the carer has got to know the client and their family by delivering care in their home environment prior to the client becoming terminally ill. When the client eventually does die the support worker may experience a sense of loss due to the nature of the bond that they have formed.

There has been much research into the impact of bereavement (Wilson & Kirshbaum, 2011). This developed from Freud (1949) who studied melancholia following the death of a loved one, and it has continued through to recent theorists who have highlighted the importance of making sense of the bereavement (Neimeyer, 2001). One way of doing this can involve the bereaved person creating a story to enable them to integrate the memory of the deceased into their ongoing way of life (Walter, 1996).

Freud (1949) tried to differentiate grief from depression, a subject that still provokes debate and controversy as the removal of the “bereavement exclusion” from Major Depressive Disorders in DSM-5 indicates (Doka, 2016). Freud (1949) developed the idea that the process of mourning is a task to rebuild one’s inner world by experiencing powerful feelings of loss that reawaken the loving affect of the deceased person (Doka, 2016). The death of a loved one can cause people to lose their sense of identity (Freke, 2004). Freud (1949) went onto theorize that, in grieving, the bereaved person lets go of multiple attachments involved in the formation of the relationship, and when the loss is accepted the ego accommodates the loss by enabling the bereaved to search for new attachments (Humphrey and Zimpfer, 1998). This theory implies that one detaches from the deceased, reinvests in life, and recovers from the loss (Doka, 2016).

Freud’s theory is at odds with other theories of grief, such as the continuing bonds theory of grief (Klass, Silverman, & Nickman, 1996). Klass, Silverman, & Nickman (1996) in their seminal work, *Continuing Bonds: New Understandings of Grief,* argued that bereavement or grief was never completely resolved, and that it was normal for mourners to maintain a connection with the deceased. (Klass, Silverman, & Nickman, 1996; Pearce, 2016). This was in direct contrast to the view of Freud who thought the only way to resolve grief was to severe ties with the deceased (Pearce, 2016). Instead of recovering from grief Klass, Silverman, & Nickman (1996) proposed that the bereaved person negotiates and renegotiates the meaning of the loss over time. While death is permanent, the grieving and mourning of the deceased means that they are remembered and continue to have an active, and meaningful role, in the life and memories of the bereaved (Klass, Silverman, & Nickman, 1996; Thompson, 2019).

Previous research has demonstrated that healthcare support workers develop an emotional attachment, and bond, with their end of life clients (Denham et al, 2006; Schell & Kayser-Jones, 2007; Herber & Johnston, 2013). They are also usually excluded from any involvement in the rituals surrounding death, from formal farewells, funerals, memorial events, and in any collective mourning processes (Wilson & Kirshbaum, 2011). This could mean that community support workers are unable, or not allowed, to express their grief and when they do exhibit a grief response they are likely to experience disenfranchised grief as they have nowhere to go to express it (Doka, 1987).

2b. Theories of Grief:

Grief is defined as the multifaceted response to death and losses of all types, this includes the emotional, psychological (encompassing cognitive and behavioural responses), social, and physical reactions (Stroebe et al, 2001). Emotional manifestations of grief include despair, anxiety, loneliness, and anger. Behavioural symptoms include withdrawal, irritability, fatigue, and tearfulness. Cognitive responses can include a preoccupation with thoughts of the deceased person, disassociation, diminished self-esteem, problems with concentration or memory, a sense of helplessness, and hopelessness. Physiological problems include loss of energy, exhaustion, poor diet, disturbed sleep, somatic or physical complaints, and susceptibility to illness (Stroebe et al, 2001; Rando, 2000; Waldrop, 2007).

Bereavement is defined as the death of a significant person (Waldrop, 2007). Whereas, mourning is the process of adapting to the loss. Mourning can involve re-negotiating one's psychological ties with the deceased person (Klass & Walter, 2001). Therefore, the bereaved develops an identity without the deceased person and must adapt to living without their presence (Rando, 2000). The multifaceted nature of loss, bereavement, grief, and mourning highlights the significance of viewing the response from a biopsychosocial perspective (Waldrop, 2007).

From her work as a Swiss psychiatrist Elizabeth Kubler-Ross (1969) conceptualised grief into a staged model. This model was originally designed to explain the experience of those dying from terminal illness but is now widely used to explain the process of grief more generally (Freeman, 2005). Kubler-Ross's (1969) model highlighted how bereaved people experience stages of denial, anger, bargaining, depression, and acceptance. The model implies that failure to complete any of the stages of grieving would result in a multiplicity of complications, any of which could have implications for a community support worker grieving for their deceased clients. However, staged models of grief have been criticised for suggesting people must move through these stages and for not capturing the complexity, diversity, and idiosyncratic nature of grieving. Furthermore, staged models of grief do not address the many, and varied, physical, psychological, social, and spiritual needs of bereaved people (Hall, 2014). Other theorists have also developed models following their own research and studies into grief. These include Parkes (1975) and Worden (2008) who both identified tasks through which grieving people need to work to grieve successfully (Wilson & Kirscbaum, 2011).

Stroebe & Schutt (1999) developed The Dual Process Model of Grief which addresses some of the criticisms of staged models of grief. It describes how a bereaved person must cope with the experience of death and the resultant lifestyle changes (Buglass, 2010). The model explains how bereaved people alternate between behaviours that are related to grieving ("loss orientated") and behaviours that are related to making adjustments to be without the deceased person ("restoration orientated") (Hall, 2014; Wilson & Kirschbaum, 2011). From this perspective grief is a process of oscillation between "loss orientated" and "restoration orientated" ways of being (Hall, 2014). While loss orientated factors relate to the death experience, restoration orientated factors relate to making lifestyle changes, coping with everyday life, and establishing new roles (Buglass, 2010). For a community support worker balancing these two processes might have an impact on their ability to undertake their work in different situations, and their work with different client groups. These two processes might give an insight into how resilient a support worker is when dealing with end of life care. However, this model does not seem consider the importance of interpersonal relationships in helping people cope with bereavement (Buglass, 2010).

Worden's task based model of grief (Worden, 1982) moved away from passive phases of grief to the active task of mourning (Buglass, 2010). This model was developed in response to staged models, which implied passivity, and identified four tasks that the bereaved was actively involved in accomplishing to resolve their grief (Worden, 1982; Pearce 2016). Mourning involves engagement with the active tasks of: (1) Accepting the reality of the loss, (2) Working through and experiencing the pain of grief, (3) Adjusting to an environment without the deceased person, and, (4) To withdrawing emotionally from the deceased and moving on to invest in new relationships (Buglass, 2010, Worden 1982).

It should be noted that Worden (1991) added to his theory over time and in the second edition of his book altered the final task of mourning to be concerned with relocating the deceased within one's own life, and identifying ways of memorialising them (Worden, 1991; Pearce, 2016). Arguably, this pre-empted a move away from a model of detaching from the deceased towards a model of continuing bonds (Klass, Silverman, & Nickman, 1996; Pearce, 2016). This addressed the criticism that therapist's interpretation of staged models of grief (e.g. Kubler-Ross, 1969) were too prescriptive and shifted the responsibility for one's grief work to the individual concerned, while practitioners could still guide them along the way (Pearce, 2016).

Worden (2008) also identifies seven factors that are crucial to understanding the experience of mourning: (1) Who the deceased was, (2) The nature of the attachment to the deceased, (3) How the person died, (4) Historical antecedents, (5) Personality variables, (6) Social variables, and (7) Concurrent stressors (Hall, 2014). For community support workers the strength and nature of their attachment to the deceased, their own attachment style, and death related factors could pose them with psychological issues and challenges to the task of mourning. Mourning for previous losses is not always complete and working with end of life clients could trigger suppressed and postponed grief (Van der kolk, McFarlane, & Weisaeth, 1996). This in turn could impact on their ability to carry out their work.

Should a support worker become particularly attached to a deceased client, it might be important for them to adjust and redefine their relationship after death. This would allow for a continued bond with that client that would endure over time. This would be in line with the continuing bonds theory of bereavement (Klass, Silverman, & Nickman, 1996). The nature of this emotional bond and its implication for community support workers remains unexplored. It is unknown whether community support workers grieve for their deceased clients, if they are supported adequately, and how this affects their work and social lives.

2c. Healthcare workers experience of work related grief:

Due to the patient centred duties undertaken by nurses and healthcare assistants, they tend to have the greatest amount of physical and social contact with patients when providing care (Field, 1989). Therefore, they are more likely to form relationships with patients that are deeper than those formed by other healthcare professionals. As a result, they experience a greater sense of loss when their patients die (Anderson & Gaugler, 2007).

Previous research has shown nurses experience significant grief experiences when working with end of life patients (e.g. Papadatou et al, 2002; Saunders & Valente, 1994; Vachon, 1987). In particular, for nurses working in high mortality settings high rates of patient deaths have been linked to numerous poor outcomes, which include: Sadness & guilt (Rashotte et al, 1997), helplessness and moral distress (Papadatou et al, 2002), low morale (O'Hara et al, 1996), unacknowledged and disenfranchised grief (Kaplan, 2000; Anderson & Gaugler, 2007) chronic and compounded grief (Feldstein & Gemma, 1995), compassion fatigue (Meadors & Lamson, 2008), stress and burnout (Anderson, 2008; Vachon & Benor, 2003). It should be noted that nurses also described positive experiences when providing end of life care, and that successful grieving can provide opportunities for personal and emotional growth (Papadatou et al, 2002; Anderson & Gaugler, 2007).

These findings might translate to community support workers due to the amount of time they spend with their end of life clients and their families as well as the amount of emotional labour involved in their role which in some senses mirror nurse’s experiences. However, support workers in the current study have a mixed caseload so are unlikely to experience the same high number of patient deaths as the nurses in the studies above. Furthermore, they have not received the same degree of training as nurses, therefore, there might be significant differences in their experiences. Little research has been carried out with this population to clarify such points.

Anderson et al (2010) studied the grief experiences of 380 nursing assistants working in nursing homes in order to gain an understanding of the relationship between grief and well-being. Their findings showed that participants experienced both distress and personal growth in their grief experiences. Participants who experienced greater distress from their grief reported higher levels of burnout and lower levels of physical and psychological wellbeing. Whilst participants who reported greater personal growth from their grief experiences also reported lower levels of burnout, higher levels of psychological and physical wellbeing, and better levels of job satisfaction. These findings suggest that grief might be an important determinant of wellbeing amongst nursing assistants working in residential homes, and how they experience grief might impact directly on the quality of care provided (Anderson et al, 2010).

Again, it is unknown whether these sorts of findings would translate to a population of community support workers. The study suggests that greater distress from grief experiences would be linked to poor wellbeing, whereas personal growth from grief experiences may prove to be a protective factor. This is in line with the literature around post-traumatic growth, where positive psychological change can result from adversity and challenging situations giving rise to a higher level of functioning (Tedeschi & Calhoun, 2004). It is unclear whether community support workers experience such post-traumatic growth as part of their role. However, findings show that nurses do (Papadatou et al, 2002; Anderson & Gaugler, 2007) so the current study aims to explore this further.

Quantitative studies on grief normally include a measure of social support. However, the generic measures of social support used in these studies fails to capture the nuanced role of grief support in specific situations and populations. For those employed in community-based settings, the grief they experience in response to the death of their patients is one such case given the complex nature of their relationships with patients and the environment within which they work (Anderson et al, 2010). The current qualitative study will explore this complex relationship in greater depth.

2d. Disenfranchised Grief

Doka (1987) developed the concept that some bereaved people are unable or not allowed to express their grief. Doka (1987) researched the impact of grief in non-traditional relationships (i.e. people co-habiting, in extra-marital affairs, and in homosexual relationships). His results demonstrated that feelings of grief may be intense within these relationships, however, resources for resolving the grief outside of these relationships were limited. Informal and formal support systems, normally available, could not always be utilised due to the secretive or unacknowledged nature of these relationships by family and friends. Likewise, religion and rituals could often constrain rather than assist the grieving process in these instances. Doka (1987) named this concept disenfranchised grief. He defined this as a grief experienced by an individual but that is not openly acknowledged, publicly observed, or socially validated (Doka, 2002). Healthcare staff can experience this grief as they might feel that it is unacceptable to express their emotional response to a patient's death in their working environment. Furthermore, they might be required to support others in their loss without any acknowledgement that the death is also a loss for them (Wilson & Kirsbaum, 2011). It is highly likely that community support workers will experience such a grief response as they often working alone in the community with much less contact with colleagues and support than their residential based contemporaries. This means they are more likely to be left unsupported to deal with their losses alone.

The culture that people live or work contains social norms of behaviour to which they adhere in response to a death (Doka, 2002). These norms of behaviour affect our emotion, behaviour, and cognition, as well as dictating what losses should be grieved over, who is eligible to grieve, and how the grief is expressed (Wilson & Kirschbaum, 2011). For example, friends and family are the most eligible to grieve for the bereaved whilst healthcare workers, who had relationships with the deceased, are not eligible and can feel that their grief is not acknowledged. Anderson and Gaugler (2007) found this to be the case in their study of 136 nursing assistants employed in 12 homes. While some care staff experienced disenfranchised grief, others were more able to express their emotions around death and grief. Care staff who were more able to speak openly about their patient's deaths reported fewer prolonged grief related symptoms (Wilson & Kirschbaum, 2011).

Literature into support workers and nurses working in care homes has demonstrated that these professionals do not feel supported in sharing their grief at work due to their heavy workloads and time constraints. This results in them bringing their grief home with them

(Marcella & Kelley, 2015; Kaasalainen et al, 2007). Durall (2011) highlighted how there is a, “culture of silence” around grief and loss within healthcare that needs to be broken. This could then help to provide ways of managing healthcare staff’s grief by: (1) Creating a working environment in which staff can express their grief within a supportive clinical team, and by, (2) Creating a meaningful context within which to place death (Durall, 2011; Burack & Chichin, 2010). This would be in line with the findings of Anderson et al (2010) who demonstrated that healthcare assistants who felt their feelings of loss were validated experienced greater personal growth from the experience of loss (Marcella & Kelley, 2015).

These findings suggest that if community support workers are provided with an opportunity to share their grief experiences, speak openly about their losses, and place them within a meaningful context at work they will be less likely to experience a sense of disenfranchised grief and more likely to experience a sense of post-traumatic growth following the death of a patient. The current study aims to explore this relationship further.

3. Impact of care work on community support workers psychological functioning:

We will now move onto to explore the literature around the affect that delivering end of life care work, as part of a mixed caseload, has on the psychological functioning of community care workers more generally. The literature around chronic and compounded grief as well as the psychological consequence of delivering end of life care work will be considered.

3a. Compounded & Chronic Grief

Feldstein and Gemma (1995) undertook a quantitative study into the grief experiences of oncology nurses. They used the Grief Experience Inventory, as a measure of grief, due to its sensitivity to the longitudinal process of bereavement. Data was collected over the course of a year from 50 professional nurses (termed “stayers” and “leavers”) employed in adult oncology units. They found that both the nurses who stayed on, and those that left this area of nursing, all experienced above normal levels of despair, somatization, and social isolation from their job caring for cancer patients. This study demonstrated that these oncology nurses suffered chronic and compounded grief as a result of their caring role. It is unknown whether community support workers suffer a similar grief response when providing end of life care within a community setting. It should be noted they will not be working with such high mortality rates as the oncology nurses making it less likely that they will suffer the same degree of chronic or compounded grief.

3b. Burnout Syndrome

Burnout syndrome was identified in the 1970s in human service professionals, most notably in healthcare workers (Maslach et al, 2001). It has been described as the inability to cope with the emotional stress of work (Pines & Maslach, 1978), or as the excessive use of personal resources and energy resulting in feelings of failure and exhaustion (Freudenberger, 1986). Burnout has also been defined as, *“a defensive response to prolonged occupational exposure to demanding interpersonal situations that produce psychological strain and provide inadequate support.”* (Jenkins & Baird, 2002, p.424). Unlike depression, which affects nearly every aspect of a person’s life, symptoms of burnout occur only at work, albeit decreasing overall wellbeing (Iacovides et al, 1978). Burnout is characterised by emotional exhaustion, a loss of a sense of personal accomplishment at work, and feelings of depersonalisation characterised by negative or cynical attitudes toward patients (Maslach et al, 2001; Poncet et al, 2007). Workplace climate and workload are both predictors of burnout (McManus et al, 2004), and there have been wide variations of in the prevalence across specialities in doctors and nurses (Ramirez et al, 1996; Lu et al, 2005).

Poncet et al (2007) conducted a questionnaire study into the prevalence of burnout syndrome in the nursing staff working in 165 intensive care units in France. 2,392 nursing staff responded. Their results indicated that one third of respondents were suffering with severe burnout and that the levels of burnout were similar for head nurses, nurses, and nursing assistants. Further research is required to address the levels of burnout amongst community-based healthcare workers. It should be noted that the mortality rates experienced in community settings are unlikely to be at the same level as ICU nurses which in turn may have a knock-on effect in terms of the level of burnout.

3c. Compassion Fatigue

This is defined as severe malaise that can arise from consistent caring for patients who are in pain and / or suffering (Sabo, 2006). It is considered an overarching term used to describe the emotional impact of working with traumatised individuals, including secondary trauma and burnout (Figley, 2002, 2013; Stamm, 2010; Hannah & Woolgar, 2018). Compassion fatigue is often the consequence of working with prolonged exposure to trauma and is recognised as a negative effect for professionals working with such patients (Hannah & Woolgar, 2018). It can lead to problematic symptoms that affect both the home and work life of the caregiver concerned (Figley, 1995).

Compassion fatigue can be linked to a new clinical category in DSM-V, namely, Persistent and Complex Bereavement Disorder (PCBD) (APA, 2013). PCBD is a category that requires further study and is different from “normal” and “uncomplicated” mourning due to its persistence and pervasiveness (Prigerson et al., 2009; APA, 2013, Bruno et al., 2019). It should be noted that the topic of “pathological” grief has been faced by numerous perspectives (Freud, 1949; Bowlby, 1980), but in the last twenty years research has brought more specific contributions, and has led to a gradual definition of a diagnostic criteria for various pathological patterns that have previously been named things such as, "pathological grief" (Horowitz et al., 1993), "complicated grief", (Stroebe et al., 2000), and "traumatic grief" (Jacobs et al., 2000; Prigerson & Jacobs, 2001), and helped psychiatry to arrive at the new clinical entry PCBD (Bruno et al., 2019). DSM-V has also removed the bereavement exclusion and states, *“a person who meets the full symptom, severity, duration and impairment criteria for major depressive disorder (MDD) will no longer be denied that diagnosis, solely because the person recently lost a loved one (APA, 2013, Pies, 2018)”.* This has raised concerns that the grieving process will become increasingly medicalized and diagnosis related stigma will be attached to the grieving process (Shear et al., 2011). While proponents assert that only with proper clinical assessment will those suffering with incapacitating levels of grief obtain the diagnosis, and consequently, benefit from appropriate treatment (Shear et al., 2011). It should be noted that complicated grief has been treated effectively by approaching the reactions in the same way as trauma reactions (Shear, 2005; Bonanno, 2006), there would appear to be a clear analogy here to compassion fatigue.

Ultimately, compassion fatigue can lead to a formal caregiver’s diminished capacity, and interest, in being empathic to suffering patients (Adams, Boscarino, & Figley, 2006) Compassion fatigue could have long-term implications for the care provided to these patients as caregivers must be prepared to assist the families of dying patients, but they also need to be prepared to deal with their own grief (Brosche, 2003). Research has shown that compassion fatigue amongst oncology nursing staff can result in higher rates of absenteeism, loss of productivity, and staff choosing to leave the workplace place permanently (Medland et al, 2004). Meaders and Lamson (2008) studied this phenomenon among nursing staff in paediatric intensive care units. Results of 185 questionnaires demonstrated that as children lived longer with chronic conditions nursing staff had increased and prolonged exposure to suffering and dying children. This was traumatic and resulted in compassion fatigue (Wilson & Kirschbaum, 2011).

A similar effect maybe demonstrated among community support workers working with terminally ill patients. This is because they care repeatedly for patients with chronic and terminal illnesses, therefore, over time it might be that they feel unable or unwilling to feel compassion for these patients as they witness them suffer and ultimately die (Wilson & Kirschbaum, 2011). However, community care workers do not deal with the same numbers of terminally ill patients as the nurses in the above studies and they are mainly involved in working with adult populations as opposed to paediatric ones. The current study aims to examine such a relationship further.

3d. Primary & Secondary Traumatization

Primary traumatization is the process which may occur from having direct contact with a traumatic event (Peebles-Kleiger, 2000). Symptoms depend on three criteria: (1) Proximity: how close the individual is to the traumatic event. (2) Intensity: how extensive and extreme the traumatic event is, and; (3) Duration: how long the individual is involved with the traumatic event (APA, 2002). Decreased appetite, social withdrawal, irritability, increased anxiety, and sadness are common symptoms of people suffering with primary traumatization (Munson, 2002). It is quite common for these symptoms to go unnoticed amongst healthcare workers as many do not acknowledge their own reactions to their patient's traumatic events (Munson, 2002). While secondary traumatization occurs through an indirect exposure to a traumatic event, from hearing about it, or through caring for somebody who has experienced such an event (Peebles-Kleiger, 2000).

Healthcare worker may be personally affected by the primary traumatization of their patient. The healthcare worker might then start to experience some of the same symptoms as their patient. Secondary traumatization has been described as an over identification with the patient's experience or coping response, and therefore, the healthcare worker starts to experience similar levels of traumatization as the traumatized patient. These symptoms tend to have an ongoing affect in the healthcare workers personal and professional lives until the underlying issues of trauma are addressed (Meadors & Lamson, 2008). Research into secondary traumatization has mainly focused on mental health providers that have worked with traumatized people (Sabin-Farrell & Turpin, 2003; Salston & Figley, 2003; Meadors et al, 2010). Bride (2007) showed how mental health workers, and particularly social workers, developed similar symptoms to PTSD via secondary traumatization. Abendroth & Flannery (2006) were able to establish that secondary traumatization was a significant problem for nurses working in hospices (Meadors et al, 2010). It is easy to speculate on how community support workers could be traumatised when providing palliative and end of life care in the community. However, to date, little research has been done with this specific group.

4. The need for support and education for staff delivering end of life care:

Boerner et al (2015) found that symptoms of grief, similar to those experienced by family caregivers, were commonplace among direct healthcare staff. This quantitative, American study, used standardised assessments, structured questions, and utilised the Texas revised Inventory of grief to study healthcare staff's grief after patient deaths. 140 nursing assistants and 80 homecare workers were recruited. Results highlighted feelings of being "not at all prepared" for resident's deaths; and of struggling with the "acceptance of death" were prevalent among participants. Participant's grief was more intense when the relationship between the deceased and the staff member were closer, for the longer they had known each other, and when staff felt emotionally unprepared for the death. It was concluded that better training and support is likely to be needed when providing palliative care both in the community and in nursing home settings (Boerner et al, 2015).

Whittaker et al (2007) undertook a questionnaire study to identify educational needs of care assistants providing end of life care in private nursing home. They recruited 508 care assistants employed in private care homes in one UK region. Their findings showed that most participants required information about the principles and philosophy of palliative care. They also showed how care assistants were often not given adequate preparation to provide end of life care within private nursing homes. They concluded that education and time should be spent developing the knowledge and skills of this staff group (Whittaker et al, 2007).

Fryer et al (2016) undertook a focus group, qualitative study, into the views and experiences of New Zealand health care assistants when caring for dying residents. They identified the lack of value placed on their knowledge and experience by other members of multidisciplinary teams as a barrier to maximising their contribution to supporting dying residents. An educational need for additional palliative and end of life care training was identified. With a preference for this training to be "hands on" as opposed to the current didactic training that they currently receive (Fryer et al, 2016).

Wilson & Kirschbaum (2011) undertook a literature review into the effects of patient death on nursing staff. They concluded that patient deaths impact nurses, and this can affect them both in and outside of their work. They found that education around grief theory, and support from others, were helpful in developing strategies to cope with patient bereavement (Wilson & Kirschbaum, 2011).

As the current study involves research with community support workers who are a relatively low paid, and unskilled workforce, it is unlikely that they will have received the level of support identified in the studies above for working with end of life clients. Those studies demonstrate that education, training, and support appear to be protective factors against adverse psychological consequences. Research is required to investigate this and to examine the levels of support, education, and training provided for community support workers who deliver end of life care as part of their role.

5. The current study:

This study aims to explore the psychological affect that delivering end of life care has on community support workers as well as the impact that patient death has on them. To date no research has been undertaken with a sample of community support workers who deliver end of life care as only one part of their job description. It is important to understand the lived experience of delivering end of life care, as part of a mixed caseload, as this could impact on their ability to carry out their work. As well as providing end of life care, participants deliver health and social care to a range of adults with physical difficulties, mental health problems, and learning difficulties. Given the changing nature of community health services this participant group is likely to become more representative of the healthcare workforce as time passes. Therefore, it is crucial for us to learn how we can support these people in their training, knowledge, and emotional processing as they carry out an essential public health duty that is economically viable.

Previous research has identified that nurses delivering end of life care can be affected psychologically in a number of ways: Increased sadness & guilt (Rashotte et al, 1997), a sense of helplessness and moral distress (Papadatou et al, 2002), low morale (O'Hara et al, 1996), unacknowledged and disenfranchised grief (Kaplan, 2000) chronic and compounded grief (Feldstein & Gemma, 1995), compassion fatigue (Meadors & Lamson, 2008), secondary traumatization (Abendroth & Flannery, 2006), increased stress (Anderson, 2008), and burnout (Anderson, 2008; Vachon & Benor, 2003). While protective factors appear to be allowing opportunities to successfully grieving (Papadatou et al, 2002; Anderson & Gaugler, 2007), personal and emotional growth from their experiences akin to a sense of post-traumatic growth (Tedeschi & Calhoun, 2004), education around grief theory, training, support from others, and help in developing strategies to cope with patient bereavement (Wilson & Kirschbaum, 2011). It is unknown whether the community support workers are affected in a similar way to nurses who work in different settings, have greater specialist training, and better support systems in place.

It is important to understand the nature of the bond community support workers develop with their clients, how they are affected by client death, and whether they grieve for them so as adequate support, training, and education can be put in place as required. Research with healthcare assistants providing end of life care in residential care settings has identified challenges, including: A lack of training and education around providing end of life care (Fryer et al, 2016; Whittaker et al, 2007), a lack of support dealing with staff grief (Broener et al, 2015), and a sense of disenfranchised grief (Anderson & Gaugler, 2007). Yet there has been little research into the psychological effects of delivering end of life care on community support workers, particularly since the phasing out of the Liverpool Care Pathway in the UK. This makes the current research both novel and necessary. The current research also addresses some of the recommendations in the Neurberger et al (2013) report, and the previous research of Herber & Johnston (2013).

As bereavement, grief, loss, and the associated psychological sequalae are the primary focus of large parts of counselling psychologists clinical work, insights from this study could be beneficial to clinical practice. Furthermore, given the changing nature of the social care and health workforce, healthcare organisations might choose to make support available to their community support workers by employing counselling psychologists within an organisational context. Potentially this could have a positive economic effect by reducing staff "burn-out", sickness, and stress levels. However, little is known about the psychological effects of providing end of life care on community support workers.

METHODOLOGY

6. Research Design:

This study uses a qualitative research method known as IPA (Interpretative Phenomenological Analysis). The study is suited to qualitative research as it is concerned with rich and detailed understanding communicated by the participants' narratives (Rubin and Rubin, 1995).

IPA research is based around a model of the person that is self-reflective and self-interpreting (Braun & Clarke, 2013). As "self-interpreting beings" (Taylor,1985) people are actively involved in interpreting events, objects, and people in their lives (Pietkiewicz & Smith, 2014). To examine this process IPA research draws on the fundamental principles of phenomenology, idiography, and hermeneutics (Pietkiewicz & Smith, 2014). These epistemological assumptions align with the researcher's viewpoint that a real and knowable world exists underneath the subjective and socially located knowledge that research can access (Madill et al, 2000; Braunn and Clarke, 2013). As knowledge is socially influence it reflects a separate reality that we can only partially access, this critical realist position holds that some "authentic" reality exists to produce knowledge that could make a difference (Braunn and Clarke, 2013). This critical realist position acknowledges the way that people make meaning of their experiences together with the way that the broader social context impinges on these meanings, whilst also retaining a focus on the material and other limits of "reality" (Braunn and Clarke, 2006).

The epistemological assumptions of IPA research mean that it is idiographic in nature, concerned with the particular and unique, not the nomothetic like most empirical work in psychology. Therefore, research focuses on particular, detailed, case exploration not the search for universal laws (Smith, Harre, & Van Langenhove, 1995). IPA research is also concerned with the phenomenological and involves a detailed examination of human lived experience, as well as the meanings people attach to these experiences (Smith et al, 2009; Braun & Clarke, 2013). Research attempts to understand what it is like to stand in participants shoes and through interpretative activity make meaning comprehensible (Pietkiewicz & Smith, 2014). IPA research is a dynamic process with the researcher taking an active role in influencing the extent to which participant's experience is accessed and how via interpretative activity they make sense of their personal worlds (Pietkiewicz & Smith, 2014). Therefore, the analytical process involved in IPA consists of a dual interpretive process ("a double hermeneutic") as, firstly, the participants make meaning of their world, and then, secondly, the researcher attempts to make sense of the participants meaning making (Smith et al, 2009; Braun & Clarke, 2013; Smith & Osborn, 2003). Essentially, the researcher attempts to understand an experience form the participants perspective (Pietkiewicz & Smith, 2014). A main feature of IPA's idiographic analysis involves balancing experiential claims against an interpretative analysis (Larkin et al, 2006). IPA studies focus on small, usually homogenous, samples and use verbatim participant accounts (Braun & Clarke, 2013) as in this study.

The current study is concerned with community support workers lived experience of delivering end of life care and "how" (Marecek, 2003) they are affected by their work. It is suitable for an IPA research design as it is based around the meaning of experiences, and questions concerned with broader meaning making (Braun & Clarke, 2013). In line with the theoretical underpinnings of IPA it aims to understand the personal lived experience of being a community support worker (and the associated psychological affects) involved in the process of delivering "end of life care" in the community, while the researcher attempts to interpret and make sense of their meaning making process. As with many IPA studies the participant's stories should reflect how they understand and make sense of their experiences (Smith et al, 2009), as well as offering a detailed and rich description of participants' individual experiences (Smith, 2011).

Other qualitative research methods were ruled out as they appeared incompatible with the research design. For instance, Grounded Theory concerns itself with identifying social processes from the data along with the generation of an explanatory theory (Willig, 2008), while Discourse Analyses is concerned with discourse practices in the construction of social and psychological realities and "what" participants are doing with their talk (Palmieri, 2018). An IPA approach was preferred to a Thematic Analysis as the research question was focused on support workers experiences within a phenomenological framework using interviews. The data was attempting to capture first person accounts of their experience via semi-structured interviews. The sample used was a small homogenous one and the analysis aimed to have an idiographic focus making it more suitable for an IPA approach (www.pysch. auckland.ac.nz/en/about/our-research/research-groups/thematic-analysis).

Therefore, an IPA design was adopted. In-depth, qualitative interviews with support workers about their lived experience of providing end of life care were undertaken. In line with recommendations that students undertaking a professional doctorate should carry out between four and ten interviews when using IPA (Smith et al, 2009), five interviews were undertaken. A semi-structured interview protocol was developed (see appendix). The semi-structured interviews expanded on individual responses and explored further what emerged during the interviews. It created an open forum for dialogue between researcher and participant, allowing them to express any views that they deemed important. It also allowed the researcher to identify common themes across the data set for later analysis.

7. Participants:

For this research a "community support worker" was defined as somebody who delivered both health and social care within the community. Part of their job description was the provision of end of life and palliative care. Participants were active members of "end of life care teams" or had been employed in this role within twelve months of their interview. For the remainder of this text the term “community support worker” is used interchangeably with the more generic term “carer”.

Five community support workers were invited to participate in this study. These support workers were based in Plymouth and were employed by the same care agency that the researcher had previously worked. The care agency consented to their employees being approached. The researcher only approached participants who had worked on "end of life care teams". This represented an opportunity sample.

As the researcher was previously employed as a community support worker it created an ethical problem because of his dual role. To avoid ethical issues the researcher approached participants in his role as a "trainee counselling psychologist". This was made explicit to participants initially in writing, and subsequently re-affirmed verbally. In his former role as a "community support worker" the researcher had not delivered any end of life or palliative care for approximately 24 months before commencing interviews. To avoid any undue influence over the interviews the researcher did not approach participants he knew socially, or people he worked with other than on a very infrequent basis.

Table 1. Participant Demographic Information:

Psuedo Name	**Gender**	**Ethnicity**	**Age**	**Parent**	**Sexuality**	**Faith**	**Relationship Status**	**Currently working in community care**	**Class**
Dan	Male	White British	30's	No	Heterosexual	None	Married	No	Working
Reg	Male	White British	20's	No	Heterosexual	None	Co-habiting	Yes	Working
Mike	Male	White British	50's	No	Not stated	Pagan	Single	Yes	Working
Kim	Female	White British	30's	Yes	Bisexual	None	Co-habiting	Yes	Working
Emma	Female	White British	30's	Yes	Heterosexual	None	Co-habiting	No	Middle

8. Procedure:

Interviews were undertaken on a face-to-face basis at a location convenient to the participants. Prior to the interview the participants were given an information sheet (see appendix) that explained the purpose of the study and outlined ethical considerations. The participants were asked to read this sheet, after which they were asked to sign a consent form (see appendix) giving their informed consent participate in the study.

The information sheet confirmed that all information provided would be kept strictly confidential, except as may be required by the law or professional guidelines for psychologists. Participant names or other identifying information would not be associated with any research reports or publications resulting from the interviews, and they would be given fictional names to protect their anonymity. Data was stored in accordance with the Data Protection Act 1998 and UWE's data protection policy. The researcher and his supervisors were the sole people who had access to the data. Participants were given the right to withdraw from the study at any point within the first six months of the study. Relevant sources of support were provided in the information sheet for distressed participants. Participants were given the opportunity to ask questions before the interview took place and after the interview. Participants were fully debriefed on completion of their interviews.

The participants were asked open questions to obtain detailed accounts of their experience of end of life care. The interviews were audio recorded and transcribed verbatim. After this their responses were analysed qualitatively to identify recurrent themes across the data set.

9. Ethical considerations:

Ethical approval was obtained from the University West of England Faculty Research Ethics committee. The study was carried out according to BPS ethical guidelines.

10. Reflexivity:

Braun & Clarke (2013) highlighted how important it is for qualitative researchers to reflect upon the research process, as well as their own role as a researcher. Functional reflexivity involves giving critical attention to our research tools and how they might affect the research process. While personal reflexivity means making the researcher visible within the research process. This includes the researcher reflecting upon their various “insider positions” (the insider status we share with some of our participants), and their “outsider positions” (when the researcher does not share some group identity with their participants). In IPA research, Smith et al (2009) explained that researchers are not always aware of their own preconceptions. They recommended repeated reflective practice and bracketing to manage researcher influence over the research process. Therefore, identifying and attempting to bracket his own identity as a “support worker” and how delivering end of life care affected the researcher was critical to the research process.

11. Reflexive Account:

It is useful to start by reflecting upon my own context and how this informed my interest in the research topic (Brocki & Wearden, 2006). I have grown up in a Greek Cypriot family in the United Kingdom where concepts of “strength” and “masculinity” are closely aligned with not showing or expressing emotion as this is seen as a sign of “weakness”. This is different to the “White British” participants that I interviewed as I have been raised with a different set of culturally bound assumptions. In terms of experiencing bereavement and grief displays of upset, particularly crying, have always been discouraged amongst the men in my family and are viewed as the preserve of women. As a sensitive child I found this confusing as I was never encouraged to express my emotions by the men in my family, while the women were viewed as comforters. When undertaking these interviews it was important for me to be aware of these preconceived childhood views so as not to stereotype the female participants as “comforters”, like the Greek women I grew up with, and the men as “doers, who hide their emotions”, like the Greek men I grew up with.

As a child, when family members or close friends died, I was excluded from their funerals in order to “protect me” as I was seen as being, “too young to understand”. Afterwards these losses were rarely discussed or explained, other than giving very basic explanations such as “they are in heaven now”. Luckily, we had a close family friend, Arthur, who was English, who would encourage me to express my emotions and engage with my feelings. He served as an important attachment figure to me whilst growing up until he passed away just before I started secondary school. I was again excluded from his funeral and was upset and confused by this. An awareness of this was particularly important when carrying out the analysis of these interviews as I can see, despite my best attempts to try and bracket my experiences, how they might have influenced some of the themes that I generated. For instance, my childhood experiences of being excluded from funerals to some extent mirrors some of the interviewees who were excluded from their end of life client’s funerals and were left with a sense of “carer abandonment” and “disenfranchised grief” (two sub-themes generated) that could also be used to describe my childhood experiences. While some of the explanations my parents gave me about death as a child were rationalizations to protect me from feeling the pain of loss. Again, I can see how this might have played into the theme around “cognitive coping strategies” as all the carers I interviewed used as rationalizations as a coping strategy. This in turn left me to speculate whether the rationalizations the carers used were a way to protect them from the pain of losing their clients (like my parents were trying to do for me as a child).

I can also recall an early memory of my father talking about a “traditional” Greek Cypriot funeral in Cyprus that he saw as “barbaric” whereby the body of a relative was held in her house for twenty-four hours after she died so that anyone could visit and pay their last respects. My father described the female mourners as being “hysterical” as they engaged in a shared outpouring of emotion, yet he neglected to mention the men. After twenty-four hours a “hole in the ground” was dug in which the body was “immediately” placed and then everyone was encouraged to fill it with earth, my father thought that this was particularly “barbaric”. My father refused to see any dead body after this relative’s funeral. His explanation was that it was, “just a shell, they are not there anymore”, however, this explanation seemed to protect him from an underlying fear of death, a traumatic experience as well as his own emotional reaction. As a child this culturally specific story served to fuel my fear of death and dying, I am aware of being traumatized by the content, as my father was possibly traumatized by his experience. This is important as a sub-theme generated in the analysis related to “traumatic memories and post-traumatic growth”.

As a teenager my uncle passed away to cancer. This was the first time that I had witnessed the process of losing someone close-up and I was struck by the shock of losing him so quickly, my own sense of powerlessness, and the magnitude of my feelings of upset. There are some parallels here with some of my participant’s first experiences of end of life care that I was particularly mindful of.

Around this time, I was also entrusted with the task of telling my cousin, who I was very close with, that his father (my uncle) had cancer. When my uncle did pass away, I was left to tell his youngest son that his father had died. I had acquired a caring role from an early age, and at that time, it was very much before I was ready. Predictably there were many arguments after my uncle died amongst my male family members. This seemed to reflect an inability to express emotion properly and their anger with each other seemed to be a manifestation of their upset and grief. For me I struggled to express some of my emotion at that time, instead coping with drink. Drinking was my own, dysfunctional, “behavioural coping strategy” the name of a sub-theme I used in the analysis to describe what carers did to cope with the emotional demands of their job. I also feel that these experiences around death and dying, and reflecting upon them, have ultimately helped me connect with my own emotions that then led onto me working in the caring professions, in a sense my own “post-traumatic growth” via self-awareness and learning.

From February 2013 until April 2016 I worked as a community support worker. This is clearly an “insider” position that required much reflecting on throughout the research process in order to bracket my own preconceptions and biases particularly when carrying out interviews and analysing the data. A reflexive journal was kept in which entries were made after each interview and when analysing each interview self-reflective comments were included from the outset to help bracket my own preconceptions. It should be noted that it was a struggle not to see my participant’s experiences of end of life care, and loss, through the lens of my own experiences of loss, of being a support worker, and of working in the community.

I worked on end of life care teams during the first year of my job and found the role challenging for several reasons. Firstly, it was stressful moving between end of life clients and other health care clients. There was little time to process emotions or to reflect on what had happened between jobs, and it left me carrying my emotions to the next client as well as not being my "normal" self. I also preferred the social support aspect of the work (like most of the people I interviewed) and requested to be removed from end of life teams after a year to which my employer reluctantly agreed. When interviewing I found myself noticing similarities between my own experiences and the participants narratives very quickly due to my insider position, therefore, I was careful to reflect, and bracket these, when undertaking analysis.

Secondly, I became close to some end of life clients and their families. Their deaths were difficult to process because once deceased there was no further contact with the client's family or opportunity to bid farewell. However, I did not work with them for long enough to form proper bonds, instead these experiences keyed into my early experiences of loss and grief. There was support available from office staff, however, they lacked the necessary counselling and interpersonal skills in this area. Instead, I talked things through with colleagues and took issues to my own personal therapy. I was able to use the therapy space to reflect on, and process, issues surrounding bereavements in my own family, how my own family deals with death, and to work on my own unprocessed / unacknowledged grief stemming from my younger years, which end of life work triggered. I recognise that personal therapy is not an option for most of the support workers that I interviewed and that financially this would not have been viable for them. This reflects a difference in economic and social status as many of the participants described themselves as "working class", who had financial struggles which created an additional pressure on the work they undertook. It was much easier for me to say "no" to jobs or ask to come off end of life teams when working in care as I could afford to do this, however, many of the participants I interviewed could not demonstrating my own relative position of privilege.

I found the job of delivering end of life care to be stressful, emotionally demanding, and required emotional resilience. The skill set required to do the job far outstripped the requirement to be employed as a community support worker. I was not adequately supervised or paid well enough for such a demanding job. My life outside of work, my personal relationships, and my ability to relax were all affected while carrying out end of life care as I found that I was taking work home with him. This highlighted to me the need for better self-care and the need to bring about change. I became aware of this partly due to my educational background and I was able to make change due to my economic background. This highlights another position of privilege in terms of education and finance that enabled me to bring about change that many of the participants in this study did not have.

I acknowledge that these are all examples of potential sources of bias when interviewing and analysing the data. However, I have tried to remain mindful throughout, that despite any shared characteristics between myself and the participants, their meanings were indeed individual to them. While throughout the entire research process I have attempted to be aware of my own thoughts and feelings especially when deciding upon themes. As little research has been undertaken into the lived experience of being a community support worker I hope that the current study will be able to address some of their concerns and give voice to this participant group, in doing so I have aimed to bracket his own experiences (some of which are included above) within this research process.

12. Data Analysis:

The researcher made notes of his impressions and feelings in a reflexive diary after each interview to bracket his own pre-conceived thoughts before starting analysis. The data analysis involved a six-step process as per IPA methodology (Smith et al, 2009). The first step involved the researcher immersing himself in the data by re-listening to the first recorded interview, transcribing it verbatim, and then re-reading it several times to familiarise himself with both its structure and content. Secondly, the researcher made initial, exploratory annotations arising from the text by writing notes in the right-hand margin. He also made self-reflective notes in the left-hand margin to help bracket his pre-conceived views. Thirdly, the researcher developed emergent themes from the interview by organising his initial exploratory comments into a structure with the initial themes emerging from these notes. These themes captured and reflected an understanding of the data. Fourthly, the researcher searched for connections between his emergent themes and started to fit these themes together to produce a clear structure pointing to the most interesting and pertinent aspects of the participants account. Superordinate themes were developed under the process of abstraction by which a series of emergent, sub-themes were clustered together. Some emergent themes acquired a superordinate status by the process of subsumption, while others were identified as polar opposites within the same sub-theme. (See the appendix for an extract of an interview with Emma along with analytical notes, and a handwritten note of the initial list of themes generated from that interview). Fifthly, this procedure was repeated for each subsequent case in turn. Once all the cases had been analysed in this way, the sixth stage involved looking for patterns across the cases (Smith et al, 2009). A table was then comprised that consisted of each super-ordinate theme, with its sub-themes, and third level input to the sub-themes. (See the appendix for a handwritten note of the initial overarching themes that were generated, and for a table of how these evolved into the final overarching themes). Relevant quotations were used to bring to life each theme. These are illustrated in the two diagrams below in the results section:

RESULTS

Diagram 1. Superordinate Themes and Sub-themes:

1a. Getting close with the client

"I used to really look forward to seeing her, I was really close to her."

1c. Reversal of care

"There were times where actually the carer role was reversed."

THEME 1. FORMING BONDS

"…you do get taken in as part of an extended family almost"

1b. Getting close with the family

"They knew how close I'd become and like to the family."

1d. Blurring of boundaries

"I would always go there and they were like, "Oh, Reg, we've made you something to eat.""

2a. End of life care different to other types of care work

"It's not like.. many other jobs in the sense like, you don't always have to… a lot of other jobs you won't see people deteriorating or dying."

2b. Different types of end of life experience

"...in a sense it was a very typical end of life care"

THEME 2. WORKING IN THE TERMINAL SPACE

"...you kind of watch the deterioration and they become sort of thinner and weaker, they're more bed bound, they're more prone to bed sores, that sort, sort of thing at the end of life."

2d. Managing family and relatives

"Dealing with the family, for me, was the hardest part because for them it was more a case of when, when is it going to happen?" What, what is going to happen? How, how is it going to happen?"

2e. Significance of first end of life client

"That one, definitely. I think because it was my first end of life"

2c. Adapting communication at the end

"…right at the end there are certain things that you won't say"

THEME 3. AFTER A DEATH

“…you feel quite empty actually…it’s almost like losing a friend…there’s a little gap there.”

3a. Bereavement and loss

“…disappointment because he was such a good customer, a really nice person that I enjoyed going to.”

3b. Carer abandonment

“When they passed away, erm, you kind of felt abandonment almost”

3c. Disenfranchised grief

“In terms of, um, my own… grieving process if you like it… I didn’t feel I had a, I had a right.”

3d. Continuing bond

“I think about her now sometimes weirdly.”

3e. Traumatic memories and post-traumatic growth

“…they go onto the next one and then they break down in floods of tears cuz it brings back all the memories almost like a post traumatic.. type of thing.”

THEME 4. CARING FOR THE CARER

“then not actually recognise, hey well look there’s a carer here. Well, how do they feel? They com, they completely miss out one of the most important people there.”

4a. Carer dilemmas

“Like you can’t pick somebody up if they’ve fallen on the floor you can’t sort of change somebody’s pad on your own if they are meant to have two people there, if the other person is 45 minutes late and somebody is laying there in their own faeces you are going to do it.”

4b. Behavioural coping strategies

“…share our experiences and give advice to each other.”

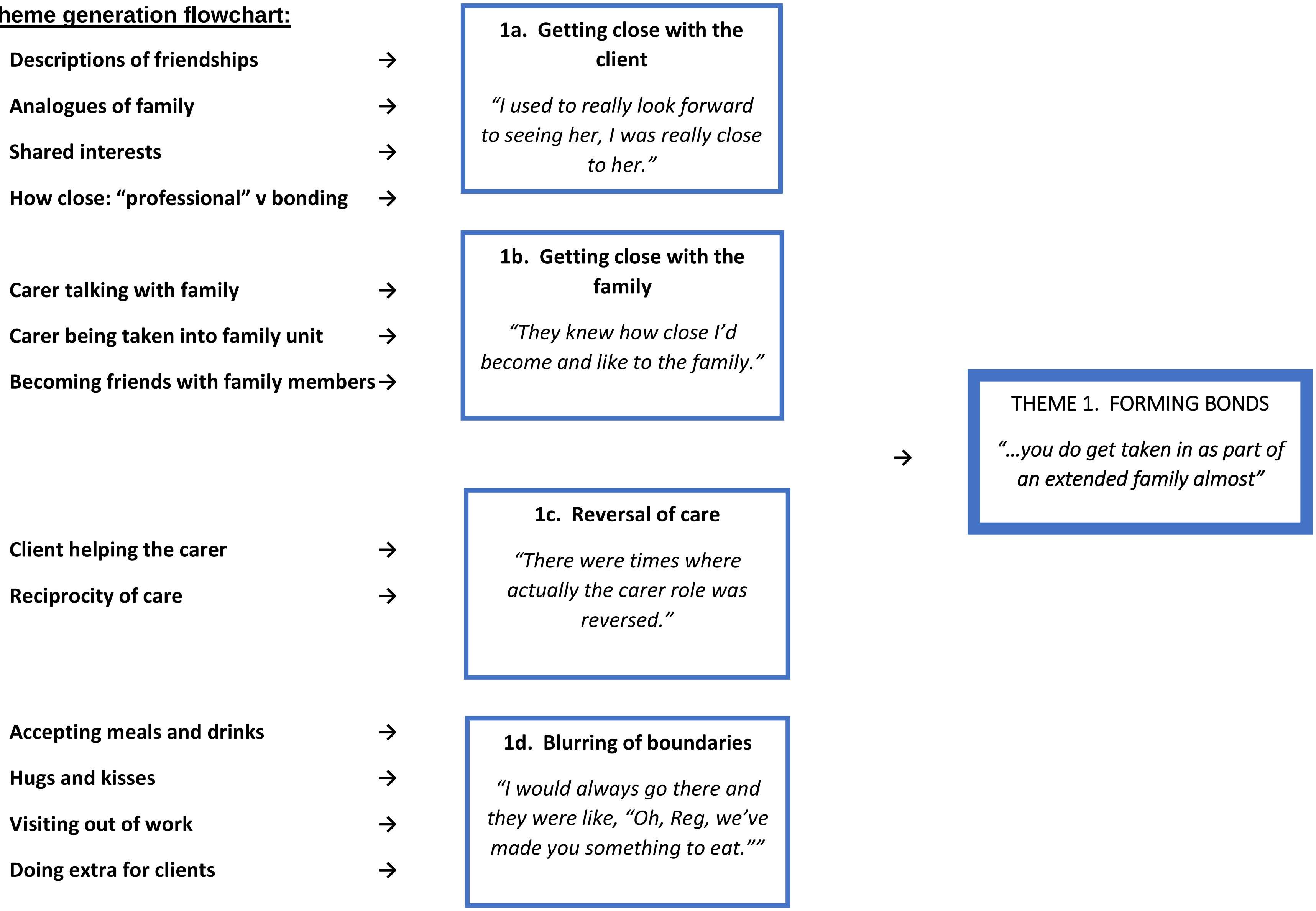
4c. Cognitive coping strategies

“well everybody dies, everybody gets ill.”

4d. The help that doesn’t exist

“in theory you could go and speak to the people in the office, “I’m worried about so and so” or if there was a safeguarding issue or whatever, but there, there was no real, “come and chat to us, are you okay? You should go home, you don’t look very well” or whatever. That just doesn’t exist”

Diagram 2. Theme generation flowchart:



Descriptions of friendships →

Analogues of family →

Shared interests →

How close: "professional" v bonding →

1a. Getting close with the client

"I used to really look forward to seeing her, I was really close to her."

Carer talking with family →

Carer being taken into family unit →

Becoming friends with family members →

1b. Getting close with the family

"They knew how close I'd become and like to the family."

Client helping the carer →

Reciprocity of care →

1c. Reversal of care

"There were times where actually the carer role was reversed."

Accepting meals and drinks →

Hugs and kisses →

Visiting out of work →

Doing extra for clients →

1d. Blurring of boundaries

"I would always go there and they were like, "Oh, Reg, we've made you something to eat.""

→

THEME 1. FORMING BONDS

"…you do get taken in as part of an extended family almost"

Witnessing client decline →

Inevitability of client death →

Carer's tasks change at the end →

2a. End of life care different to other types of care work

"It's not like.. many other jobs in the sense like, you don't always have to… a lot of other jobs you won't see people deteriorating or dying."

Predictable decline (e.g. cancer) →

Unpredictable decline

(e.g. cognitive / mental health issues) →

2b. Different types of end of life experience

"...in a sense it was a very typical end of life care"

Empathic communication at end →

Pressure on communication at end →

Caution with communication at end →

2c. Adapting communication at the end

"…right at the end there are certain things that you won't say"

Managing family questions at end →

Managing family emotions at end →

Managing family helping at end →

2d. Managing family and relatives

"Dealing with the family, for me, was the hardest part because for them it was more a case of when, when is it going to happen?" What, what is going to happen? How, how is it going to happen?"

Lasting impact of first client →

Learning from first client →

Lack of preparation for first client →

2e. Significance of first end of life client

"That one, definitely. I think because it was my first end of life"

→

THEME 2. WORKING IN THE TERMINAL SPACE

"…you kind of watch the deterioration and they become sort of thinner and weaker, they're more bed bound, they're more prone to bed sores, that sort, sort of thing at the end of life."

Emotional, behavioural, & →

cognitive responses to loss →

Physiological responses to loss →

Social responses to loss →

3a. Bereavement and loss

"…disappointment because he was such a good customer, a really nice person that I enjoyed going to."

Exclusion from funerals →

Unsupported at work after death →

3b. Carer abandonment

"When they passed away, erm, you kind of felt abandonment almost"

Exclusion from collective grieving →

Attendance (Kim) v non-attendance →

Carer unacknowledged after death →

3c. Disenfranchised grief

"In terms of, um, my own… grieving process if you like it… I didn't feel I had a, I had a right."

Secure attachment and c. bond →

Insecure attachment and c. bond →

3d. Continuing bond

"I think about her now sometimes weirdly."

Traumatic memories →

Mediators (learning from trauma,

personal insight, growth, self-esteem) →

3e. Traumatic memories and post-traumatic growth

"…they go onto the next one and then they break down in floods of tears cuz it brings back all the memories almost like a post traumatic.. type of thing."

→

THEME 3. AFTER A DEATH

"…you feel quite empty actually…it's almost like losing a friend…there's a little gap there."

Colleague issues →

Job type preference →

Safety issues →

4a. Carer dilemmas

“Like you can’t pick somebody up if they’ve fallen on the floor you can’t sort of change somebody’s pad on your own if they are meant to have two people there, if the other person is 45 minutes late and somebody is laying there in their own faeces you are going to do it.”

Supportive relationships (informal) →

Supportive relationships (formal) →

Safety behaviours →

Self-soothing →

4b. Behavioural coping strategies

“…share our experiences and give advice to each other.”

Rationalizations →

Minimizing and positive thinking →

Mental preparation and planning →

Self-reflection and adjusting →

4c. Cognitive coping strategies

“well everybody dies, everybody gets ill.”

Lack of training →

Lack of employer support →

Suggested improvements →

4d. The help that doesn’t exist

“in theory you could go and speak to the people in the office, “I’m worried about so and so” or if there was a safeguarding issue or whatever, but there, there was no real, “come and chat to us, are you okay? You should go home, you don’t look very well” or whatever. That just doesn’t exist”

→

THEME 4. CARING FOR THE CARER

“then not actually recognise, hey well look there’s a carer here. Well, how do they feel? They com, they completely miss out one of the most important people there.”

13. Superordinate Theme 1. Forming bonds:

"…gradually as a support worker, working with people for that period of time, you do get taken in as part of an extended family almost." (Dan 63)

All carers attached great importance to the relationships they formed when delivering end of life care. These relationships were often reciprocal in nature and enduring. Carers described how they struggled when these relationships deepened, and attachments formed, as this impacted on their perception of carrying out a "professional" and well boundaried job. Lines often blurred between friendships and working relationships, with carers often going beyond their job descriptions.

1(a) Getting close to the client:

"I used to really look forward to seeing her, I was really close to her." (Emma 55)

Carers worked with their clients for a considerable time in the community, often providing care prior to them developing a terminal condition, this led onto palliative and end of life care. This allowed additional time for strong bonds and relationships to form which might not be the case in other settings. All the participants described how they formed bonds with their end of life clients and that these deepened over time.

"We would just have fun, it was, it was, more like being mates after a while than being a support worker and a client." (Dan 57)

Terms like "grandson", "grandparents", and "daughter", all evocative of family were used by carers to describe their clients:

"Obviously I cared about her. I always treat people like my own grandparents." (Kim 41)

As well as clients describing carers in such terms:

"He was always like, "you remind me of my grandson." (Reg 42)

Bonds of friendship based on mutual interests developed and relationships deepened over time:

"We used to talk all the time he would love to talk about football, and his early experiences as a kid, you know, and we built up quite a rapport." (Mike 172 – 173)

What began as working relationships quickly developed beyond that of carer and client into something much closer.

A struggle for all the carers was how close to get to their end of life clients as they tried to strike a balance between maintaining a “professional” distance and forming or maintaining a bond with them:

“I always try to keep in mind that I am there to do a job but when you work with somebody for an extended period of time, when you know they are going to pass away at some point you do build up those relationships regardless of how professional you are.” (Dan59)

The balance between remaining professional and getting close was particularly difficult to strike when first coming into end of life care but became easier to manage with experience.

1(b) Getting close with the family:

“They knew how close I’d become and like to the family.” (Reg 218 – 219)

All carers described how they were taken into the family unit of their closest end of life clients and became close to families when care. Working in family homes, being surrounded by family members, and regularly seeing the same clients meant these bonds deepened:

“The, um, daughter of the man that died that she come to like us so much she come to seen us as, as family, and that was lovely.” (Mike 123)

Mike describes not only how the whole end of life team became seen as “family” but also how his individual relationships developed with certain family members:

“I became very good friends with her (client’s wife).” (Mike 166)

These relationships go beyond the dynamic of a client - carer role and represents a deeper familial bond.

1(c) Reversal of care:

“There were times where actually the carer role was reversed.” (Emma 64)

Such closeness lead to a reciprocity in the caring relationship for some carers. For Emma this is highlighted in a reversal of the caring role:

“I went through a horrible breakup and went to see her…she put her arm around me and gave me a hug. Made me a cup of tea…we were actually quite close.” (Emma 64)

Her client’s affection for Emma is demonstrated physically with a hug and practically by making her a cup of tea as well as the further wisdom she imparts:

"going through… the kind of the relationship breakdown that I was going through at the time.. with someone.. like her supporting me, I think maybe yeah, I think she did.. teach me.. about love and what… a, sort of what a good relationship.. was meant to look like." (Emma 89)

Their closeness is apparent in the way that care is a two-way street which helped to deepen their bond. This dynamic appears representative of an adult to adult attachment bond similar to that of a mother and daughter.

1(d) Blurring of boundaries:

"I would always go there and they were like, "Oh, Reg, we've made you something to eat."" (Reg 40)

As carers got more attached to their clients the boundaries blurred between a professional working relationship and a more informal type of relationship. This was reflected in different behaviours that carers engaged as they became closer to their clients and their families.

Male carers more readily accepted food and drink from their clients as they grew closer, a clear blurring of professional boundaries but also a less overt way of accepting or displaying affection.

"… they were kind hearted and he always used to, like, give me something to eat and a cup of tea." (Reg 26)

"…come in, have a coffee, sit yourself down." (Mike 88)

This contrasted to the female carers who did not talk about accepting meals from their clients but did engage in physical displays of affection, such as:

Hugging:

"he was really upset, I give him a cuddle and that." (Kim 94)

Kissing:

"..she would always kiss my hand." (Kim 91)

Holding hands:

"…he was holding my hand and he looked terrified." (Emma 178)

And accepting gifts:

"…who gave me like a little polished brass thing that I keep my pennies in, I've still got it." (Emma 260)

Although overstepping professional boundaries these more overt displays of affection demonstrate the human side of the situation that these women found themselves in as well as the closeness that they had with their clients. No male carers described being physically affectionate perhaps reflecting their perception of masculinity as they were comfortable with accepting less overt forms of affection like taking food.

A further difference between the genders was that the female carers would visit their clients outside of working hours, between shifts, on bank holidays, and even on their days off:

"The more ill she got the more I would want to go and see her and I would actually…go and see her on my days off…I went to see her on Christmas day one year." (Emma 69 - 71).

The men did not describe acting in this way and appear to be far more boundaried with their activities outside of working hours. This could reflect a greater degree of emotional investment for the female carers into these relationships than their male counterparts. It should be noted that this could also be reflective of the fact that the females in the sample were parents while the males were not, so perhaps caring was keying into their maternal instincts, as Emma states:

14. Superordinate Theme 2. Working in the terminal space:

"...you kind of watch the deterioration and they become sort of thinner and weaker, they're more bed bound, they're more prone to bed sores, that sort, sort of thing at the end of life." (Emma 109)

The second overarching theme concerns itself with carers experience of working with clients at the terminal stage of their condition, in their homes, and a specific set of challenges that this posed.

2(a) End of life care different to other types of care work:

"It's not like.. many other jobs in the sense like, you don't always have to, you don't.. a lot of other jobs you won't see people deteriorating or dying." (Reg 247)

All participant described how end of life care was very different to the other types of care work that they engaged in as part of their mixed caseload. This difference had many facets to it, firstly, carers described how they witnessed the decline and death of their clients:

“they’re much weaker.. um, but often it’s, uh [sighs] I don’t know, some..maybe their eyes, something goes in their eyes. It’s almost like you can see the life kind of coming out of them.” (Emma 158)

As their clients declined the carers tasks changed with fewer practical tasks, feeding a sense of powerlessness:

“his medication did change substantially over the last month of his life, he had to go from tablet based medication to liquid forms, and ultimately a syringe driver and he had to go from drinking cups of tea to then sipping from a straw, to,err, and then eventually going to the little sticks with sponges on the end that just hydrates your lips a little bit, and then all the way to just running an ice cube over the lips to get that little bit of moisture into him., and even with meals he went from being, a fairly good eater. He was never a brilliant eater but to then picking at food, to being, not, not tolerant of food as it were and he was sustained by a (sigh) like a PEG feed almost but it was through the nose.” (Dan 22 – 24)

Carers are faced with the inevitability of their client’s death fuelling a sense of helplessness:

“…whatever you do it’s not going to change the outcome and there is a massive amount of helplessness there, you sometimes feel like you’re in the way.” (Reg 105)

A sense of awkwardness and anxiety were also conveyed. Carer anxiety appeared to peak just prior to the client passing as there was an underlying fear for carers of being present when the client died:

“… you’re worried are they going to die when you’re actually there…that’s quite a distressing thought…that’s the biggest worry. I think, I think most carers will admit that.” (Mike 229)

On occasions witnessing client suffering just prior to their death was almost unbearable and some felt the more compassionate thing would have been for the client to die. Mike hinted at arguments for euthanasia:

“We were all almost actually like praying for him to die... and he was like that for several weeks and that was very distressing to watch it’s not something I would like to go through again. Yeah, very distressing.” (Mike 45 – 50)

Feelings of distress, helplessness, and powerlessness in the lead up to a client’s death fed a greater sense of anxiety around end of life care:

“it was something… more uneasy about it (end of life care).” (Reg 85)

2(b) Different types of end of life experience:

"...in a sense it was a very typical end of life care" (Emma 109)

Carers generally spoke about two different kinds of end of life experience. The first involved a gradual decline in their client's physical health typified by diseases such as cancer. There is a sense of predictability about how the client declines and there is nothing too unexpected about this for the carer. Emma describes this experience above and has had similar experiences on many occasions.

The client's suffering reaches a climax at the end, as does the trauma and sense of helplessness for the carer:

"she really, really suffered, like physically she was just swollen and she hadn't eaten for ages, she was covered in bed sores because no amount of turning her, and rolling her was stopping them coming, and she was, she was so poorly. Um, she had a really unpleasant end, bless her. So I'm you know, it was.. it was quite memorable" (Emma 253)

This contrasts to the second type of experience that was described. The decline here is characterized by its non-linear and very unpredictable nature and was found in clients who had a mental health or cognitive condition together with a physical health issue. This unpredictability and uncertainty created an additional sense of anxiety, caution, and fear for carers when visiting.

Mike describes such a client with Alzheimer's disease:

"You felt, very warry of going in there, what you were going to expect, what you were going to find…you just didn't know what you were going to get." (Mike 60 – 62)

Dealing with these clients left carers feeling deskilled, unprepared, and out of their depth for this type of work. Often specialist input would be required but was not always forthcoming, heightening carers anxiety:

"…it was quite difficult to get a, a psychiatric nurse in for more evaluations… I think if we could have got that in a lot quicker it would have been much better for us all." (Mike 110 – 111)

However, right at the end the unpredictability and anxiety around how the client was going to react was replaced by the trauma of seeing the suffering climax just before death. Again, this is characterized by a sense of powerlessness and helplessness for the carer:

"He wasn't eating , he was shaking, he was convulsing…he was just laying there dying effectively." (Mike 46)

Emma also spoke of a very specific set of challenges when working with a client with mental health issues who was also trying to end her life. This created an additional anxiety for carers around issues of risk management and medication:

"I would try and encourage her to take her medication…we had to be very careful with that…she would ferret it away so she could take an overdose." (Emma 94 – 95)

"she wasn't terminal but she was suicidal…and eventually she starved herself to death and it was kind of treated as end of life in the end. She was so frail and so ill she just laid on the sofa and…eventually just didn't wake up." (Emma 50 – 53)

Clients with mental health or cognitive issues created additional challenges for carers when working at the end of life. Carers were not always fully supported or trained leaving them feeling "out of my depth" increasing both anxiety and stress for the carers.

2(c) Adapting communication at the end:

"…right at the end there are certain things that you won't say, you won't say, "I'll see you next time", talk about the future much, you talk very little about yourself you want it to be about the client and centred around them, and their experiences, often toward the end of their life, they want to talk about their memories a bit more" (Emma 286)

A challenge when working in the dying space was knowing how, or if, to adapt communication with clients. Reg and Emma, talked of the importance of adapting their communication style demonstrating heightened compassion, empathy, and a client centred approach.

However, this came with an additional anxiety and stress around saying something insensitive or inappropriate:

"the thing is with end of life care you've got to be careful..about every conversation you have, how you do things, you've got to watch yourself a bit more and be a bit more…uh, it's, it's difficult, you've got to, like what you say so it can't be interpreted in anyway cuz this is such a sensitive time for like for obviously family members and stuff like that, like saying something in jest or wrong is not the time for it, you know what I mean, you need to be a bit more, be a bit more careful." (Reg 51 – 52)

There was also the additional pressure of having to adapt communication to the particular people concerned:

"…, you need to reinforce the fact that you are not an expert, quite frequently, um, because you're not. "I am not a doctor but" you really have to be able to gage the families and what sort of information that you caaaan tell them and what you can't tell them." (Emma 138 – 141)

While dealing with family members was anxiety provoking for all the carers:

2(d) Managing family and relatives:

"*Dealing with the family, for me, was the hardest part because for them it was more a case of when, when is it going to happen?" What, what is going to happen? How, how is it going to happen? And those were questions that we would get time and time again as support workers, and those questions we could not answer. And it made you just feel [sighs] quite awkward in a sense, when they were asking these questions because you simply did not know." (Dan 93 – 96)*

This proved to be one of the most challenging aspects of the carer's role. Participants struggled to answer family members questions leaving them feeling awkward, powerless, anxious, and deskilled:

"It's a real struggle to answer, answer some questions cuz they will look, look to you for, for advice and things and.. aa ask, ask questions that we might not know…a lot of it is sort of like medical, sort of responses and stuff like that. I mean we haven't always got the answers." (Reg 97 – 98)

Dealing with family members emotions was difficult as their upset again feed a sense of powerlessness and helplessness for carers:

"Looking at the family, seeing how, how upset they was and feeling so helpless." (Reg 215)

For Kim attempting to console family members provided a practical way to help while also helping to manage her own anxiety by "doing" something:

"I've obviously got to console the family and because they're obviously going to be rightfully upset." (Kim 425)

While Emma was aware of a need to preserve her own emotional energy for the client as opposed to their family, creating an additional pressure for her:

"working in sort of like end of life care with families present can be quite difficult, you comfort the family but only to a point, you kind of, I was always quite conscious that I

would have to preserve my emotional resources for the client rather than their family." (Emma 120 – 121)

Families reactions could be unpredictable which was challenging for carers to manage:

"Some families would react quite angrily, like you haven't done enough. And some families would just feel overwhelming thanks for what you have done. And it was really difficult to, to envisage that." (Dan 103 – 104)

Dan goes onto state:

"For me it wasn't… they were targeting me, they were angry at the situation…they were angry at this person is essentially leaving them…it's just a case of how they react to the situation… at that point in time." (Dan 106 – 107)

Here Dan engages a clever and thoughtful approach by acknowledging that the family members were often upset at the situation as opposed to taking things personally thereby easing the emotional burden that he places on himself.

Furthermore, family members would often want to get involve and offer practical help to carers which was usually valued and appreciated:

"…they were quite hands on so if you needed help with rolling and changing they would get involved which was…good actually." (Emma 123)

However, these well-meaning attempts to help could also create a problems for carers, feeding stress levels, and leading to a need for them to be assertive with the family:

"…sometimes you have to tell family members to, to get out..."" …if the family members are getting in the way, if they're flapping, if they're faffing you just have to tell them to get out because ultimately the, the, the wellbeing of the client is going to be compromised." (Emma 145 - 149)

It should be noted that not all carers are as able to be as assertive as Emma, as well as helping carers, well-meaning family members can create pressure and stress for carers attempting to do their jobs. Leading to a need for carers to "say no".

2(e) Significance of first end of life client:

"That one, definitely. I think because it was my first end of life." **(Kim 61 – 62)**

In the narrative of each participant an importance is placed on the experience of working with their first end of life client. A lack of, or inability to, prepare left them with a sense of fear, uncertainty, and anxiety going in:

"The first time…I was very nervous…not having done anything like that before…there was always the, the feeling… cuz at the time I had never seen a dead body before so there was always the thing was I going to go in and find someone..dead" (Mike 7)

This was linked to a lack of training:

"back then…there wasn't a lot of training that happened." (Reg 289- 290)

To try and manage their anxiety carers developed idiosyncratic ways of coping. Dan would play over possible scenarios that "might" happen as a way of preparation:

"I had gone over the different scenarios that could possibly happen probably a million times in my head at that point… I played over the possible scenarios, I thought, I, I kind of said to myself what's the worst outcome, what's the best outcome?" (Dan 41)

For some carers, like Reg, an important learning experience emerged from this experience:

"I think I learned, learned quite a lot from my first end of life care customer about myself mainly…like to be a bit more professional I think." (Reg 145 – 148)

He learned lessons about how to keep better boundaries, and how to adapt his approach demonstrating awareness and self-reflection:

"…you're not their family…you're literally there to help, help in whatever way you can like, you know, within reason obviously so, so I mean that's, that's the main thing I learned from my first one." (Reg 155 – 156)

Whereas for others, like Mike, it was the presence of nurses that aided his practical, experiential learning:

"…that first end of life I told you about we had the Marie Cure nurses there." (Mike 203)

15. Superordinate Theme 3. After a death:

"…you feel quite empty actually…it's almost like losing a friend…there's a little gap there." (Mike 209)

This theme concerns how carers are affected after the death of their end of life clients. It highlights the grieving process that carers go through, the sense of abandonment that they are often left with, and how they process client deaths in different ways.

3(a) Bereavement and loss:

"…disappointment because he was such a good customer, a really nice person that I enjoyed going to." (Mike 191)

It was noticeable that many emotions associated with grief were mentioned by the participants interviewed in this study following the death of important end of life clients that they had grown close to and bonded with. All the participants described sadness:

"I feel that emotion, feel like being upset." **(Kim 197)**

Feelings of sympathy for the family:

"…feel quite, sort of, I don't know, sympathy for them" (Reg 197)

And, often there was a sense of relief as death brought an end to suffering:

"I was slightly relieved for her, because she suffered an awful lot towards the end." (Emma 252)

The emotions associated with Kubler-Ross's (1969) staged model of grief (denial, anger, bargaining, depression, and acceptance) were present in the experiences of the participants. Denial was linked to the shock participants experienced when a client died:

"It's finally happened, and it takes time to sink in." (Mike 132)

Anger manifested in many ways: at colleagues, the deceased's family, their employer, and turned inwards against themselves:

"I was… really cross with myself because I hadn't been to see him (before client died)." (Emma 270 – 271)

Depression was described after some losses:

"…you are a bit down…emotionally you are down as well" (Mike 293 – 294)

While the guilt experienced by the female participants can be linked to a form of bargaining:

"I still feel it now if I think about it, it's that guilt feeling, that should have been me cuz I could have said goodbye." (Kim 48 – 49)

Consequently, Kim finds it difficult to say "no" to her client's and is always doing extra for them:

"I mean I always do that extra" **(Kim 168)**

This appears to be a form of bargaining for the loss of the client she was unable to say goodbye to, by doing extra for her current clients she compensates.

As well the emotions associated with Kubler-Ross's (1969) staged model of grief, carers also described psychological (encompassing cognitive and behavioural responses), social, and physical reactions to the deaths of important clients, that are consisted with a grieving process (Stroebe et al, 2001; Rando, 2000; Waldrop, 2007).

Behavioural responses included, demotivation:

"I was thinking, "I don't really want to be here."" (Dan 216)

Irritability:

"(I get) very patient, very impatient of other carers who didn't show such high levels of empathy" (Emma 288 – 289)

Fatigue:

"Physically you are very tired…emotionally you are tired as well…you might go to sleep at nights and go to work the next day but you're still very tired" (Mike, 245)

and tearfulness:

"…I think I had like, a sort of like a mini breakdown at one point. Like, not a mini breakdown but like I was really emotional." (Emma 35 – 36)

Physiological responses described, included, a loss of energy:

"I was mentally and physically exhausted." (Emma 333)

disturbed sleep:

"I mean more than once I've gone to work the next day without sleeping at all…you try and sleep cuz you're stressed out, you just can't switch off" (Mike 362 – 363)

"If I keep thinking about bad things…that's when it's going to start playing on me a lot and I won't be able to sleep" (Kim 200)

and headaches:

"I mean I get headaches quite a lot I think that's because obviously all this stuff you're processing."" (Kim 265)

While cognitive responses included, detachment:

"I detached myself from it a little bit, I think maybe." (Emma 28)

Playing over memories:

"…you lay in bed and you just start overthinking it all." (Kim 277)

rumination:

"…it's like, plays on your mind" (Reg 168)

and, catastrophizing:

"…you think a lot about yourself…I've obviously dealt with a lot of dementia, that's something I think about, and I think I would not like to go like these people…it makes you think about your own future." **(Mike 337 – 340)**

Carers social lives were affected outside of work with the most noticeable issue being a sacrificing of their own personal lives in order to keep busy and fulfil the demands of work after a client death. This led to bereaved carers experiencing a lack of time to process loss and grieve for their clients. Keeping busy kept some carers from experiencing the full emotional impact of their loss:

"...when I first got the, the call for my first one (first client death)… I was on shift, I was expected to carry on like." (Reg 188 – 189)

Indeed, while distraction was mentioned as being helpful after a loss by many carers:

"You're expected to go…straight back and just carry on, and, I suppose to a degree like, I think that is the right thing to do keep busy." (Reg 175 – 176)

There was a downside to this with carers subsequently feeling resentment to their employers for the sacrifices they had made in their social lives:

"Why have I just sacrificed my entire social life? Why am I sacrificing my friendships? Why am I sacrificing actually living myself?" **(Dan 154)**

While working long hours also increased the risk of burnout amongst care staff.

There were delayed consequences of distraction techniques as carers did not always fully acknowledge feelings commonly associated loss at the time resulting in longer term issues. In Emma's case her grief manifested itself later as postponed or compounded grief:

"Then I definitely do have days when I cry uncontrollably for seemingly no reason so maybe that is just a sort of later manifestation of this behaviour that started to emerge when I was doing end of life stuff." (Emma 207 – 211)

While issues such as burnout and compassion fatigue were also highlighted by Emma and Mike:

"Compassion fatigue is a real risk…you know by person sixteen you just don't care anymore…as soon as I started feeling that I thought I can't keep doing this." (Emma 342 - 343)

"I've actually have been thinking of getting out of the...the system like, and trying to find other work." (Mike 326 – 327)

Emotions experienced by carers after a death linked directly to feelings of loss and grief as well as the psychological, social, and physiological aspects of grief that carers appeared to suffer when losing important clients. These contrast to the emotions in the build-up to a client's death which were largely anxiety based.

3(b) Carer abandonment:

"When they passed away, erm, you kind of felt abandonment almost" (Dan 126)

A common theme after a loss was being left unsupported afterwards by their employer:

"it was just like.. it's all happened now, get on with it, it's part of the job… I do think there needs to be more support out there." (Kim 9)

Carers were excluded from the funerals of end of life clients that they had grown close too, as Emma explains:

"You don't get told about funeral arrangements" (Emma 75)

While Reg described how he wanted to attend a client's funeral but was excluded. This approach served to fuel feelings of abandonment as carers need for "closure" were not met:

"Obviously like a sort of closure sort of thing…for the staff. We wanted to be invited to the funeral …but obviously because of policies or whatever it was probably decided we, we shouldn't go." (Reg 166 - 167)

He goes onto state:

There could've been something to, to get us all together and…have some sort of closure." (Reg 292)

Participants reported being able to collectively grieve and share memories would have helped provide a sense of closure. Feelings of abandonment, lack of closure, and lack of support fed feelings of disenfranchised grief (Doka, 2002):

3(c) Disenfranchised grief:

"In terms of, um, my own… grieving process if you like it… I didn't feel I had a, I had a right." (Reg 199)

Most participants experienced disenfranchised grief (Doka, 1987). Feelings of grief were intense within their caring relationships but resources for resolving grief outside of these relationships were limited. Both informal and formal support systems, normally available, could not always be utilised due to the unacknowledged nature of the carer – client relationship:

"I also thought well this is a family thing we may have been the carers, this is their family, their father, and really it's their time to be, you know, for their sorrow so I decided not to go (to the funeral)." (Mike 138 – 139)

Carers were usually excluded from collective grieving processes:

"…you don't get told about funeral arrangements, the family don't know who you are. You suddenly become aware of your position in their life again" (Emma 75 -76)

As carers grief is not openly acknowledged, publicly observed, or socially validated they experience a disenfranchised grief (Doka, 2002) as a sequelae to their job.

The exception to this was Kim who actively attended her client's funerals, maintained bonds with family members, and collectively processed her grief with her support work colleagues:

"We all met up beforehand and then went and did the funeral, and it was nice to hear what their grandchildren had to say and they, they even said like a little paragraph about the carers being there for her, I can't remember exactly what you said, erm, yeah it, it, it was upsetting…but it's nice to be part of all that as well with the family, yeah, and think it's also closure for us." (Kim 55)

Kim also kept in touch with some family members afterwards:

"I still keep in touch with some of the family members…it's literally like, "how are you?" (Kim 437 - 438)

Whilst aiding her grief resolution it should be noted that her approach does create tensions in terms of maintaining professional boundaries and breaching her employer's policies.

3(d) Continuing bond:

"I think about her now sometimes weirdly." (Emma 81)

Some carers became close important end of life clients and maintained an internalized continuing bond after they passed:

“And when I think about like, love. I think about her and kind of how you’ve really got to, I don’t know, you’ve got to make the most of life, I guess… yeah but I think just in the context of love and relationships I do think about her …I think she did teach me about love and what a…good relationship was meant to look like. I mean I don’t think, at the time, I really digested it. But I think in hindsight the things that she said were incredibly wise.” (Emma 84 – 90)

Emma appears to exhibit a secure attachment style where a continuing bond with her deceased client is an important aspect of grief resolution. She appears to have internalized a representation of her client as an important role model who is a valued part of her autobiography. Her client is internalised as an inner comforting presence where Emma can be sustained by a mental representation of her deceased client without the need for her physical presence. This is in line with the continuing bonds theory of grief (Field et al, 2005).

This contrasts to Dan:

“…there on a professional level you can have your detachment, as it were.” (Dan 62)

Dan expands on his more detached approach:

“I’ve gradually learned over the years to build up a kind of, almost resistance to people telling me their life stories and their tales about when they were younger and things like that, and it’s not because I’m not interested it’s just… you take it in but you don’t really sort of play on it at all. The amount of stories I’ve heard over the years but the amount of stories that I can repeat back to you is probably next to none. I would hear them and it would effectively go in one ear and out the other.” (Dan 69)

This means Dan does not form a continuing bond with his clients once they have passed away. He describes a “defensive exclusion” of attachment related feelings (Mikulincer et al, 2003). This interferes with processing loss, the implications of the loss, and working through painful thoughts and feelings associated with loss (Field et al, 2005). It indicates an insecure avoidant attachment style resulting in a failure to revise schemas of attachment to the new reality of life without the deceased (Field et al, 2005). This means Dan only has a limited ability to make effective use of a continuing bond in coping with client loss due to his tendency of defensive exclusion.

3(e) Traumatic memories and post-traumatic growth:

“I’ve seen some people dealing with a death like I did, absolutely fine, but they go onto the next one and then they break down in floods of tears cuz it brings back all the memories almost like a post traumatic.. type of thing.” (Dan 120 – 121)

The carers in this sample all described memories which they found upsetting and distressing relating to their experiences of end of life care. They were left with some lasting, enduring, and traumatic memories stemming from this work:

"…it was awful. I mean watching him, suffer, I mean we we couldn't do much for him." (Mike 82)

For some participants these memories crossed sensory modalities:

"…it's the smell that sticks with you and it's not something you want to experience again it was the only time I think, the first time I'd actually been to, uh, a shift where I actually wanted to be sick." (Mike 65 – 66)

Here Emma talks of the horror and trauma of watching her first end of life client, who she had become particularly attached to, starve herself to death:

"essentially she'd starved herself to death, um.. and it was, it was kind of treated as end of life in the end cuz she was so frail and so ill and she just laid on the sofa and, you know, eventually just didn't wake up." (Emma 52 – 53)

Such memories seem to fit a post traumatic type of reaction.

There was a noticeable difference in how carers reacted to these traumatic memories. Neither Mike nor Emma described any personal growth or sense of achievement from these experiences. As we have already seen they felt burnt out and were suffering with compassion fatigue. Emma had already left care and Mike was looking to leave care at the time their interviews took place.

Their responses contrasted to Dan and Reg who described similar types of traumatic memories but for them a clear sense of post-traumatic growth emerged.

Here Dan describes a traumatic memory of his first end of life client saying goodbye to his two young children:

"...he had two young daughters and I believe they were around the ages of 10 and 6 at the time, erm, but they were, they were divorced so they did not actually live with the gentleman, erm, and, it was just really hard seeing those, the family, particularly the little girls saying goodbye to their Dad." (Dan 17)

However, this memory was balanced by another rewarding memory of Dan enabling the same client fulfil his final wish:

“...one of my ever lasting memories of him is (sigh) just a few months prior to him passing away, um, myself and my colleague we fulfilled the persons last wish…his last wish was to go swimming one last time.” (Dan 8 – 9)

Dan found the additional responsibility of end of life care rewarding:

“I loved the responsibility of dealing with medications and supporting that person to lead a medically stable life…that made me feel really good.” (Dan 233 – 234)

He also had a sense of pride in doing his best for his clients which proved to be a motivating factor for him:

“I would be really proud that not only had I helped that person on their journey, that I had done it to the best of my ability…and that’s what kept me going forward.” (Dan 87)

and this would give him a sense of achievement

“I like the feeling that I got when I know I done my job well.” (Dan 173)

Taken together this sense of achievement, pride in his work, and added responsibility all fed his self-esteem and fuelled a new ambition for Dan:

“I do want to pursue a career in nursing eventually…it’s changed my life…before I was a healthcare worker…I was floating around doing random jobs. I was floating around, just doing random jobs. There would be no job that I was ever stable in. Umm. I did factory work for a while, I did mechanics for a while, I did IT for a while, but nothing really sort of.. sparked my enthusiasm or my passion like healthcare did, so yeah it changed my life.” (Dan 249)

A clear sense of post-traumatic growth had emerged from his end of life work.

Similarly, Reg found his first end of life experience particularly traumatic and challenging:

“It was difficult particularly my first time, I learned a lot from that to be fair.” (Reg 20)

A clear sense of post-traumatic growth emerged from this due to his ability to reflect, learn, and grow from this experience:

“Nowadays, like, you go in there, you’re more professional…you’ve got to approach it all, everyone differently and read what, what you feel .. what you feel is right, you know, a lot of this, obviously, in end of life care it’s not really a, a time always to make people laugh or try, try and be jokey with them…a lot of them might have.. you know.. sort of wishes that they didn’t ever carry out and… might want to make peace with some

people in their family it's, it's so many different sort of circumstances around it so… so that, that, that probably has changed from my first one to how I am now." (Reg 59 – 62)

He also was able reflect on the positives and take some sense of achievement in his job:

"…I made a little bit of a difference to how their, their feeling, however small it might be, then I.. that's when I've, I've say like, that's the positive for me." (Reg 92)

Unlike Emma and Mike, it was noticeable how Dan went onto pursue a career in nursing and Reg remained in care work having both seemingly experienced post-traumatic growth from their experiences of end of life care.

16. Superordinate Theme 4. Caring for the carer:

"I think the companies themselves could be more understanding… they should give that support even if it is a telephone call after…and maybe follow up calls, for them.. to be able tooooooo just say, "ah, that person was lovely, it such a shame that they've died" but then not actually recognise, hey well look there's a carer here. Well, how do they feel? They com, they completely miss out one of the most important people there." (Dan 126 – 127)

This theme relates to the dilemmas and challenges that carers are faced with while undertaking their job in the community. It incorporates the coping strategies that carers used as well as the failings that they identify together with suggested improvements that would help them undertake their job more effectively.

4(a) Carer dilemmas:

"Like you can't pick somebody up if they've fallen on the floor you can't sort of change somebody's pad on your own if they are meant to have two people there, if the other person is 45 minutes late and somebody is laying there in their own faeces you are going to do it." (Emma 142)

Carers described many dilemmas that they were faced with when providing end of life care in the community. The dilemma most frequently identified by participants related to client safety and whether to act alone when providing care to clients who required two to one support as often their colleague would be running late or might not even turn up to the shift at all.

As you can see from the quotation above from Emma she does not hesitate to act alone, despite policy, as she is far more concerned with the immediate human aspect of helping a person in need than abiding by company policy. She will deal with any consequences later.

However, for other carers the approach is different as Mike explains:

"I used to think…if he doesn't show up (colleague) I'm on me own…if the guy needs moving on his own now, I can't do it like. We're not allowed to pick them up…if the guy needs moving on his own now I, I can't do it like, you know, we're not allowed to.." (Mike 115 – 117)

Here you can see how Mike, like Emma, struggles with company policy and how it creates an anxiety around being left alone with clients who need two to one support as acting alone would contravene policy and any risk assessment or care plan. Anxiety and stress are fuelled by a fear that acting alone would have repercussions from his employer. While not acting and waiting for a colleague to arrive also creates a worry around the client's wellbeing.

These situations served to increase carers anger and resentment toward some colleagues:

"certain carers have been shirking their, their job like, they are leaving it to somebody else, cuz, they, they didn't like doing the job. I feel a bit angry." (Mike 346 - 347)

But more often this was directed at their employer:

"I should have picked up the phone and spoke to them (employer) but I didn't…I think I half expected them to contact us… I thought if they, if they can't be bothered why can, why should I?" (Mike 288 – 292)

This was due to a perceived lack of support from their employer as well as placing carers in potentially dangerous and compromising situations. This increased carer anxiety, worry, and fear around attending clients who required two to one care.

A further dilemma for carers was that they all had a clear preference for one aspect of their job while disliking the other. Most commonly carers preferred enabling or support work to the healthcare or end of life work. This is highlighted by both Reg and Mike:

"you know I always found the, the support type work, enabling, quite, quite a lot easier, so it's more sort of, what I enjoy doing…if they say like I have to do end of life care or sent me to that I wouldn't turn it down…I wouldn't choose it for myself but if they sent me, I wouldn't, I wouldn't also.. um… I wouldn't refuse to do it…I'd rather not, I probably would (chuckles) let them know, I'd rather not do it." (Reg 227 – 232)

"if I could, um, get away with doing enabling or something like that, or, or non-end of life then I would rather do it than actually do it." (Mike 223)

Both carers clearly do not enjoy end of life care due to the additional emotional demands and stress as well as finding it much less enjoyable than social support. However, they feel unable to speak with their employer about this fuelling disenchantment and resentment towards them. They are stuck with an aspect of their job that they would prefer not to be doing creating job dissatisfaction. This creates a dilemma for them around whether to continue in the job as they enjoy doing the social support aspect of the job but would rather not be doing the healthcare and end of life aspect.

This situation also worked in reverse in the case of Dan:

"If there's health care issues or aspects I would rather deal with those, I would rather use my skill set that I had sorting those out, to help out with those. Instead of..uh, almost going back to doing menial things in terms of social care. That aren't for the grand scheme of things, it's not important for the health of that person. It's because they want to do it. Whereas a healthcare situation, particularly end of life, it's because they need to have that there is no they want to do this, they need to have that, and for me that far outweighs… the, the social care." (Dan 226 – 232)

This demonstrates how having a mixed caseload of social, healthcare, and end of life clients can cause additional demands and strains on carers. The different types of care work resulted in them needing to adapt to the different demands of their various clients. As Emma puts it:

"when it's end of life it's slightly different… your day to day, popping in to give Doris her meds." (Emma 344)

Reg speaks of his frustration when switching from end of life to enabling clients:

"You'd go to a shift with end of life care where the guy was, you know, practically struggling for breathe and, and dying, you know, and then to go to, like a person a total opposite, and I mean I know they have disability and stuff but…playing it a bit more…I think I found that quite frustrating." (Reg 134 – 135)

While Dan struggled to adapt his personality when switching from healthcare to social care clients with little time to prepare himself between jobs:

"…part of the problem is with, with the health and social care aspect of it is you would go from, like you already say, you would go from an end of life scenario to a social care one, and you have to do that in fifteen minutes. Fifteen minutes, to, to switch personalities almost, and, for me I never really found it too difficult but if that person is having a bad day as well. I guess that could make, or would make me react a bit more negatively about their situation." (Dan 205 – 206)

This switching between health and social care clients clearly adversely affected carers moods. This was heightened when having to rush between clients with little, or no time to adapt to the needs of the next client. This created an additional sense of pressure and stress for the carers.

This suggests that having a clearly demarked role as either a healthcare assistant or social support worker might benefit carers and help retain them in their jobs.

4(b) Behavioural coping strategies:

"…share our experiences and give advice to each other." (Reg 312 – 313)

The experience that carers most valued it helping them cope with the demands of their job was being able to share experiences within supportive relationships. This most often took the form of obtaining support from work colleagues:

"the support that my actual colleagues gave me at the time was fantastic" (Dan 176)

This support took various forms, be it practical support:

"The guy I was with had worked there on several occasions so he, he knew what to do, so he was able to, um, show me what I had to do…that was the good part of it." (Mike 7 - 8)

having a shared level of empathy when working with a colleague to provide care:

"…it's not about experience, it is purely about empathy sometimes you find someone that you work really well with and you don't even have to discuss, anything, you just intuitively work together really well…walk into a room and both sense at the same time what's going on but that's so rare" (Emma 292 – 294)

being able to informally share of experiences:

"We all spoke about it (dying client) openly." (Mike 287)

the ability to provide each other with emotional support:

"We text each other all the time…if there's any problem she'll let me know and vice versa." (Kim 139 – 140).

and seeking informal advice and guidance from each other:

"You could always just call up your colleague and have a chat with them, and nine times out of ten they would have far better advice than what the office ever could because they had been there." (Dan 182)

The striking feature here is that the ability to discuss, share experiences, and support each other seemed to help improve carer wellbeing and psychological functioning.

It was also apparent that other supportive relationships were also used to help carers cope with the demands of their work. Both Reg and Kim talked with family members who worked in care:

"My girlfriend is in care as well so I think she understands and like we…could have a little talk about things…we are there to help each other support through it really." (Reg 245)

"I had… people I could speak to…and like my Mum cuz she's been in care." (Kim 10)

When a manager or supervisor was perceived to be supportive and approachable they were also used as a source of support:

"…if I needed five minutes I'd ring my boss up…I could always ring them if I need that support…my supervisor…she would most probably come out and meet me." (Kim 209 – 210)

However, all too often carers had mixed experiences of supportive and unapproachable employers making them far less likely to be used as a source of support. Sharing experiences and talking about issues with partners, family members, colleagues, and supportive managers all proved effective in helping carers cope. It should also be noted that some of this sharing could over step confidentiality boundaries, such as talking to people outside of work, raising ethical issues. This highlighted the need for a supportive working environment.

Carers engaged in many other behaviours to help them cope with the demands of their work. Some of these were unhealthy coping strategies, or ways of self-soothing, to manage the stress of work such as smoking (four of the five carers were smokers):

"Go outside, have a fag or whatever if you smoke" (Kim 419)

and drinking:

"stuff like going out after work for a pint, just chat over a pint." (Dan 181)

While all the carers found that keeping busy acted as a good distraction when dealing with end of life work:

"What helped was that we were so busy, we were so under staffed." (Mike 27)

Keeping busy helped stop carers from dwelling on their end of life clients and ruminating on their anxieties, particularly in the short-term. However, in the longer run distraction this could merely act as a delay in processing difficult feelings and could have a cumulative effect.

Carers used many similar safety behaviours aimed at reducing their levels of anxiety, these seemed to work in the short-term but in the longer-term had a detrimental effect and in fact increased anxiety. These included, seeking reassurance:

"I did phone the office the next morning and they said that's absolutely fine. He actually really likes you…it makes you feel better." (Kim 280)

Avoidance behaviour:

"…it's something I would like to avoid (end of life care)" (Mike 242 – 243)

Hiding emotions:

"…you've got to be the strong one…you can't be showing your emotions" (Kim 205)

and bottling up feelings:

"when I feel sad about stuff or whatever I just bury it, bury it, bury it, bury it, bury it, and you know, because you have to function…but then I definitely do have days when I cry uncontrollably for seemingly no reason so maybe, maybe that is just a sort of later manifestation of this behaviour that.. started to emerge while I was doing end of life stuff." (Emma 210 – 211)

Here you can see how by bottling up her feelings it served to keep Emma safe in the short term and help her function in her day to day role. However, in the longer run this only served to compound her upset and grief which manifested itself later.

More functional ways carers found of coping included keeping their home and work life separate:

"I do try and keep…my home life completely separate…try not to let if affect you." (Reg 245)

This allowed for a greater sense of relaxation outside of work, as Kim states:

"(I) get me daughter and that's it then, work's forgotten about it's family time like." (Kim 261)

Kim also found that having some chill out time at the end of the working day was very helpful:

“I go home and I’ve got an hour before the school run, so I think, I’ll just chill out for the hour, make sure everything’s fine.” (Kim 261)

This sort of coping strategy could be particularly useful when aligned with CBT strategies such as time being set aside for “worry time”.

4(c) Cognitive coping strategies:

“well everybody dies, everybody gets ill.” (Emma 201)

Support workers used many cognitive strategies to help them cope with the demands of their work. Often these strategies were aimed at reducing the emotional impact of the work and, in particular, at managing their levels of anxiety. The most commonly used strategy was rationalizations, something that all carers did:

“they’re at rest now, they’ve got no more pain, nothing so then it does turn into happiness after that.” (Kim 198)

Here you can see how Kim uses a rationalization to help defend against the emotional pain of her client’s loss and lift her own mood.

Often these rationalizations were closely linked to carers excluding the negatives so that emotionally painful content was minimized:

“I never took it in a negative or a bad way, um, I have always been the type of personality that looks on the bright side of life anyway.” (Dan 30)

Here Dan is talking about the death of a client and it is hard to see any “bright side of life” to death, instead he appears to be minimizing his own pain by excluding the negatives. This also links to carers focusing on the positives or positive thinking:

“I’m kind of glad that she’s, she’s had that life and she did have a good life. And I know that she did, and obviously she’s got a good family out of it, so you kind of feel happy in a way that she’s peaceful now and she’s not in pain and, you know, struggling to breathe and, yeah.” (Kim 51 – 52)

This is a way to not only minimize their own pain but also a way of holding onto good memories of their clients and lifting their mood.

When delivering end of life care some carers found mental preparation and planning ahead useful strategies to help reduce their own worries and fear. For instance, Kim would prepare herself for a client’s death to help reduce its emotional impact when it did occur:

"I'm obviously preparing myself for it mentally anyway, going in and finding her. I think that's going to be the worse bit." (Kim 126 – 128)

She would also plan ahead so she would be in the right mental space before seeing a client:

"…another staff member during the night shift would text me to say, "she wasn't so good last night" So at least then I'm prepared myself before I've gone in not to be so happy, happy, you know, you kind of just go in quietly." (Kim 26 – 28)

Perhaps, the most insightful of cognitive coping strategies were support workers who were able to increase their own self-awareness, reflect upon their learning from the job, and adapt their approach appropriately:

"I had to really reflect on how I approached it, why I let it get, get to me as much as it did and…move on from that…and reflect on how I can change for the next person. So that's what I did, and it was, it was easier." (Reg 158 – 161)

Here Reg shows how self-reflection aided him and made it easier to cope in his job. This ability to self-reflect was closely linked to the ability to develop a sense of self-awareness, as Reg explains:

I do a lot of reflecting on how I could've approached it differently so…I do that and carry that through now, and, and not allow myself to get as close like I did, so…I've learned a lot." (Reg 268 – 269)

Clearly Reg learns from his experience and this increases his ability to cope with the demands of the job.

For Emma becoming more self-aware made her aware of her own limitations as well as her strengths. Ultimately this awareness led her to move away from care work due to the amount of compassion fatigue and emotional blunting that she suffered:

"…I just became really aware of my limitations like. Like emotionally I'm strong because I can handle like the really hardcore stuff. It's the day to day stuff that almost I [sighs] could handle but almost I just lost a bit of… I started losing compassion I think for some of them…and that really bothered me." (Emma 349)

Clearly becoming more self-aware made Emma realize she could no longer cope with the demands of the role.

4(d) The help that doesn't exist:

"in theory you could go and speak to the people in the office, "I'm worried about so and so" or if there was a safeguarding issue or whatever, but there, there was no real, "come

and chat to us, are you okay? You should go home, you don't look very well" or whatever. That just doesn't exist" (Emma 323)

Carers identified many failings in how they were supported within the community. The most striking of which was the lack of support they received from their employers, this took many forms.

This ranged from them not providing any emotional support:

"I don't think I got any su, em..emotional support from our, from.., if you was to say from the office or from, from the senior sta..staff in the office, no, not at all. We got nothing from them." (Mike 97)

treating carers with a lack care:

"many support companies they don't… they, it almost seems like they just don't care about their carers." (Dan 139)

and without compassion:

"I mean that is the level of compassion that you're working with, with the office people. We weren't (supported) my experience of working in these companies…and I've worked in three, possibly four companies, um, and it's the same everywhere you go. Total lack of compassion." (Emma 317 – 321)

Support workers continually recounted tales about how the deaths of their end of life clients were relayed to them by text message or e-mail:

"We just, we just, get an email or a text saying so and so has passed away take them off your list. That's it, there is no support." (Emma 80)

"…then one day we got the text to say, "she's gone"" (Kim 147)

"…the text came in that he'd passed and so there was no need to go to the shift anymore." (Mike 20)

This shows how carers are treated in an undervalued and unappreciated way. This served to fuel distrust of management and animosity. This absence of compassion also reflects an underlying fear of approaching management for personal support in case it reflected badly on the carer:

"if I was to, to go in and say I was struggling with it. It would probably re, in some ways may, may've reflected badly on, on how I'm handling it." (Reg 143 – 144)

All carers highlighted the lack of specialist end of life care training provided by their employers.

"I can't remember having any training for end of life care." (Mike 265)

While training that was delivered emphasised the practical aspects of the job neglecting the emotional and psychological aspects of the work:

"Minimal, yeah. Just again no, no focus on the emotional needs of the client. Um, just kind of.. focus on sort of hygiene, manual handling that sort of thing, the, the practical elements really that's what was covered." (Emma 327 – 328)

This shows how carers were left feeling unprepared and with a lack of training for certain aspects of their jobs. This heightened carers anxiety, particularly initially, when their practical on the job experience was lacking.

The carers in this sample identified many ways in which they could be better supported in their role. Some of their suggestions build on strategies that they already use to help them cope. For instance, carers wanted their employer to provide a more formal setting for them to share their experiences in and support each other:

"…just like something for the staff to get together and have a little chat maybe." (Reg 167)

"There could've been something to, to get us all together and…have some sort of closure." (Reg 292)

"Just some kind of better support network." (Dan 130)

This is something that carers already do in an informal way but having a specific time set aside for them to do this would help further ease the strain on carers and build trust with employers.

Other suggestions address the lack of emotional support provided by their employer:

"…just some emotional support is needed in these companies, absolutely." (Emma 324)

Many suggestions were made as to how this relationship could be improved and built upon. Firstly, if management had a shared understanding of the carers role by visiting clients and carers in the community it would help to build mutual trust and respect:

"Before the bosses make any decisions at all they should come and see for themselves." (Dan 178)

Better communication with carers to check how they are coping would help ease the emotional burden:

"…maybe just, like, a call to see how you are doing" (Reg 177)

and providing some in house supervision would mean carers did not have seek out informal or external sources of support, again improving relations with their employer:

"I think having some sort of in house supervision almost like counsellors have supervision…because you're aware that you absorb a lot of negative energy… or you need to bounce things around or whatever." (Emma 322)

Further suggestions addressed what is lacking in terms of training with better end of life training suggested:

"I'd like to see training where you go out in the community with community nurses, maybe Marie Curee and MacMillan, and see how they operate with their, with their patients." (Mike 266 – 267)

Other carers stressed the need to address the psychological aspects of the job:

"psychologically is where the, the training needs to be more aimed towards." (Reg 302)

While others felt a more holistic approach to training was needed to training, stressing the importance of client centred care:

"…I think a more holistic approach and teaching people about client centred care, rather than just this is how you do X, this is how you do Y, I think.. you know, enforcing.. or stressing the idea that these are individuals, um, also preparing carers for sort of the emotional side of the job." (Emma 330)

What emerges is a sense of carer disillusioned with management as well as a sense of fear and resentment created by an unapproachable management style. Therefore, when carers struggled with aspects of their job, they were more likely to seek informal support (from colleagues, friends, and family) than to approach management. However, these good relationships with colleagues could be built be upon by managers by providing a formal setting for cares to meet and support each other. While relationships with employers could quite easily be improved by providing better support, communication, and training.

DISCUSSION

The discussion will consider, firstly, the effect of patient death on community care workers, and then secondly, go onto explore the impact that end of life care work has on their psychological functioning more generally.

17. The effect of patient death on community care workers:

It is significant that all the participants in the current study described how they formed an adult attachment bond with at least some of their end of life clients. These adult to adult attachment bonds although different to child - parent bonds (Hazan & Ziefman, 1999) did appear to serve a similar function for both carer and client (Field et al, 2005). Participants formed particularly close adult attachment bonds with their first end of life client and those who they had worked with for long periods of time. This is consistent with attachment theory (Bowlby, 1980). It was marked by how this bond was strengthened by working in their client's homes, becoming integrated as part of their family, by sharing in communal activities, and sharing displays of affection. These included sharing meals, drinks, gifts, hugs, and kisses with their clients, all of which increased the sense of closeness as well as causing a blurring of boundary between support worker and client. Bonds quickly became something more meaningful akin to family or a close friendship. Upon the death of their clients the participants described a sense of loss and a range of feelings associated with grief such as shock, guilt, sadness, anger, depression, emptiness, and disappointment. These feelings seem to link in well with staged models of grief such as that of Kubler-Ross (1969) who sites stages of denial, bargaining, anger, depression, and acceptance which people oscillate between when processing the loss of a significant another.

In line with findings of Boerner et al (2015) the current study found that support workers described symptoms of grief analogous to those experienced by family caregivers and other direct healthcare staff upon the death of their clients. They displayed many of the behavioural, cognitive, and physiological symptoms associated with grief. These symptoms included irritability, fatigue, tearfulness, a loss of energy, tiredness, demotivation, disturbed sleep, physical complaints, rumination, detachment, a sense of helplessness, and hopelessness. These are in line with symptoms described in the findings of other such studies (Stroebe et al, 2001; Rando, 2000; Waldrop, 2007) that characterize a grieving process. This evidence supports the fact that when community support workers experience the loss of a significant client, who they have become particularly attached to, they appear to go through a grieving process.

The experience of participants appears to be somewhat aligned to a dual process model of grief where they oscillate between behaviours that are related to grieving ("loss orientated") and behaviours that are related to making adjustments to be without the deceased person ("restoration orientated") (Stroebe & Schutt, 1999; Hall, 2014; Wilson & Kirschbaum, 2011). For instance, support workers described how they replayed traumatic memories of client losses, ruminated on their deaths, and grieved for them, all of which are "loss orientated" behaviours. While at the same time they described how they, kept busy at work, spoke about their experiences, and described how they learned from their experiences helping to shape their future practise with end of life clients. All of these appear to be “restoration orientated” behaviours. The dual process model of grief suggests that oscillating between these two states helps in the processing of grief (Stroebe & Schutt, 1999).

Findings can also be linked to the task-based model of grief (Worden, 2008) which moves away from passive phases of grief to the active task of mourning (Buglass, 2010). Support workers described many obstacles to the task of mourning important end of life clients. These included being unable to attend client funerals, being excluded from collective grieving experiences, and not having any time to process client death as they were kept so busy with work. This was coupled with not being given any adequate emotional support from their employer and not having as much contact with colleagues as they might have liked to talk through feelings and share experiences of loss. It should be noted, that at least in some part, these barriers arose due to the nature of working in the community and carers often working alone.

Despite these barriers community support workers appeared able to, at least partially, work through some of the tasks of mourning identified by Worden (2008). Carers described how they went through a grieving process which enabled them to gradually come to terms with the reality of the loss of their important end of life clients. Carers also appeared to work through and experience some of the pain of their grief by feeling the sadness attached to their losses, although there were barriers to this with carers suffering with disenfranchised grief, unprocessed trauma, chronic and compounded grief. Carers had little choice but to adjust to a new physical (or external) environment without their deceased clients as they were no longer able to visit them at home and, ultimately, they were replaced by other new clients on their rotas. An exclusion from collective, shared grieving made the task of mourning far more difficult, however, some carers were still able to do establish a continuing bond with important deceased clients, adjusting their “internal” environment, making it easier to emotionally withdraw and move on (Worden, 2008).

Some participants, particularly Emma, provided details of how they did this by integrating the memory of a significant bereaved client into their ongoing narrative and way of life (Walter, 1996) as a way of making sense of the bereavement (Neimeyer, 2001). This is in line with a continuing bonds theory of grief (Klass, Silverman, & Nickman, 1996) where the carer adjusts and redefines their relationship with their significant client after death allowing for a bond that endures over time. In Emma’s case her interview points to a secure attachment style which would enable such a continuing bond to form, and continue, after the client’s death aiding her with the processing of grief. However, for participants such as Dan, who appears to exhibit an insecure avoidant attachment style, a continuing bond did not form with significant bereaved clients after their deaths. This was due to an associated “defensive exclusion” of attachment related feelings (Mikulincer et al, 2003) which interfered with the processing of loss and his ability to work through related painful thoughts and feelings. In his case any help or intervention provided based on a continuing bonds theory of grief is unlikely to be effective due to his attachment style. In terms of supporting carers with their grief this shows how their individual attachment style is an important consideration.

This also highlights how certain factors, identified by Worden (2008), are crucial to understanding the experience of support worker mourning after a client death. Clearly factors such as: the strength of the relationship between the carer and the deceased client, the nature of their attachment, and how the deceased died, all play an important role in understanding each individual carer’s experience of mourning. These need to be considered alongside other factors that Worden (2008) identifies such as the social variables, personality variables, and concurrent stressors that all play a role in how each support worker engage with the tasks of mourning.

Some of the participants in this study experienced a clear sense of post-traumatic growth (Tedeschi & Calhoun, 2004) after client death. Reg is very clear about how he learned and grew from his first difficult and traumatic experience of end of life care. He described how he became too close to his first client, over stepped professional boundaries, and breached company procedures. Yet this experience helped him to become more self-reflective, self-aware, and to develop his practice with end of life clients based on these initial experiences. While, Dan explained how working in community care and delivering end of life care helped him to re-appraise his career path, gain personal insight, and develop a new ambition to work in nursing.

Other participants did not experience this same sense of post-traumatic growth. For instance, Mike was left feeling disillusioned, unsupported, tired, distressed, and looking to move out of care work altogether. He sighted the fact that he did not enjoy end of life work and was quite traumatized by some of his experiences. Whereas, Emma left care work altogether approximately a year ago due to the emotional impact of the work. It should be noted that she described feeling burned out, having compassion fatigue, and feeling distressed by her work before deciding to change jobs and get out of care work altogether. This appears to be consistent with the findings of Anderson et al (2010) who found that nursing assistants who experienced greater distress from their grief experiences reported higher levels of burnout, like Emma and Mike. While those who reported greater personal growth from their grief experiences also reported lower levels of burnout, higher levels of wellbeing, and better levels of job satisfaction, like Reg and Dan in the current study.

All support workers in the current study, except for Kim, were excluded from collective grieving processes, rituals, farewells, funerals, and memorials following the death of their end of life clients. This exclusion was to be expected given the previous literature on the subject (Wilson & Kirshbaum, 2011) and care agency policies described by the participants. Being excluded from them impacted on participants ability to process their loss and left them with a sense of disenfranchised grief (Doka, 1987). Although support workers individually experienced grief after the loss of important clients, it was not a grief that was not openly acknowledged, publicly observed, or socially validated (Doka, 2002). This meant that carers were often left with nowhere to go with their grief and experienced a sense of disenfranchised grief. Participants experienced a sense of abandonment and a need for closure as they lacked formal systems of support. Many were left seeking ad hoc informal support from sources such as colleagues and partners.

The exception to this was Kim who did attend the funerals of important clients and continued to stay in contact with their families after they passed. Although this approach seems to have contravened care agency policy and best practice it did aid Kim in her mourning her losses and with grief resolution. Kim clearly described a greater sense of “closure” after important client deaths than the other participants. Furthermore, was not left with a sense of disenfranchised grief unlike the other participants. However, her approach did create a blurring of boundaries between her work and private life as well as potentially causing tension with her employer by going beyond the limits of her role.

It was apparent from the findings that community support workers received a varying amount of social support to helping them deal with their grief. Formal support systems provided by employers appeared to be inadequate, as in line with previous studies with residential care workers (Boerner et al, 2015), and care assistants in private nursing homes (Whittaker et al, 2007). There was also a shortcoming in the specialist end of life care training provided in line with the findings of Fryer et al (2016) who studied healthcare assistants working in a residential setting and the systematic review carried out by Herber and Johnston (2013). However, it was clear that the participants in the current study found social support, to varying degrees, from various informal channels such as speaking with colleagues, partners, friends, and family members. Some of this is in line with previous literature that found peer support and a sense of cohesiveness amongst colleagues to be a supporting factor (Herber & Johnston, 2013) for those delivering palliative and end of life care in community settings.

18. Impact of end of life care work on support workers psychological functioning:

Many findings were replicated in this study that were found in previous research carried out with nurses delivering end of life care. For instance, all community support workers exhibited symptoms of increased sadness, and some experienced feelings of guilt following client deaths. This was similar to the findings of Rashotte et al (1997). Carers showed an increased sense of sadness and moral distress like those reported in Papadatou et al (2002), however, it should be noted that this study was with a paediatric population as opposed to adults. Unacknowledged and disenfranchised grief were described as in Kaplan (2000), while compassion fatigue, similar to Meadors and Lamson (2008), and burnout as found by Anderson (2008) and Vachon and Benor (2003) were described by some particpants. Both Emma and Mike exhibited symptoms of burnout that were characterised by emotional exhaustion, a loss of a sense of personal accomplishment in their work, and feelings of depersonalisation (Maslach et al, 2001; Poncet et al, 2007). Ultimately, Emma decided to choose to leave support work as she noticed herself losing empathy for her patients and experiencing emotional blunting. Such a presentation is characteristic of burnout. Furthermore, predictors of burnout such as a heavy workload and a stressful workplace climate (McManus et al, 2004) were reported by participants. It was telling how participants in this study reported a lack of specialized end of life care training as well as a failure in support, particularly emotional support, from their employers. While participants also complained of many community specific challenges which increased their stress levels and risk of burnout. These most stress inducing of these challenges for carers concerned how information was communicated to them by their employers. Taken together these factors increased their risk of carer burnout and compassion fatigue as well as indicating one possibility as to why there is a high level of staff turnover amongst community carer workers in the industry more generally.

It is revealing that both Mike and Emma described lasting, traumatic memories of their work with end of life clients. This is a sign of primary traumatization which occurs through having direct contact with a traumatic event (Peebles-Kleiger, 2000), symptoms of irritability, increased anxiety, and sadness that are characteristic of primary traumatization (Munson, 2002) were described by these participants. However, there was no evidence of secondary traumatization as had been experienced in populations of mental health workers, social workers (Bride, 2007), and nurses working in hospices (Abendroth & Flannery, 2006). It was also revealing that neither of Mike nor Emma described a sense of post-traumatic growth (Tedeschi & Calhoun, 2004) form their care work and remained affected by their experiences in the longer-term. This is revealing as an experience of post-traumatic growth would appear to be a protective factor against burnout and ongoing trauma.

Finally, the participants in this study reported more anxiety related symptoms in the lead up to a patient death such as feelings of fear, worry, apprehension, stress and irritation. Whereas after a death they were left with more symptoms related to depression and grief such as feelings of sadness, emptiness, disappointment, and depression itself. This is consistent with an experience of death anxiety in the build up to a patient dying and experiencing a bereavement and grieving process afterwards of which depression has been identified as a stage of grief (Kubler-Ross, 1969)

19. Limitations and recommendations for future research:

As a qualitative study generalisability of research findings are not sought due to the exploratory nature of qualitative research. The sample chosen was a small homogenous one consisting mainly of working class, white British participants who resided in the same area. This sample was appropriate for an IPA study, and partially reflective of the demographic make-up of the geographical area. However, it does not reflect the increasing numbers of non-British and migrant workers employed in the health and social care workforce. Due to the increasing demand for this relatively low paid form of work the composition of the workforce is likely to continue to change in the future. For instance, it is not yet known what impact Brexit and associated government policy is going to have on this workforce. The ethnic diversity present in the community health and social care workforce has not been captured by the current sample. This is pertinent this may have implications in terms of the rituals, attitudes, and beliefs that different ethnicities have around death and dying. This may in turn impact upon the caring relationships that carers form with their clients and their families while working within the community as well as on their own psychological wellbeing. These issues merit further exploration in future research.

A further issue is that the sample of people interviewed did not mention the ages of the clients that they worked with. This is relevant because a younger person or child becoming ill and dying could be considered a more unexpected and abnormal death than an elderly person (Palmieri, 2018). It could also provoke a stronger reaction than an elderly person particularly especially if the support worker was a parent themselves. Working with a child or young person is likely to provoke a different reaction as a different type of bond may form than with an adult or elderly client. This could be more akin to a parent to child attachment bond than an adult to adult bond. Therefore, the phenomenon of support workers delivering end of life care in the community with young people and children is something that should be explored further in future research.

It should also be recognised that IPA involves a double hermeneutic with the researcher trying to make sense of the participants making sense of their experiences of delivering end of life care in the community. Therefore, the analysis represents just one possible construct of the phenomenon under study which was influenced by the researchers own subjectivity. It is likely that another researcher would have produced different themes dependent on their perspective (Elliot et al, 1999; Palmieri, 2018).

Recommendations that stem from this research link into previous research and highlight the sparsity of specialist training for support workers delivering end of life care, the lack of emotional support from their employers, the absence of any bereavement support, and the sense of disenfranchised grief that support workers are often left with. The current research demonstrates how challenging community support workers first end of life client is and how they were particularly affected by the loss of their first end of life client. This is clearly somewhere that additional training and support could be focused to help support workers adapt to this aspect of their job, to aid them with their psychological functioning, and to help employers retain their care staff.

The participants in this study all valued the support of their colleagues following a client death and in helping them with their grief. This is clearly something that could be built upon when considering how best to support them and recommendations made by Durall (2010) seem particularly pertinent when they recommend breaking the "culture of silence" around grief and loss within healthcare. Support work staff would benefit from the creation of a working environment in which they can express their grief within a supportive team, and it would help if a meaningful context within which to place their grief could be created at work (Durall, 2011; Burack & Chichin, 2010). The participants in the study made suggestions that would appear to reinforce these recommendations. For example, Dan talked about needing a, *"better support network",* Emma wanted *"some emotional support"* and Reg wanted, *"something for the staff to get together and have a little chat"* to, *"get us all together and…have some sort of closure."* These recommendations might in turn help support workers have their feeling validated which has been shown to increase the opportunity of personal growth from the experience of loss (Anderson et al, 2010; Marcella & Kelley, 2015) which is a protective factor from adverse long-term psychological difficulties, burnout, and compassion fatigue (Anderson et al, 2010). These recommendations also have the potential to help support workers with feelings of disenfranchised grief by placing client death within a meaningful context, while at the same time staying within their employers rules on attending funerals and not seeing bereaved family members after a death. Finally, it is also recommended that research be carried out into providing these more supportive conditions to community support workers.

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APPENDICES

a. Journal article submitted:

End of Life Care: The Psychological Impact on Community Carers

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This paper is submitted as part of my doctoral studies in counselling psychology.

End of Life Care: The Psychological Impact on Community Carers

Research studies with nurses and health care staff in residential settings have demonstrated a range of adverse psychological symptoms and protective factors when delivering end of life care. Little research has been undertaken with community carers and none with those working with mixed caseloads. The current study aims to gain an understanding of the lived experience of delivering end of life care in the community, the psychological impact, and effect of patient death.

Five community carers working with mixed caseloads of health, social, and end of life care clients undertook semi-structured interviews. Data was analysed using Interpretative Phenomenological Analysis.

Superordinate themes relating to “Bonds” they formed, working in the “Terminal Space”, and grieving after a “Loss” emerged.

Carers formed attachment bonds with some clients, experienced disenfranchised grief, and lacked systems of support. Some experienced post-traumatic growth while others were left traumatized. Carers would benefit from a working environment in which they can express grief within a supportive team and create a meaningful context within which to place their grief.

Keywords: “end of life”; “community care”; “bereavement”; “grief”; “support worker”; “health care assistant”.

Introduction:

The majority of people would prefer to die at home so long as they were assured of receiving good quality care (Higginson & Sen Gupta, 2000; Herber & Johnson, 2013). Estimates suggest 70% of the U.K. population would choose to die at home (NICE, 2014). There has been a reversal in the trend of institutionalised dying (Gomes et al, 2012). From 1974 to 2003 home deaths almost halved (Gomes et al 2012; Gomes & Higginson, 2008). This was reversed from 2003 to 2010 with home deaths increasing steadily from 18.3 % in 2004 to 20.8% in 2010 (Gomes et al, 2012).

There are major challenges for end of life, and palliative home care, posed by an ageing population with more chronic conditions and complex care needs (Gomes et al, 2013; Gomes et al, 2012; Gomes & Higginson, 2008). A dramatically expanded health and social care workforce combining registered professionals with unqualified support staff is required (Ingleton & Seymour, 2008; Ingelton et al, 2011). Patient centred multidisciplinary care enables compilation of suitable care plans for dying people. Community carers (health care assistants and support workers) provide a key role in the provision of community palliative care, and end of life care (Herber & Johnson, 2013). Their role was introduced by the 1990 NHS and Community Care Act (Department of Health, 1990; Lovatt et al, 2015). No formal training or mandatory qualifications are required. Specific duties vary according to individual settings and services (Lovatt et al, 2015; Mc Kenna et al, 2004). Emotional labour is a major part of their role. This includes listening to the patient, their family and informal carers, offering advice on what to expect during the illness, and being a reassuring presence up to death (Clark et al, 2000; Denham et al, 2006; Lovatt et al, 2015). Previous research has demonstrated healthcare workers develop an emotional attachment with their end of life clients (Denham et al, 2006; Schell & Kayser-Jones, 2007; Herber & Johnson, 2013; Lovatt et al, 2015). This suggests an attachment bond might form (Bowlby,1980).

Bowlby (1980) developed attachment theory and the notion of separation anxiety when a loved one dies (Wilson & Kirshbaum, 2011). This suggests children develop an attachment to their primary caregivers despite individual differences in the quality of this bond (Field et al, 2005). Attachment bonds in adults are considered different from child to parent bonds because both adults can serve as an attachment figure to each other (Hazan & Ziefman, 1999). There is greater reciprocity than child to adult bonds, however, adult to adult bonds serve a similar function. This distinguishes attachment relationships from other types of relationship (Field et al, 2005).

Research into bereavement developed from Freud (1949) who studied melancholia following the death of a loved one (Wilson & Kirshbaum, 2011). This continued to recent theorists who highlight the importance of making sense of bereavement (Neimeyer, 2001). This can involve the bereaved creating a story enabling them to integrate the memory of the deceased into their ongoing way of life (Walter, 1996). This allows for a continuing bond that endures over time, in line with the continuing bonds theory (Klass et al, 2014).

Community carers are normally excluded from rituals surrounding death, funerals, memorial events, and collective mourning processes (Wilson & Kirshbaum, 2011). This makes expressing grief difficult after a patient death and increases the likelihood of disenfranchised grief (Doka, 1987). Grief is the multifaceted response to death and losses of all types, including the social, emotional, behavioural, cognitive, and physiological (Stroebe et al, 2001; Rando, 2000; Waldrop, 2007).

Kubler-Ross (1969) was the first theorist to conceptualise grief into a staged model showing how bereaved people experience denial, anger, bargaining, depression, and acceptance. Such models have been criticised for suggesting people must move through these stages and not capturing the complexity, diversity, and idiosyncratic nature of grieving (Hall, 2014). Parkes (1975) and Worden (2008) identified tasks through which people work to grieve successfully (Wilson & Kirscbaum, 2011). The task-based model of grief (Worden, 2008) moved away from passive phases to the active task of mourning (Buglass, 2010). For community carers the strength and nature of their attachment to the deceased, their own attachment style, and death related factors could pose challenges to the task of mourning. Mourning previous losses is not always complete and end of life work can trigger suppressed or postponed grief (Van der kolk, McFarlane, & Weisaeth, 1996).

Research has shown nurses experience significant grief when working with end of life patients (e.g. Papadatou et al, 2002; Saunders & Valente, 1994; Vachon, 1987). Nurses in high mortality settings suffer numerous poor outcomes, including: sadness and guilt (Rashotte et al, 1997), helplessness and moral distress (Papadatou et al, 2002), low morale (O'Hara et al, 1996), unacknowledged and disenfranchised grief (Kaplan, 2000; Anderson & Gaugler, 2007), chronic and compounded grief (Feldstein & Gemma, 1995), compassion fatigue (Meadors & Lamson, 2008), stress and burnout (Anderson, 2008; Vachon & Benor, 2003). Positive experiences were also reported with successful grieving providing opportunities for personal and emotional growth (Papadatou et al, 2002; Anderson & Gaugler, 2007).

Research with carers in residential homes showed they feel unsupported with grieving, sighting heavy workloads and time constraints (Marcella & Kelley, 2015; Kaasalainen et al, 2007). Durall (2011) highlighted a “culture of silence” around grief within healthcare that needs to be broken. He suggested supporting staff by: (1) Creating a working environment in which staff can express their grief within a supportive clinical team, and, (2) Creating a meaningful context within which to place death (Durall, 2011; Burack & Chichin, 2010).

Anderson et al (2010) demonstrated healthcare assistants whose feelings of loss were validated gained greater personal growth from the experience (Marcella & Kelley, 2015). In comparison those who experienced greater distress reported higher levels of burnout, worse job satisfaction, and poorer psychological wellbeing (Anderson et al, 2010). Therefore, personal growth from grief experiences maybe a protective factor. This follows literature around post-traumatic growth, where positive psychological change can result from adversity leading to a higher level of functioning (Tedeschi & Calhoun, 2004). It is unclear whether community carers experience this.

This study aims to explore the lived experience of delivering end of life care in the community as part of a mixed caseload. No research has been undertaken with a sample of community carers who deliver end of life care as part of a mixed caseload of health and social care clients. The current study will explore, what is it like, and what are the impacts, of caring for terminally ill clients in the community?

Method:

Semi-structured interview data was analysed using IPA, this draws on the fundamental principles of phenomenology, idiography, and hermeneutics (Pietkiewicz & Smith, 2014). Research aims provide a detailed and rich description of participants' lived experiences from their own perspective (Smith, 2011). The researcher plays an active role in the analytical process which consists of “a double hermeneutic” with participants making meaning of their world, and, the researcher attempting to make sense of their meaning making (Smith et al, 2009; Braun & Clarke, 2013; Smith & Osborn, 2003). IPA's idiographic analysis involves balancing experiential claims against interpretative analysis (Larkin et al, 2006). IPA studies focus on small, homogenous, samples and use verbatim participant accounts (Braun & Clarke, 2013).

Participants:

A "community carer" was defined as somebody who delivered health and social care within the community. Part of their job was the provision of end of life care. Participants were active members of "end of life teams" or had been employed so within twelve months of their interview. Recruitment was through a local care agency and represented an opportunity sample.

Table 1 should be placed here.

Ethical considerations:

Ethical approval was obtained from the University West of England Faculty Research Ethics committee. The study was carried out according to BPS ethical guidelines.

Procedure:

Interviews were undertaken on a face-to-face basis at locations convenient to the participants. Prior to the interview participants were provided with information sheets that addressed issues such as confidentiality, sources of support, and anonymity. Informed consent was obtained and the opportunity to ask further questions prior to interview. Participants were asked open questions to obtain detailed accounts of their experience. Interviews were audio recorded and transcribed verbatim. Debriefing followed completion of interviews and participants could withdraw from the study at any point within the first six months.

Data Analysis:

Interviews were analysed qualitatively to identify recurrent themes across the data set. The researcher made notes of his impressions and feelings in a reflexive diary after each interview to bracket his own pre-conceived thoughts before starting analysis. This was to manage researcher influence over the research process as they are not always aware of their own preconceptions (Smith et al, 2009). The researcher had an “insider position” having previously delivered end of life care in the community. His identity as a "community carer" was bracketed and how delivering end of life care affected him was critical to the research process. Data analysis involved the six-step process as per IPA methodology set out by Smith et al (2009).

Results:

Theme 1 - Bonds:

"…gradually as a support worker, working with people for that period of time, you do get taken in as part of an extended family almost." (Dan 63)

Participants attached great importance to the relationships they formed when delivering end of life care. These relationships were often reciprocal in nature and enduring. Carers struggled when these relationships deepened, and attachments formed, as this impacted on their perception of carrying out a "professional" job. Lines blurred between friendships and working relationships, with carers going beyond their job descriptions.

1 (a) Closeness with clients:

"I used to really look forward to seeing her, I was really close to her." (Emma 55)

Carers worked with clients for a considerable time, often providing care prior to them developing terminal conditions, leading onto palliative and end of life care. This allowed time for close relationships to form. All participants described attachments with end of life clients:

"We would just have fun, it was, it was, more like being mates after a while than being a support worker and a client." (Dan 57)

Terms like "grandson", "grandparents", and "daughter", all evocative of family were used by participants to clients. Relationships began as working relationship but quickly developed beyond that:

"We used to talk all the time he would love to talk about football, and his early experiences as a kid, you know, and we built up quite a rapport." (Mike 172 – 173)

All carers struggled with how close to get to their clients. Striking a balance between maintaining a "professional" distance and forming a "caring" bond proved challenging. Boundaries would blur and carers would accept meals, gifts, and hugs:

"… he always used to, like, give me something to eat and a cup of tea." (Reg 26)

Finding this balance was particularly difficult when first starting end of life care but became easier with experience.

1 (b) Closeness to family:

"They knew how close I'd become and like to the family." (Reg 218 – 219)

Participants described how they were taken into the family unit of some clients. Working in homes, being surrounded by family, and regularly seeing the same clients meant bonds deepened:

"The, um, daughter of the man that died that she come to like us so much she come to seen us as, as family, and that was lovely." *(Mike 123)*

Mike describes how the whole end of life team became seen as "family" and individual relationships developed:

"I became very good friends with her (client's wife)." (Mike 166)

This dynamic goes beyond that of a working relationship and represents a deeper attachment.

1 (c) Caring for the carer:

"There were times where actually the carer role was reversed." (Emma 64)

Closeness lead to a reciprocity in the caring relationship:

"I went through a horrible breakup and went to see her…she put her arm around me and gave me a hug. Made me a cup of tea…we were actually quite close." (Emma 64)

Affection is demonstrated physically with a hug and practically by making her a cup of tea together with the wisdom she imparts:

"going through… the kind of the relationship breakdown that I was going through at the time.. with someone.. like her supporting me, I think maybe yeah, I think she did.. teach me.. about love and what… a, sort of what a good relationship.. was meant to look like." (Emma 89)

This dynamic represents an adult attachment bond with reciprocity of care present.

Theme 2 - The Terminal Space:

"...you kind of watch the deterioration and they become sort of thinner and weaker, they're more bed bound, they're more prone to bed sores, that sort, sort of thing at the end of life." (Emma 109)

This theme concerns the experience of working with terminal clients in the dying space and the associated challenges.

2 (a) End of life care is different:

"It's not like.. many other jobs in the sense like, you don't always have to, you don't.. a lot of other jobs you won't see people deteriorating or dying." (Reg 247)

All participants described how end of life care was different to the other types of care work. This difference had many facets. Carers witnessed the decline and death of their clients:

"they're much weaker.. um, but often it's, uh [sighs] I don't know, some..maybe their eyes, something goes in their eyes. It's almost like you can see the life kind of coming out of them." (Emma 158)

As clients declined carers tasks changed with fewer practical tasks this fed a sense of powerlessness. Carers were faced with the inevitability of death fuelling a sense of helplessness:

"...whatever you do it's not going to change the outcome and there is a massive amount of helplessness there, you sometimes feel like you're in the way." (Reg 105)

On occasions, witnessing suffering was so traumatic death would be more compassionate. Mike hints at arguments for euthanasia:

"We were all almost actually like praying for him to die... and he was like that for several weeks and that was very distressing to watch it's not something I would like to go through again. Yeah, very distressing." (Mike 45 – 50)

Feelings of distress, helplessness, and powerlessness fed a greater sense of anxiety around end of life care:

"it was something... more uneasy about it." (Reg 85)

2 (b) Adapting communication:

"…right at the end there are certain things that you won't say, you won't say, "I'll see you next time", talk about the future much, you talk very little about yourself you want it to be

about the client and centred around them, and their experiences, often toward the end of their life, they want to talk about their memories a bit more" (Emma 286)

Communication was a major challenge for all carers at the end. Reg and Emma, talked of the importance of adapting their communication style with dying clients demonstrating compassion, empathy, and a client centred approach.

However, this created additional anxiety, pressure, and stress around saying something insensitive or inappropriate. Adapting to each person was also challenging:

""I am not a doctor but" you really have to be able to gage the families and what sort of information that you caaaan tell them and what you can't." (Emma 139 – 141)

Communication with family members was anxiety provoking for all:

"*Dealing with the family, for me, was the hardest part because for them it was more a case of when, when is it going to happen?" What, what is going to happen? How, how is it going to happen? And those were questions that we would get time and time again as support workers, and those questions we could not answer. And it made you just feel [sighs] quite awkward in a sense, when they were asking these questions because you simply did not know." (Dan 93 – 96)*

2 (c) Significance of first client:

"That one, definitely (most memorable). I think because it was my first end of life." (Kim 61 – 62)

Each participant placed importance on the experience of working with their first end of life client. A lack of, or inability to, prepare left them with a sense of fear, uncertainty, and anxiety:

"The first time…I was very nervous…not having done anything like that before…there was always the, the feeling… cuz at the time I had never seen a dead body before so there was always the thing was I going to go in and find someone..dead" (Mike 7)

This linked to a lack of training:

"back then…there wasn't a lot of training that happened." (Reg 289- 290)

To manage their anxiety carers developed idiosyncratic coping strategies. Kim would seek reassurance from professionals, while Dan would play over scenarios that "might" happen in preparation. All carers used rationalizations and kept busy as a means of distraction.

For Reg important learning emerged around keeping boundaries, adapting to his client and in self-reflective practice culminating in post-traumatic growth:

"I think I learned, learned quite a lot from my first end of life care customer about myself mainly…like to be a bit more professional" (Reg 145 – 148)

For Mike nurses aided his practical, experiential learning:

"…that first end of life I told you about we had the Marie Cure nurses" (Mike 203)

However, no post-traumatic growth emerged only enduring, traumatic memories.

Theme 3 - Loss:

"…you feel quite empty actually…it's almost like losing a friend…there's a little gap there." (Mike 209)

Emotions associated with grief were described by all carers, particularly sadness:

"I feel that emotion, feel like being upset." (Kim 197)

Emotions linked to Kubler-Ross's (1969) staged model of grief. Denial was like shock participants experienced after a death. Anger manifested in many ways: at colleagues, family members, employers, and turned inwards against themselves:

"I was… really cross with myself because I hadn't been to see him." (Emma 270 – 271)

Depression:

"…you are a bit down…emotionally you are down as well" (Mike 293 – 294)

Guilt experienced by female participants linked to bargaining:

"I still feel it now if I think about it, it's that guilt feeling, that should have been me cuz I could have said goodbye." (Kim 48 – 49)

Consequently, Kim found it difficult to say "no" to her clients:

"I mean I always do that extra" (Kim 168)

Kim is bargaining by doing extra for her current clients to compensate for the client she could not say goodbye to.

Emma's grief manifested later as compounded grief:

"Then I definitely do have days when I cry uncontrollably for seemingly no reason so maybe that is just a sort of later manifestation of this behaviour that started to emerge when I was doing end of life stuff." (Emma 207 – 211)

3 (a) Carer abandonment:

"When they passed away, erm, you kind of felt abandonment almost" (Dan 126)

Carers felt unsupported by their employer after a loss:

"it was just like.. it's all happened now, get on with it, it's part of the job… I do think there needs to be more support out there." (Kim 9)

Dan expresses this explicitly:

"I think the companies themselves could be more understanding… they should give that support even if it is a telephone call after…and maybe follow up calls… …but then not actually recognise, hey well look there's a carer here. Well, how do they feel? They com, they completely miss out one of the most important people" (Dan 126 – 127)

Exclusion from funerals fuelled feelings of abandonment:

"We wanted to be invited to the funeral …but obviously because of policies or whatever it was probably decided we, we shouldn't go." (Reg 166)

Reg goes onto state:

There could've been something to, to get us all together and…have some sort of closure." (Reg 292)

Being able to collectively grieve would have helped carers. Feelings of abandonment, lack of closure, and lack of support fed disenfranchised grief (Doka, 2002):

3 (b) Disenfranchised grief:

"In terms of, um, my own… grieving process if you like it… I didn't feel I had a, I had a right." (Reg 199)

Most participants experienced disenfranchised grief (Doka, 1987). Resources for resolving grief were limited as informal and formal support systems, normally available, could not be utilised due to the unacknowledged nature of the carer – client relationship:

"...this is their family, their father, and really it's their time to be, you know, for their sorrow so I decided not to go (to the funeral)." (Mike 138 – 139)

Carers were excluded from collective grieving processes:

"...you don't get told about funeral arrangements, the family don't know who you are. You suddenly become aware of your position in their life again" (Emma 75 -76)

Their grief was not openly acknowledged, publicly observed, or socially validated so carers experienced disenfranchised grief (Doka, 2002).

The exception was Kim who actively attended her client's funerals, maintained bonds with family members, and grieved with colleagues, aiding her grief resolution:

"We all met up beforehand and then went and did the funeral, and it was nice to hear what their grandchildren had to say and they, they even said like a little paragraph about the carers being there for her, I can't remember exactly what you said, erm, yeah it, it, it was upsetting…but it's nice to be part of all that as well with the family, yeah, and think it's also closure for us." (Kim 55)

3 (c) Continuing bond:

"I think about her now sometimes weirdly." (Emma 81)

Some carers maintained an internalized continuing bond with important clients after they passed:

"I do think about her ...I think she did teach me about love and what a…good relationship was meant to look like. I mean I don't think, at the time, I really digested it. But I think in hindsight the things that she said were incredibly wise." (Emma 84 – 90)

Emma exhibited a secure attachment where a continuing bond with her deceased client played an important part in grief resolution. She internalized a representation of her client as a role model who is a valued part of her autobiography. Her client is an internalised, inner comforting presence where Emma can be sustained by a mental representation without need for her physical presence. This follows the continuing bonds theory of grief (Field et al, 2005).

This contrasted to Dan:

"I've gradually learned over the years to build up a kind of, almost resistance to people telling me their life stories and their tales about when they were younger and things like that, and it's not because I'm not interested it's just… you take it in but you don't really sort of play on it at all. The amount of stories I've heard over the years but the amount of stories that I can repeat back to you is probably next to none. I would hear them and it would effectively go in one ear and out the other." (Dan 69)

Dan did not form a continuing bond with his deceased clients. He describes "defensive exclusion" of attachment related feelings (Mikulincer et al, 2003) interfering with processing loss, its implications, and working through associated painful memories (Field et al, 2005). This indicates an insecure avoidant attachment style resulting in a failure to revise schemas of attachment to a reality of life without the deceased (Field et al, 2005). This means Dan has limited ability to make effective use of a continuing bond in coping with loss.

Discussion:

All participants described how they formed an adult attachment bond with at least some of their end of life clients. These adult to adult attachment bonds did appear to serve a similar function for both carer and client (Hazan & Ziefman, 1999, Field et al, 2005). These were strongest for carers first end of life client and those they worked with longest. This is consistent with attachment theory (Bowlby, 1980). Bonds were strengthened by working in client's homes, becoming integrated into the family, and sharing displays of affection.

Upon patient death participants described a range of emotions associated with grief. Carers described symptoms of grief like family caregivers and other direct healthcare staff in Boerner et al (2015). They displayed behavioural, cognitive, and physiological symptoms associated with grief, including: tearfulness, ruminating on the deceased, helplessness, and hopelessness (Stroebe et al, 2001; Rando, 2000; Waldrop, 2007). Feelings linked to Kubler-Ross's (1969) model of grief which sites stages of denial, bargaining, anger, depression, and acceptance. Carers experienced grief for significant clients but experienced more anxiety related symptoms leading up to a death. This is consistent with experiencing anxiety around patients dying and grieving afterwards.

Some participants integrated the memory of significant clients into their ongoing narrative and way of life (Walter, 1996) helping make sense of the bereavement (Neimeyer, 2001). This follows the continuing bonds theory of grief (Klass et al, 2014) where the carer adjusts and redefines their relationship with the deceased allowing for a bond that endures over time and aids with grief resolution. However, there were those that exhibited an insecure avoidant attachment style who did not form a bond with significant bereaved clients due to "defensive exclusion" of attachment related feelings (Mikulincer et al, 2003). This demonstrates how attachment style can be an important consideration in bereavement support.

As with previous literature carers were excluded from collective grieving processes, rituals, farewells, funerals, and memorials (Wilson & Kirshbaum, 2011). The importance of these are long established in mourning loss (Lindermann, 1944). Being excluded effected carers ability to mourn and left them experiencing disenfranchised grief (Doka, 1987; Doka, 2002). They experienced abandonment, a need for closure, and lacked systems of support.

Kim was the exception, attending funerals and staying in contact family members after client death aiding her mourning and giving closure that other participants lacked. This is consistent with the task-based model of grief (Worden, 2008) which focuses on active tasks of mourning (Buglass, 2010).

Participants who experienced personal growth following client death reported post-traumatic growth (Tedeschi & Calhoun, 2004). However, others were left feeling disillusioned, tired, distressed, and looking to change jobs, while Emma left care feeling "burned out" and having "compassion fatigue". This is consistent with Anderson et al (2010) as nursing assistants who experienced greater distress from grief experiences reported higher levels of burnout. While those who reported greater personal growth reported lower levels of burnout, higher levels of wellbeing, and better job satisfaction.

Findings replicated research carried out with nurses delivering end of life care. Community carers exhibited symptoms of increased sadness and guilt, similar to findings of Rashotte et al (1997), a sense of sadness and moral distress like those reported by Papadatou et al (2002), unacknowledged and disenfranchised grief as in Kaplan (2000). There was some evidence of primary traumatization through having direct contact with traumatic deaths (Peebles-Kleiger, 2000), as symptoms of irritability, increased anxiety, and sadness characterize primary traumatization (Munson, 2002). However, no evidence of secondary traumatization was found unlike populations of mental health workers, social workers (Bride, 2007), and hospice nurses (Abendroth & Flannery, 2006). Findings highlighted how formal support systems provided by employers were inadequate, as with residential care workers (Boerner et al, 2015), and care assistants in private nursing homes (Whittaker et al, 2007). Shortcomings in end of life training as in Fryer et al (2016) and Herber and Johnson (2013) were also demonstrated.

As an IPA study with a small sample, generalisability of findings is not supported due to the exploratory nature of qualitative research. However, future research could explore larger samples or less homogenous cohorts of community carers. There was a demographic limitation as the sample consisted of working class, white British participants from Plymouth. Though partially reflective of the local demographic, it did not capture the diversity of the overall health and social care workforce, particularly the ethnic diversity. This is pertinent as this has implications in terms of the rituals, attitudes, and beliefs that minority groups have around death. These could impact the relationships that they form with their clients, their own psychological wellbeing, and how they grieve. These issues merit further exploration.

IPA involves a double hermeneutic with the researcher making sense of the participants making sense of their experiences. Therefore, the analysis represents just one possible construct of the phenomenon under study which was influenced by the researchers own subjectivity. Another researcher would have produced different themes dependent on their perspective (Elliot et al, 1999; Palmieri, 2018).

A further limitation is that participants did not mention the ages of their clients. A younger person becoming ill and dying could be considered a more unexpected and abnormal death than an elderly person (Palmieri, 2018). Working with young people could provoke a different reaction and a different bond may form than with an adult or elderly client, possibly more like a parent - child attachment bond than an adult - adult bond. Therefore, carers delivering end of life care in the community with young people or children merits further research.

Findings link into previous research and highlight the sparsity of specialist end of life training for community carers, the lack of support from employers, and an absence of bereavement support. The first end of life client is particularly challenging suggesting this is where additional training and support could be focused. Recommendations by Durall (2010) around breaking the “culture of silence” around grief and loss within healthcare seem pertinent. Carers would benefit from the creation of a working environment in which they can express their grief within a supportive team and create a meaningful context within which to place their grief (Durall, 2011; Burack & Chichin, 2010). This would help to validate carers feelings and with disenfranchised grief. This would increase the opportunity for personal growth from the experience of loss (Anderson et al, 2010; Marcella & Kelley, 2015), a protective factor from adverse long-term psychological difficulties, burnout, and compassion fatigue (Anderson et al, 2010). It is recommended that further research be undertaken around providing these more supportive conditions to community carers.

Word Count: 4,989

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Appendix:

“Psuedo” Name	**Gender**	**Ethnicity**	**Age**	**Sexuality**	**Faith**	**Relationship Status**	**Currently working in community care**	**Class**
Dan	Male	White British	30’s	Heterosexual	None	Married	No	Working
Reg	Male	White British	20’s	Heterosexual	None	Co-habiting	Yes	Working
Mike	Male	White British	50’s	Not stated	Pagan	Single	Yes	Working
Kim	Female	White British	30’s	Bisexual	None	Co-habiting	Yes	Working
Emma	Female	White British	30’s	Heterosexual	None	Co-habiting	No	Middle

Table 1. Participant Demographic Information

b. Draft Interview Protocol:

ABOUT THE JOB:

- How long have you been delivering end of life care?
- What kind of things do you do?
- What do you like, and not like, about the work?

BOND WITH CLIENTS:

- Can you tell me about a memorable client?
- What sort of bond did you have?

BEREAVEMENT:

- What is it like for you when a client dies?
- How do you grieve?
- What are you left with?

PSYCHOLOGICAL EFFECTS:

- How does your job effect the rest of your life?
- Psychologically, how are you affected?
- What sort of support do you have?

ADDITIONAL COMMENTS:

- Is there anything else you would like to talk about?

c. Ethics Form:

University of the
West of England
BRISTOL

Details of the proposed work:

PLEASE COMPLETE ALL SECTIONS. IF YOU THINK THE QUESTION IS NOT APPROPRIATE, PLEASE STATE WHY.

1. Aims, objectives of and background to the research:

BACKGROUND:

End of Life Care in the Community:

There is strong evidence to suggest that people prefer to be cared for, and die, in their own homes **(Gomes et al, 2013).** The research evidence suggests the majority of people would prefer to die at home so long as they were assured of receiving good quality care and support **(Higginson & Sen Gupta, 2000; Herber & Johnson, 2013).** It is estimated that 70% of the UK population would choose to die at home **(NICE, 2014).** In the UK there has been a reversal in the trend of institutionalised dying **(Gomes et al, 2012).** From 1974 to 2003 the number of deaths at home almost halved **(Gomes et al 2012; Gomes & Higginson, 2008).** However, this trend was reversed from 2003 to 2010 with home deaths increasing steadily from 18.3 % of deaths in 2004 to 20.8% in 2010 **(Gomes et al, 2012).**

There are major challenges for end of life care, and palliative home care, posed by a rapidly ageing population with increasing complexity in their care needs **(Gomes et al, 2013; Gomes et al, 2012; Gomes & Higginson, 2008).** Couple this with an increase in the prevalence of long-term chronic conditions and it results in the need for a dramatically expanded health and social care workforce **(Ingelton et al, 2011)**. This workforce will need to combine registered professionals with unqualified support staff to ensure that care in the community can be provide to all those that require it **(Ingleton & Seymour, 2008; Ingelton et al, 2011).**

In the UK, regardless of setting, patient centred multidisciplinary care provides the means to compile suitable care plans for dying people. Individualised care plans encompass physical symptoms (e.g. pain, breathlessness, and fatigue), psychological symptoms (e.g. anxiety, depression), social needs, and spiritual needs (for some people). It is acknowledged that good communication is required to ensure people feel involved in the decision making process around their care. If done successfully, this contributes to their perceptions of being treated with care, dignity, and respect **(NICE, 2014).**

It is widely recognised that health care assistants provide a key role in the provision of community palliative care, and end of life care in the UK **(Lovatt et al, 2015).** Community support workers involved in the provision palliative and end of life care operate as part of these multi-disciplinary teams **(Herber & Johnson, 2013)**. In the UK their role was introduced as part of the 1990 NHS and Community Care Act **(Department of Health, 1990; Lovatt et al, 2015).** In order to perform this role no formal training or mandatory qualifications are required, and specific duties can vary according to the individual settings and services **(Lovatt et al, 2015; Mc Kenna et al, 2004).**

A systematic review of the literature carried out by **Herber & Johnson (2013)** examined the role and tasks of community support workers providing end of life and palliative care, as well as the challenges and supporting factors associated with their ability to provide this care. Their findings demonstrated that community support workers undertook a number of tasks. These included the provision of emotional and personal care, domestic support for families, and respite care. The challenges for support workers included the ambiguity of their role, the paucity of their training, and the degree to which they became emotionally attached to their clients. The supporting factors included peer support, a sense of cohesiveness amongst colleagues, and task orientation **(Herber & Johnson, 2013).** It was recommended that future research:

(i) Identify caring situations in which challenges occur.

(ii) Deduce interventions tailored specifically to support workers requirements.

(iii) Look at how to improve support workers performance in order to reassure patients. **(Herber & Johnson, 2013).**

In 2002 The Liverpool Care Pathway was designed as a clinical tool to improve care for dying patients, and was subsequently recommended as best practice in the UK national end of life care strategy **(DH, 2008; Venkatatsalu et al, 2015)**. The Liverpool Care Pathway was seen as a way of transferring the model of "excellence" in care from hospices to other healthcare settings **(NICE, 2014).** However, following media criticisms, Baroness Neuberger's review of the Liverpool Care Pathway entitled, *"More care less pathway",* highlighted numerous concerns. These included a lack of strong evidence for the Liverpool Care Pathway improving the quality of end of life care **(Neuberger et al, 2013; Venkatatsalu et al, 2015).** As a consequence the UK government decided to phase out The Liverpool Care Pathway by July 2014 **(Chan & Webster, 2013).** This has left a challenge for the NHS, and other health service providers, to ensure that the care delivered to people in the last days of their life is evidence based, of high quality, and based on the needs of the dying individual **(NICE, 2014).** The **Neurberger et al (2013)** recommendations included:

(i) The CQC undertake a thematic review of how dying patients were treated across various settings, including in the community;

(ii) Research into the experience of dying should be undertaken as there, "are critical and legitimate social and health objectives and benefits that must be understood, in how patients, their relatives or carers experience care at the end of life.” **(p.18, Neuberger et al, 2013).**

(iii) A pressing need for, "more evidence based education and care in all settings that care for the dying **(p.46, Neuberger et al, 2013).**"

OBJECTIVES:

Psychological aspects for support workers providing end of life care:

ATTACHMENT AND LOSS:

According to attachment theory, children develop an attachment to their primary caregivers, despite individual differences in the quality of this attachment bond **(Field et al, 2005).** Attachment bonds in adults are considered different from child to parent bonds, largely due to the fact that both adults can serve as an attachment figure to each other **(Hazan & Ziefman, 1999).** However, adult to adult bonds are understood to a serve similar function for those involved. These functions distinguish attachment relationships from other types of relationships **(Field et al, 2005)**. Previous research has demonstrated that healthcare support workers develop an emotional attachment, and bond, with their end of life clients **(Denham et al, 2006; Schell & Kayser-Jones, 2007; Herber & Johnson, 2013).** The nature of this emotional bond and its implication for community support workers remains unexplored. It is unknown whether community support workers grieve for their deceased clients, if they are supported adequately, and how this affects their work and social lives. The current study aims to address this.

BEREAVEMENT:

The current study will investigate whether community support workers go through a grieving process, and how is this mediated, following the deaths of their clients.

This grieving process could be related to a stage model of grief such as the one proposed by **Kubler-Ross (1969)** where bereaved people experience the emotions of denial, anger, bargaining, depression, and acceptance. This model implies that failure to complete any of the stages of grief would result in a multiplicity of complications, which could have implications for a community support worker dealing with other clients. However, staged models of grief have been criticised for suggesting people must move through these stages and for not capturing the complexity, diversity, and idiosyncratic nature of grieving. Furthermore, stage models do not address the many, and varied, physical, psychological, social, and spiritual needs of bereaved people **(Hall, 2014).**

The Dual Process Model of Grief **(Stroebe & Schut, 1999)** addresses some of these criticisms. It describes how a bereaved person must cope with the experience of death and the resultant lifestyle changes **(Buglass, 2010).** From this perspective grief is a process of oscillation between "loss orientated" and "restoration orientated" ways of being **(Hall, 2014)**. Loss orientated factors relate to the death experience, whereas restoration orientated factors relate to making lifestyle changes, coping with everyday life, and establishing new roles **(Buglass, 2010).** For a community support worker balancing these two processes might have an impact on their ability to undertake their work in different situations, and their work with different client groups. These two processes may give an insight into how resilient a support worker is when dealing with end of life care. However, this model does not seem consider the importance of interpersonal relationships in helping people cope with bereavement **(Buglass, 2010).**

The Task-based model of grief **(Worden, 2008)** moves away from passive phases of grief to the active task of mourning **(Buglass, 2010).** Mourning involves engagement with the tasks of: (1) Accepting the reality of the loss, (2) Working through and experiencing the pain of grief, (3) Adjusting to an environment without the deceased person, and, (4) To withdrawing emotionally from the deceased and moving on **(Buglass, 2010)**. Worden (2008) identifies seven factors that are crucial to understanding the experience of mourning: (1) Who the deceased was, (2) The nature of the attachment to the deceased, (3) How the person died, (4) Historical antecedents, (5) Personality variables, (6) Social variables, and (7) Concurrent stressors **(Hall, 2014).** For community support workers the strength and nature of their attachment to the deceased, their own attachment style, and death related factors could pose them with psychological issues and challenges to the task of mourning. Mourning for previous losses is not always complete, and working with end of life clients could trigger suppressed and postponed grief **(Van der kolk, McFarlane, & Weisaeth, 1996).** This in turn could impact on their ability to carry out their work.

Finally, if a support worker became particularly attached to a deceased client, it might be important for them to adjust and redefine their relationship after death. This would allow for a continued bond with that client that would endure over time. This would be in line with the continuing bonds theory of bereavement **(Klass et al, 2014).**

PSYCHOLOGICAL CONSEQUENCES:

The psychological consequences of end of life care on community support workers remain relatively unexplored.

It is possible that this type of work could provoke an existential crisis whereby support workers question whether their own lives have any purpose, meaning or value. This could trigger avoidance behaviour and precipitate a period of depression **(James & Gilliland, 2012).**

Support workers might be traumatised by their work with end of life clients. Rumination, poor motivation, and feelings of guilt are all consequences of traumatic loss **(Scott & Stradling, 2006).** It is possible that they could experience symptoms or sequelae of PTSD as set out by the DSM - IV. This could encompass a range of problems from emotional blunting, to having flashbacks, re-livings, and nightmares of particular situations. Therefore, this type of care work could trigger or exacerbate underlying mental health issues for support workers engaged in it. This could in turn lead to heightened anxiety around undertaking end of life work.

AIM OF CURRENT STUDY:

The current study aims to investigate the psychological impact that providing end of life care has on community support workers, and how this could affect their ability to carry out their work. This research is necessary as it addresses some of the recommendations in **Neurberger et al (2013)** report, and the previous research of **Herber & Johnson (2013)**.

2. Research methodology to be used (include a copy of the interview schedule/ questionnaire/ observation schedule where appropriate):

This study aims to understand the personal experience of being a community support worker, and the associated psychological affects, involved in the process of delivering end of life care. Therefore, an Interpretative Phenomenological Analysis (IPA) will be undertaken. This involves undertaking in-depth, qualitative interviews with support workers about their experience of end of life care. It is recommended that students undertaking a Professional doctorate aim to carry out between 4 - 10 interviews when using IPA **(Smith et al, 2009).** In order to do this a semi-structured interview protocol will be developed, as follows:

DRAFT INTERVIEW PROTOCOL

ABOUT THE JOB:

- How long have you been delivering end of life care?

- What kind of things do you do?

- What do you like, and not like, about the work?

BOND WITH CLIENTS:

- Can you tell me about a memorable client?

- What sort of bond did you have?

BEREAVEMENT:

- What is it like for you when a client dies?

- How do you grieve?

- What are you left with?

PSYCHOLOGICAL EFFECTS:

- How does your job effect the rest of your life?

- Psychologically, how are you affected?

- What sort of support do you have?

ADDITIONAL COMMENTS:

- Is there anything else you would like to talk about?

A semi-structured interview expands on individual responses and explores further areas that might emerge during the interview. This creates an open forum for dialogue between researcher and participant, allowing them to express any views that they deem to be important. It will also allow the researcher to identify common themes across the data set for later analysis.

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3. Selection of participants:

Will the participants be from any of the following groups?*(Tick as appropriate)*

NO: Children under 18

NO: Adults who are unable to consent for themselves[2]

NO: Adults who are unconscious, very severely ill or have a terminal illness

NO: Adults in emergency situations

NO: Adults with mental illness (particularly if detained under Mental Health Legislation)

NO: Prisoners

NO: Young Offenders

NO: Healthy Volunteers (where procedures may be adverse or invasive)

NO: Those who could be considered to have a particularly dependent relationship with the investigator, e.g. those in care homes, medical students

NO : Other vulnerable groups

YES: None of the above

([2] Please note, the Mental Capacity Act requires all intrusive research involving adults who are unable to consent for themselves to be scrutinised by an NHS Local Research Ethics Committee – Please consult the Chair of your Faculty Research Ethics Committee, or Alison Vaughton (RBI) for advice)

If any of the above applies, please justify their inclusion in this research:

N/A

Note: If you are proposing to undertake research which involves contact with children or vulnerable adults, you may need to hold a valid DBS (Disclosure and Barring Service, formerly Criminal Records Bureau – CRB) check.

Where appropriate, please provide evidence of the check with your application.

4. Please explain how you will determine your sample size/recruitment strategy, and identify, approach and recruit your participants. Please explain arrangements made for participants who may not adequately understand verbal explanations or written information in English.

It is recommended that students undertaking a Professional doctorate aim to carry out between 4 - 10 interviews when using IPA **(Smith et al, 2009).**

<u>RECRUITMENT OF PARTICIPANTS:</u>

For the purposes of this research a "community support worker" will be defined as somebody delivering health and social care within the community. In addition to this definition, part of the their job description will be the provision of end of life and palliative care. Participants will also be members of "end of life care teams".

Between 4 and 10 community support workers will be invited to participate in this study. These support workers will be based in Plymouth, and will be employed by the care agency that the researcher previously worked with. The care agency has given their consent for their employees to be approached. The researcher will only approach participants who are on "end of life care teams".

As the researcher was formerly employed as a community support worker it creates an ethical problem because of his dual role. In order to avoid ethical issues the researcher will approach participants in his role as a "trainee counselling psychologist". This will be made explicit to participants initially in writing, and subsequently re-affirmed verbally.

In his previous role as a "community support worker" the researcher did not deliver any end of life or palliative care for approximately 18 months. Furthermore, in order to avoid any undue influence over the interview process the researcher will not approach participants that he knows socially, or people he works with other than on a very infrequent basis.

Due to the nature of their work, participants employed by the agency are fluent in English and are able to read, write and understand English. Therefore, additional arrangements will not be required.

Participants will be approached in writing by e-mail or letter and asked if they would like to participate in the study. The e-mail / letter will be worded similarly to this:

" Dear xxxxxxx,

As an employee of SDS you are invited to participate in a study being carried out by The University of West England psychology department. The research is investigating the psychological impact of end of life care on community support workers. The research is being conducted by Zeon Kallis, a trainee counselling psychologist and former care worker with SDS.

Should you wish to participate in this study please read the enclosed information sheet and reply to Zeon Kallis on zeonkallis@hotmail.com or on 07796 092412. Alternatively, if you do not wish to participate please dispose of this letter/e-mail and you will not be contacted any further.

Should you choose to take part in this study all information that you provide will be anonymous and the final research paper will be made available upon conclusion.

If you have any further questions or comments please contact Zeon directly, by e-mail at or by telephone on 07796 092412.

Yours sincerely,

Zeon Kallis"

5a. What are your arrangements for obtaining informed consent whether written, verbal or other? (where applicable, copies of participant information sheets and consent forms should be provided)

See attached information sheet:

*"**Procedures:***

...Before an interview can take place you must read this information sheet as it explains the purpose of the study and outlines the ethical considerations. Prior to the interview the researcher will go over this information sheet with you and answer any questions that you may have. The researcher will then ask you if you still wish to participate in the study. If this is the case you will be asked to sign a consent form, confirming that you understand the information provided in this sheet and that you are willing to participate in the study."

b. What arrangements are in place for participants to withdraw from the study?

See attached information sheet:

"Withdrawal/Premature Completion:

Once you have consented to participate in this study you can still withdrawn at any time within the first six months. Your participation in the study is voluntary, and you may discontinue at any time within the first six months, without prejudice. If, after consenting to participate, you decide that you no longer wish to be included in the study please contact the researcher who will ensure your information is removed from the study and your data will be destroyed."

6. If the research generates personal data, please describe the arrangements for maintaining anonymity and confidentiality or the reasons for not doing so.

See attached information sheet:

"Procedures:

...Any identifying information provided, of both yourself and others named, will be anonymised in the transcript with fictitious names. Once transcribed your interview will be analysed together with the other interviews to identify themes across the data set. Participants names or other identifying information will never be associated with any research reports or publications that result from these interviews. Participants will always be given fictional names to protect their anonymity."

"Confidentiality:

Any information that you give will be kept strictly confidential, except as may be required by the law or professional guidelines for psychologists. All information will be identified by an identification code, not your name. Your name or other identifying information will never be associated with any research reports or publications that use the results of this study."

7. Please describe how you will store data collected in the course of your research and maintain data protection.

See attached information sheet:

"Data Storage:

Once disclosed this information will be stored securely in accordance with The Data Protection Act 1998 and The University West of England's data protection policy. The researcher and his supervisors will be the only people who have access to this data. Electronic data will be stored on a password protected, encrypted memory stick. Any physical data will be stored in a locked filing cabinet at the researchers place of residence.

The data obtained during the interview will be used solely for the purposes of this research and in accordance with the ethical standards of confidentiality that govern psychologists.

The interview transcripts and data will be destroyed within two years of completion of the study. "

8. What risks (eg physical, psychological, social, legal or economic), if any, do the participants face in taking part in this research and how will you overcome these risks?

See attached information sheet:

"Potential Risks and Ethical Consideration:

(i) The main risk associated with these interviews is possible discomfort or distress when answering some of the questions relating to your job and the psychological impact that it has on you. If at any time during the interview you find yourself becoming distressed the interview will be stop to allow you to regain your composure, and if necessary the interview will be terminated. The interviewer will then discuss possible

sources of support with you and signpost you to appropriate organisations such as: your GP for medical advice, The Samaritans for a free 24 hour listening service who provide emotional support (116 123), Plymouth Options for psychological therapies in Plymouth (01752 435419), and if appropriate the community mental health team for more serious concerns.

(ii) *Should you encounter any discomfort or distress once the interview has been completed you should contact your GP immediately who will be able to advise you further.*

(iii) *You should be aware that this interview is confidential and the data generated will have no bearing on your current employment. Any information generated will not be provided to your employer."*

9 Are there any potential risks to researchers and any other people impacted by this study as a consequence of undertaking this proposal that are greater than those encountered in normal day to day life?

When details of the interview have been arranged with the participants details of the venue will be logged and shared with the researchers supervisor. A chaperone will also drop the researcher off and collect the researcher after the interviews. In case of an emergency the chaperone will be contactable by telephone for the duration of the interviews.

10 How will the results of the research be reported and disseminated?

(Select all that apply)

YES: Peer reviewed journal

YES: Conference presentation

YES: Internal report

YES: Dissertation/Thesis

NO: Other publication

NO: Written feedback to research participants

YES: Presentation to participants or relevant community groups

NO: Other (Please specify below)

11 Are there any other ethical issues that have not been addressed which you would wish to bring to the attention of the Faculty and/or University Research Ethics Committee?

No

Checklist

Please complete before submitting the form.

	Yes/No
Is a copy of the research proposal attached?	**Yes**
Have you explained how you will select the participants?	**Yes**
Have you described the ethical issues related to the well-being of participants?	**Yes**
Have you considered health and safety issues for the participants and researchers?	**Yes**
Have you included details of data protection including data storage?	**Yes**
Have you described fully how you will maintain confidentiality?	**Yes**
Is a participant consent form attached?	**Yes**
Is a participant information sheet attached?	**Yes**
Is a copy of your questionnaire/topic guide attached?	**n/a**
Where applicable, is evidence of a current DBS (formerly CRB) check attached?	**n/a**

d. Risk Assessment:

Describe the activity being assessed: Semi-structured, face to face interviews in the research study entitled, "End of Life Care: The Psychological Impact on Community Support Workers."	**Assessed by:** **Tony Ward**	**Endorsed by:** Zoe Thomas
Who might be harmed: Participants in interview may become emotionally distressed due to topic area being discussed. Researcher might be at risk through lone working. **How many exposed to risk:**	**Date of Assessment:** 03.06.2016	**Review date(s):** 06.06.2016

Hazards Identified *(state the potential harm)*	**Existing Control Measures**	**S**	**L**	**Risk Level**	**Additional Control Measures**	**S**	**L**	**Risk Level**	**By whom and by when**	**Date completed**

Lone Working / Researcher safety	The interviews will take place at a location agreed with each participant. The researcher will have a chaperone who will drop him off at the beginning of the interview and collect him on completion of the interview. The chaperone will be available by telephone for the duration of the interview in case of an emergency. All participants work for a care agency who have fully vetted them, and DBS approved them.	1	2	2						
Emotional Distress to Participants	Participants will be provide with information by e-mail / post prior to interview enabling them to decide if they would like to take part in the study i.e. "opt in" NOT opt out. Participants will be provided with information about sources of support in the information sheet prior to interview. Participants will also have the chance to discuss matters with the researcher prior to interview.	2	2	4						

	Informed consent will be obtained before these interviews take place. If participants become distressed during interviews they will be stopped to allow them to recover their composure or terminated if appropriate. The researcher will then guide distressed participants to appropriate sources of support and ensure that they are in a safe place upon conclusion. Participants will be fully debriefed on completion of interview and left with telephone numbers of further sources of support should they become distressed. Participants will have the right to withdraw at any point within the first 6 months of their interview by contacting the researcher on telephone number or e-mail address provided.									

RISK MATRIX: (To generate the risk level).

Very likely **5**	**5**	**10**	**15**	**20**	**25**
Likely **4**	**4**	**8**	**12**	**16**	**20**
Possible **3**	**3**	**6**	**9**	**12**	**15**
Unlikely **2**	**2**	**4**	**6**	**8**	**10**
Extremely unlikely **1**	**1**	**2**	**3**	**4**	**5**
Likelihood (L) **Severity (S)**	**Minor injury – No first aid treatment required** **1**	**Minor injury – Requires First Aid Treatment** **2**	**Injury - requires GP treatment or Hospital attendance** **3**	**Major Injury** **4**	**Fatality** **5**

ACTION LEVEL: (To identify what action needs to be taken).

POINTS:	RISK LEVEL:	ACTION:
1 – 2	NEGLIGIBLE	No further action is necessary.
3 – 5	TOLERABLE	Where possible, reduce the risk further
6 – 12	MODERATE	Additional control measures are required
15 – 16	HIGH	Immediate action is necessary
20 – 25	INTOLERABLE	Stop the activity/ do not start the activity

Describe the activity being assessed: Semi-structured, face to face interviews in the research study entitled, "End of Life Care: The Psychological Impact on Community Support Workers."	**Assessed by:** **Tony Ward**	**Endorsed by:** Zoe Thomas
Who might be harmed: Participants in interview may become emotionally distressed due to topic area being discussed. Researcher might be at risk through lone working. **How many exposed to risk:**	**Date of Assessment:** 03.06.2016	**Review date(s):** 06.06.2016

Hazards Identified *(state the potential harm)*	**Existing Control Measures**	**S**	**L**	**Risk Level**	**Additional Control Measures**	**S**	**L**	**Risk Level**	**By whom and by when**	**Date completed**
Lone Working / Researcher safety	The interviews will take place at a location agreed with each participant. The researcher will have a chaperone who will drop him off at the beginning	1	2	2						

	of the interview and collect him on completion of the interview. The chaperone will be available by telephone for the duration of the interview in case of an emergency. All participants work for a care agency who have fully vetted them, and DBS approved them.									
Emotional Distress to Participants	Participants will be provide with information by e-mail / post prior to interview enabling them to decide if they would like to take part in the study i.e. "opt in" NOT opt out. Participants will be provided with information about sources of support in the information sheet prior to interview. Participants will also have the chance to discuss matters with the researcher prior to interview. Informed consent will be obtained before these interviews take place.	2	2	4						

	If participants become distressed during interviews they will be stopped to allow them to recover their composure or terminated if appropriate. The researcher will then guide distressed participants to appropriate sources of support and ensure that they are in a safe place upon conclusion. Participants will be fully debriefed on completion of interview and left with telephone numbers of further sources of support should they become distressed. Participants will have the right to withdraw at any point within the first 6 months of their interview by contacting the researcher on telephone number or e-mail address provided.									

e. Information Sheet:

University of the
West of England
BRISTOL

INFORMATION SHEET

Purpose of Study

The purpose of this study is to investigate the psychological impact that providing end of life care has on community support workers, and how this could affect their ability to carry out their work. Results from the study could give us a better understanding of the impact that end of life care has on community support workers and lead to developments in the way that they are trained and supported when providing this type of care.

Procedures

Should you choose to take part in the study you will be required to undertake an informal interview with the researcher that will last approximately one to two hours. The interview will be undertaken on a face-to-face basis at a location that is convenient to you. The location will be negotiated with the researcher.

Before an interview can take place you must read this information sheet as it explains the purpose of the study and outlines the ethical considerations. Prior to the interview the researcher will go over this information sheet with you and answer any questions that you may have. The researcher will then ask you if you still wish to participate in the study. If this is the case you will be asked to sign a consent form, confirming that you understand the information provided in this sheet and that you are willing to participate in the study.

During the interview you will be asked some questions that relate to your job, your clients, and the psychological effect it has on you. These interviews will be audio recorded and transcribed verbatim.

Any identifying information provided, of both yourself and others named, will be anonymised in the transcript with fictitious names. Once transcribed your interview will be analysed together with the other interviews to identify themes across the data set. Participants names or other identifying information will never be associated with any research reports or publications that result from these interviews. Participants will always be given fictional names to protect their anonymity.

Data Storage

Once disclosed this information will be stored securely in accordance with The Data Protection Act 1998 and The University West of England's data protection policy. The researcher and his supervisors will be the only people who have access to this data. Electronic data will be stored on a password protected, encrypted memory stick. Any physical data will be stored in a locked filing cabinet at the researchers place of residence.

The data obtained during the interview will be used solely for the purposes of this research and in accordance with the ethical standards of confidentiality that govern psychologists.

The interview transcripts and data will be destroyed within two years of completion of the study.

Remuneration

There will be no remuneration for participation in this study.

Potential Risks and Ethical Consideration

(iv) The main risk associated with these interviews is possible discomfort or distress when answering some of the questions relating to your job and the psychological impact that it has on you. If at any time during the interview you find yourself becoming distressed the interview will be stop to allow you to regain your composure, and if necessary the interview will be terminated. The interviewer will then discuss possible sources of support with you and signpost you to appropriate organisations such as: your GP for medical advice, The Samaritans for a free 24 hour listening service who provide emotional support (116 123), Plymouth Options for psychological therapies in Plymouth (01752 435419), and if appropriate the community mental health team for more serious concerns.

(v) Should you encounter any discomfort or distress once the interview has been completed you should contact your GP immediately who will be able to advise you further.

(vi) You should be aware that this interview is confidential and the data generated will have no bearing on your current employment. Any information generated will not be provided to your employer.

No other risks are known to the investigator at this time.

Benefits

Participation in this study could result in a greater understanding of how community support workers are effected by end of life care, and could inform support, policies, and procedures in this area.

Confidentiality

Any information that you give will be kept strictly confidential, except as may be required by the law or professional guidelines for psychologists. All information will be identified by an identification code, not your name. Your name or other identifying information will never be associated with any research reports or publications that use the results of this study.

Withdrawal/Premature Completion

Once you have consented to participate in this study you can still withdrawn at any time within the first six months of the interview having taken place. Your participation in the study is voluntary, and you may discontinue at any time within the first six months, without prejudice. If, after consenting to participate, you decide that you no longer wish to be included in the study please contact the researcher who will ensure your information is removed from the study and your data will be destroyed.

Informed Consent

By signing and returning the last page of this information sheet you are giving you informed consent to participate in this study entitled, “End of Life Care: The Psychological Impact on Community Support Workers.” In doing this you will be confirming that you have read and understood the Information Sheet.

Invitation to ask further questions

Should you wish to ask any further questions concerning this study before you agree to participate please feel free to contact the researcher by e-mail at zeonkallis@hotmail.com or by telephone on 07796 092412.

Questions or concerns about the study can be addressed to the Chair of the Ethics Committee, School of Psychology, University West of England, Bristol.

f. Consent Form:

University of the West of England
BRISTOL

CONSENT FORM

I give my informed consent to participate in this study entitled, “End of Life Care: The Psychological Impact on Community Support Workers.” I confirm that I have read and understand the Information Sheet.

- Participant Name: ……………………………………………

- Participant Signature:…………………………………………

- Date:…………………………………………………………..

- Investigator Name: ……………………………………………

- Investigator Signature:…………………………………………

- Date…………………………………………………………

j. Table showing how final overarching themes were derived:

Superordinate Themes	Sub-Themes	Third level sub-themes
~~RELATIONSHIPS~~ **1. FORMING BONDS**	~~1. Forming attachment & bonds~~	**1a. Getting close with the client** **1b. Getting close with the family** **1c. Reversal of care** ~~1ci. How close to get~~ **3d. Continuing bond**
	1d. Blurring of boundaries	~~1di. Meals / drinks~~ ~~1dii. Hugs / kisses~~ ~~1diii. Doing extra~~ ~~1div. Visits~~
	4 a. Carer dilemmas	~~4ai. Safety~~ ~~4aii. Colleagues~~ ~~3c. Support~~ ~~3ci. Funerals~~ ~~4aiii. Job Type~~
	2d. Managing family & relatives	~~2di. Dealing with family questions~~ ~~2dii. Dealing with family's emotions~~ ~~2diii. Dealing with family trying to help carers~~ ~~4d. Adapting communication~~
~~WORKING AT THE END~~ **2. WORKING IN THE TERMINAL SPACE**	**2a. End of life care work different to other types of care work**	~~2ai. Witnessing client decline~~ ~~2aii. Change in carer's tasks~~ ~~2ciii. Inevitability of client death~~

		~~2c. Changes in communication with client~~ **2c. Adapting communication at the end**
	2b. Different types of end of life experience ~~Conditions~~	~~2bi. Physical health~~ ~~2bii. Mental health~~
	2e. Significance of first end of life client	~~2ei. Lasting memory of first client~~ ~~2eii. Lack of preparation for first client~~ ~~2eiii. Learning from first client~~
3. AFTER A DEATH		~~3ai. Lack of time to process loss and grief~~ **3a. Bereavement and loss** **3b. Carer abandonment** ~~3bi. Need for closure~~ **3c. Disenfranchised grief** **3e. Traumatic memories and post-traumatic growth**
~~WORKING IN THE COMMUNITY~~	~~1. Community specific challenges~~ ~~4a. Community specific issues~~	~~1a. Travel~~ ~~1b. Rota~~ ~~4di. Communication~~
	~~2. Systemic care issues~~	~~2a. Contracts~~ ~~2b. Pay~~ ~~2c. Overtime~~ ~~2d. Staff turnover~~ ~~2e. Funding~~

		~~2f. Politics~~ ~~4dii. Training~~
4. CARING FOR THE CARER	~~3. Supporting the carers~~ **4d. The help that doesn't exist**	~~4diii. Successes~~ ~~4div. Failures~~ ~~4dv. Improvements~~ ~~4dvi. What helps~~ 4dvii. What could be improved
~~IMPACT OF WORK ON SUPPORT WORKERS~~	~~1. Rewards of caring~~ ~~3ei.Post-traumatic growth and rewards of care work~~	~~3eii. Self-esteem~~ ~~3eiii. Learning~~ ~~3eiv. Personal insight and growth~~ ~~1d. Communal / social rewards~~
	~~2. Impact on self~~	~~3ai. Emotional~~ ~~3aii. Physiological~~ ~~3aiii. Behavioural~~ ~~3aiv. Cognitive~~ 3ai. – 3div above can be linked to theme 3a. Bereavement & Loss
	~~3. Coping strategies~~ **4b. Coping strategies - Behavioural** **4c. Coping Strategies – Cognitive**	~~3a. Emotional~~ ~~3bi. Physiological~~ ~~3bii. Behavioural~~ ~~3ci. Cognitive~~