"It's like walking in blindfolded" The Experiences of Patient-facing Volunteers in a UK Hospice, an Interpretative Phenomenological Analysis

Laura Harland

University of Cumbria

Abstract

Around 125,000 people volunteer in hospices each year in the UK, and due to the predicted increase in the UK ageing population within the next 20 years (AgeUK, 2016), the recruitment and retention of volunteers is crucial in the future development of palliative care. To date, there is a distinct lack of literature regarding the experiences of hospice volunteers. Therefore, the present qualitative study aims to (a) explore how hospice volunteers' experiences have influenced their perceptions of palliative care; (b) identify the potential stressors experienced by volunteers and the way in which they cope and adapt; and (c) provide recommendations for the hospice with regards to improving well-being and role satisfaction in volunteers. Six hospice volunteers were interviewed using a semi-structured interview schedule. Interviews were analysed from an interpretative phenomenological framework. Three master themes were identified: 1) psychosocial constructs of death and dying; 2) protection of self; and 3) self-esteem. The analysis revealed that volunteers experienced mortality salience, which stemmed from society's perceptions of death and dying. This was demonstrated as a perceived role hierarchy within certain areas of the hospice. The way in which volunteers cope with the confrontation of mortality varied dependent upon their levels of self-esteem. Further research into hospice volunteers is discussed and improvements regarding emotional support and staff communication are explored.

Keywords: hospice, palliative care, volunteers, IPA, experiences

The hospice care sector supports at least 120,000 people with terminal and life-limiting conditions each year in the UK (NHS, 2016). The majority of hospices have developed alongside the NHS but remain largely independent in terms of funding and management (Morris, Payne, Ockenden & Hill, 2015). Volunteerism has long been rooted in the hospice sector and since its emergence, volunteers have supported patients and their families in hospices and helped to maintain quality of care (Dein & Abbas, 2005). Currently in the UK, 125,000 people volunteer in hospices each year (HospiceUK, 2015). Patient-facing roles provide psychosocial support for terminally ill patients and their families within a variety of settings including children's ward, adult ward and day hospice (Arnup, 2011). Duties may include, sitting with patients, the ordering of meals, feeding and assisting with social activities (Mundle, Naylor & Buck, 2012).

From a societal perspective, volunteers bridge the gap between hospices and the surrounding community by providing them with an educative role that can de-stigmatise negative perceptions (Morris et al., 2015. According to HospiceUK (2014), the financial value of volunteers to hospice care was over £112 million in 2014. Thus, volunteering represents a significant social and economic contribution, and the ability to effectively recruit and retain volunteers is, therefore, of fundamental interest.

The motivations behind volunteering have been explored in several studies (see Wilson et al., 2005). However, to summarise some key factors, Shye (2010) proposed that the need for a sense of purpose and to strengthen social relationships is a primary motivator, whereas Marie Curie (2016) argue that experiences of loss inspires volunteers to 'give something back'. The literature therefore supports that satisfying such motives is vital to retaining volunteers long-term (Elliott & Umeh, 2013).

Although academic interest in studying volunteerism has grown since the 1970's (Horton Smith, 2013) there is a distinct lack of literature regarding hospice volunteers (Candy, France, Low & Sampson, 2014).   The USA and Canada currently dominate the literature in this area, of which some may have similarities to UK hospice care, for example the challenges of an increasing ageing population, causes of mortality and a move to include the support of patients' families as part of palliative care (Higginson, 2005). However, Centeno et al. (2013) stated that due to political, cultural and economic constraints, hospice volunteering differs considerably between countries. For example, in the UK, volunteering centres around the hospice building, whereas in Canada and the USA volunteers mainly operate within the patient's home (Arnup, 2011). Due to the number of significant cultural

differences between countries, one may question how relevant international literature may be to the experiences of UK hospice volunteers. Additionally, there is a lack of recent literature, with most studies being ten years or older (e.g. Fox, 2003; Claxton-Oldfield et al., 2004; Dein & Abbas, 2005). This is significant as in the past decade; palliative care in the UK has changed considerably. For example, mortality trends have changed towards people living longer and dying from chronic diseases at an older age (Calanzani, Higginson & Gomes, 2013). Therefore, patients with dementia and cognitive impairments that are receiving hospice care have nearly doubled in the past ten years and will continue to grow (NHS, 2016). A further significant change involves the Liverpool Care Pathway, which was a new model of practice in hospice care introduced in the 1990s but phased out by 2014 (NHS, 2015). There is also a distinct lack of qualitative research into UK palliative care (Elliott & Umeh, 2013). Holloway and Wheeler (2010) stated that this gap in knowledge is a missed opportunity for researchers to gain deeper understanding into the human thought, perception and behaviour processes that may take place during the final stages of life. There are, however, several explanations as to the lack of research. For example, research in palliative care receives limited funding in comparison to other areas of the NHS (Candy et al., 2014). In addition, the sensitive and confidential nature of palliative care could result in difficulties in gaining ethical clearance to carry out such research (Mohanti, 2009).

Hospice and palliative care faces an uncertain future. The number of people aged 65 years and over in the UK is expected to increase by over 40% in the next 20 years (Office for National Statistics, 2015). The ageing population, combined with more people over 65 living alone than ever before has the potential to cause significant financial difficulty to UK hospices (AgeUK, 2016). Over half of the 21,000 UK people surveyed by HospiceUK in 2015 worried that there will not be enough hospice care available within five years. This predicted increase in demand for hospice care will, therefore, inevitably lead to an increased demand for volunteers (NHS, 2016). As a vital source of unpaid labour in hospices, together with their potential to improve current perceptions of palliative care, it is clearly vital that the experiences of hospice volunteers are explored to increase role satisfaction and thus aid in the recruitment and retention of volunteers in the challenging years to come. Therefore, the present study aimed to explore the lived experiences of volunteers within a UK hospice. The specific areas of focus included:

1. To explore how their experiences as a hospice volunteer have influenced their perceptions of palliative care.

2. To identify the potential stressors experienced and the ways in which they cope and adapt.

3. To provide suggestions for the hospice with regards to improving volunteer well-being and role satisfaction.

Methodology

Influenced by Husserl's (1970) philosophy of phenomenology and Heidegger's (1962) study of hermeneutics, the present research process anchored within a constructivist-interpretivist paradigm. It is important to note that the researcher was also a hospice volunteer. It was therefore essential to identify and address the impact that their personal experiences may have had on the findings (Cresswell, 2003). The current study was conducted using an interpretative phenomenological approach to explore the personal experiences of hospice volunteers, involving a double hermeneutic process using different levels of interpretation (Smith, 2004). This approach allowed the researcher to make sense of the participants' process of mean making whilst also acknowledging their role as researcher within the analysis (Smith & Osborn, 2003)

Research Design
Data collection method

IPA requires 'rich data' where participants have the opportunity to share their experiences both freely and reflectively (Smith, Flowers & Larkin, 2009). Therefore, due to the sensitive and confidential nature of the environment being researched, semi structured, one to one interviews were deemed the most ethical and preferred method of data collection (Shineborne, 2011).

Constructing the interviews

A semi-structured interview schedule was prepared in advance to facilitate the discussion of relevant areas (Smith et al., 2009). An interview schedule was developed to explore three main areas: how volunteering at the hospice may have changed them as a person, how they cope with experiences at the hospice, and how they switch off when their shift has ended.

Sampling and participants

Data collection was carried out in February 2016. The method of recruiting participants was initially discussed with the Volunteer Manager at the hospice, who became what Frankel and Devers (2000) described as a 'recruitment gatekeeper'. He publicised the study within the hospice based on the inclusion and exclusion criteria provided.

Exclusion and inclusion criteria

A homogenous sample was purposively selected (Smith & Osborn, 2003). Participants were selected if 1) they currently volunteered within a patient-facing role for a minimum of 4 hours per week, and 2) they had volunteered for more than six weeks. Participants who had experienced recent bereavement were excluded from the study on ethical grounds. Volunteers who expressed interest were provided with the researcher's contact details, resulting in a total of six participants taking part. This represented a homogenous sample to which the study would be significant. To ensure anonymity, all participant demographics have been removed and pseudonyms applied (Seidman, 2013).

Conducting the interviews

The interviews lasted between 25 – 90 minutes and were recorded verbatim using a digital recorder. To fulfill the role of active co-participant (Smith & Osborn, 2003), the researcher chose to memorise the interview schedule, enabling them to fully engage with participants. This involved using prompts to indicate the level of depth and detail required (Smith, 2004).

Analytical guidelines

Smith et al. (2009) provided the present research with a heuristic framework as a guide. The process was multi-directional and highlighted the importance of the moving between the part and the whole of the hermeneutic circle.

Analysis and Discussion

Analytical Overview

Three master themes were created. What follows is the interpretive phenomenological analysis of the data and how it relates to the surrounding literature, using verbatim extracts from participants' interviews to illustrate each theme.

Master theme 1: Psychosocial constructs of death and dying

In this master theme, the participants' experiences and views of death and dying are discussed. Participants described a variety of literal and figurative ways in which they felt forms of death anxiety either towards the self or others and how this increased self-awareness affected their behaviour within the hospice, thus the first emergent theme to be considered is (a) fear of the unknown. All participants discussed these fears as being a psychosocial construct of the social stigma surrounding death. Several discussed how these feelings are deeply rooted within their own personal experiences of grief and how this impacts on their perception of the hospice as a whole. The remaining four emerging themes to be considered are (b) experiences of loss, (c) the finality of death, (d) social stigma, and (e) separate entities.

Emergent theme 1a: Fear of the unknown. Participants shared initial feelings of apprehension towards their role within the hospice. Within the coding of this emergent theme, psychosocial consequences of death, fear and anxiety begin to surface through the participants' use of figurative and metaphorical interpretations. Emma highlighted this when describing when she first began volunteering at the hospice:

> 'I mean… I was very apprehensive when I started. I didn't really want to… I mean… it wasn't that I was frightened to go on the ward … I did tiptoe around a bit though to begin with.'

Emma described how she did not feel frightened to begin her role at the hospice. Yet, the contradictory use of the term 'tiptoe', the idea of tiptoeing around something could be interpreted that she is scared to approach something she is unsure of, which may reflect Emma's underlying fear of facing her own mortality. In another quote, Sam described her shock in finding out that a patient had died and how it affected her own views surrounding death:

> 'Then one day you'll ask where is Sally? Sally is gone. Oh. And that happens on a regular basis. And you know it's going to happen, it's always shocking. It does come up and catch you if you're not careful.'

Harland, L. (2016) "It's like walking in blindfolded" The Experiences of Patient-facing Volunteers in a UK Hospice: An Interpretative Phenomenological Analysis. *Journal of Applied Psychology and Social Science, 2* (2), 30-64

In this extract, Sam used the word "it" to describe Sally's death, as though the word "death" is socially unspeakable. This is interpreted as her avoidance to reflect on her own mortality. Interestingly, Sam later described a similar experience of a patient dying, but this time; she does use the word "death":

> 'He was very upbeat but he did, in a week he was gone [long pause]. Death
> caught up with him in the end I guess.'

Sam's change in description could be due to her connecting the death to the patient themselves, whereas the previous quote is more focused inwards by using the term "you". Therefore, by hiding behind her role as a volunteer, it allowed her to ignore the inner conflict of her own existence and provided her with the confidence to confront the mortality of others. This self-detachment together with the term "catching you", feels like death to her is almost trap-like in its nature, thus reinforcing the interpretation of death being perceived as an unpredictable and threatening entity to be avoided at all cost.

Sam then went on to describe how this self-awareness of her own mortality can impact on patients:

> 'You're very aware of wanting to do things right, like if I didn't say anything
> at all, it would have been awful. But you know you could be annoying by
> talking too much, it's difficult.'

Sam's description shows how this heightened awareness of her own existence has also made her consider her relation to the vulnerable life surrounding her and how the smallest mistake can have a significant impact. By mentioning the choice to say nothing at all first, demonstrated her discomfort in confronting something that she is unsure of.

This theme considered the way in which, when confronted with death and dying, volunteers became more aware of their own mortality. This is consistent with Becker's (1973) proposition that a human's ability to understand death as inevitable leads to a salient fear of mortality. Following on from Becker's analysis, Greenberg, Pyszczynski and Solomon's (1986) Terror Management Theory (TMT) defined this anxiety as mortality salience, which has been found to be particularly prominent within palliative care (Holland & Neimeyer, 2005). Sam highlighted this existential fear when she described death 'catching you if you're

not careful'. In addition, this same quote emphasised her avoidance in using the actual word 'death' when talking about her own mortality. These findings support Kelly and Smith's (2012) study where two thirds of participants described discomfort in using words like 'death' and 'died' due to their own fear of dying. Interestingly, in a later quote, Sam does use the word 'death' when discussing the mortality of a patient. Kubler-Ross (1969) would argue that it is easier to conceive the death of others as it reinforces our unconscious belief in our own immortality. Therefore, one could posit that volunteering within a hospice environment would relieve potential mortality salience, not heighten it (e.g. finding comfort in 'it's them, not me'). This contradicted the current findings; possibly because the hospice environment acts as a reminder of personal bereavement, which increases mortality salience.

Emergent theme 1b: Experiences of personal loss. Participants shared their personal experiences of loss and how seeing the family members of patients going through similar grieving processes served as a painful reminder of the mortality of others close to them. Sarah initially highlighted this in a description of a patient that she was close to within the adult ward:

> 'I'd pop in just to visit him… and you see the family and how they dealt with
> it. I've been through it myself. It upsets me when I can't help them. It's kind
> of worrying for me.'

In this extract, it seemed that Sarah feels more empathy towards the family rather than the patient themselves. It is interpreted that by seeing the death through the eyes of the family, she was reflecting on her own experiences of grief which pushed previous feelings of helplessness and lack of control to the front of her consciousness, causing her to experience frustration. Similarly, when Terri shared an experience on the adult ward she focused on the families of the patients:

> 'Like, I get upset about the patient… but they know why they're here but the
> families sometimes upset me. Because I'm scared of losing people close to
> me and I feel bad for them that they are losing someone.'

Harland, L. (2016) "It's like walking in blindfolded" The Experiences of Patient-facing Volunteers in a UK Hospice: An Interpretative Phenomenological Analysis. *Journal of Applied Psychology and Social Science, 2* (2), 30-64

Terri's detached approach towards the patient translates into a lack of concern for her own mortality and death in general. However, due to family dynamics she may have identified more with the patient's family. Thus the experience of watching a family grieve may be forcing her to confront her own fear of losing loved ones.

These findings are in accord with other recent studies indicating that volunteers draw connections between the death of patients and the death of those close to them (Arnup, 2011; Harvell & Nisbett, 2016). Joireman and Duell (2005) considered that existential anxiety may also lead to positive outcomes including pro-social attitudes. As personal bereavement has been found to be one of the primary motives for individuals choosing to volunteer in palliative care (Elliott & Umeh, 2013), one could therefore suggest that mortality salience not only helps volunteers feel connected to those who have died, but aids in the recruitment and retention of volunteers.

Emergent theme 1c: The finality of death. In this theme, the experiences of coming to terms with the inevitability of death are discussed. Most participants described feelings of shock when confronted with the harsh reality of death. Sarah described this when sharing her experience of finding out that a child has died on the ward:

'That does hit you like (hand clap). It was a bit of a shock really.'

Sarah used the term 'hit' to express the destructive nature of death. The sound-symbolic relationship between what Sarah says and the sound she makes (hand clap) transcends this perception further as the impact of death having both an emotional and physical effect on the self. Sam also used sound to describe her experience of loss:

'We were chatting away… such a lovely lady (long pause) but two days later (click fingers) she was gone (long pause).'

Aside from the physical effect that the patient's death has on Sam, the long pauses she used could be interpreted as her realising the existential void of permanent loss. Alternatively, this long pause could also be interpreted as Sam taking time to positively reflect on her time with the patient.

This emergent theme considered how finding out that a patient had died affected volunteers both emotionally and physically, and this was reflected in the different ways in which they recounted their experiences. In Sam's quote about Sylvia, she incorporated paralinguistic elements with long silences to describe her shock. Fernandez (2006) suggested that this allows a person to communicate their emotions without relating it back to their own mortality. Arnup (2011) argued that Sam's description could simply reflect how emotionally and physically connected she was toward the patient. However, the current findings may lead one to further question that if participants were indeed experiencing a heightened awareness of mortality, then the death of a patient should not come as a shock to individuals who regularly volunteer in palliative care. Pyszczynski, Greenberg and Solomon (1999) proposed that people employ various different defensive processes to cope with our own mortality and when regularly confronted with death and dying, we employ proximal defenses to push these thoughts out of direct awareness. Thus, reinforcing the present findings that regular working within a hospice environment may not necessarily alleviate the psychological impact of the death of patients.

Emergent theme 1d: Social stigma. In this theme, participants discussed perceptions of death and dying within a social context and consider the ways in which stigmatising attitudes affect how they feel about the hospice. Terri highlighted this when describing her initial view of the hospice:

> 'I kind of feel like people think we sit and hold hands with dying people all day. I thought it would be really clinical and dark and horrible, but it's really homely and light.'

Terri's use of the terms "light" and "dark" symbolises society's archetypal imagery of life and death. The idea that the hospice could represent positivity and warmth conflicts with Terri's socially constructed views of death and dying. This is further demonstrated in Sam's quote:

> 'I think everybody sees the hospice as hospice, cancer, death. There's no other options.'

Sam described society's 'black and white' view of life and death, where we are either alive or dead with nothing in between. Interestingly, when Sam described how she sees the hospice, there are clear similarities between the two quotes:

> 'Anything you do, you get used to it. If you worked in a slaughterhouse,
> you'd just get used to it. And we do.'

The comparison that Sam gave between the hospice and "a slaughterhouse" mirrors how she described society's perception of the hospice as a place where you go to die. The bluntness and lack of emotion in her description demonstrated that volunteering within the hospice has done little to change those perceptions, thus highlighting the powerful effects of social stigma. Alternatively, Sam's extract could also be interpreted as her trying to explain how any experience of death, regardless of the context can emotionally affect you and it is something that hospice volunteers must therefore overcome.

This emergent theme explored how society's perceptions of death and dying shape how volunteers perceive the hospice. The current findings further support the concept of society seeing death as a taboo subject to be avoided (Smith, Joseph & Das Nair, 2011; Harvell & Nisbett, 2016) and how the stigma surrounding death also impacts on how society views palliative care overall (Weeks & MacQuarrie, 2010). Terri emphasised this when describing what she expected the hospice to be like, compared to how she views it now. One unanticipated finding was how society's perceptions of palliative care continues to have a negative influence on how volunteers themselves view the hospice, as highlighted in Sam's graphic quote where she compared the hospice to a slaughterhouse. These findings differ from recent studies where hospice volunteering was found to transform perceptions of death into more positive evaluations (Arnup, 2011; Smith et al., 2011; Lancaster, Bowman & Harvell, 2016). However, they are consistent with Centeno et al.'s (2013) report, which identified that societal attitudes towards death and dying are perceived as a barrier to the future development of hospice and palliative care. The findings also reflect on Kubler-Ross' (1969) own personal experiences of interviewing terminally ill patients where hospice staff restricted access to patients as they felt that patients did not need reminded of their imminent death, thereby suggesting that societal attitudes of death and dying remain largely unchanged.

Emergent theme 1e: Separate entities. Several participants discussed feeling separated from the other areas of the hospice and within the coding of this emergent theme; a socially constructed existential divide within the hospice begins to surface through the participants' interpretations. When asked if she had ever considered volunteering in the children's ward of the hospice, Pauline replied:

'No. I haven't. That…I think it would get to me. Very hard. I've never been in there. It's very different to the hospice isn't it, so it's probably not for me. It takes someone a lot stronger than me to work in there.'

Pauline's extract highlighted her perception of the children's hospice as a place focused solely on end of life care for young children. It is interpreted that her socially constructed view of child bereavement has caused her to create an existential divide between the two areas of the hospice to protect her core self from confronting the cruel nature of child mortality. Sarah described a similar experience of a patient moving from day hospice to the adult ward:

'You don't always make the connection between the two... I don't think it really sunk in for me that she'd be going into the adult ward…she was so full of life…I'm not sure why. Maybe because I don't see that bit as being part of the hospice? I know that probably sounds weird because it *is* a big part…obviously.'

Sarah's experience highlighted that she can easily keep the reality of patients dying hidden when in the hospice environment. Therefore, disconnecting the adult ward from the day hospice allowed Sarah to focus on the living and keep the reality (and fear) of death below the surface. Interestingly, perceptions of the day hospice were very similar:

'They're a different species (laughs). We don't mix much if you know what I mean.'

Pauline's use of the term "species" highlighted the stark contrast between her perception of herself as an adult volunteer and the day hospice staff. It is interpreted that Pauline views

her role and the patients within the adult ward as more important than those within the day hospice, thus reflecting society's archetypal image of what a dying patient should look and act like.

This theme highlighted the impact of the psychosocial constructs of death and dying when exploring participants' experiences of the different areas of the hospice (e.g. adult ward, day hospice and the children's hospice). The current findings highlighted how the areas were seen as very separate from each other. The purpose of this divide was described in a number of ways. In Sarah's quote about how she does not see the adult ward as connected to the day hospice, demonstrated that volunteers perceived the adult ward as a place of death and dying, whereas the day hospice focused more on the living. Parson (1972) described this as the application of the 'dying role' and the 'sick role'. By applying the 'sick role' to patients within the day hospice, it enabled volunteers to protect and detach themselves from the realisation that the patient will not recover from their illness. This self-detachment is made more salient as the volunteers' acknowledgement of the transition from day hospice to adult ward may emphasise that they have not fulfilled their responsibilities and obligations of their role (Parker-Oliver, 2000). Greenberg et al. (1990) would argue that mortality salience leads individuals to have more positive evaluations of those who share one's worldview and more negative evaluations of those who hold worldview different from one's own. In-group bias is demonstrated in Pauline's quote about how the day hospice volunteers are a different species to adult ward volunteers. This is interpreted in the analysis as a perceived role hierarchy within the hospice, where certain volunteering roles are deemed more important/worthwhile than others. For example, participants feeling that the children's ward volunteers are above the adult ward, and adult ward volunteers are above those in the day hospice. This particular finding differs from other studies where volunteers reported experiences of solidarity and equality within organisations (Becker & Dhingra, 2001; Musick & Wilson, 2007). To date, perceived role hierarchy of hospice volunteers has not been covered in published literature and therefore has important implications when identifying the motives for volunteers choosing specific areas of a hospice over others. The issue of division within volunteer roles could also be explained by a lack of familiarity within different areas of the hospice. Becker (1973) described this as one's fear of the unknown, which restricts social development and personal growth. It is important to also explore the potential implications this particular finding may have on hospice patients themselves, for example, when a children's ward patient is transferred to the adult ward. It is therefore recommended

that volunteers have the opportunity to experience the different areas of the hospice through specific volunteer placements. Many UK hospices have a volunteer placement scheme for young adults looking to gain experience before moving on to Higher Education, where they spend a minimum of six weeks in each area, from the kitchen to the children's ward (Macmillan Cancer Support, 2015). Based on the current findings, it is therefore suggested that this scheme is made available to hospice volunteers of all ages.

Master theme 2: Protection of self

This master theme explored the different cognitive and behavioural coping styles developed by participants as ways of managing potential psychological distress and building resilience. Several participants discussed their need to separate the role of volunteer from their core self, whilst by contrast others discussed the comfort in knowing more about death and dying through patient experience. Thus, the emergent themes to be considered are that of (a) avoidance and (b) acceptance.

Emergent theme 2a: Avoidance. Several participants shared examples of avoidance-motivated behaviour as a way to separate and protect their inner-self from their role. Pauline initially described how she likes to switch off after a shift:

'I go home and walk the dogs. I move on and shut the door as it were.'

Pauline's quote described how she both physically and emotionally distances herself from her role. Her use of the word "door" represents a conscious barrier, designed to protect her from grieving the death of others and reflecting on her own mortality. Equally, when Sam described her experiences of dealing with emotional distress, she shared how she deliberately kept these feelings below the surface:

'I think you're better off not saying anything at all. Because you're just bringing things to the surface constantly, reinforcing those feelings… getting worse every time. You're better off realising there's nothing you can do about it and just leave it in that box.'

Harland, L. (2016) "It's like walking in blindfolded" The Experiences of Patient-facing Volunteers in a UK Hospice: An Interpretative Phenomenological Analysis. *Journal of Applied Psychology and Social Science, 2* (2), 30-64

Sam's decision to keep hospice experiences to herself and by using the word "box" reinforces the present interpretation of participants creating barriers to help them control (and therefore avoid) their death-related fears. Sam also described her struggle to keep these fears under the surface, which demonstrated that this maladaptive behaviour strategy may only be effective in the short term.

Emergent theme 2a considered the ways in which volunteers protect the core self by demonstrating avoidance-motivated behaviours. This is highlighted in Pauline's quote about shutting the door. Pauline's attempt to distance herself from her role is consistent with literature surrounding detached concern and mortality salience, where one protects their core self by pushing thoughts of death further from consciousness (Psyszczynski et al., 1999; Fox, 2006). In addition, the stance of avoidance commonly includes denial as an unconscious protective mechanism and is found to occur when there is an increase in mortality salience (Zimmerman, 2004; Harvell & Nisbett, 2016). Kastenbaum (2015) argued that compartmentalising is often mistaken for denial, where the reality of death and dying is acknowledged but not fully realised. This is reflected in Sam's quote about the box. However, Muliira and Bezuidenhout (2015) argued that compartmentalising is still a form of avoidance behaviour and therefore supports the current findings.

Emergent theme 2b: Acceptance. Participants described experiences of acceptance through normalisation and forming relationships with patients as a way to build resilience and to regulate their emotions through positive growth. When asked how Sam views her own mortality, she replied:

'I've met lots of guys who have gone ….erm but yeah it's just trying to normalise it… in my own head. And what I think now is, I'm here, I'm right here, right now and that's okay.'

By attempting to confront and normalise her feelings of anxiety towards death, Sam was making sense of the fragile nature of her existence, which led her to feel acceptance and in control of her own mortality. Emma described how the experiences of patients has changed the way that she views death and dying:

'I've never heard a patient say anything other than how lovely and peaceful it is. I've never come across a patient who is frightened to die. So I'm not frightened of death.'

Emma found comfort in sharing patients' positive experiences of dying. It is interpreted that Emma found that by allowing the role of volunteer to become part of her core self, this allowed her to emulate the emotions felt by patients and reflect on her own mortality in a positive and meaningful way.

In this emergent theme, volunteers described ways in which forming relationships with patients helped them to accept their own mortality. Emma highlighted this in her quote about how she no longer feared death and instead felt at peace. These findings are consistent with Kubler- Ross' (1969) research that suggested inner peace is achieved through the acceptance that death is inevitable. Furthermore, Weisman (1972) stated that denial and acceptance form a selective process whereby an individual may accept or deny the realities of death dependent upon the relationship they have with the person. Thus, supporting TMT's mortality salience hypothesis that when individuals feel connected to others, it protects them from death anxiety and therefore they are more likely to accept and view their own mortality in a positive and meaningful way (Solomon, Greenberg & Pyszczynski, 2015). Blauner (1966) offered an alternative explanation that we are more accepting of our own mortality when we are close to those who have lived long and fulfilled lives. However, it is unclear how participants perceive their own mortality when confronted with the 'unfulfilled' death of a younger patient (Kastenbaum, 2015). Therefore, more research on this topic needs to be undertaken before the relationship between a volunteers' mortality salience and the death of younger hospice patients is more clearly understood.

Master theme 3: Self-esteem

In this master theme, participants' experiences of working within the hospice and how this affects self-esteem were explored. Participants were encouraged to share their underlying motives for beginning their role within the hospice, with many discussing the desire to help in an area that is deemed as most needing of their support. The first emergent theme to be considered is (a) reciprocal altruism. Participants' feelings towards access to patient information was a particular area of conflict with several participants discussing that knowledge increased their sense of personal worth, and improved patient relationships,

whereas others discussed how remaining in the background allowed them more freedom. Therefore, the remaining two emergent themes to be considered are that of (b) the power of knowledge, and (c) invisibility.

Emergent theme 3a: Reciprocal altruism. Participants shared their desire to help others as the main reason for why they volunteer at the hospice. In addition, several participants also discussed how volunteering within the hospice increased their feelings of relational value, heightening their sense of identity. Sam highlighted this when discussing her previous volunteering role:

> '… But I wasn't really satisfied with that, like a lot of them didn't really need help. A lot of the time it was driving old age pensioners to museums and then back to their care home. I mean, they could have just got the bus.'

Sam's experience is translated as her need to find meaningfulness within her role. The previous volunteering position did not satisfy this need, as it does not fulfill her perception of self-worth. Emma strengthened this interpretation further when she discussed her role within the hospice:

> 'Since retiring, I help out … at the moment a lot of staff are off sick. They wouldn't have anybody if it weren't for volunteers. There would be hardly anyone there to look after patients sometimes.'

Emma viewed her role as central to the hospice, where patients might suffer as a result of her absence. It is interpreted that Emma's recent retirement resulted in an existential crisis where she has lost her previous sense of belonging and is therefore seeking to increase her relational value through her role as a volunteer.

In emergent theme 3a, participants discussed how their experiences of volunteering within the hospice affected self-esteem. Solomon et al. (2015) stated that self-esteem enables us to believe we are enduring, significant beings, without it we have no meaning or purpose. Therefore, people are highly motivated to protect their self-esteem by ensuring that their actions are meaningful and valued (Leary, 1999), which has been found to also be a primary motivation for those choosing to volunteer in palliative care (Arnup, 2011). This is

Harland, L. (2016) "It's like walking in blindfolded" The Experiences of Patient-facing Volunteers in a UK Hospice: An Interpretative Phenomenological Analysis. *Journal of Applied Psychology and Social Science, 2* (2), 30-64

highlighted in Sam's quote about the importance of choosing a role that was most in need of her help. The findings are consistent with those of Musick and Wilson (2003) who described how sense of purpose provides volunteers with self-worth and increased resilience. However, it is important to also consider the potential implications of when volunteers do not feel valued and important. Planalp and Trost (2009) would suggest that self-esteem would reduce, resulting in volunteers becoming more susceptible to existential anxieties, thus encouraging maladaptive behaviour strategies such as denial and avoidance. Another possible explanation for this may be a volunteer's need for symbolic immortality whereby becoming part of something greater than themselves allows them to remain relevant and remembered (Harvell & Nisbett, 2016). The current findings therefore highlighted potential implications on hospice volunteer retention. For example, Elliott and Umeh (2013) found that role satisfaction was related to longevity of service among volunteers.

Emergent theme 3b: The power of knowledge. Participants discussed knowledge (in particular knowledge of patients) as an important part of their role. However, participants' experiences differed; with some feeling that knowing more about patients would empower them to form special bonds with patients, whilst others described that a lack of knowledge made them feel more in control of their own emotions. Terri discussed how increased patient knowledge would help her to tailor the care she provides:

> 'All you have is the sheet with names on. You'll know there is a Mary in that room but that's it… she's just a name. I know nothing about the person… to know how best to approach her… does she have a room full of visitors… or has she had no one for days?'

At first glance, Terri's description emphasised her frustration at how a lack of knowledge can impact on patient care. However, when Terri described not knowing how best to approach the patient it is interpreted that by not knowing more about "Mary" she felt unconfident in her own ability to approach the patient in the right way. Equally when Sarah described her experiences of meeting patients for the first time, she shared a similar experience:

'When you get your menu sheet on a morning, it just has names on it so
sometimes you can walk in a room and be shocked by the age or condition of
the patient, or sometimes even their gender, you know. It's like walking in
blindfolded.'

Sarah used the term "blindfold" as an expression of powerlessness and vulnerability.
Interestingly, Terri and Sarah both made reference to the "sheet" as their main source of
patient knowledge. This is interpreted as the sheet signifying a meaningful sense-making tool
that strengthens their ability to care for patients. This interpretation is further reinforced by
Emma's description of the physical comfort she experienced from having the menu sheet
with her:

'I like to carry that menu sheet everywhere with me, even when I don't
necessarily need it.'

The significance of the menu sheet demonstrated how several participants find security and
self-confidence in knowing more about patients. Yet in contrast, Susan shared how she felt
empowered by knowing little about patients:

'I find it refreshing. I mean… I can guess a lot of the time anyway of course.
But I don't know for sure and I don't want to know. Erm… it doesn't bother
me at all to be honest. I think it's kind of more relaxing for me because I
don't have to worry about it.'

Susan found the lack of knowledge as a way to emotionally detach from her role.
Although this could also be interpreted as a way for Susan to see the person instead of the
condition, thus allowing her to feel more emotionally connected to patients, which is further
described in Sam's quote:

'I'm just a person that pops in and they can tell me things they maybe
couldn't tell a nurse. That's something special.'

Harland, L. (2016) "It's like walking in blindfolded" The Experiences of Patient-facing Volunteers in a UK
Hospice: An Interpretative Phenomenological Analysis. *Journal of Applied Psychology and Social Science, 2*
(2), 30-64

Sam highlighted how the role of volunteer is powerful in its own right and can enhance a patient's experience in a special and unique way to that of other members of staff. Therefore, increasing her feelings of self-worth and value within the hospice.

Within this particular theme, access to patient information was found to be a particular area of conflict, with many describing that the lack of shared patient knowledge led them to question if their role contributed something valuable to the hospice. This is very consistent with the literature on confidential information and hospice volunteers. For example, Elliott and Umeh (2013) reported that a lack of knowledge regarding a patient's diagnosis and prognosis made volunteers feel disempowered and emotionally disconnected from patients. Terri highlighted this with her quote about Mary. Howlett (2009) stated this may not only promote feelings that volunteers are untrustworthy but may also prove detrimental to the care of the patients. In addition, it is important to also address the potential ethical implications in providing volunteers with more patient information. For example, for volunteers who build close relationships with patients may find that knowledge of their condition causes further stress and anxiety (Dein & Abbas, 2005). Furthermore, it is also about ensuring that the patients are protected with regards to confidentiality (Mohanti, 2009). Thus, further research, which takes these ethical concerns into account, will need to be undertaken.

In contrast, lack of knowledge was also found to empower some participants and was perceived to strengthen patient relationships. Sam described this in her quote about the patient/volunteer relationship being unique to that of a nurse. Cain (2015) suggests this distinctive relationship as a volunteer being able to see the person as they are rather than being defined by their illness, thus highlighting the significance of volunteers in the field of palliative care. The overall current findings propose that providing volunteers with important healthcare information (where appropriate) may help them to perform their role better and increase self-confidence, however it is essential to find the right balance of gaining knowledge whilst also respecting the freedoms inherent in the role. Doyle, Scott and Howlett (2009) suggested that by improving communication between volunteers and paid staff would help inform such a balance.

Emergent theme 3c: Invisibility. Participants discussed sense of presence within the hospice and how it affected their view of the volunteer role. Some described an 'us vs. them' dichotomy and felt that acknowledgement and feeling involved within the hospice would

increase feelings of self-value and importance, whilst others felt that the role of volunteer is defined by the power of being unseen.

Terri described how she felt whilst volunteering on the adult ward:

'I wasn't on the adult ward for a long time I know, but no one ever asked my name or anything… or introduced themselves… I'm just a person who helps the staff but still… I am here.'

In this poignant quote, Terri described how her lack of acknowledgment made her reflect on her self-worth. The term "just a person" is translated as her questioning whether she meaningfully contributes to the lives of patients enough to be deserving of acknowledgement. A further quote by Terri highlights how her lack of self-confidence results in her inability to approach nurses for herself:

'When I was on the adult ward, when that man wasn't there anymore… he was very ill… I didn't know what had happened to him… whether he'd just gone home… or died. That was difficult. He felt like a friend to me. I didn't speak to the nurses about it… I wasn't sure if I could.'

Terri was fully aware that the patient has most likely passed away, however her lack of self-confidence to speak to any nurses about her feelings has resulted in her being unable to accept and grieve her loss. In contrast to Terri's experiences, Susan discussed how she feels more confident when remaining in the background:

'I was a bit apprehensive… but only because I thought I may have treated some of the patients on a ward previously. And I don't know if that would make any difference to them. I don't know… being recognised by patient's families might make me feel a bit uncomfortable really.'

Susan's feeling of discomfort at being recognised is interpreted as her need to distance herself from the role and not be defined by it. By separating the role from her core self allowed her to feel in control of her emotions.

Harland, L. (2016) "It's like walking in blindfolded" The Experiences of Patient-facing Volunteers in a UK Hospice: An Interpretative Phenomenological Analysis. *Journal of Applied Psychology and Social Science, 2* (2), 30-64

This particular theme, considered the way in which volunteers perceived their roles as invisible to paid members of staff (e.g. nurses, doctors). For example, Terri described in her quote about never being acknowledged. This contradicts the literature surrounding staff/volunteer relationships, where nurses viewed volunteers as valued members of the patient care team (Claxton-Oldfield, Hastings & Claxton-Oldfield, 2008) and made their nursing roles easier (Cain, 2015). A possible explanation for this unanticipated finding may be that volunteers are often not provided with feedback about their contributions and information about what is happening within the hospice, so therefore may feel isolated from other members of staff (Addington-Hall & Carlsen, 2005). Volunteers may also feel that others see their work as devalued, for example 'if it were that important, it would be a paid position' (Musick & Wilson, 2007). To date, the issue of volunteers experiencing invisibility is noticeably absent in the literature. Harvell and Nisbett (2016) propose that this may be due to mortality salience increasing a person's sensitivity to social rejection. Doyle et al. (2009) suggested that a way to alleviate feelings of isolation in volunteers is to improve communication through the inclusion of volunteers in staff meetings, patient handovers and regular hospice newsletters.

Summary of Analysis

The aim of the present study was to explore the experiences of hospice volunteers and in the absence of research, bridge the current gap in knowledge. The analysis revealed that volunteers felt both conscious and unconscious fear of their own death or the death of others. These fears often stemmed from experiences of personal loss and society's perceptions of death and dying. Furthermore, these stigmatising views were found to be alive and sentient within the hospice itself, which was seen to cause division within certain areas of the hospice. The way in which volunteers cope with the confrontation of mortality varied dependent upon their levels of self-esteem and how they felt other members of hospice staff perceived their role. A summary of the analysis is illustrated in figure 1 below:
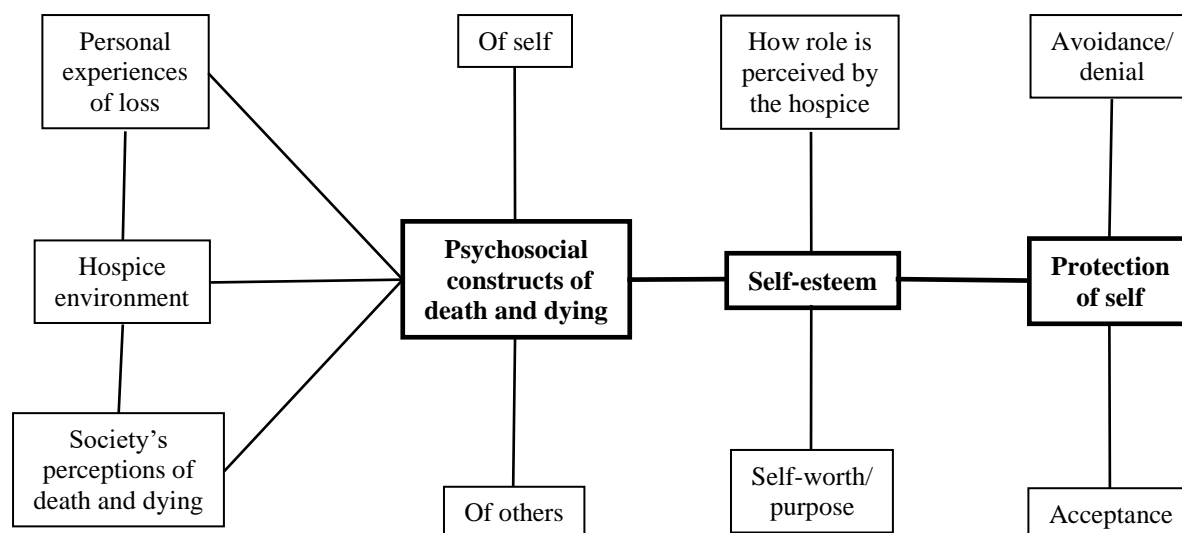
Figure 1. A summary of the main findings

Evaluating the quality of the research

Qualitative researchers must be able to demonstrate that their studies are rigorous, and produce findings that are as valuable as those from quantitative research (Willig, 2013). In light of this, Yardley (2008) devised a series of four core principles for evaluating the validity of qualitative research:

Sensitivity to context

The present study has acknowledged current literature and identified a distinct gap in knowledge, which the study has aimed to address. Informed consent was sought and confidentiality addressed (with methods adapted where necessary) to protect participants at all times.

Commitment and rigour

To ensure homogeneity of the sample, participants were purposively selected to ensure that their accounts provided the study with a true and honest reflection of volunteers' experiences. For example, both male and female participants were recruited within a wide range of ages and length of time they had volunteered for.

Impact and importance

The current findings have the potential to make a positive difference to volunteers within the hospice. The findings have suggested ways to improve staff communication and training. It is hoped that by increasing role satisfaction and self-esteem in volunteers, it will have a positive impact on how volunteers cope with hospice-related stress and anxiety. Therefore the present study has important implications regarding the future recruitment and

retention of hospice volunteers, which may, in turn help to improve society's perceptions of palliative care.

Limitations of the procedure

Although the dual role of the researcher/hospice volunteer has been previously discussed, it clearly may have had an impact on the researcher's objectivity during the study and the reflective journal kept by the researcher throughout this process highlighted such issues. For example, unconsciously dismissing participants' thoughts and experiences if they did not mirror those felt by the researcher. Smith et al. (2009) stated that this is to be expected, as the bracketing off of pre-conceptions can only ever be partially achieved. However, the reflective journal enabled issues to be addressed and adaptations made to further parts of the research process. For example, upon realising how such preconceptions had potentially influenced the analysis, the researcher began the full analysis again to ensure nothing had been previously overlooked.   Additionally, the relationship between the researcher and the hospice may have strengthened the research in a way that could not have been demonstrated by an independent researcher. For example, one participant in particular appeared to open up more once they realised that the researcher shared the same role.

Reflections on impact of themes

In line with Langridge's (2007) practice of reflexivity guidelines, the researcher aimed to explore the experiences of hospice volunteers to identify ways in which they coped and adapted to stressful situations and how the hospice environment may have influenced their perceptions of death and dying. This was achieved by using in-depth analysis, allowing the researcher to fully immerse in the data and create themes that accurately reflected the participants' experiences. The themes created highlighted several ways in which societal attitudes towards death can negatively impact upon the hospice and its volunteers. The findings have recommended several specific issues in need of further exploration, which may raise awareness of UK palliative care and improve society's perceptions towards death and dying.

Future directions

The present study has identified several key areas where improvements may result in increased self-esteem and role satisfaction for volunteers within the hospice. The training of hospice volunteers could include a section on anxieties surrounding death and dying and effective ways of coping (Brown, 2011). This could be demonstrated through role-play, using specific scenarios where volunteers can talk about the best ways to handle those situations.

This would also be a positive way for the hospice to highlight what emotional support is available for volunteers.

Hospice volunteers could also be encouraged to gain experience in each section of the hospice before deciding which they would like to volunteer in. This is already offered to younger adults and it is therefore recommended that this is made available to all volunteers. This would encourage a 'one hospice' approach, rather than 'a variety of sections under the same roof'. It would also allow volunteers to see the hospice through the eyes of the patients, as they too may move from one area to another. Furthermore, it is recommended that volunteers are included in staff meetings, patient handovers and hospice newsletters to enhance feelings of inclusion and value (Doyle et al., 2009).

The present study acts as a base for future research into the experiences of hospice volunteers and has highlighted specific areas for attention. For example, the present study found evidence of a perceived role hierarchy between volunteers. This has not previously been covered in published literature and if further explored, may have significant implications for volunteer recruitment and retention within specific areas of the hospice. Furthermore, the issues of volunteers experiencing invisibility within the hospice also seem invisible within current literature. More research may help the hospice to adopt effective ways in which to engage with volunteers, thus improving volunteers' well-being.

Conclusion

Hospice volunteering represents a significant social and economic contribution in the UK. However, at present, hospice volunteers remain the most under-researched area of palliative care. In light of this, the present study aimed to explore hospice volunteer' experiences; the analysis revealed that volunteers experienced both conscious and unconscious fears of their own death or the death of others. These fears often stemmed from their own experiences of personal loss and society's perceptions of death and dying. In addition, it was interpreted that the hospice environment had not reduced these negative perceptions, where participants described a perceived role hierarchy between volunteers and the different areas of the hospice. The way in which volunteers coped with the confrontation of mortality varied dependent upon their levels of self-esteem, and how they felt their role was perceived by other members of staff.

Harland, L. (2016) "It's like walking in blindfolded" The Experiences of Patient-facing Volunteers in a UK Hospice: An Interpretative Phenomenological Analysis. *Journal of Applied Psychology and Social Science, 2* (2), 30-64

The growing demand for palliative care means that role satisfaction is more important than ever before to ensure that volunteer recruitment and retention rates remain in line with the increasingly aging population. This study is the first of its kind to explore UK palliative care from the perspective of those who volunteer and has uncovered several aspects of hospice volunteering that has not been found in previously published literature (e.g. experiences of a role hierarchy and invisibility). It is hoped that the current findings inspire positive changes within the hospice itself and also provide a starting point for future research. The current findings mark a new beginning of celebrating and exploring the role of hospice volunteers within society and current literature. Further research into this area of palliative care has the potential to make a real difference to those who are not always seen but now (more than ever) need to be heard.

References

Addington-Hall, J. M., & Karlsen, S. (2005). A national survey of health professionals and volunteers working in voluntary hospice services in the UK. I. Attitudes to current issues affecting hospices and palliative care. *Palliative Medicine*, *19*(1), 40-48. doi: 10.1191/0269216305pm930oa.

AgeUK. (2016). *Later life in the United Kingdom.* Retrieved May 4, 2016, from http://www.ageuk.org.uk/Documents/ENGB/Factsheets/Later_Life_UK_factsheet.pdf ?dtrk=true.

Andersson, B., & Öhlén, J. (2005). Being a hospice volunteer. *Palliative Medicine*, *19*(8), 602-609. doi: 10.1191/0269216305pm1083oa.

Arnup, K. (2011). Caring to the end: The meanings of hospice volunteering. *Transition*, *41*(1), 9-12. doi: 10.1177/1084822314535089

Bandura, A. (1982). Self-efficacy mechanism in human agency. *American Psychologist*, *37*(2), 122. doi: http://dx.doi.org/10.1037/0003-066X.37.2.122.

Becker, E. (1973). *The denial of death.* London: Souvenir Press Ltd.

Becker, P. E., & Dhingra, P. H. (2001). Religious involvement and volunteering: Implications for civil society. *Sociology of Religion*, *62*(3), 315-335. doi: 10.2307/3712353.

Ben-Ari, O. T., Florian, V., & Mikulincer, M. (1999). The impact of mortality salience on reckless driving: A test of terror management mechanisms. *Journal of Personality and Social Psychology*, *76*(1), 35. doi: http://dx.doi.org/10.1037/0022-3514.76.1.35.

Blauner, R. (1966). Death and social structure. *Psychiatry*, *29*(4), 378-394. doi: 10.1521/00332747.1966.11023480.

Block, E. M., Casarett, D. J., Spence, C., Gozalo, P., Connor, S. R., & Teno, J. M. (2010). Got volunteers? Association of hospice use of volunteers with bereaved family members' overall rating of the quality of end-of-life care. *Journal of Pain and Symptom Management*, *39*(3), 502-506. doi:10.1016/j.jpainsymman.2009.11.310.

Brown, M. V. (2011). The stresses of hospice volunteer work. *American Journal of Hospice and Palliative Medicine*, *28*(3), 188-192. doi:10.1177/1049909110381883.

Bowen, D. J., Andersen, M. R., & Urban, N. (2000). Volunteerism in a Community-Based Sample of Women Aged 50 to 80 Years1. *Journal of Applied Social Psychology*, *30*(9), 1829-1842. doi: 10.1111/j.1559-1816.2000.tb02470.x.

Brinkmann, S., & Kvale, S. (2008). Ethics in qualitative psychological research. In C. Willig & W. Stainton-Rogers (Eds.), *The SAGE handbook of qualitative research in psychology* (pp. 263-279). London: Sage Publications.

British Psychological Society. (2014). *Code of human research ethics.* Leicester: BPS.

Brown, M. V. (2011). The stresses of hospice volunteer work. *American Journal of Hospice and Palliative Medicine*, *28*(3), 188-192. doi:10.1177/1049909110381883.

Buss, D. M. (1997). Human social motivation in evolutionary perspective: Grounding terror management theory. *Psychological Inquiry*, *8*(1), 22-26. doi: 10.1207/s15327965pli0801_3.

Cain, C. L. (2015). Suffering and identity: "Difficult patients" in hospice care. In *World suffering and quality of life* (pp. 91-100). Netherlands: Springer.

Calanzani, N., Higginson, I., & Gomes, B. (2013). *Current and future needs for hospice care: An evidence-based report.* Retrieved May 2, 2016 from http://cdn.basw.co.uk/upload/basw_103716-5.pdf

Candy, B., France, R., Low, J., & Sampson, L. (2015). Does involving volunteers in the provision of palliative care make a difference to patient and family wellbeing? A systematic review of quantitative and qualitative evidence. *International Journal of Nursing Studies*, *52*(3), 756-768. doi: http://dx.doi.org/10.1016/j.ijnurstu.2014.08.007.

Centeno, C., Lynch, T., Donea, O., Rocafort, J., & Clark, D. (2013). EAPC atlas of palliative care in Europe 2013-full edition. Retrieved on April 11, 2016, from EAPC_Atlas_Palliative_Care_Europe_2013_Full_Edition_pdf.

Creswell, J. (2003). *Research design: Qualitative and quantitative approaches*. London: Sage Publications.

Claxton, J. W. (1993). Paving the way to acceptance: Psychological adaptation to death and dying in cancer. *Professional nurse (London, England)*, *8*(4), 206-211. Retrieved from Europe PMC database.

Claxton-Oldfield, S., Crain, M., & Claxton-Oldfield, J. (2007). Death anxiety and death competency: The impact of a palliative care volunteer training program. *American Journal of Hospice and Palliative Medicine*, *23*(6), 464-468. doi: 10.1177/1049909106294882.

Claxton-Oldfield, S., Hastings, E., & Claxton-Oldfield, J. (2008). Nurses' perceptions of hospice palliative care volunteers. *American Journal of Hospice and Palliative Medicine*, *25*(3), 169-178. doi:10.1177/1049909107312595.

Dávila, M. C., & Díaz-Morales, J. F. (2009). Age and motives for volunteering: Further evidence. *Europe's Journal of Psychology*, *5*(2), 82-95. doi: http://dx.doi.org/10.5964/ejop.v5i2.268.

Claxton-Oldfield, S., Jefferies, J., Fawcett, C., Wasylkiw, L., & Claxton-Oldfield, J. (2004). Palliative care volunteers: why do they do it? *Journal of Palliative Care*, *20*(2), 78. Retrieved from PubMed.gov database.

Dein, S., & Abbas, S. Q. (2005). The stresses of volunteering in a hospice: A qualitative study. *Palliative Medicine*, *19*(1), 58-64. doi: 10.1191/0269216305pm969oa.

Dick, R. (1990). *Convergent interviewing*. Brisbane: Interchange.

Doyle, D., Scott, R., & Howlett, S. (2009). *Volunteers in hospice and palliative care.* London: Oxford University Press.

Elliott, G., & Umeh, K. (2013). Psychological issues in voluntary hospice care. *British Journal of Nursing*, *22*(7), 377-383. doi: http://dx.doi.org/10.12968/bjon.2013.22.7.377.

Fernández, C. (2006). The language of death: Euphemism and conceptual metaphorization in Victorian obituaries. *SKY Journal of Linguistics*, *19*, 101-130. Retrieved from academia.edu database.

Finkelstein, M. A. (2008). Predictors of volunteer time: The changing contributions of motive fulfilment and role identity. *Social Behavior and Personality: An International Journal*, *36*(10), 1353-1363. doi: http://dx.doi.org/10.2224/sbp.2008.36.10.1353.

Finkelstein, M. A., Penner, L. A., & Brannick, M. T. (2005). Motive, role identity, and
    prosocial personality as predictors of volunteer activity. *Social Behavior and
    Personality: An International Journal*, *33*(4), 403-418. doi:
    http://dx.doi.org/10.2224/sbp.2005.33.4.403.

Fischer, L. R., & Schaffer, K. B. (1993). *Older volunteers: A guide to research and practice*.
    London: Sage Publications, Inc.

Fox, J. (2006). "Notice how you feel": An alternative to detached concern among hospice
    volunteers. *Qualitative Health Research*, *16*(7), 944-961.
    doi: 10.1177/1049732306290233.

Frankel, R. M., & Devers, K. J. (2000). Study design in qualitative research--1: Developing
    questions and assessing resource needs. *Education for Health*, *13*(2), 251. doi:
    10.1080/13576280050074534.

Freud, S. (1948). Further Recommendations in the Technique of Psycho-analysis (1913).
    Collected Papers, Vol. II. *Hogarth. London*, 342.

Gadamer, H. (1990/1960). *Truth and method.* New York: Crossroad.

Goldenberg, J. L., McCoy, S. K., Pyszczynski, T., Greenberg, J., & Solomon, S. (2000). The
    body as a source of self-esteem: The effect of mortality salience on identification with
    one's body, interest in sex, and appearance monitoring. *Journal of Personality and
    Social Psychology*, *79*(1), 118. doi: http://dx.doi.org/10.1037/0022-3514.79.1.118.

Greenberg, J., Pyszczynski, T., & Solomon, S. (1986). The causes and consequences of a
    need for self-esteem: A terror management theory. *Public self and private self* (pp.
    189-212). New York: Springer. doi: 10.1007/978-1-4613-9564-5_10.

Greenberg, J., Solomon, S., Pyszczynski, T., Rosenblatt, A., Burling, J., Lyon, D., ... & Pinel,
    E. (1992). Why do people need self-esteem? Converging evidence that self-esteem
    serves an anxiety-buffering function. *Journal of Personality and Social
    Psychology*, *63*(6), 913. doi: http://dx.doi.org/10.1037/0022-3514.63.6.913.

Greenberg, J., Pyszczynski, T., Solomon, S., Rosenblatt, A., Veeder, M., Kirkland, S., &
    Lyon, D. (1990). Evidence for terror management theory II: The effects of mortality
    salience on reactions to those who threaten or bolster the cultural worldview. *Journal
    of personality and social psychology*, *58*(2), 308. doi: http://dx.doi.org/10.1037/0022-
    3514.58.2.308.

Harvell, L., & Nisbett, G. (2016). *Denying death.* London: Routledge.

Heidegger, M. (1962/1927). *Being and time.* Oxford: Blackwell.

Harland, L. (2016) "It's like walking in blindfolded" The Experiences of Patient-facing Volunteers in a UK
Hospice: An Interpretative Phenomenological Analysis. *Journal of Applied Psychology and Social Science, 2*
(2), 30-64

Holland, J. M., & Neimeyer, R. A. (2005). Reducing the risk of burnout in end-of-life care settings: The role of daily spiritual experiences and training. *Palliative and Supportive Care*, *3*(03), 173-181. doi: http://dx.doi.org/10.1017/S147895150505050297.

Holloway, I., & Wheeler, S. (2010). *Qualitative research in nursing and healthcare* (pp. 11). Oxford: Wiley-Blackwell.

HospiceUK. (2014). *Volunteering.* Retrieved January 30, 2016, from https://www.hospiceuk.org/about-hospice-care/volunteering-in-hospice-care.

Howlett S. (2009). Setting the scene: The landscape of volunteering. In: Scott R, Howlett S, (Eds.), *Volunteers in Hospice and Palliative Care* (pp. 11-19). Oxford: Oxford University Press.

Husserl, E. (1970). *The crisis of European sciences and transcendental phenomenology.* (D. Carr, Trans.). Evanston: Northwestern University Press.

Joireman, J., & Duell, B. (2005). Mother Teresa versus Ebenezer Scrooge: Mortality salience leads proselfs to endorse self-transcendent values (unless proselfs are reassured). *Personality and Social Psychology Bulletin*, *31*(3), 307-320. doi: 10.1177/0146167204271593.

Kastenbaum, R. J. (2015). *Death, society, and human experience*. London: Routledge.

Kelly, N., & Smith, R. (2012). Global attempts to avoid talking directly about death and dying. *BMJ.* Retrieved from http://blogs.bmj.com/bmj/2012/08/16/richard-smith-and-nataly-kelly-global-attempts-to-avoid-talking-directly-about-death-and-dying/

Kubler-Ross, R. E. (1969). *On death and dying: What the dying have to teach doctors, nurses, clergy and their own families.* New York: Scribner.

Langdridge, D. (2007). *Phenomenological psychology: Theory, research and method*. Essex: Pearson Education.

Lancaster, A., Bowman, N., & Harvell, L. (2016). "Death is coming, but I'm too scared to think about it". In Harvell, L., & Nisbett, G (Eds.), *Denying death* (pp. 136-149). London: Routledge.

Larkin, M., & Griffiths, M. D. (2002). Experiences of addiction and recovery: The case for subjective accounts. *Addiction Research & Theory*, *10*(3), 281-311. doi: 10.1080/16066350211866.

Leary, M. R. (1999). The social and psychological importance of self-esteem. Washington: American Psychological Association.

Legislation.gov.uk. (1998). *Data protection act 1998.* Retrieved April 10, 2016, from

http://www.legislation.gov.uk/ukpga/1998/29/contents

Macann, C. E. (1993). *Four Phenomenological Philosophers: Husserl, Heidegger, Sartre, Merleau-Ponty*. New York. Routledge.

Macmillan Cancer Support (2015). *Involving young people in hospice care*. Retrieved April 2, 2016, from

http://www.macmillan.org.uk/aboutus/healthandsocialcareprofessionals/newsandupdates/macvoice/spring2015/involvingyoungpeopleinhospicecare.aspx.

Marie Curie. (2016). *Help people in your local area.* Retrieved March 24, 2016 from

https://www.mariecurie.org.uk/get-involved/volunteering/opportunities/help-people.

Mayor, S. (2010). UK is ranked top out of 40 countries on quality of death thanks to hospice network. *BMJ*, *341*, c3836. doi: http://dx.doi.org/10.1136/bmj.c3836.

McKenna, W. (2012). *Husserl's "Introductions to phenomenology": Interpretation and critique* (Vol. 89). The Hague. Martinus Nijhoff Publishers. doi: 10.007/978-94-009-7573-6.

Merleau-Ponty, M. (1962). *Phenomenology of perception.* London: Routledge.

Midlarsky, E., & Kahana, E. (1994). *Altruism in later life*. Thousand Oaks: Sage Publications, Inc.

Mohanti, B. K. (2009). Ethics in palliative care. *Indian Journal of Palliative Care*, *15*(2), 89. doi: 10.4103/0973-1075.58450.

Morris, S. M., Payne, S., Ockenden, N., & Hill, M. (2015). Hospice volunteers: Bridging the gap to the community? *Health & Social Care in the Community*. Retrieved from Europe PMC database.

Muliira, R. S., & Bezuidenhout, M. C. (2015). Occupational exposure to maternal death: Psychological outcomes and coping methods used by midwives working in rural areas. *Midwifery*, *31*(1), 184-190. doi: 10.1016/j.midw.2014.08.005.

Mundle, C., Naylor, C., & Buck, D. (2012). *Volunteering in health and care in England. A summary of key literature.* London: The King's Fund. Retrieved April 12, 2016 from https://kf-ssl-testing.torchboxapps.com/sites/files/kf/field/field_related_document/volunteering-in-health-literature-review-kingsfund-mar13.pdf.

Musick, M. A., & Wilson, J. (2007). *Volunteers: A social profile*. Bloomington: Indiana University Press.

NHS. (2012). *News analysis: What is the Liverpool Care Pathway?* Retrieved May 2, 2016 from http://www.nhs.uk/news/2012/11November/Pages/What-is-the-Liverpool-Care-Pathway.aspx.

NHS. (2016). *End of life care: What end of life care involves.* Retrieved March 21, 2016, from http://www.nhs.uk/Planners/end-of-life-care/Pages/what-it-involves-and-when-it-starts.aspx.

Nyatanga, B., & de Vocht, H. (2006). Towards a definition of death anxiety. *International Journal of Palliative Nursing*, *12*(9). Retrieved from EBSCO database.

Office for National Statistics. (2011). *National bereavement survey (voices).* Retrieved March 13, 2016 from www.ons.gov.uk/ons/rel/subnational-health1/national-bereavement-survey--voices-/2011/stb-statistical-bulletin.html.

Office for National Statistics (2015). *National population projections for the UK, 2014-based.* Retrieved April 30, 2016 from http://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationprojections/bulletins/nationalpopulationprojections/2015-10-29.

Okun, M. A. (1994). The relation between motives for organizational volunteering and frequency of volunteering by elders. *Journal of Applied Gerontology*, *13*(2), 115-126. doi: 10.1177/073346489401300201.

Omoto, A. M., & Snyder, M. (2002). Considerations of community the context and process of volunteerism. *American Behavioral Scientist*, *45*(5), 846-867. doi: 10.1177/0002764202045005007.

Parker-Oliver, D. (2000). The social construction of the "dying role" and the hospice drama. *OMEGA-Journal of Death and Dying*, *40*(4), 493-512. doi: 10.2190/YT9D-12Y2-54LY-TCMN.

Parsons, T. (1972). Definitions of health and illness in the light of American values and social structure. In E. G. Jaco (Ed.), *Patients, physicians, and illnesses* (pp. 97–117). New York: The Free Press.

Pesut, B., Hooper, B., Lehbauer, S., & Dalhuisen, M. (2014). Promoting volunteer capacity in hospice palliative care: A narrative review. *American Journal of Hospice and Palliative Medicine*, *31*(1), 69-78. doi:10.1177/1049909112470485.

Peters, H. J., Greenberg, J., Williams, J. M., & Schneider, N. R. (2005). Applying terror management theory to performance: Can reminding individuals of their mortality

increase strength output. *Journal of Sport and Exercise Psychology*, *27*(1), 111-116. Retrieved from PsycNET database.

Planalp, S., & Trost, M. (2009). Reasons for starting and continuing to volunteer for hospice. *American Journal of Hospice and Palliative Medicine*. doi: 10.1177/1049909109333929.

Public Health England. (2013). *National End of Life Care Intelligence Network: What we know now.* Retrieved February 15, 2016, from http://www.endoflifecare-intelligence.org.uk/resources/publications/what_we_know_now_2013.

Pyszczynski, T., Greenberg, J., & Solomon, S. (1999). A dual-process model of defence against conscious and unconscious death-related thoughts: An extension of terror management theory. *Psychological review*, *106*(4), 835. doi: http://dx.doi.org/10.1037/0033-295X.106.4.835.

Reid, K., Flowers, P., & Larkin, M. (2005). Exploring lived experience. *Psychologist*, *18*(1), 20-23. Retrieved from ProQuest database.

Robinson, O. C. (2014). Sampling in interview-based qualitative research: A theoretical and practical guide. *Qualitative Research in Psychology*, *11*(1), 25-41. doi: 10.1080/14780887.2013.801543.

Roose, G. A., & John, A. M. (2003). A focus group investigation into young children's understanding of mental health and their views on appropriate services for their age group. *Child: Care, Health and Development*, *29*(6), 545-550. doi: 10.1046/j.1365-2214.2003.00374.x.

Rubin, H., & Rubin, I. (2012). *Qualitative interviewing: The art of hearing data.* Thousand Oaks: Sage Publications.

Sallnow, L., & Paul, S. (2015). Understanding community engagement in end-of-life care: Developing conceptual clarity. *Critical Public Health*, *25*(2), 231-238. doi: 10.1080/09581596.2014.909582.

Sartre, J-P. (1956/1943). *Being and nothingness.* New York: Washington Square Press.

Shye, S. (2010). The motivation to volunteer: A systemic quality of life theory. *Social Indicators Research*, *98*(2), 183-200. doi: 10.1007/s11205-009-9545-3.

Schleiermacher, F. (1998). *Hermeneutics and criticism and other writings* (A. Bowie, Trans.). Cambridge: CUP.

Schusterschitz, C., Flatscher-Thöni, M., Leiter-Scheiring, A. M., & Geser, W. (2014). Building a committed hospice volunteer workforce: Do variables at the experience

stage matter? *Journal of Community and Applied Social Psychology*, *24*(5), 422-438. doi: 10.1002/casp.2182.

Seidman, I. (2013). *Interviewing as qualitative research: A guide for researchers in education and the social sciences*. New York: Teachers college press.

Shinebourne, P. (2011). The theoretical underpinnings of interpretative phenomenological analysis (IPA). *Existential Analysis*, *22*(1), 16-32. Retrieved from Ebscohost database.

Smith, J. (2004). Reflecting on the development of interpretative phenomenological analysis and its contribution to qualitative research in psychology. *Qualitative Research in Psychology*, *1*(1), 39-54. doi: 10.1191/1478088704qp004oa.

Smith, J. (2007). Hermeneutics, human sciences and health: Linking theory and practice. *International Journal of Qualitative Studies on Health and Well-being*, *2*(1), 3-11. doi: 10.1080/17482620601016120.

Smith, J. (2008). *Qualitative psychology: A practical guide to research methods.* London: Sage Publications, Inc.

Smith, J., Flowers, P., & Larkin, M. (2009). *Interpretative phenomenological analysis: Theory, method and research*. London: Sage Publications, Inc.

Smith, A., Joseph, S., & Das Nair, R. (2011). An interpretative phenomenological analysis of posttraumatic growth in adults bereaved by suicide. *Journal of Loss and Trauma*, *16*(5), 413-430. doi: 10.1080/15325024.2011.572047.

Smith, J., & Osborn, M. (2003). Interpretative phenomenological analysis. In J. Smith (Ed.), *Qualitative psychology. A practical guide to research methods* (pp. 51–80). London: Sage Publications.

Solomon, S., Greenberg, J., & Pyszczynski, T. (2015). *The worm at the core: On the role of death in life*. New York: Random House.Webb, E. (1998). Ernest Becker and the psychology of worldviews. *Zygon®*,*33*(1), 71-86. doi: 10.1111/0591-2385.1271998127.

Vachon, M., Fillion, L., & Achille, M. (2012). Death confrontation, spiritual-existential experience and caring attitudes in palliative care nurses: An interpretative phenomenological analysis. *Qualitative Research in Psychology*, *9*(2), 151-172. doi: 10.1080/14780881003663424.

Weeks, L. E., & MacQuarrie, C. (2010). Supporting the volunteer career of male hospice–

palliative care volunteers. *American Journal of Hospice and Palliative Medicine*, 1049909110389322. doi:10.1177/1049909110389322.

Weisman, A. D. (1972). *On dying and denying: A psychiatric study of terminality*. New York: Behavioral Publications.

Willig, C. (2013). *Introducing qualitative research in psychology*. Maidenhead: Open University Press.

Wilson, D. M., Justice, C., Thomas, R., Sheps, S., MacAdam, M., & Brown, M. (2005). End-of-life care volunteers: A systematic review of the literature. *Health Services Management Research*, *18*(4), 244-257. doi: 10.1258/095148405774518624.

Wright, M., Wood, J., Lynch, T., & Clark, D. (2008). Mapping levels of palliative care development: a global view. *Journal of pain and symptom management*, *35*(5), 469-485. doi: 10.1016/j.jpainsymman.2007.06.006.

Yardley, L. (2008). Demonstrating validity in qualitative psychology. In Smith, J (Eds.), *Qualitative psychology: A practical guide to research methods* (pp. 235-251). London: Sage Publications, Inc.

Zimmermann, C. (2004). Denial of impending death: A discourse analysis of the palliative care literature. *Social Science & Medicine*, *59*(8), 1769-1780. doi: 10.1016/j.socscimed.2004.02.012.