"The experiences of volunteers in a childhood cancer charity"

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Abstract

Introduction: Serious childhood illness has a significant impact on the child and their family, but it is known that strong supportive relationships can act as a buffer. Due to limited NHS resources, volunteers are becoming integral to the support of such families. Despite this, little is known about the experiences of volunteers in such roles, and more specifically, those choosing to volunteer in emotionally challenging areas such as childhood cancer.

Method: A sample of seven volunteers working for Candlelighters childhood cancer charity were interviewed using semi structured interviews; transcripts were analysed using interpretative phenomenological analysis.

Results: Volunteer's experiences of working in a childhood cancer charity were described in terms of five superordinate themes: 'Motivation', 'Identity and Roles', 'Coping', 'Community', and 'Family'. Overall, the themes captured what motivates individuals to volunteer and in particular why they chose the area of childhood cancer. The themes also reflected the impact that the role has on their sense of identity and self, and how the participants seemed to cope with that role. It is speculated that this is in part due to the protective experience of belonging to a community as described by the participants, with frequent allusions to an even deeper link in terms of feeling part of a family.

Discussion: The findings of this study are related to the wider literature with consideration of role identity theory and the significance of community and relationships. The strengths and limitations are discussed to assess the quality of the

study. Implications for our current understanding of volunteers and suggestions for future research are proposed.

Table of Contents

- 10 -

List of Tables

List of Figures

List of Abbreviations

IPA- Interpretative Phenomenological Analysis

NHS- National Health Service

PAS- Post traumatic Adjustment Scale

PICU- Paediatric Intensive Care Unit

VFI- Volunteers Function Inventory

PIP- Paediatric Inventory for Parents

LQTS- Congenital long QT syndrome

Chapter 1: Introduction

This literature review will first introduce paediatric cancer as the context within which this study was carried out. The wider literature on psychological aspects of serious childhood illness will be discussed, before returning to paediatric cancer in more detail later in the literature review to consider the significance of the condition in child and parental wellbeing. The review will cover what we know about the impact of serious illness on the child themselves, impact on their parents and factors that may modify the severity of the impact. The review will then consider the impact of the childhood illness on the wider families' lives and relationships with one another, before examining the importance of relationships in mediating the impact that an individual or their family experiences, and furthermore moving on to discuss different sources of support, including healthcare professionals and third sector charity organisations. The review will then consider paediatric oncology in more detail and the significance of this illness for such research.

Volunteers within third sector organisations may be in a position to offer longer term support to families and individuals than the NHS (NHS England, 2017). To address and fully understand volunteering and the extent to which volunteers can support families with childhood illness, the review will endeavour to outline the impact of volunteers in our society and the potential motivating factors for becoming a volunteer. The review will then attempt to understand the roles of volunteers in health settings, and what challenges they may be faced with.

Finally, Candlelighters, a third sector organisation that supports families during and post treatment for paediatric cancer in Yorkshire and is hosting this research will be

introduced. The charity holds the relationship and support they offer the families at the heart of the work they do. Due to the charity's funding being provided through fundraising alone, they are able to offer long term support to the families, at times for years post treatment. The review will consider the work of the charity and the impact it has on service users.

Paediatric cancer as context

Roughly 9000 children are diagnosed with paediatric cancer within a year in America (Toro, 2007); whilst in the UK, figures of newly diagnosed paediatric cancer are closer to 1600 cases annually (Children With Cancer UK, 2017). Paediatric cancer has been reported to be the most prominent cause of death in children under the age of 15, demonstrating the level of severity for all those affected by this illness (Toro, 2007).

Serious illness in childhood

'Serious illness' as a term may cover any illness that is life limiting in both morbidity and mortality, and has the potential to bring about significant emotional distress (Molzahn et al., 2012). There are many different terms used within the literature base, for example, 'Chronic illness', which is any illness which lasts for three months or longer (Von Korff, Gruman, Schaefer, Curry, & Wagner, 1997). In addition 'Critical illnesses' have been defined as severe sepsis, the need for mechanical ventilation, or an illness with a risk of fatality whilst receiving treatment in hospital (Seymour et al.,2010). Studies looking at either 'chronic illness', 'critical illness' or 'serious/ severe illness' have been reviewed to ensure a comprehensive review of serious, life impacting childhood illness is presented.

UK national prevalence rates of life limiting conditions (conditions in which there is little possibility of being cured) has risen in a 10 year period from 25 to 32 per

10 0000 population (Fraser et al., 2011; Fraser et al.,2012). Medical care and treatment of diseases and illnesses have dramatically improved in recent years. Fatal illnesses such as tuberculosis and polio have been effectively eradicated, however figures of childhood illness have not been observed to significantly decrease in the way that might be expected (Eiser, 2012). This may be that whilst the advancement of medical care and treatment has reduced certain fatal diseases, an increasing number of children survive or now have a longer life expectancy for serious illnesses such as kidney disease, cystic fibrosis and cancer but face living with the impact of such illnesses. However, treatment for such conditions is often lengthy, intrusive and very unpleasant, frequently resulting in long term psychological problems for the child themselves and their family (Eiser, 2012).

Whilst such research is widespread, the level of clarity in the definition of childhood serious illness is lacking. Consequently, there are few prevalence estimates for such conditions, and these often vary where documented. Variations may result from some figures including both mental and physical conditions, whereas others only include physical conditions. Additionally, the means by which the data is collected can vary; many rely on parental reports alone, whereas some are based purely on clinic information or are population based (Newacheck, & Taylor, 1992). More recent literature on prevalence and definitions does not provide any further clarity. In fact such literature outlines the same difficulties as reported in 1992 by Newacheck and Taylor. A systematic review carried out on all English and Dutch articles up to 2006 provided further evidence that as a whole, we have little clarity on the definition of serious/ chronic childhood illness (van der Lee, Mokkink, Grootenhuis, Heymans, & Offringa, 2007). From all the articles included in the review, a wide range of definitions were used, with the following four being the most frequent; 'chronic conditions', 'chronic health conditions', 'chronic illness', and '(children with) special health care needs'. In

addition to the wide range of definitions used, it was found that the studies were all using different ways to measure the different concepts leading to a wide range of prevalence rates found; ranging from 0.22% to 44% (van der Lee et al., 2007). It is clear that this significant lack of clarity will affect the literature on childhood illness and the knowledge we hold about its subsequent impact.

Impact of serious illness on the child and their wider system

Impact on the child

Experiencing a serious or chronic illness in childhood is often extremely distressing and destabilising. The literature outlines the emotional trauma associated with a potentially fatal diagnosis. Alongside the distress caused by the diagnosis, distress may be experienced as a result of physical changes to the body, a need for numerous intrusive medical procedures, and an individual's own thoughts and beliefs about what it means to have the illness (Rachamim, Mirochnik, Helpman, Nacasch, & Yadin, 2015). It has been reported that children with a chronic medical illness are more likely to experience difficulties with anxiety disorders than physically healthier children of a similar age (Bosk, 2011). In addition to this, qualitative data on children's experiences of having cancer revealed that whilst there were some more positive aspects discussed such as attention and being given gifts, children spoke of the illness and associated treatments being horrible experiences. In addition to this, children spoke of the level of restriction such illnesses can impose on their lives, for example not being able to take part in hobbies (Griffiths, Schweitzer, & Yates, 2011).

Many children or adolescents experience post-traumatic symptoms following medical treatment (such as anxiety, irritability, and avoidance of reminders of the treatment) and can develop debilitating fears such as needle phobia, a fear of health

professionals and post traumatic symptoms relating to specific treatment procedures (Stuber & Shemesh, 2006).

The impact of childhood illness can also continue into later life with adult survivors of childhood cancer reporting higher levels of emotional distress than their healthy counterparts and healthy siblings. It has been suggested that childhood medical treatments can cause chronic health conditions as an adult, perhaps contributing to such emotional distress (D'agostino et al., 2016; Huang et al., 2017; Vuotto et al.,2017).

Impact on parents

From a systems framework perspective, the impact of a childhood illness is not restricted to the child, but the problem is felt at every level of the system (Kazak, 1989). Within the family system, each family member will feel the effect in some way, and there is a wealth of literature outlining the impact felt by parents.

Paediatric intensive care services (PICU) provide medical care and assistance to children who are admitted to hospital with life threatening illnesses (Shudy et al.,2006). Parents of such children are placed under significant stress and psychological suffering, often in response to a disabling sense of uncertainty, trying to balance changing family roles and managing living between two worlds (PICU and the ongoing home environment) (Hagstrom, 2017; Stremler, Haddad, Pullenayegum, & Parshuram, 2017). Parents may also experience many difficult feelings such as helplessness and irritation (Shudy et al.,2006). Forinder, Claesson, Szybek and Norberg (2015) interviewed parents of children with a life threatening illness. The study revealed that parents can experience difficult thoughts such as intense fear of the child's illness recurring and traumatic images (eg. strong memories of the child's illness or treatment) with regards to past events, and concerns and worries in the present and future.

The impact of childhood critical illness on the parents can also be demonstrated through the high prevalence of long term psychological distress, worry related to the child's illness and relationship difficulties reported in parents of children with cancer (21-44%) (Ljungman et al., 2014).

Parental stress has received attention from clinicians and researchers with aims of quantifying and measuring the impact. Streisand, Braniecki, Tercyak, & Kazak (2001) developed an outcome measure to monitor the levels of stress experienced by parents who look after a child with an illness, known as the Paediatric Inventory for Parents (PIP). Whilst the authors acknowledged the value of general outcome measures for monitoring distress in these parents, they highlighted the lack of specific measurement of the impact of critical illness experiences. Such specific experiences may include the impact of the strict medical regime, negotiation of the system and the hospital environment, and the emotional impact of seeing their child in pain. The study found that in a group of families who had a child diagnosed with cancer, the PIP scores correlated with levels of parenting stress as measured by the Parenting Stress Index-Short Form (PSI-SF) (Abidin, 1990). This measure (PIP) has been used in multiple studies demonstrating an increased level of parenting stress for parents of children with illnesses such as cancer and diabetes (Lewin et al., 2005; Vrijmoet-Wiersma et al., 2010). More recently, Samuel, Colville, Goodwin, Ryninks & Dean (2015) carried out a randomised controlled trial in which screening measures such as the Post traumatic Adjustment Scale (PAS) (O'Donnell et al.,2008) were used to predict significant levels of psychological distress following their child being admitted to PICU. The study further evidenced the distress experienced by parents when their child is seriously unwell, and in addition found that close monitoring of the parent's vulnerability to distress using the PAS enabled early identification of those at risk of post-traumatic stress, anxiety and depression following the admission to hospital.

Modifiers of parental impact

The impact felt may also depend on the varying levels of onset of the illness. It is hypothesised that those illnesses with an acute onset require the family to process and adjust to the illness in a short space of time, presumably requiring more crisis management skills than those with a more gradual onset. It is suggested that families with a higher tolerance for a collectively high emotional arousal, have an ability to problem solve and utilise external resources, and therefore may show more resilience when faced with a sudden illness (Rolland, 1987). More recent research has investigated the process by which the adjustment takes place, and how the illness is conceptualised by the family. For example, a qualitative study found that families responses could be grouped into four different categories; 'possibility,' 'focus on illness,' 'denial,' and 'anger.' The different ways of making sense of the illness impacted on how the family described the child's illness, the impact it had on them, and the way in which they coped on a day to day basis. The study found no link between the trajectories described and the type or length of illness (data elicited from medical records). Therefore it can be assumed that the different trajectories correspond to family process and structure, rather than specifics of the illness itself such as type and duration (Cipolletta,Marchesin & Benini, 2015).

Such an impact on parents can be seen not only in critical, life threatening conditions, but also in chronic childhood illnesses. A systematic review on levels of stress among parents of children with a chronic illness reported that they experienced significantly more general parenting stress than parents of healthy children. It was reported that such stress was linked with managing treatments for their child, and was not related to length of illness or severity as suggested previously (Cousino, & Hazen, 2013). Knafl and Zoeller (2000) reported that experiences of families with a child diagnosed with a chronic illness may differ depending upon how shared the experience

was perceived to be. In a sample of parents with children diagnosed with a chronic illness which impacted on day to day functioning and required a high level of input, many parents adopted a shared perspective of the illness and the impact it had on the family. Commonly, the shared view minimised the impact felt by the family, contributing to family resilience. In cases in which parents held different perspectives of the experience, the mother reported a more negative impact of the illness.

A significant amount of the research describing parental responses and impact of the child's illness is very heavily reliant on the mother's response or experience. Yarnell (2016) explored the perceptions and experiences of fathers with children diagnosed with Congenital long QT syndrome (LQTS); a complex genetic disorder of the heart. In this study, fathers reported fear and confusion upon initial diagnosis. Gaining more information and knowledge about the condition moderated such fears, as did the passage of time. Fathers who felt better able to manage, viewed the condition, and saw their child respond to the condition, in a more positive manner, thereby aiding fathers' responses and ability to cope with the experience. The stress associated with uncertainty, however, remained constant throughout.

Impact on the family as a whole

The literature reviewed so far has indicated a clear impact of the illness on the individual themselves and on their parents. However, whilst previous thinking considered family process to be simply an accumulation of individual thoughts and experiences, it is now considered that family dynamics work within the framework of a holistic system (Bateson 1972; Stanton & Welsh, 2012).

In a review of literature from 1999-2009 on the impact of childhood illness, 34 studies were analysed, revealing one of three key themes to be the impact of social support. Many studies found that family life was disrupted, often due to frequent

hospital visits and admissions. Families found ways to manage this, such as one parent supporting the child in hospital, and one parent supporting the other child. Despite such efforts to maintain some sense of normality and ensure children's needs are met, it was found that family relationships were often strained (Smith, Cheater & Bekker, 2015).

Houtzager, Grootenhuis and Last (1999) carried out a review of 35 studies investigating siblings' adaption to paediatric cancer. The review concluded that siblings are commonly found to struggle with behavioural problems and experience high levels of emotional pain. However, whilst it is to be noted that these symptoms do not often meet clinical significance, they can have a serious detrimental impact on the individual's wellbeing. This being said, siblings have also been noted to have increased levels of empathy, maturity and supportiveness, indicating some positive effects can be observed. More recent research on siblings' response to childhood cancer indicate high levels of cancer-related PTSD symptoms (Kaplan, Kaal, Bradley & Alderfer, 2013).

More generally, a meta-analysis reported a negative effect on siblings' psychological functioning, peer activities and level of cognitive ability when they had a sibling with a chronic illness, in comparison to controls. Recommendations from the meta-analysis included support and intervention with the siblings (Sharpe & Rossiter, 2002).

Secondary impacts of a critical illness may significantly impact a family with regards to financial implications, and subsequent impact on the family's wellbeing and financial security (Miedema, Easley, Fortin, Hamilton & Mathews, 2008). Al-Hassan and Hweidi (2004) discussed the impact of critical illness on the family as a whole, their wellbeing and level of need as a family unit. Many studies have reported that as the severity of the illness increases, so does the impact on the family both socially and in terms of levels of apparent family dysfunction (Wade, Taylor, Drotar, Stancin & Yeates, 1998; Winthrop et al., 2005).

It is of note that whilst there is a clear impact of critical illness on the family, the level and severity of the impact is fluid throughout the course of the illness. Rolland (1987) describes the three phases of an illness trajectory, which may impact the family in different ways. Firstly, Rolland proposes there is a crisis phase in which the individual may experience symptoms before the illness is diagnosed, and post diagnosis, experience a period of adjustment to their new reality. The subsequent chronic phase is characterised by the family's day to day adaptations of living with the illness and continual functioning, despite a debilitating feeling of uncertainty. Finally, in situations where the illnesses are terminal, family life may become dominated by the illness and preoccupation with separation and grief. The proposed illness trajectory highlights the complexity of the illness's impact on the family, and the fluidity of the systems' response. Recent research has looked at this concept more intricately, comparing parents' perceptions of illness trajectories with medical views (Burke, Kauffmann, LaSalle, Harrison & Wong, 2016). Whilst there was a loose association between the two for classification into either chronic or life threatening, perceptions of the probable progression of the illness were found to differ. A recent confirmatory factor analysis, in which questionnaires assessing parental experience were scanned for time spanning items, revealed three illness trajectories. Namely these were; slowly declining, life shortening and life threatening , and the movement of parents between different trajectories, often triggered by a period of hospitalization (Burke, Kauffmann, LaSalle, Harrison & Wong, 2016).

Whilst such research clearly outlines the direct impact of critical illness on a family, the term 'family' must be viewed with caution. The term 'family' is a concept in itself, and it has undergone many changes in recent times. It was once perhaps only used to refer to a heterosexual couple and their children, an image maintained through media representation (Dallos & Draper, 2015). Recently, many different constructs of

families, including childless couples, homosexual couples, single parents, and close family friends have been increasingly acknowledged (Asen, 2002). Such different family constructs may add a varying dimension to the impact of the illness on the family, although they are often not well represented in much of the research within this area (Shudy et al., 2006).

Serious illness and relationships

Relationships and social support

The bioecological model of human development (Bronfenbrenner, 1986) considers the individual as being embedded within a wider context of multiple systems. Micro-systems include the individual's close family and friends, school and the wider family network, all of which can be influenced by the individual's macro-systems. Such macro-systems may include parental employment situation and societal expectations on the child and their family. When considering a child suffering from a severe or chronic illness within this model, such macro-systems may also include support from the NHS, influence of third sector organisations, and societal norms of illness management (Bronfenbrenner, 1986). The support in each system will determine the impact of the childhood illness on the child or family. For example, within each system, the presence of familial, social, or professional relationships can act as a buffer for many of the stressors felt as a result of the illness. Later revisions to the bioecological model of human development incorporated the concept of time to capture the impact of historical events on an individual's development and current experience (Bronfenbrenner, 1995).

In the present literature base, the bioecological model of human development has been cited over 15 000 times as of September 2012. Whilst it is clear that the model still holds much influence in current systemic thinking, there has been more recent development in the thinking around the relationship between the different systems as

'networked' as opposed to nested, as portrayed by Bronfenbrenner. Neal and Neal (2013) proposed a 'social network model' in which the importance of the different systems and impact of time is maintained. However the model proposes that the different systems are all inter-linked and may differ in the pattern of the associations between individuals.

Impact of relationships between parental coping and family outcome

The presence and quality of family relationships have a mediating impact on the effects of childhood illness. Studies show that often all members of the family, including the child, report that family support facilitates their level of coping with the illness (Van Schoors, Caes,Verhofstadt, Goubert & Alderfer, 2015). Due to the demands of childhood illness, it is necessary for families to be flexible in their roles, able to communicate well and manage their own emotions. Such requirements necessitate complex family-level processes (Van Schoors et al.,2015).

Kazak, Reber and Carter (1988) consider the concept of social networks in its structural parts, including size and density. In families with a child who has phenylketonuria (a metabolic disorder which can lead to brain damage), it was found that those with larger social networks were less likely to experience as much psychological distress as those with smaller social networks, further supporting the importance of relationships in buffering the impact of childhood illness. More recently, reviews on major research findings have found key themes supporting the variable impact of relationships and social networks on health outcomes. Such research reviews indicated that larger social support networks are more beneficial due to the having a larger pool of people to obtain support from when necessary (Umberson & Karas Montez, 2010).

There is widespread literature available outlining the importance of relationships between parents and medical staff with regards to their experience of caring for a child with a chronic or critical illness (Bry et al.,2016; Brooten et al., 2013; Thorne & Robinson, 1988; Gibson, 1995). Such findings demonstrate that parents in emotionally distressing situations such as having a child in intensive care valued compassion and sensitivity from the medical professionals they were involved with (Brooten et al., 2013) and that such support increased with training on communication (Bry et al.,2016). This relationship is dynamic and changes over time; findings from semi-structured interviews indicate that parents of chronically ill children may move between trusting professionals and feeling somewhat disenchanted, before commonly moving into a prolonged stage of guarded trust (Thorne & Robinson, 1988). Parents report that when trying to manage and negotiate the realities of caring for a child with a chronic illness or managing through the grieving process, establishing a positive relationship with professionals is imperative (Snaman, Kaye,Torres,Gibson & Baker, 2016; Swallow & Jacoby, 2001).

Importance of relationships in patient outcome

The benefits of a healthy and supportive relationship between staff members and patients in physical health settings have been widely reported, not only in mediating the impact of the illness on the family, but also in patient outcome. Experiencing ill health in any situation, and even more so in an unfamiliar setting such as a hospital, can be unsettling. Such an experience may be both threatening and strange, highlighting the importance and necessity of good quality relationships within a healthcare setting. Good quality care, from the perception of patients and carer's was defined as care that was delivered through a genuine and caring relationship (Attree, 2001). Ciechanowski et al. (2004) found that in a sample of patients with diabetes, those who had a dismissive

attachment style (individuals who were more likely to find it difficult to trust others) were less likely to exercise, regularly maintain good footcare, and adhere to diabetic medication. These associations were found to be mediated through the strength of relationship between the clinicians and the patients, emphasizing the importance of such a relationship for preventative measures and long term cost reduction. Similarly, Bennett, Fuertes, Keital and Phillips (2011) found that working alliance was positively associated with adherence, satisfaction and health related quality of life in a sample of 193 participants diagnosed with Systemic lupus erythematosus- a chronic and potentially life-threatening autoimmune disease. This study, which utilised surveys to demonstrate the association, signifies the importance and benefits of a therapeutic relationship from the view of the patient, and the wider impact this relationship has on the patient's life.

Relationships within the healthcare system

The prominence of relationships within the healthcare system can be seen through the adoption of a 'relationship centred care' framework. This is a system wide model in which care is centred around relationships between staff and patients, and such relationships are genuine, and inclusive of emotion and affect (Beach & Inui 2006).

However, the provision of healthcare with a focus on relationships has not always been the customary approach. Over the last 50 years, healthcare practice and policies have changed, due to the changing relationship between patients and clinicians. Relationships have moved away from a more paternalistic and hierarchical process to the patient adopting a more active role. Relationships in today's society hold such significance that many health and financial outcomes are dependent upon them and patient satisfaction is now paramount (Boyer & Lutfey, 2010).

Paediatric oncology

The literature review so far has outlined the prevalence of childhood illness and the impact it has on the child, the parents, and on the family's functioning as a whole. The 'buffering' role that good quality relationships can have on lessening the impact of serious childhood illness has been discussed, and in particular the effect of relationships between the family and healthcare staff. One of the most emotionally challenging, and common areas for a need for good quality support is paediatric cancer.

Paediatric oncology is the treatment of malignant conditions associated with cancer in childhood (NHS England, 2013). Within the last 30 years, there has been a move from paediatric oncology services to specialist treatment centres in the UK, contributing to a dramatic improvement in survival rates and prognosis, with around 70% of children making a complete recovery (NHS England, 2013). However a substantial number of these individuals will suffer from long term side effects from their treatment (McCaffrey, 2006). Alongside this, the stresses and psychological distress that accompany a cancer diagnosis for many children has been widely documented. Stressors such as the treatment itself, the hospital environment, a lack of control and fear all have been reported to impact upon individuals and their families going through such conditions (McCaffrey, 2006).

The NHS Standard Contract for Paediatric Oncology stipulates that services should tailor treatment for children to their developmental stage, and adopt a holistic approach within services to address the impact on the wider family (NHS England, 2013). Therefore, the need for supportive services in which the wider family and the individual themselves are supported throughout treatment and beyond is imperative.

An observational study which investigated the needs of young children diagnosed with cancer during their first stay in hospital, revealed a need to have parents

in close proximity, a need to play, and a need to have a good relationship with staff (Björk, Nordström & Hallström, 2006). Despite the need for good relationships and support within a paediatric oncology setting, the sensitive nature of the area make the task somewhat more complex. Research shows that open conversations with patients, including full information about diagnoses and prognosis, although upsetting, enables difficult decisions to be made and may help to maintain hope (Mack, Wolfe, Grier, Cleary & Weeks, 2006). However, information exchanges and discussions between healthcare staff and patients in paediatric oncology often tend to be complex, highly emotional, and commonly lacking certainty, often reducing the occurrence of such required openness (Sobo, 2004).

It is clear that childhood illness has an unequivocal impact on the child and their family, and that relationships with healthcare staff and social support networks are important in mediating the severity of the impact. However, in paediatric oncology, relationships can be challenged due to the highly emotive nature of the situation. Additionally, a family's functioning and stressors may not be static and may fluctuate over the course of the illness and beyond (Henry, Sheffield, Morris, & Harrist, 2015; Kazak, 1989). Furthermore, there is much less research and knowledge about the impact of the illness on the individual and family post hospital discharge (Shudy et al., 2006). Therefore, the time limited input that the NHS can offer may leave a family feeling unsupported and alone once the child is no longer using NHS services. Third sector organisations can often offer longer term support, and play a vital role in the care of such families. Organisations that are neither government or privately funded rely heavily on volunteers to deliver such effective services.

Roles of Volunteers

Introduction of volunteers

What is volunteering?

Due to the wide variety of situations that one can volunteer in, a simple definition of volunteering is not easily found, nor appropriate (Bussell & Forbes, 2002). Research on shared definitions of 'Volunteering', found that the public perception of volunteering was the concept of work without pay, closely followed by an individual giving up their time to help others, often at a disadvantage to themselves (Paine, Hill & Rochester, 2010). A research agency, The Institute of Volunteering research (IVR) is an initiative of Volunteering England to focus and fund more research on volunteering. The IVR found government led definitions to hold similar themes such as unpaid work, and there commonly being an altruistic aspect to the activity (Paine, Hill & Rochester, 2010).

Importance of volunteers in society

In the 2012 Olympics, 70 000 volunteers were recognized as enabling the event to be a success. Kings Fund publications report an estimated figure of around 3 million individuals within England who volunteer in health and social care (Addicott, 2013). In numerous healthcare settings, volunteers are viewed as a vital part of the team. Research has indicated that volunteers play a key role in providing a better experience for service users. This is done by ensuring communication and the development of a good working relationship between services and communities, and finally working to decrease health inequalities (Naylor, Mundle, Weaks & Buck, 2013).

With many public services increasingly being provided by volunteers, the basic essence of volunteering is quickly changing (Naylor, Mundle, Weaks & Buck, 2013). Volunteers are becoming increasingly involved in a wider range of aspects of service

delivery (Naylor, Mundle, Weaks & Buck, 2013). As a result of this, it has been reported that there is high unease amongst staff around job security, causing tension between paid and unpaid staff (Naylor, Mundle, Weaks & Buck, 2013).

Voluntary sector providers can increase awareness of their individual causes and can model good quality care on a national level. In comparison to statutory services, the voluntary sector may have access to a wider pool of resources, and it may be the case that they can utilise such resources more rapidly, enabling more immediate change. In addition to this, the voluntary sector provides service users with more choice, an increase in shared decision making and service user independence (Addicott, 2013).

Politically, there has been a movement towards encouraging and supporting the voluntary sector through policies such as 'Building the Big Society' promoted by the Cabinet Office in 2010. The policies outlined in this document focus on increasing the number of individuals adopting an active role in their communities. The document outlines the government commitment to supporting the development of cooperatives and social enterprises in the provision of public services (Cabinet Office, 2010). Following this, in 2011, the government released a white paper on giving and the importance of charity and third sector organisations. The paper focuses on the need for new social norms within charitable giving, and management of the levels of red tape that may discourage people from giving up their time and money (HM Government, 2011). Societal awareness of the voluntary sector was maintained through a focus on the voluntary sector in the Conservative Party's 2015 manifesto (Woodhouse, 2015). Such a political focus highlights that there is a place for the third sector and in particular in the provision of public services. In services such as healthcare, volunteers may differ from the NHS in being able to offer more broad emotional or practical support.

Faulkner and Davies (2005) analysed interview data collected from two independent studies investigating their respective volunteer programmes and the role that such volunteers adopted. The volunteers in these studies either supported older adult patients in hospitals (Davies et al. 2001) or patients in general practice surgeries (Faulkner 2003, 2004). The analysis found that the role of "social support" described by participants was congruent with a framework suggested by Langford et al. (1997). This framework was comprised of four parts: emotional support; informational support; appraisal support; and instrumental support, all of which were found to be important in this study's analysis. However, as this data was collected for the original studies (Davies et al. 2001 and Faulkner 2003,2004), the analysis carried out in this study was a secondary analysis. As the two original studies were based in different contexts with different participants, combining data from both studies and analysing it as one generalises the data and may render the results hard to generalise to a wider population.

Hotchkiss, Unruh and Fottler (2014) carried out a comprehensive literature review of literature on volunteerism, the role of volunteers, benefits of the role and how this can be measured. Roles of volunteers were found to be wide ranging including assisting both clinical and non- clinical staff through participation in fundraising, administration duties, frontline support to patients, and formal roles such as assuming the role of a board member. The review reported that the use of volunteers can be significantly financially beneficial for hospitals and may have a positive impact on their profit margins, and quality indicators such as patient satisfaction. However, this review expressed a focus on under researched areas of volunteering and so did not include literature on the motivations of volunteers.

What is the motivation to volunteer?

Whilst we can see the importance of volunteers from a societal perspective, the question still remains as to why individuals volunteer.

The concept of altruism has been defined in the literature as an 'intentional and voluntary act performed to benefit another person as the primary motivation and either without a conscious expectation of reward (altruistic approach) or with the conscious or unconscious expectation of reward (pseudo-altruistic approach)' (Feigin, Owens, & Goodyear-Smith, 2014, p.1). A field in which altruism is widely researched is within the literature around organ donation, an act which is often thought of as entirely altruistic. Research within this area shows us that those higher in altruism and empathic concern are more likely to indicate a willingness to donate (Cohen & Hoffner, 2013; Morgan & Miller, 2002). Perhaps even more demonstrative of altruism is the notion of unspecified kidney donation, in which a healthy person donates an organ to an unknown recipient. Despite complications being rare in such a procedure, when they do occur it can be fatal. In a study investigating the experience of such donors, two major themes were identified 'uneasy negotiations with others' and 'connected to others'. The first theme highlighted the challenges such individuals faced when discussing their decision to donate with their loved ones. The latter theme identifies the reward gained from donating, and perhaps suggesting at the motivation for such an act; a sense of being connected to somebody (Clarke, Mitchell & Abraham, 2014).

However, the literature around altruism is complex with many different definitions, and complications around whether or not the concept of 'true altruism' exists. The literature contains many different theoretical positions, with little agreement on the motivations behind such seemingly altruistic acts (Feigin, Owens & Goodyear-Smith, 2014). It may be the case that altruism plays a key part in the motivation to

volunteer, whilst not being the sole explanation, leaving room for exploration of additional motivating factors.

Clary et al. (1998) proposed six functional aspects of motivation for volunteering. These consist of the role matching a person's values, gaining an increase in understanding (new learning experiences), obtaining a social aspect (do something with friends/ do something socially favoured), furthering career, protective elements (reduce guilt over being more fortunate than others—protect ego from negative features of self) and enhancement (maintaining positive affect). A measure named the Volunteers Function Inventory (VFI) was developed using the outlined hypotheses and tested on 465 volunteers across a diverse sample. All suggested functions were found and psychometric soundness was reported.

Empirical testing of this multifaceted approach included studies asking volunteers open ended questions about their motivations and assessing how closely linked the answers were with the VFI scales. Whilst all the functions outlined in the VFI were confirmed through this study, three additional motives were also identified; enjoyment, religiosity, and team building (Allison, Okun, & Dutridge, 2002).

The VFI has also been used in a range of settings, for example in use with older adults, who were both volunteers and non-volunteers. A modified version of the VFI was used, in that the career element was eliminated due to the age of the participants, and revealed results that supported the use of the VFI in such an area (Yoshioka, Brown & Ashcraft, 2007). In addition to this, web based self-reported survey data to volunteer online panellists (who primarily provide data online to marketing companies) provided further support for the use of the VFI with volunteers online (Vocino & Polonsky, 2011).

More recently, a systematic review of 48 studies assessing the VFI confirmed the previously outlined 6 factors as a comprehensive and accurate assessment of common motives in volunteers (Chacón, Gutiérrez, Sauto, Vecina & Pérez, 2017).

What might the role of volunteers be in health settings?

Volunteers in a hospital setting/ health setting

As previously mentioned, around 3 million individuals volunteer in health and social care settings within England. However, this figure is inexact, due to a surprising lack of precise figures or data (Naylor, Mundle, Weaks & Buck, 2013). In an analysis on the 2010 National Minimum dataset for social care, it was reported that almost half of the volunteers were in community care settings, and adopted an eclectic range of roles, for example care workers, counselling, support and advice, and advocacy (Hussein, 2011). Additionally, roles may include being a 'buddy' or mentor, collecting patient feedback, peer support and friendship schemes (Naylor, Mundle, Weaks & Buck, 2013).

Burbeck et al., (2013) reported figures on volunteering in a national survey of volunteer activity in palliative care services for children and young people (a total of 31 hospices/ palliative care services participated). The report outlined the median number of volunteers per service who were directly working with patients or families was 25, with some services relying completely on volunteers, such as complementary therapy and faith based support. Services that supported patients in the community had less volunteers in their service than inpatient services, and common roles of the volunteers included emotional support and participation in activities with families.

Patients in hospitals report the benefits of volunteers, such as the flexibility of their time, and the more humane aspect of somebody supporting you who is not being paid to do it (Naylor, Mundle, Weaks & Buck, 2013).

A systematic review of end of life care volunteers (including hospices and palliative care hospitals) and their experiences revealed three main themes within the literature, indicating important areas when considering the experience of volunteers (Wilson et al.,2005). The themes centred around the roles that the end of life volunteers adopted, the training they received alongside the organizational needs and outcomes with regards to the impact of volunteering on volunteers and volunteering on end of life care. Overall, studies showed that there was a need for training that was preparatory in nature, and that volunteers gained life skills from volunteering and from training programmes provided. Many also felt supported and an integral part of the organisation (Wilson et al.,2005). Despite this, the literature review described only found 18 research articles in this area, indicating a lack of literature and gap in our knowledge.

What might the role of volunteers be in paediatric oncology settings?

In a paper considering the impact of information on parental coping within one of the six main paediatric cancer treatment settings in Sweden, participants named the importance of hearing from others' lived experiences (Ringnér, Jansson & Graneheim, 2011). In addition to this, the participants reported that volunteers from the Regional Childhood Cancer Association served refreshments and were available on the ward weekly to support and offer up their own experiences when appropriate. As many of these volunteers had lived experience of their child having cancer, participants reported they valued this support greatly and discussed the value in being able to learn from others (Ringnér, Jansson & Graneheim, 2011).

Challenges of the volunteer role

Whilst there are clear benefits of working as a volunteer as proposed by the Volunteer Functions Inventory (Clary et al., 1998), volunteering, as with any occupation, does not come without its challenges.

The practicalities of a volunteer role

Merrell (2000) discussed the challenges associated with incorporating volunteer positions within a larger organisation. The study highlighted that volunteers within formal organisations may experience role ambiguity due to job roles not always being clearly defined, and differentiated from paid staff roles. In a national survey of volunteering, it was reported that on average only 17% of volunteers have their job description in writing (Smith, 1998). In Merrell's study, there was uncertainty over general volunteering etiquette such as giving advice or personal disclosure, with some individuals clearly stating this should not be done, and others discussing times they have undertaken either of these. It is widely recognised that at present there is a significant need for training in psycho-oncology for volunteers working in the field of cancer care (Pourtau, Taleb, De Oliveira, Sagatchian & Ferrand-Bechmann, 2016).

Impact of having lived experience

A significant number of volunteers have lived experience of their own (Aguirre & Bolton, 2013; Pourtau et al., 2016). Indeed, as suggested by the Volunteer Function Inventory (Clary et al., 1998) such lived experience may be the driving factor for seeking the role, and may provide therapeutic benefits for the individual themselves. Volunteers with lived experience can be of great importance to those they support. For example, facilitating hope, and reducing feelings of being alone and isolated (Kornhaber,Wilson, Abu-Qamar, McLean & Vandervord, 2015). Pourtau et al., (2016) interviewed 74 volunteers and 25 employees supporting current patients in a variety of

cancer associations in France, along with focus groups and on site observations. The study found that many of the volunteers had lived experience of their own, and such lived experience afforded them credibility when supporting current patients. This research also suggested that volunteers with lived experience working in such a role risk viewing the patient's experience through their own eyes rather than through the patient's eyes (Pourtau et al.,2016). It should be noted however that this study was carried out in the French healthcare system which cannot be directly compared to the English NHS. Additionally, perhaps due to the larger sample size, this paper did not provide much information on the participants themselves which would have helped to situate the sample providing appropriate quality checks as suggested by Elliott, Fischer and Rennie (1999). Nor did they outline the specific qualitative analysis method used, leaving the rigour of this study difficult to assess. Research on hospice volunteers outlines how some volunteers cope with the emotional impact of the work through both problem focused coping (such as seeking advice from others) and emotion focused coping (such as talking to others, pet therapy, avoidance and religious beliefs) (Brown, 2011). However, there seems to be little literature on how volunteers with such lived experience manage the emotional impact of the work and any memories this may bring up for them.

Compassion fatigue, compassion satisfaction and burnout

Showalter (2010) discusses the necessity for a professional to be present and be alongside their client. Whilst empathic relationships have been shown to harness motivation, emotional contagion and empathy that is associated with genuine relationships has been found to increase the likelihood of burnout and emotional distress (Omdahl & O'Donnell, 1999; van Mol, Kompanje, Benoit, Bakker & Nijkamp, 2015).

The terms 'burnout', 'compassion fatigue' and 'secondary traumatic stress' are sometimes used interchangeably, although, despite this, they are defined in the literature as separate phenomena. 'Burnout' is defined as a source of stress staff experience resulting from an incongruence between demands of the role and accessible resources (Weintraub, Geithner, Stroustrup, & Waldman, 2016). Not only is burnout distressing and difficult for the individual, but high levels of burnout within an organisation leads to high levels of turnover. High levels of turnover within an organisation are costly, and reduce the effectiveness and cohesiveness of a team (Conrad & Kellar-Guenther, 2006). 'Compassion Fatigue' is certainly a component of burnout, although it differs in that it can be brought about through one exposure to trauma as opposed to a more cumulative effect (Conrad & Kellar-Guenther, 2006). Compassion fatigue is specifically defined as distress that caregivers experience due to direct contact with service users who are suffering (Weintraub, Geithner, Stroustrup, & Waldman, 2016). Finally a similar yet distinct term 'Secondary traumatic stress' is defined as ''the natural and consequent behaviors and emotions resulting from knowing about a traumatizing event experienced by a significant other—the stress resulting from helping or wanting to help a traumatized or suffering person'' (Figley, 1995, p.7) .

Whilst many papers distinguish between these different terms, research in the area has not routinely distinguished between burnout, compassion fatigue or secondary traumatic stress. Therefore, whilst there is an abundance of literature written about this area, many of the different terms have been used interchangeably, leading to inconsistency (Najjar, Davis, Beck-Coon, & Doebbeling, 2009; Sinclair et al., 2016; van Mol, Kompanje, Benoit, Bakker, & Nijkamp, 2015).

Despite the differences between compassion fatigue, burnout and secondary traumatisation, the common factor within all of these is empathy (Najjar, Davis, Beck-

Coon, & Doebbeling, 2009). Empathy is one's ability to experience and embody another individuals current state and viewpoint at any specific time point (Wilson & Lindy, 1994). Najjar, Davis, Beck-Coon & Doebbeling (2009) highlight the risk of this in relationships in which there are similarities in lived experience between the two parties and there is a potential for identification, for example in volunteers with lived experience.

However, Weintraub, Geithner, Stroustrup & Waldman (2016) highlighted compassion satisfaction as one of the more rewarding aspects of the role, and refers to a fulfilment and self-gratification that one obtains when helping others.

Compassion fatigue and compassion satisfaction can be measured through the use of the 'Compassion Satisfaction and Fatigue Test' (Stamm, 2002). Originally developed to purely measure compassion fatigue in 1995, the measure now also assesses whether an individual experiences any compassion satisfaction (Stamm, 2002).

In a study investigating the prevalence of compassion fatigue and burnout in child protection staff, compassion fatigue, burnout and compassion satisfaction were all found to be predictive of each other (Conrad & Kellar-Guenther, 2006). In addition to this, it is known that individuals who have high levels of compassion satisfaction are found to have lower levels of compassion fatigue and burnout, perhaps indicating the presence of compassion satisfaction as a protective factor (Conrad & Kellar-Guenther, 2006). Sorenson, Bolick, Wright, & Hamilton (2016) carried out an integrative review of all studies on compassion fatigue in healthcare providers between 2005 and 2015. This review found compassion fatigue and related concepts to be prevalent across a wide range of healthcare professionals such as inpatient nurses, genetics workers, midwives and child protection workers. However, it should be noted that this review outlined the difficulty in conceptualising compassion fatigue and due to the literature

often interchangeably using burnout, compassion fatigue, compassion stress and secondary traumatic stress, they decided to group all terms under the overarching name of "compassion fatigue and related concepts". Because of this difficulty conceptualising the different terms and a lack of clarity within the literature around these terms, the validity of the integrative review may be compromised.

A similar relationship between compassion satisfaction and compassion fatigue has also been found within research with traumatic bereavement volunteers (Thieleman & Cacciatore, 2014).

Potter et al., (2010) define 'compassion fatigue' as the trauma experienced by a volunteer as a direct result of supporting others. Often this is a relational source of stress, and is common in oncology nurses (Sorenson, Bolick, Wright, & Hamilton, 2016). This is perhaps not surprising due to the emotionally challenging nature of working in oncology. For example many roles in these departments involve exposure to feelings of loss, a high chance of grief, and a role of supporting and consoling a patient's family (Simon, Pryce, Roff, & Klemmack, 2006).

Whilst it is clear that compassion fatigue and burnout are common among healthcare staff, it is important to consider the variability within individuals' responses to different experiences. Therapist, staff and volunteer's reactions to their service user's stories may differ depending on their own personal and professional experience (Cerney, 1995; Pourtau et al.,2016). It has been reported that professionals in a helping profession who have their own personal experiences of trauma may have an increased risk of developing compassion fatigue (Adams, Boscarino, & Figley, 2006). Whilst volunteers may spend less time with clients who have been exposed to trauma, research indicates there is still a risk of compassion fatigue (Baird & Jenkins, 2003). Lydon (2009) discussed the importance of considering compassion fatigue in the voluntary

sector due to an inevitable lower level of training in this population. Undoubtedly, the nature of being a volunteer creates a unique dynamic of pressures and protective factors. For example, on the one hand, volunteers may not have the same level of training or continuous supervision. Conversely, the voluntary aspect of the role also indicates the individual may not be subject to the same financial or professional pressures of the role, and may work fewer hours, resulting in less exposure to any trauma (Lydon, 2009). A recent study reported low levels of burnout in Samaritan volunteers, although burnout was more prominent in the younger volunteers who adopted avoidant coping styles (Roche & Ogden, 2017).

Burnout and compassion fatigue is a risk for both paid and unpaid staff and may be of particular importance in an emotionally challenging area such as paediatric oncology (Liakopoulou et al., 2008 ; Mukherjee, Beresford, Glaser & Sloper, 2009; Roth et al.,2011). On the contrary however, there is also literature reporting that whilst oncology staff may be expected to experience increased levels of burnout due to the emotional aspects of the role, this is not demonstrated in many reported statistics. For example, in a national study of 7000 physicians, paediatric oncologists had lower burnout rates than other paediatric specialists (Shanafelt & Dyrbye, 2012). Although it should be noted these are US statistics and so do not directly compare to the British healthcare system. As discussed above, the impact of compassion fatigue, burnout or secondary traumatisation may differ depending on role and personal experience. Therefore, such presentations may be especially prominent within the voluntary sector, and may be of interest particularly with cancer charities.

Candlelighters charity

Candlelighters is a Yorkshire based organisation, which aims to support anybody affected by childhood cancer. This extends from the individual themselves to

immediate family, extended family, and close friends. Support is provided within the hospital on the wards, in their family support centre, or out in the community. Such support may take the form of wellbeing treatments, friendly conversations with team members, and the provision of fun activities for children. In addition, the charity also provide a space for support groups to be run by members, should they wish to set them up (Candlelighters, 2018). The support offered by Candlelighters can often be offered much longer term than in the NHS. Indeed, as previously mentioned, some individuals receive support from the charity for years following treatment. Volunteers play a huge role in supporting the work that Candlelighters do, many having lived experience of their own.

In summary, it is clear that serious childhood illness has a significant impact on the child, the family and their wider system. How severe the impact of the illness is on the family's wellbeing and day to day functioning, can be mediated through supportive relationships within the family, friends, healthcare staff or through contact with third sector organisations. Volunteers play a vital role in such charitable organisations, however little is known about their experience and contribution in the area of childhood illness.

This study aims to investigate the experiences of volunteers in this area by answering the following research question:

"What are the experiences of volunteers working in a childhood cancer charity?"

Chapter 2: Method

Method

The next section will outline the rationale for the choice of methodology, whilst also providing information on the research design, choice of analysis and analysis procedures. Finally, this section will discuss the data collection protocol, including quality checks undertaken.

Design

Sampling

Purposeful sampling was utilised in this research project, to ensure the inclusion criteria was met.

Smith et al.(2009) discuss the contextual nature of ideal sample size for studies and advise a study by study basis, although they do recommend around four to ten participants for professional doctorates. IPA has an in-depth nature which results from interpretation and detailed analysis, and the focus on idiography and the individual's voice. Due to these features, 6-10 participants should allow for a thorough exploration of the volunteer's experiences, whilst not involving unnecessary interviews and impinging on time allocated for comprehensive analysis.

In addition to this, following discussions with Candlelighters, 6-10 was the number of individuals that Candlelighters as an organisation felt comfortable with recruiting for the purpose of this research. With this in mind, the study aimed to recruit 6-10 participants.

Inclusion Criteria

The inclusion criterion was to be holding a volunteering role or have held a volunteering role with the Candlelighters charity.

There were no exclusion criteria.

Recruitment

The recruitment process began October 2017. The participants were identified by the Candlelighters charity. Candlelighters identified potential recruits for the project from their pool of volunteers.

A member of the Candlelighters team approached volunteers via an email including the participant information sheet (Appendix A), explaining the research project and making participants aware of the research and the drop in session. I held a drop in session one afternoon at the Candlelighters base which allowed an opportunity for individuals to find out further information about the research without signing up to it. Following this, Candlelighters invited me to their volunteers meeting to provide further opportunity for potential participants to enquire about the research, again with no obligation to take part.

If respondents replied to Candlelighters and gave permission for their contact details to be sent to me, I then made contact with the participants directly. Email correspondence and phone calls continued between myself and the participants to arrange a suitable date and time for interviews.

To further improve chances of adequate recruitment to the study and better understand the organisation's day to day running, I attended an induction day with the Candlelighters organisation. The induction provided me with information about Candlelighters and the work they do. This also allowed me to meet members of the team and added to my relationship with the organisation as a whole.

Ethical Issues

Overview of Ethical issues

Full ethical approval (SomREC/16/143 Appendix B) was obtained from the School of Medicine Research Ethics Committee at the University of Leeds on the 11th August 2017. It became clear that many participants would prefer not to attend for interview at the Candlelighters base in Leeds, as originally planned, but were willing to take part in telephone interviews. To satisfy this request, an ethical amendment was resubmitted. Approval was granted for this on 5th December 2017.

Anonymity and Confidentiality

An information sheet outlining the research and interview process was given to the participant and explained verbally to ensure informed consent (Appendix C) was obtained. The information sheet and consent form were included in the initial email that Candlelighters sent out to the volunteers to introduce the research. Participants who had a face to face interview were also given another copy at the beginning of the interview, and signed the consent form then. Those who had a telephone interview were emailed another copy of the information sheet and consent form, and they typed their name into the consent form and returned it via email. As outlined in the information sheet, all information given by the participants was confidential. It was explained that the only exception to this would have been if a participant divulged any information with regards to being at serious risk of being harmed or harming others. In this circumstance, I would have had to inform Candlelighters and ensure that they followed their safeguarding protocol, as already discussed and agreed with Candlelighters. The participant was made aware that the information obtained would be written up into a report that would be submitted as part of a doctorate degree, and would be uploaded onto an online thesis repository. The information sheet also outlined that, in the case of publication, all

material would be anonymised and where excerpts from interviews were used as quotations, identifying details would be omitted, and a pseudonym of the participant's choice used. It was made clear that due to direct quotes being used verbatim within the report, complete anonymity could not be guaranteed, and there was always a small chance someone may have been able to identify them.

Prior to the interviews the participant was also reminded of their responsibility to protect confidentiality of anyone they have worked with, and to ensure they do not give any identifiable information to any experiences they may discuss. As I transcribed the interviews myself, in the event that a small amount of identifiable data was spoken about within the interview, I anonymised such details at the transcript stage.

Participant distress

Whilst volunteering itself may not always be regarded as a sensitive issue, the charity for which the volunteers work for is a childhood cancer charity, an area which may be particularly emotionally challenging. The volunteering may bring about difficult conversations with service users, and in addition to this, many of the volunteers who work for the charity have lived experience. Taking this into account, I was mindful that the interview process may bring up difficult emotions and memories for the participant, despite the interview not asking directly about the participant's own lived experience. At the beginning of the interview, the participant was also encouraged to look after themselves in whatever way they needed to, for example encouraging them to utilize their support network. In addition to this, the participant was also encouraged to stop for a break whenever they wished and to stop the interview early, should they have felt this necessary. Following the interview time was allowed for a debrief, and participants were signposted to support, if this was needed.

Data Protection

The participant information sheet informed participants that any audio recordings taken from the interviews would be transferred straight from a dictaphone to a file stored on the researcher's password protected personal area on the University server. This would be accessed by the researcher via the University's Desktop Anywhere service. Once stored on this personal drive, the transcripts were deleted from the USB stick.

I transcribed all the interviews myself, in order to fully immerse myself in the data and to ensure confidentiality of the participants was protected. The participant was informed that the transcripts would be kept for three years before being destroyed.

Data Collection

Qualitative data

Qualitative data allows for exploration of meaning, and allows for the researcher to present how participants make sense of the world and their experiences. Qualitative methods have been reported to allow the researcher to include the depth of participant's experiences, and to capture complex and dynamic relationships (Sofaer, 1999). Sofaer (1999) suggested that qualitative data is widely recognised as being particularly useful for research in healthcare services, in which the environment and interactions tend to be complex and at times challenging. Similarly, it may be that the same events or concepts are related to and recounted in different ways by different people. Qualitative data allows for an exploration of such interpretations and can contribute to policy making, implementation and prediction of consequences (Sofaer, 1999). As this research aimed to understand participants' experience of working as a volunteer in a cancer charity, the onus is on being able to capture someones' experience, as opposed to isolating a cause-effect relationship. The use of quantitative data techniques would require variables to be

defined before the researcher begins the research, therefore being dictated by the researcher's meanings instead of the participants (Willig, 2001). For these reasons, qualitative research methods were chosen for this study to enable the participant's voice to be heard, and the experience to be told from the participant's viewpoint.

The use of interviews allowed for an exploration of volunteers experiences in a rich and meaningful way. Interviews can also be useful in health settings as they can facilitate the investigation into interpersonal aspects of care that are of particular interest in the current climate (Pope, van Royan & Baker, 2002;Sofaer 1999).

The use of interviews may be criticised in that they can be time consuming and it may take longer to develop themes between individuals. An alternative method such as focus groups would be more time efficient, enabling a larger proportion of people to be interviewed at the same time (Grbich, 1998). Themes may be more apparent in a focus group more quickly, and it may be easier to identify culture and group norms within the staff team (Kitzinger, 1995). However, whilst the benefits of focus groups are apparent, consequences arise with regards to the public nature of the method. It may be that many of the representations obtained of individuals' experiences are skewed towards a more 'public' idea than 'private' ideas of the research question, due to the fear of others' appraisals within the focus group (Grbich, 1998). Many of the volunteers who were approached to take part in this study were newly recruited and so fear of others' social appraisals may be relevant. To reduce this factor, individual interviews were employed to obtain a more accurate representation.

Considerations have been made for alternative data collection methods such as offering telephone interviews. McCracken (1988) states how time consuming, intrusive and emotionally exhausting interviews can be for participants. Collecting qualitative data through telephone interviews may be more convenient for participants, and

research indicates an increase in participant confidence and perception of anonymity, potentially leading to more honest and accurate portrayal of individual's experiences (Greenfield, Midanik & Rogers, 2000). However, it must be noted that telephone communication diminishes the information gained from informal, non-verbal communications and it may be more difficult to establish a good rapport with the participant (Creswell, 1998).

For this study potential participants were from a wide geographical base, and balancing the above information it was decided to offer, interviews either at the Candlelighters base or over the phone, at the participant's preference. This was done with the aim of increasing accessibility for those who wanted to take part in the interviews, and ensuring familiarity and ease in the environment.

The researcher and the project supervisors developed an interview topic guide (Appendix D). A topic guide was used as opposed to a semi structured interview to allow the participant more flexibility in what they wanted to talk about, and allow the 'lived experience' to be told as opposed to pre-determined ideas (Alase, 2017). Open questions were utilised to enable the participant to fully describe their experience without feeling restricted (Alase, 2017). The topic guide was tested on two individuals who had experience of volunteering, albeit not within a children's cancer charity. One of the individuals was a psychologist in clinical training, the other was a friend of the researcher working in a non-related field. There were no major changes to be made to the topic guide from this process. These data were not included in the final sample.

Interview Process

Participants were given up to an hour for their interview, most lasting between 27 and 45 minutes. All interviews were audio recorded to enable the researcher to be fully involved with the interview process. A reflective diary was kept by the researcher,

and filled out immediately post interview, and reflections were discussed with project supervisors and utilised within the analysis. The researcher transcribed all the interviews to help with familiarisation with the data. Transcription conventions outlined for IPA (Smith, 2008) were followed, in that all the words spoken were transcribed, including laughs, illegible words and significant pauses (…) .

Data Analysis

Alternative methods considered

Grounded theory

Grounded Theory is a common method for qualitative research and hence was also thought about when considering the most appropriate methodology for this research project.   Grounded Theory provides a method for data analysis in which the researcher can follow a set of guidelines on identifying categories, making links between them and establishing relationships within the data. This allows for the researcher to understand and present the data within the context of a framework, providing theory (Willig, 2001).   As the aim of grounded theory is to produce a theory driven from the data, a larger sample size is required with the intention of explaining a phenomenon at a broad enough level to account for many experiences (Charmaz, 2008). The origins of grounded theory are also in sociology, which can be observed in grounded theory's leaning towards social processes (Charmaz, 2008). Taking this into account, and the aim of this research study being to investigate individual participants' experiences of volunteering within a specific charity, grounded theory may not be best suited for such a study.

Discourse Analysis

A discourse analysis approach was considered for this study. Discourse analysis is a qualitative method derived from linguistic studies and those using the approach reason that it is not the words themselves that hold the meaning we obtain from language, but the collective and mutual use of the words that creates meaning (Starks & Brown Trinidad, 2007). The purpose of this approach is to understand how individuals are using language in any given phenomenom (Starks & Brown Trinidad, 2007). People use language to communicate, obtain a mutual understanding and perspective, and create a desired emotion in another (Gee, 2014). In carrying out discourse analysis, researchers use evidence from transcripts of interviews to ascertain how participants are using their language to obtain an objective (Starks & Brown Trinidad, 2007).

Whilst this study recognises the importance of shared language in capturing the essence of a shared phenomena, discursive studies view language as an entity that affects perception and reality. The scope of this study is more aligned with understanding the meaning that somebody holds from their lived experience, and therefore values language as an expressive tool to communicate the core of their experience. A methodological approach that sits more closely to this understanding of language is Interpretative Phenomenological Analysis, which as a methodological approach is better suited to meet the aims of this study.

Interpretative Phenomenological Analysis

The analysis method which will be used is Interpretive Phenomenological Analysis (IPA). Within IPA the researcher tries to enable the participants to have a voice and endeavours to make sense of the participants' transcripts. Methodologically, IPA studies generally consist of semi structured interviews, focus groups or use of diaries. The data collected is then analysed in a highly detailed manner and the

researcher attempts to pull out patterns of meaning which can then be reported in a thematic way (Larkin, Watts & Clifton, 2006). The use of interpretative phenomenological analysis has been reported as being an appropriate method for exploring how individuals understand their personal and social world (Smith & Osborn, 2008).Specifically, it is how the individual experiences the phenomenon and how they understand it, as opposed to breaking down and reporting on the phenomenon itself (Eatough & Smith, 2017).

There are many parts to IPA, however the main concept of the approach places it within the family of 'phenomenological' approaches. Such a notion indicates the method is concerned with obtaining the participant's lived experience of an event or phenomena and attempts to report the individual's personal perception of the topic (Smith & Osborne, 2008). Another defining aspect of IPA research is that it explicitly considers the 'interpretation' of an experience. Interpretation can be thought about in many ways, one part of this being 'the hermeneutic circle'. This concept allows researchers to engage with their data in a dynamic, non-linear manner, in which the data is thought of as individual parts on their own as well as part of a wider context. As IPA focuses on sense making of an experience, it also incorporates the idea of a double hermeneutic. This concept involves the analysis comprising of a combination of the participants' understanding and meaning of the topic area, and the researcher's own understanding and sense making of the participants' experience (Eatough & Smith, 2017).

To fully accept and reflect on the impact of the researcher's hermeneutic, IPA accepts the researcher's biases and assumptions, and encourages reflection upon these to better understand how they shape understanding of the data.

More specifically, the ability of IPA to acknowledge and utilise subjective knowledge for psychological understanding aids a more personal account of an individual's experiences (Eatough & Smith, 2017).

The majority of research in IPA is in health psychology and would be appropriate as it allows for a detailed analysis of a small number of participant's experiences (Brocki & Wearden, 2006). As already mentioned, Smith, Flowers and Larkin (2009) advise between four to ten participants for professional doctorates. This would mean that high levels of recruitment would not be necessary, which is useful in a setting in which some voluntary roles have only been newly recruited and filled. In addition to this, the method of interpretative analysis allows the relation of the accounts to a wider context, enabling the context of the third sector and social influences to be considered (Larkin, Watts, & Clifton, 2006).

Validity and Reliability

It is important to note that whilst IPA embraces the researcher's individual views and subjectivity, some may argue that validity and reliability may be compromised (Brocki & Wearden, 2006). The concept of reflexivity is one which affects all qualitative research. In IPA this is managed through encouraging the researcher to notice their own preconceptions and biases that they may bring to the analysis, therefore making such assumptions explicit and transparent (Brocki & Wearden, 2006).

Larkin and Thompson (2012) argue that some methods of improving validity may not be appropriate for IPA studies such as 'member checking', in which the researcher goes back to the participant to check their understanding of the interview. Because of researcher interpretation, the effect of interviewing multiple participants and anonymising their transcripts may render member checking to be disadvantageous.

Larkin and Thompson (2012) do however identify different ways to ensure credibility and quality to increase validity and reliability of the study. Amongst their suggestions they discussed balancing the focus of the research in a detailed manner though an idiographic approach, with noting shared aspects of interviews. Suitable utilisation of triangulation methods such as credibility checking with supervisors and peers was also suggested. Finally, Larkin and Thompson suggested that providing an adequate level of context for each of the quotes allows the reader some insight into the participant's world and the influences around them. I have outlined below the measures I took.

Quality Checks

To ensure credibility of this study, I engaged in a number of processes. Firstly, I read each transcript and re-read them multiple times. This practice was to ensure I immersed myself in the data fully, brought to mind the atmosphere and experience of the interview and established my perspective.

Secondly, immediately following the initial interview, I had a supervision meeting with my project supervisors to reflect on the quality of the interview, make any changes to the topic guide to ensure its effectiveness at eliciting rich data, and note any initial reflections.

Throughout the following interviews, I shared my themes and selected anonymised extracts with my research supervisors to check whether or not my account of the interpretations was credible (Elliott, Fischer &Rennie, 1999; Larkin & Thompson, 2012).

Throughout the research process, I kept a reflective journal. I was rigorous in ensuring following each interview I immediately wrote in the journal to capture any initial thoughts and biases. Pre- data collection I participated in a reflective interview, carried out by a fellow psychologist in clinical training, in order to understand my

position, biases and potential influences on how I may interpret the data (Elliott, Fischer &Rennie, 1999).

Reflexive interview reflections

Through the interview, I recognised that over the time I had been liaising with Candlelighters for this research, I built a good relationship with them and held a positive view of them as an organisation. This may have posed a potential bias if not acknowledged, as naturally having a good relationship with the charity I may be biased to in some way to look for more positive comments from participants. By acknowledging this and making it explicit, I was able to be mindful of any pull to achieve a positive outcome, modify my interview technique and note any bias in analysis.

Additionally, I acknowledged my own personal experience of cancer affecting family members, friends and colleagues. On the one hand, these experiences allowed a connection to the data and to the research area. However, my experiences are very different to those of the participants, and I was mindful that such experiences could also lend themselves to the development of assumptions. By acknowledging and discussing such experiences prior to interviews, I was able to ensure that whilst it was inevitable that my own experiences would shape the way in which I interpret the interviews, I could be mindful of this, and did not present the data as purely objective.

Analysis stages

To analyse the transcripts I used guidelines published by Smith et al. (2009):

Stages:

Stage one:

1) Immediately following each of the interviews I wrote in my reflective journal to capture my initial responses to the participant and to ascertain my sense making of their story.

2) I listened to the audio recording of the interview, noting down throughout my thoughts, significant ways in which the participant told aspects of their story and use of language, and absences.

3) I showed my supervisors copies of the transcripts. We reflected on and discussed interview technique, and ways in which the topic guide and my questioning may be adapted to ensure rich data.

4) Following transcription of the interview, I re-listened to the audio recording to ensure the transcription was correct.

Stage two:

1) I re-read the transcript using the margin to note down and capture codes that emerged line by line. Each comment noted was supported by a quote.

Stage three:

1) I listed all the themes that I identified in stage two and tried to work out their natural relation to one another through clustering. Such a process was done by clustering those that shared similar meanings, experiences, or had a hierarchical relationship to one another. This was carried out by printing out the annotated transcripts and cutting them up and grouping them together.

Stage four:

1) I created a list summarising all the main themes and sub-themes that add information to the research question. The list outlined the theme and a brief keyword.

Stages one to four were repeated for each interview. It is important to note that each transcript was analysed in this way individually before moving on to the next one. This was advised by Smith et al. (2009) and ensures that the latter interviews were not analysed differently due to previous interviews, and the experience of each person is honoured as a unique and individual experience.

Stage five:

1) Once all the interviews had been analysed individually, I compared the themes that specifically related to the phenomena of interest across the collection of cases, noting similarities and differences across each of the interviews.   I then grouped and selected the themes into superordinate and subordinate themes. The superordinate themes were those in which there was a commonality across participants, and the theme aimed to capture the essence of this shared experience. The sub-ordinate themes were more specific aspects of the superordinate themes and included the array of experiences that were found within the interviews.

An example of the development of superordinate and sub themes from the initial coding can be seen in Appendix E and Appendix F.

Chapter 3: Results

In this chapter, I will provide demographic details for the participants (See Table 1) and outline pen portraits to give the reader a broader sense of the volunteers and the context within which they present their experiences of volunteering. I will then outline the results of the analysis through describing emergent themes and evidencing these with direct quotes from the transcripts.

Table 1. Demographics details of participants

Participant Number & Pseudonym	Age range	Interview Type	Time volunteering (Candlelighters)	Volunteering elsewhere simultaneously	Personal experience (cancer)	Personal experience (Candlelighters)
1 - Jamie	30-40	Telephone	6 years	Yes	Yes	Yes
2 - Alex	40-50	Face to Face	4 years	No	Yes	Yes
3- Charlie	Data unavailable	Telephone	9 months	Yes	Yes	No
4- Jordan	20-30	Telephone	3 months	No	No	No
5 - Ali	50-60	Telephone	1 year	No	Yes	No
6 - Ashley	40-50	Face to Face	3 months	Yes	No	No
7 - Francis	30-40	Telephone	7 months	No	Yes	Yes

Pen Portraits

The pen portraits provided aim to enable the reader to understand the context within which an individual's experiences have arisen. However, it should be noted that due to the participants being recruited from a small group of people who may be able to identify each other, some detail has not been included to best protect the volunteers' confidentiality. Additionally, gender neutral pseudonyms and pronouns have been

utilised for this purpose. I will also be providing reflections about my experience of the interviews with each participant.

1. *Jamie*

Jamie was the first person that I interviewed, and they stated they wanted to be able to help out Candlelighters in whatever way they could, hence their response to take part in these interviews. They have had personal experience of Candlelighters through support when their own child was ill with cancer. Jamie spoke about having good friends, and sounded as if they had a good support network, talking about a particularly close relationship with one of their colleagues at Candlelighters.

As this was my first interview I was particularly nervous, and this may have been exacerbated by it being a phone interview, and the first time I have carried out a phone interview that was not a pilot. I found phone interviews particularly restricting in being able to convey empathy and show I was listening, whilst not interrupting or placing myself in a clinical role. Jamie however sounded particularly relaxed on the phone, and engaged with the interview in a relaxed and informal way, which hopefully indicated the experiences discussed were of importance to Jamie, and not overly dictated by the interview schedule. When talking to Jamie, I was struck by their sense of connection to Candlelighters. They spoke about how the charity had become a way of life for them and their family, and that they would do almost anything to help them out.

2. *Alex*

Alex has been volunteering for Candlelighters for four years. They are a bereaved parent, who has previously been a recipient of Candlelighters' services.

Whilst the interview with Alex was one of the shortest interviews I conducted, it felt incredibly rich and detailed. I experienced Alex to know their own boundaries, and to

share what felt comfortable to share. Alex had a real sense of humility whilst talking about personal achievements and work with Candlelighters, whilst at the same time exuding an enormous sense of pride. I felt comfortable in the interview, perhaps influenced by the face to face nature of the interview, which allowed me to convey empathy more naturally and connect with Alex's story. Throughout the interview it seemed important to Alex to express the process of change whilst volunteering for Candlelighters; both in confidence and skill base, but also more fundamentally within themself.

3. Charlie

Charlie has been volunteering for Candlelighters for just under a year. At present, they have paused their work with Candlelighters , although reports this to only be a temporary break. Charlie has not had personal experience of Candlelighters, however did talk about similar experiences that were personally and emotionally challenging and how this linked to a desire to volunteer for Candlelighters. Charlie also described many of the activities much of their time was dedicated to, such as writing blogs and books, demonstrating a more holistic interest in such matters.

At times throughout the interview with Charlie, I got a sense that they perhaps did not think the questions applied to them, or that they were not expecting such personal questions. At points, I felt uneasy asking prompt questions to obtain more detail from their answers, and felt that perhaps Charlie felt I was not understanding the answers they gave. Charlie provided lots of detail around their values and what they stand for in order to try and help my understanding of their experiences. Their passion for working with those who may be more vulnerable felt incredibly important to them. They were able to articulately describe their beliefs around self care and managing difficult emotions associated with any job role.

4. *Jordan*

Jordan currently works part time, attends an educational course and volunteers for Candlelighters. They have volunteered there for around 3 months at the time of interview.

Jordan's interview was also a relatively short interview and at times I found it difficult to elicit experiences and their sense making as opposed to more concrete answers. This may be reflective of the length of time with which they have been volunteering for, and therefore the experience they have to reflect on. This interview allowed me to explore expectations of the role and motivations for volunteering from a more recent and current perspective. In addition to this, Jordan did not report having any lived experience of cancer themselves, and so offered a new perspective on volunteering with this charity.

The professionalism of the charity and the role seemed important to Jordan. I got the sense that they respected this about this particular charity, perhaps challenging some of their preconceptions about volunteering as a whole, and the associations made with being a volunteer, such as it being an easy role to acquire.

5. *Ali*

Ali volunteers for Candlelighters in a range of roles following the loss of their daughter. Ali struck me as a very passionate individual who felt they gained a lot from their involvement with Candlelighters. They seemed very keen to do the interview, and despite the process of obtaining and signing the consent form not being as straight forward as we had hoped for, they persisted and did take part in the interview. At times throughout the interview, Ali seemed to find it hard to articulate their experiences, especially when I asked for more detail on certain comments they made. Potentially this was because I was asking for more detail than they had originally expected to give.

Because of this, I wondered if some of her experience and meaning around their experiences was not captured as well as I had hoped. This being said, Ali managed to convey a rich account specifically of how much the volunteering role at Candlelighters means to them and the sense that the role fulfils a somewhat restorative purpose in helping them feel "more like [his/her] old self".

6. Ashley

Ashley has only recently begun volunteering for Candlelighters. They described much of their motivation to volunteer being around doing something productive with their time, in a charity whose aims they agree with. They noted that they did not pick Candlelighters specifically, and that this was one of many possibilities they had considered, however they did speak highly of the charity and of their experience with them. Ashley's story therefore provided an alternative narrative to the majority of the other interviews around the process of selection when choosing the charity to volunteer for. This interview was carried out face to face; I was unwell when conducting this interview, and upon reflection perhaps this may have impacted upon my ability to follow up on specific aspects that Ashley may have referred to. In addition to this, Ashley expressed confusion over the aims of the research, and perhaps held a view of psychology that studies can often deceive participants, and I wonder if this was something Ashley was concerned about happening in this interview. This perhaps led to Ashley giving less detailed answers, and focusing more on the purpose of the question, as opposed to expressing their own experience in their answers. Despite this, Ashley was able to portray an experience of volunteering in which it was the act of volunteering and not the specific charity itself that was the driver for participating in the role.

7. Francis

Francis has volunteered for Candlelighters for 7 months and supports the charity in an outreach capacity. I carried out a phone interview with Francis at their request and experienced them to be fairly relaxed throughout the interview. Francis has also personally experienced support from Candlelighters when their child was diagnosed with cancer.

Building positive relationships with the families they are supporting and responding to the needs of their own geographical area seemed important to Francis and they spoke about their involvement with the charity in a fairly autonomous and passionate manner. There were times when I tried to elicit the meaning and sense making that Francis derived from their experiences, and Francis answered by referring to how they support others. I wonder if this was indicative of not being used to such direct questions about their own sense making, or if this was quite typical of someone in a caregiver role, focusing their attention outwards.

Group Analysis

Description of Superordinate themes
The interpretative phenomenological analysis produced five main themes: Motivation, Identity and Roles, Coping, Community, and Family.

Overall, themes referred to the process by which participants came to volunteer with Candlelighters and what motivates them, and the subsequent influence of volunteering on the participant's sense of self and identity. Themes also covered the sense making of participants in describing their experiences using the analogy of family and a community, and their reflections on their place in this. The process of joining the organisation and developing a role was seen as fluid and one that changed over time.

Due to this process, there are many links between the themes, with some sub themes overlapping superordinate themes.

See Figure 1 for a thematic map demonstrating the overview of the resulting main themes, sub themes and the manner in which they all connect.
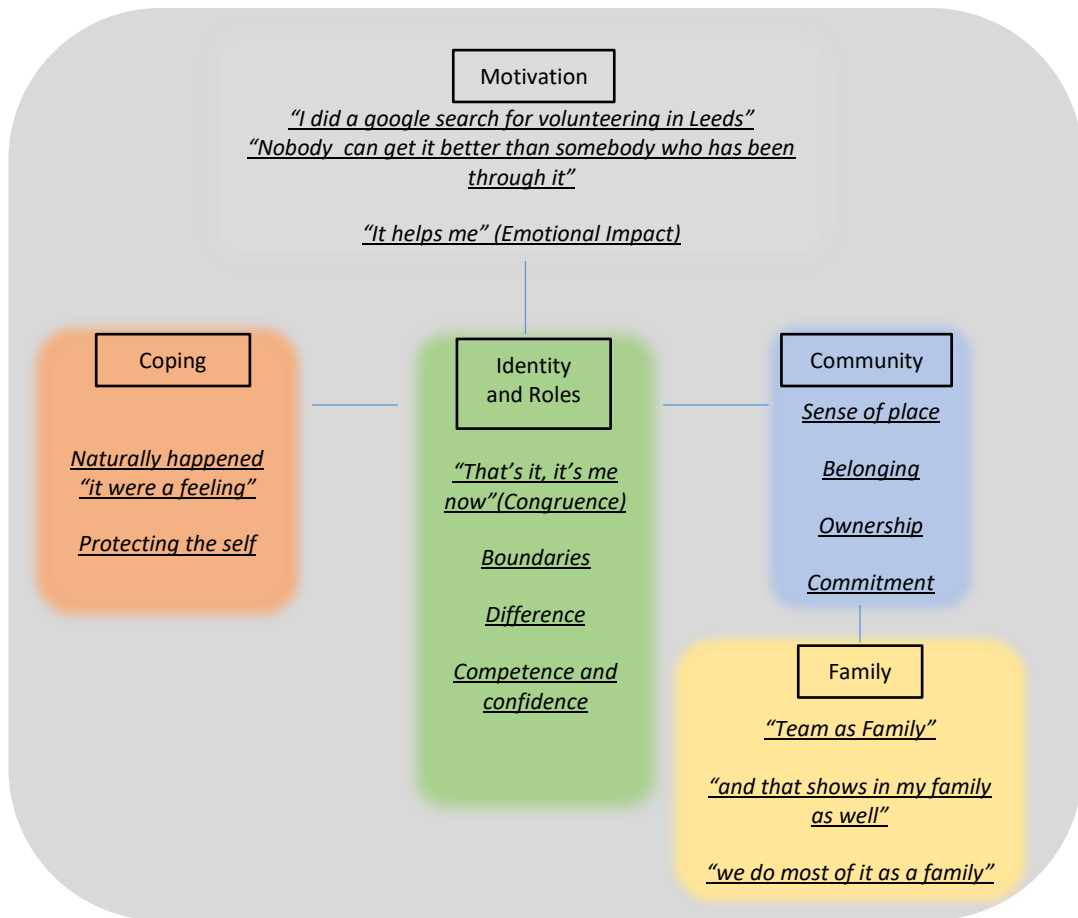
Figure 1 - Thematic map of main themes

Each theme will be described individually in detail in order to accurately capture the theme. Verbatim extracts from the participants' transcripts will be utilised to illustrate the themes in full.

Superordinate Theme: Motivation

The participants had all volunteered for a charity working in a particularly emotionally challenging area – supporting families of very ill children – and they had all considered the question of what attracted them to volunteer for that charity. Some had chosen this particular charity specifically; for others the motivation had been to volunteer for any charity and they had been drawn towards this one.

Sub Theme: "I did a google search for volunteering in Leeds"

For those whose motivation to volunteer was not specific to Candlelighters, there was a more generic sense of a desire to give to others, use their time "productively" and work for something "other than monetary gain". This aim lacked the specificity of a desire to volunteer for Candlelighters and thus the concept of volunteering seemed more abstract. This level of generality can be seen in comments made by Ashley about the process of selecting Candlelighters as the charity to work for:

Ashley: *"Erm, I have to be honest and say, it was literally I typed 'volunteering in Leeds', it came up first, I had seen it, err the charity before because err as I say it was social media or something, that a company I know was just supporting it".*

On a similar vein, participants also described simply having time to spare, and wanting to use that time for a good cause, and for something they felt was important. Here, the focus for Ashley and Charlie is not necessarily the charity itself but to feel as if their spare time is being used productively. As Charlie reports having had some personal experience of cancer, their comments around spare time being a motivating factor indicate that those with lived experience may also be drawn to volunteering, without initially seeking out Candlelighters specifically.

Charlie: *"erm, first reason was because I had extra time. I needed to get experience"*

Ashley: *"yeah, yes. I've got time on my hands, and I would like to use it so. Productively rather than, yeah."*

Importantly, some participants commented on the ease of this particular volunteering role which facilitated this process of giving to the charity and perhaps led to the choosing of Candlelighters eventually. This was reflected in comments around convenience, in that the tasks required of the role "works really well for [the participant]" and fits in with the person's life and own needs.

Jordan*:"at Candlelighters they have like actual set shifts, erm that aren't like your whole day, so like you still have some of your day to do your own thing."*

Sub theme: "nobody can get it better than somebody who has been through it"

As already described, some participants reflected on having chosen this charity specifically and shared their reasons for this. Many of these reasons reflected participants' own lived experience of Candlelighters as a recipient of support whilst their own child was unwell. Participants described the motivating role of their own personal experience of loss or threatened loss, identifying with the families the charity supports. For them, there was an awareness that their previous experiences had left them with a desire to 'give something back', both in the metaphorical sense, and more practically through replenishing resources of those giving, and the charity had afforded an opportunity to do this.

Those who described giving back in the more metaphorical sense talked about a sense of being indebted to the charity and experiencing a desire to repay this emotional debt through supporting others, as seen in comments such as Francis's:

Francis: *"oh yeah it's really rewarding, it feels like erm, I'm giving something back as well giving back to Candlelighters"*

Participants also reflected on giving back in a way that was feasible and meaningful to them as an individual. Ali describes wanting to give back following the loss of their daughter, in a way that would have been fulfilling their daughter's wishes and may help them to feel closer to their daughter. They tell us of their daughters desire to be an oncology nurse in order to help others, and whilst reflecting on this particular role not feeling appropriate for them, they reflect on being able to fulfil this wish and sense of giving back through volunteering with Candlelighters, leaving them with a sense of pride.

Ali: *"I mean she always wanted to help people and as I say she went from wanting to be a midwife to wanting to be an oncology nurse to do more for people and I just thought 'I'm too old, I can't go into anything like that' but this is my little bit of giving back that I can do and feel proud."*

On the other hand, other participants referred to 'giving back' more practically, in the sense that by receiving support from Candlelighters they had taken an amount of resources, and through volunteering for Candlelighters they were able to replace these resources. The reciprocal manner in which participants spoke about this indicated a sense of repaying a logistical debt, implied by comments of taking support and needing to replenish the charity's resources in order for it to keep running.

Alex: *"It's being able to give something back. Because you've had the support yourself, erm and its about sort of being able to, no matter how small or big, it's about being able to give something back."*

> Jamie: *"so I just I don't know why people wouldn't volunteer because it just gives you, it just gives something back to, all these organisations wouldn't run without volunteers"*

Some participants also emphasised their increased ability to offer support in this way as a direct result of their own personal experience. Participants described how in a practical sense, having been through the process themselves gave them a first hand perspective on the gaps in support. Additionally on a more emotional level, participants spoke of the empathy that they had as a result of shared experiences with the families they were supporting. This ability to empathise perhaps gave the volunteers a level of authenticity and credibility to both the volunteers and the families, suggested in comments around having knowledge and being someone who can "get it".

> Alex: *"erm, I think as I say, because you've got the knowledge of what it's been like for them, you know what people are feeling so you can empathise better with them."*

Sub theme: "It helps me" (Emotional impact)
Participants not only commented on the desire to give to others but also the gain they themselves experienced, described in a therapeutic manner. It seemed that these emotional gains contributed to volunteers continued engagement in volunteering and what sustained their motivation. Therapeutic gains were described through the positive feelings, such as "reward", "excitement" and "confidence" that participant's experienced as a result of volunteering.

> Jamie: *"Like I say I find it really therapeutic, well I don't know if therapeutic is the right word but I always feel better once I've had a bit of you know had a chat with somebody about my experience"*

> Ali: *"I was hoping that it would help me but erm, and it would like comfort me. You know, it was just like a comfort, like a safety net. And when they'd rang to say I'd got it, it was just, you know, I had like a feel of excitement again which is something I've never had since, you know for a few year, couple of year"*

For some, these feelings were only felt when volunteering and played a significant role in facilitating the grieving process. Ali described how being at Candlelighters acted in a restorative way, their mood actively changing when they were physically at the Candlelighters building.

> Ali: *"it's just so rewarding, me personally, I think it's just so rewarding, it helps me get through. You know, it helps me with my grief definitely. Just going there is such a wonderful feeling, I feel like I'm doing something you know, for others. And it's just, it helps me, it helps me so much."*

Whilst for some this process may have been helping them to work through their own experiences, for one participant, volunteering enabled reflection on their life in comparison to others, specifically reminding them of the positives in their own life, and changing their "perspective" and outlook to include more gratitude.

> Jordan: *"Like when you do come away it makes you appreciate your life, and the little things. Stuff that is so small, like in perspective to other things. Erm, it does make you appreciate little things like more."*

A final aspect of this sub theme is the importance placed on recognition and appreciation for many of the participants. Whilst the level of desire for recognition differed between participants, all participants described feeling appreciated by the charity, and expressed how important this was to them. Whilst some participants such as Alex were clear that the feeling of appreciation was more of a positive by-product as

opposed to being actively pursued, others were more forward in highlighting the wish for appreciation and the impact it has on the experience of volunteering.

> Alex: *"you don't do it for recognition you don't do it because of that but to have somebody sort of, even nominate you. I mean I think it were [staff name] that did it, erm, its just lovely and as I say to, you feel really humble by it, it were really, it were lovely"*

Such appreciation and recognition adds an acknowledgement of value to the role, suggested by participants' references to respect.

> Jamie: *Everybody does, you know when you volunteer you do it for a reason and they fully appreciate that and respect that and appreciate it so yeah it's good.*

Superordinate Theme: Identity and Roles

Across the different interviews, participants referred to who they were as a person, and how volunteering fit with this sense of self or at times challenged it. For many there was a sense that volunteering was part of their nature and that they had embraced it as their life now. The ability to act in line with this self-concept was enabled through pre-existing skills that the volunteers had to offer the charity and the sense of competence that this afforded them, whilst the new role of volunteering aided further development of such skills and introduction of new learning, leading to an increased sense of confidence. Personal boundaries appeared to provide a set of expectations for behaviour, helping to define roles, albeit presenting themselves in different ways between participants. A final aspect of this theme captures an experience of "difference" with others, both other volunteers and families being supported, and how this difference challenged participants' values and beliefs.

Sub theme: "That's it, it's me now" (Congruence)

As already mentioned, many participants described their involvement in volunteering to be something they do naturally that fits with their values. Some participants held other volunteering roles simultaneously or had done previously; others also worked in a helping profession alongside volunteering for Candlelighters. There was a sense that some people were drawn to these roles because it fit with their nature and sense of self, thereby providing a feeling of congruency and authenticity.

Jamie: *"I worked for [alternative charity] for years, the cancer charity and before I left there I worked in the volunteering section. I have always, I mean I worked for [alternative charity] prior to X being ill"*

Ali: *"That's it, it's me now. I don't see it as a job or, It's just something that I do, and I go and I enjoy. I just love it. All of it!"*

Some participants talked about their values and activities outside of volunteering that lined up with their engagement with the charity and volunteering in general. It seemed that for these individuals, volunteering was a part of a more holistic self that fit with their values, activities and interests. Acting in line with such values may serve to reduce feelings of conflict and reinforce the participants' perceived sense of self.

Ashley: *"it seems like a very good cause. It seems unfair to me that some people are affected by things like that. So yeah, I think it's a good cause."*

Charlie: *"I write blogs, I also advocate for the children and their wellbeing, I have pages on Facebook and all sorts, and I am very particular about the vulnerable community which for me potentially includes children and the elderly"*

In contrast to volunteering being part of a more holistic identity, some people described experiencing volunteering as one aspect of their identity, a specific part, and aimed to have balance in their lives. This was quite pronounced when the participant still received their own support from Candlelighters whilst simultaneously offering support to others through their volunteering role.

> Jamie: *"volunteering is a part, I'm a mum, I work part time but then I also volunteer for various… probably more for Candlelighters now and I work for the local hospice"*

> Alex: *Well I go to the bereaved mums group, I help out with the mums on treatment and post treatment but because I have two parts, there's the bit where I am still receiving support and I'm still helping so bereaved mums I just go and enjoy that and have a bit of pampering!*

Sub theme: Competence and Confidence

Whilst volunteering may be congruent with an individual's sense of self, beginning a new volunteering role demands a range of skills and knowledge from the participant. For some, being able to offer such skills and provide something practical for the charity led to a feeling of competence and confidence that they had the resources to act in line with their self-concept. For many, feelings of competency and capability and associated self-worth increased over time as they adopted the role.

Being able to provide something practical for the charity is shown in the following comments around having appropriate skills, such as IT skills or people skills and the roles therefore being a good fit for these individuals.

Ashley reflected on having something to give to the charity through IT skills. They described their current skills being appropriate and leading them to be more motivated

to apply for the role as they had something to offer, and perhaps felt the role was a good fit for them.

> Ashley: *"I thought well I've got the appropriate skills and experience for that so I applied for the role."*

Similarly, Jordan made reference to transferable skills of customer service from their paid job, indicating that they had a specific skill that might be of use to the role and a sense that this would fit well with a volunteering role at Candlelighters:

> Jordan *"it's kind of fitted in well, the whole customer service that kind of thing."*

Alternatively, for some individuals the new role enabled development of skills, increase in ability and resources to fulfil the demands of the role, as opposed to the offering of pre-attained skills. Comments were made suggesting a new familiarity with computer systems such as Excel and Publisher, and use of telephone systems. Such an increase in skills may have led to an increase in confidence both being able to deliver within the role, but also with regards to the individual's sense of self and levels of self-esteem. This change in confidence empowered participants to face new challenges such as public speaking and adopt a "give it a go" attitude, due to a stronger sense of self belief. Additionally, increased confidence enabled individuals to have the confidence to manage emotional challenges, an experience which will be reflected on further in the later theme of "coping". This change in confidence in the self was not limited to those without personal experience of Candlelighters, nor did participants only fall into one of two groups: confidence in skills or confidence in self esteem. For example Alex emphasised the benefits they gained from learning how to use Excel, whilst also noting the effect such an increase has on their level of confidence with other professionals and their sense of power and agency, as can be seen in the comments below.

Alex *:but I feel like I used to get intimidated with people that had like you know experience so say social workers or nurses and things, and I feel intimidated by them, but now I feel like I can hold my own.*

Ali: *You know I can cope with things a lot better myself, you know I've learnt how to cope with things and that's just being there and picking things up, how to distract myself when I need to and..*

Participants also made explicit links to how they were prepared for a volunteer role by the charity, in particular the training provided. The majority of the participants described a very thorough training and induction process, and made a link between being given the necessary information, and feeling sufficiently prepared for the demands of the role, presumably increasing confidence to fulfil the role.

Charlie: *I think it was quite apt, I think it covered all the bases that it needed to cover for the role, I didn't feel lost, I found myself in situations that they had erm, highlighted might happen. Erm and so, which was a good thing as, we had had the training on how to conduct ourselves, so it helped, you know, it helped me deliver appropriately when the time came.*

Sub theme: Boundaries

A new role demands navigation of new relationships, different dynamics within social interactions and subsequent expectations and behaviour. Perhaps unsurprisingly then, participants reflected on an underlying awareness of the rules and principles that guided formation of relationships and behaviour in their new role, leading to participants having a confidence in knowing what they *"had to deal with in any situation"*. Reflections on this concept can be seen through comments made around personal boundaries, the boundaries of the role and what participants felt was appropriate for a volunteer. Some participants such as Alex described a closeness with

the families whilst simultaneously emphasising the need to have personal boundaries and an awareness of the potential for dependence. This notion of boundaries may have created guidelines for a set of behaviours leading to a sense of predictability, certainty and structure seen in comments around expectation and clarity.

> Alex: *"setting the boundaries so you sort of don't overstep the mark, because they don't, although you are there to support them, you don't want to be their life line and you know them ringing you at midnight and saying 'oh I really need to talk to someone"*

In the same vein, boundaries were also talked about in facilitating self-care, whilst maintaining a caring relationship. Charlie explained that this was a key learning experience for them, and that in order to provide the best support they could to the families, they needed to keep an emotional distance. Within this comment there was a suggestion that emotional distance enabled a level of objectivity that facilitated support of families through emotionally challenging times.

> Charlie: *"That was key. Don't get emotionally involved, it doesn't mean that you lose empathy, what it means is that, you are supposed to be supporting, then you should be the pillar of strength and you can't be that pillar of strength if you find yourself in the middle of the problems that they have, so that's where the emotions come in"*

There were different views on whether the relationship between volunteer and the families being supported was a professional relationship or a friendship. Whilst participants such as Alex were clear in the need for professional boundaries, others such as Ali referred to themselves as being a 'friend' to the families, and explicitly rejecting any professional identity that may create distance, and potentially may act as a barrier.

> Ali: *Talk as just a friend, you know. Not as, you know a nurse or somebody from that background, you are just there as a friend.*

Interestingly, participants described their experience of boundaries in different ways. Some identified with this concept in a more passive way, in which they described being "told their boundaries" by Candlelighters, perhaps viewing boundaries to be externally influenced. Within this discussion they highlighted the focus on boundaries in the training, and spoke about boundaries in an external way that was directed by others. Other participants, however, spoke about boundaries in a much more natural, self - derived manner, attributing the sense of boundaries more intrinsically and portraying their experience of boundaries as a personal choice. This was seen with some participants discussing how they kept their different jobs separate and did not allow them to impact each other, and others reflecting on having the autonomy to decide whether to give out their personal number or not.

> Francis: *"knowing that it's up to you whether you wanted to just mainly keep it as a group or would you want somebody having your mobile telephone number if you wanted, so it's what you feel is right when you make that connection with that parent"*

There was also a sense that perhaps the boundaries of a paid role were different to those of a non-paid role. One participant identified the distinction between the two when reflecting on the impact of their own self disclosure with another individual, and how this may be managed. Jamie's comment perhaps indicated that they attributed less responsibility to their role as a volunteer as opposed to another staff member's paid role.

> Jamie: *"I had no idea about her journey and then she started telling me and I was like 'oh my god, I can't believe I just sat here going on about myself*

and X being X was just like 'oh, don't be silly, don't be silly you just.. this is

what' and you know obviously hers is a paid role, so hers is a bit different"

This consideration of boundaries within paid and non-paid roles seemed also to be reflected within participants' discussions around professionalism. Some participants reflected on a potential narrative that volunteering roles are easy to obtain and that charities could be perceived as less professional than some organisations. However, participants such as Jordan reflected on this perspective being different from their experience with Candlelighters due to the professionality of the charity.

Jordan: *yeah I think it formalises it a lot more, because some people might have the perception that volunteering, anyone can do it, but at Candlelighters not everyone can do it because of the nature of the environment.*

It seemed that the level of professionality perhaps added value to the role and subsequently provided expectations for behaviour within that role, even at times of heightened emotion.

Jordan: *"all the training things for the volunteers, it just like makes it professional and probably erm make you appreciate the role more because you know how professional it is. It does make you, weirdly like appreciate how professional the charity is and you need to be like that as well."*

Francis: *"don't get me wrong I do really feel for them and get upset with them but it's trying to keep the level of professionalism if you like"*

Sub theme: Difference

The alignment of identity, sense of self, values and action can lead to positive feelings of congruence and authenticity. However, such a strong sense of self can also lead to discomfort when an individual experiences others as different to themselves

either with regards to the experiences they have gone through, or the ways in which they respond to situations, leading to a clash of values.

Participants reflected on their role as a volunteer and the differences between themselves and others, both families they were supporting and fellow volunteers. For many participants, they described responding to the differences between themselves and the families, reflecting on different stages of the journey and individuals having different preferences to managing distress.

Francis: "*letting the parents freedom to talk if they want but be open and honest, it's up to them how much they want to tell, how much they want to divulge really so we just let them take it at their own pace if you like and because they are at different stages, somebody's story is going to be different from somebody else's*"

Others discussed more challenging experiences they had had with the families they were supporting, in particular when families responded to their child's illness in a different way to the way the volunteer had. One participant described difficulties in accepting this alternate response and experiencing a feeling of shock. This may be due to a clash of values and a difficulty relating to the family member.

Francis: *"I would say, I was quite shocked to be truthful, I can remember coming home and saying to my husband like she just seemed quite blasé about when we were chatting you know, and I think that that is, it did upset me I suppose in a way"*

Difficulties also arose when working alongside colleagues who had had a different experience to them with their child's illness. Some participants reflected on the feeling of guilt they experienced around their child's survival when working alongside

volunteers who were bereaved. Jamie provides an example of listening to others' experiences and feeling the need to limit their self- disclosure for sensitivity.

> Jamie: *"So sometimes when you sit and listen to other people's experiences that haven't gone the same as ours, that's difficult and you do just feel guilty about that but I just keep a bit quieter about mine and not go on and just listen to them"*

Superordinate theme: Coping

As discussed above, there are aspects of volunteering that participants found more challenging. Participants were prompted to discuss how they managed their own emotional responses whilst volunteering, revealing differences in approaches. Some participants reflected on having little awareness of doing anything in particular and described the process to be more natural. On the other hand, some participants described a more active approach in that they employed different techniques and strategies to manage the emotional challenges that presented.

It is to be noted, however, that even when participants commented on utilising strategies to manage their emotional responses many also commented on the emotional challenges being significantly less distressing than they had expected.

Sub theme: Naturally happened "it were a feeling"

Many participants alluded to the way they had seemed to develop a natural resilience to the emotional nature of the work. One participant explicitly described the experience of coping using the term 'resilience', highlighting the need to overcome adversity and the desire from the charity for volunteers to be a 'resilient person'. Within this comment there was a suggestion that resilience was perceived to be something you either had or

didn't have as a person, a static personality trait evidenced by continuing on through challenging times.

> Charlie: *"I still remember when I had the interview with X, and she asked me to say a little bit about myself and would I call myself a resilient person and I remember telling her you know, my own, what I was going through at that moment, at that period of time, and erm how much challenges I had you know left right and centre. And what was standing what I was supposed to do, and what I continued to do, because I had a goal and I kept focused"*

Other participants did not use the term 'resilience' but referred to a sense of natural coping, a feeling of 'being okay', and noting little awareness of how they were able to do this.

> Alex: *"Erm and it wasn't something that worried me because I'd been back to the hospital and I visited people and it wasn't something that I felt scared about or you know daunted by, you just, as I say it was just something that sort of naturally happened and it were a feeling."*

Friends and family outside of the volunteering role sometimes expressed surprise at how the participant managed the emotional demands that they perceived as being part of volunteering with Candlelighters. Two participants described being asked how they coped, but not really knowing how to answer – that they felt that they had no choice but to 'get on with it' and cope, but couldn't say how.

> Ali: *"I still see, you know some people that are involved and they are still there, but I don't know, I'm fine with it. You know, my sister said to me, she didn't know how I could do it, she didn't think she could be round those people because it would be too hard for her."*

> Francis: *"You know and I know that I was chatting to one of the mums and she said 'some people say, I don't know how you cope' but you don't have a choice to cope"*

Sub theme: Protecting the self

On the other hand, whilst some participants could not pinpoint what they did to cope, others described more active approaches to managing their emotions. These included socialising, being outside or having a balance with other elements of their lives. This latter experience was also referred to when discussing 'identity'.

> Jordan: *"I always have like, I always try and make time, just to have a bit of time away from everything like just to go for a walk or see my friends."*

There was also a sense that whilst some sensitive dynamics and new situations may feel challenging initially, through the process of learning and picking up ways to manage such situations, the participant can feel more equipped and better prepared to cope. This mirrors some of the findings around preparation and confidence in the "Identity and roles" theme.

> Jordan: *"what I found most difficult was, when you open a door you automatically say 'are you alright', which was one of the, I suppose a challenge that you can't, because obviously the families, they are not alright, and they are sad. Erm, so it's just learning how to deal with that"*

Francis also outlined an active choice to stay positive in their attitude, and in their approach to families. Whilst it could be speculated that this seems more like avoidance than coping, Francis's experience here is one of being in control and being able to cope with the situations they expose themselves to. If the role demanded being involved with different situations, in which they were unable to be positive, it may be that Francis's coping strategy would then not be successful.

Francis: *"I try to be erm encourage- well encouraging isn't the word, keeping it like positive within the role, I don't like to have the negative side of it, because even myself I'm thinking, you know like I might read something. I've joined a lot of erm online closed groups now where you can chat to people but sometimes I'll be reading something thinking, no no no, I don't want to know that, that side isn't what I'd want to know, so I, it's just trying to keep it positive, I don't want to go in there and it be all the doom and gloom"*

Participants described a process of change in themselves, their self-esteem and in prioritising their happiness. This was described through situations such as being more selective with their social circle in order to sustain their mood. They also reflected on how their loved ones had noticed this change and the impact that this change has on them, for example, now having strategies to cope with challenging adversities and having confidence in themselves to do this.

Ali: *I'm more like my old self, you know they can see a change in me. You know I can cope with things a lot better myself, you know I've learnt how to cope with things and that's just being there and picking things up, how to distract myself when I need to."*

This accumulation of new skills to manage emotional distress may link to the feeling of competency and control discussed in "Identity and roles". Participants may still experience the emotional distress but perhaps now feel better prepared for it.

Superordinate theme: Community

Throughout many of the participants' transcripts, there was a strong theme of 'togetherness' and the sense that they gained something both from each other as fellow volunteers, and from being part of something. There were different ways in which the

volunteers experienced this sense of community and the impact that it had on different aspects of their volunteering experience. There was the more pragmatic 'sense of place' that volunteers described, specifically gaining something from the environment itself, which seemingly was created by the staff team. From this sense of place, participants then went on to talk about a sense of belonging, something to feel part of. More subtly perhaps, it became clear that the volunteers were describing the charity in a much more active voice, indicating a sense of 'ownership' and commitment to a desired outcome.

Sub theme: Sense of place

As already mentioned, many participants spoke about the environment of Candlelighters and how this left a lasting first impression. Participants described a 'feeling' when they entered the Candlelighters building and how this feeling led to a sense of being welcome and content. There was a sense from one participant that physically being in the Candlelighters building fulfilled a restorative function for her, leaving her with a "good" feeling, which would only be renewed by returning to the Candlelighters building.

Alex: *"and the longer I'm away from can, the more down I get"*

Researcher: *"okay"*

Alex: *"once I go to Candlelighters, even if it's just to visit myself, you know for a massage, some therapy, I come away and I feel good again, I feel good about myself, it's a good feeling."*

One perspective on how this feeling is created and maintained was through the *'friendliness'*, dedication and ethos of the staff team, potentially creating a sense of safety and containment due to the belief in their cause and implication of hope, as suggested in Charlie's comment.

Charlie: *I think that Candlelighters is a great place to work. Erm they've got great staff, they have gone the extra mile to create a suitable environment to achieve what they set out to achieve. And I still remember one of the things I said to [staff name] for the interview, I got that feeling the moment I entered the office, and I thought wow this is such a calming environment to work*

The way in which participants describe the staff team indicates a genuine attachment to them which may provide a safe base for individuals to turn their attention outwards towards the families and manage any emotional challenges.

Jordan: "*the staff are so friendly and welcoming to you, and I think, that's such a nice thing. They just welcome you straight away, so straight away I felt really welcome*"

Ashley: *Erm, yeah so as I say I like the people and, I work in the office so the people there seem very nice and stuff so it's a nice place to work*

Sub theme: Belonging

Participants described their experience of being part of Candlelighters in a way that suggested a sense of belonging, acceptance as a member of the community and being part of something. This involved going to events and knowing people there, feeling part of the Candlelighters team, and a desire to create this same sense of belonging and community through volunteering in their own geographical areas:

Jamie: "*it's just nice to meet new people that have been there and obviously all the Candlelighters events that they put on, erm we meet some of the families there as well, but they are from all over Yorkshire and we are trying to get more of a group of people that are in [named area].*"

Many participants explicitly stated that the sense of belonging was not created simply through sharing experiences (albeit this being a big part of it), but by simply being together. Being with people who *"get it"*, seemed to lead to a sense of normalisation in that individuals did not feel so alone with their experiences. Participants also described a feeling of being understood, potentially through not having to explain their experiences, and others validating their experiences.

> Alex: *"My family don't know and they were there with me, you know. Unless it's actually happened to you it's just, the thing is you can try and understand part of it, but it's completely different being actually in that situation. So it's just nice being part of Candlelighters where you are all together and you are all in that same boat, if you'd like to say."*

> Jamie: *"it's just so nice to get with a group of people who know exactly what it's like to have been through that, and just not even talk, we don't even talk about it sometimes, it's just nice to be amongst those people who, it sounds really cheesy but our slogan is who get it, what it's like to be a parent who had a child with cancer."*

Whilst it may seem initially that these experiences were limited to those who had lived experience of cancer, it is important to recognise this sense of belonging and feeling part of something was also named by participants who did not discuss having such lived experience. For example, other participants referred to being with other members of the team and not feeling alone within their role or more generally whilst at Candlelighters, potentially leading to feelings of shared responsibility, subsequently reducing fear of failure or judgement from others, demonstrated through comments around help with demands of the role.

Jordan: *"Just to know that they are there for you, and they are always there to help. Erm, you are not by yourself when you are doing this role."*

This sense of belonging achieved either through shared lived experience or day to day support from colleagues, may indicate feelings of acceptance as a member of the group, shared responsibility and validation of experiences. This can be observed through direct comments around reassurance and inclusion:

Alex: *"Erm and its like silly little things because you think you're going bonkers because at one point it were strawberry yazoo and hula hoop crisps and every time I saw them I'd burst into tears because that's what he used to eat and drink. And then you've got somebody in the room who's like 'oh yeah, mine's pringles' and you think 'I'm not on my own, I'm not going barmy because I'm crying at hula hoops, there is somebody else there who understands what I'm going through' so it's having that reassurance"*

Sub theme: Ownership

It was interesting when talking to participants that the way they described their volunteering roles was done in a very active and engaged way, commonly using the pronouns "we" and "our" to describe the charity and the work carried out within these roles. This was done both in reference to the role itself, and to the desired outcome and ultimate success of the volunteering actions. Additionally, when participants spoke about the charity itself, they did so in a very active and collaborative way, indicating some level of agency and responsibility. This was demonstrated through direct comments about allegiance to the charity, and elements of leadership and continuous promotion of the charity. As can be seen in Jamie's comment, allegiance to the charity was talked about with a strong sense of long term commitment and dedication.

Jamie: *"For us, Candlelighters is our charity now and it will be for the rest of our lives"*

When describing the work that they had put into the role, there was a strong sense of pride and value in all contributions, both large and small. Subsequently, volunteers felt that they could be influential in the support that the families received both through direct and indirect input.

Alex: *"I'd seen all the work we'd put in and organising and stuff and I could sit back with pride and think yeah I've helped with this, do you know what I mean?"*

Charlie: *"whoever was having first contact, still needed, equally needed the support of the back end person, and so for me that was a long way, because I knew that whatever I did, will help effect whatever, whoever is meeting up with them. Erm, so that was for me, especially, in a way I was also reaching out to them,"*

Adding to this sense of pride, participants reflected on the growth of the charity, and their being witness to this, as well as feeling a part of it.

Jamie: *"we've probably been aware and involved with can for about six years now, and in those six years we've seen it grow massively."*

As already mentioned, it was clear that participants did not view their volunteering role as a tokenistic exercise, as demonstrated by the level of commitment and passion that participants talked about their roles. Participants spoke about volunteering in a very active manner, personally caring about the outcome and the success of the charity. This was demonstrated in participants' examples of trying to troubleshoot problems and thinking about improvements to the provision offered to the families.

Jamie: *"I personally think that we need to be approaching people or Candlelighters need to be approaching people more directly rather than. Because at the minute how they are advertising it is at clinic and on facebook."*

Francis: *"so it was trying to promote Candlelighters' as well and you know we've got posters up in quite a lot of, I took posters round supermarkets and just local shops and things like that, promoting the group as well"*

Whilst this was the case for many of the participants, two participants spoke about their volunteering role in a much more passive way, describing tasks being given to them, and just doing what the charity needed.

Ashley: *"erm I have been given various tasks, and it's important, I have been given some quite long tedious tasks in a way and so that's been a bit boring and so on, but as I say it's been, the aims of the charity are good so I'm quite happy that what I was doing was helping the charity"*

Sub theme: Commitment

Noticeably, most of the participants' involvement with Candlelighters was not episodic and exuded a sense of loyalty and dedication to the charity. On the whole, when participants spoke about their involvement with Candlelighters they referred to it in a long term sense, indicating both longevity in the support they received from Candlelighters and commitment in their dedication to Candlelighters. Jamie provides an example of receiving long term support from Candlelighters through their child's illness and recovery.

Jamie: *"you almost feel, you feel guilty and you feel like actually should we be at this event because X is well now and this should be for the children who aren't so well but everytime I say that to Candlelighters, you know I keep*

saying, when should I stop coming to the events? They are like 'never, never,

you are always a Candlelighters family, you must always come'

The long term dedication to the charity was more pronounced for those with lived

experience, presumably due to the relationship formed between the volunteer and the

charity, and the desire to give back. Charlie describes a desire to maintain a connection

with the charity despite having left the charity for a paid role. This commitment appears

reflective of a secure relationship with the charity, demonstrated by the ability of the

volunteer to move away from the role and the charity temporarily whilst still

maintaining that connection and opportunity to return.

Charlie: *That's one of the reasons why I said to X, if you could just leave*

me on your list, on your contact list, I still want to know. And any time I have

any extra time I will be up for doing it again, because they are such great people

to work with"

Superordinate theme: Family

This theme captures the concept of 'family' which arose when the participants were

talking about Candlelighters, in terms of metaphorical association, representing the

strength of their bond to Candlelighters and a depiction of how the participants

experienced being part of the Candlelighters charity. 'Family' was also referred to in a

more concrete sense with regards to the involvement and importance of the volunteers

own families in the experience of volunteering. This theme builds on the concept of

"Community", however it differs in that for some individuals, conceptualising

Candlelighters as their wider support system did not seem sufficient to capture the full

depth of their experience, and the sense they made of this relationship, leading to

"family" being identified as a theme in its own right. The different sub themes outlining these distinctions will now be presented.

Sub theme: 'Team as Family'
Five participants described Candlelighters as their 'family', sometimes using the concept of 'family' to represent their relationships to Candlelighters or drawing similarities between Candlelighters and experiences of being in a family system.

> Charlie *"I think they are doing a great job and I am very very happy to be a part of you know the Candlelighters family."*

The term 'family' was used by many of the participants alongside references to experiences that mirrored those of a family. It is unclear whether this term is part of a wider narrative that Candlelighters use when talking about the charity and its volunteers. However, regardless of this, participants appeared to place importance on this concept, and by frequently using this term, and presenting a coherent concept of family, it appeared that this was a way in which participants conceptualised their experience with the charity. The way in which participants used this term indicated a value was placed on their relationship to the charity which could only be represented by a close bond such as those often found within a family.

> Jamie: *"Erm so it's like our second family now really is Candlelighters."*

Additionally the concept of the 'Candlelighters family' implied a notion of unconditional support as associated with a family. Such support is described by participants for example, when referring to comfort and support through the grieving process.

> Ali: *"you know, Candlelighters, the people around, it's like a big family, you know. It's just like one big family and it's just so rewarding and comforting, it helps me with my grief. Erm you know, my family see a difference in myself "*

Participants also drew parallels between the Candlelighters team and different familial roles and actions.

For example;

> Jamie: *"There's always little X who was the dinner lady on the ward, she always came round with the sweet trolley, she's always at everything, erm she's like the ward mum, she's at everything."*

Jamie's reference to the depiction of a maternal "ward mum" may suggest that the perception of Candlelighters as a family arises from the sense of feeling protected and contained through different staff members, and the sense that these roles fit together to form the supportive family unit. Charlie gives an example of Candlelighters fulfilling actions that mirror those of a family, such as the giving of Christmas presents at Christmas. Charlie's appreciation of this action indicates an importance of being held in mind even when not physically present.

> Charlie: *"For example, Christmas they actually gave my daughter a Christmas present, and me a Christmas card. Things like that go a long way, you know it goes to show that you are not forgotten and you are appreciated, so yeah erm that's why I call them my Candlelighters family."*

When prompted to explain more about the use of the term 'family', many participants described different factors that influenced this experience such as frequency of time spent together and the informality of the situations they found themselves in.

Ali: *"You know that's who you see, you all become one. That's your family that you see everyday, you know it just becomes people on the ward, nurses doctors, families on the ward. They become your new family, and even when you're not in hospital, and you know, you go back, it's like you're going back home because that's how it feels, you know, they are the ones you are spending the time with."*

It was noted that often when participants referred to Candlelighters as their family, they then also began to talk about their experience on the ward and the family being extended to the doctors, nurses and peers. It seemed as if these were not processed as discrete experiences for the participants but were all interlinked and impacted on how they experienced their role with Candlelighters.

Francis: *"My husband came with me to, came to one of the meetings, unfortunately he works shift work so he can't always come, but yeah just, it's just like this connection now that you have with them, it's like we were saying, we call them our oncology family, because even like the families that we met whilst X was on his treatment, I am friends with a real lot of them now."*

Alex: *"because it's like a family when you're on treatment, you know you're in this bubble of the ward and chemo and everything else and the hospital. And you become like a little family and then when something happens all that cuts off, and you are just sort of left then. Erm, So it's nice to go to a day like that where you can catch up with people because they've been a big part of your life for three years, and you know what I mean, to lose them that sort of that quick it kind of it knocks it out of you a bit but to be able to catch up with them it's nice."*

It may be that participants conceptualised Candlelighters as their family, due to their involvement with the family through a difficult time representing the unconditional support and care of a family.

Sub theme: "and that shows in my family as well" (Benefit to participant's family)
Participants also referred to 'family' when discussing the impact of the volunteering on their own family and the concept of shared benefits. As previously discussed, participants spoke about their motivation to volunteer, and whilst there were many personal motivations, it was apparent that many volunteered with either the aim of, or experiencing an unexpected gain of facilitating benefits to the wider family. One participant described how they had hoped it would benefit their child who had had cancer to meet other children who had gone through similar experiences and be part of a community in which cancer was normalised and understood, providing the same validation of experience as discussed in the theme "community".

> Jamie: *"that is one of the reasons that I wanted to do it as well because I hoped it would like help X as well just to. Because sometimes I think he, because he is 10 and a half, nearly 11 now and I think sometimes he struggles with it as well. Because they are quite blasé about it aren't they kids, and he will randomly just come out with it to his friends or, say 'oh yeah I had cancer' and people will be like 'no you didn't, no you didn't' and I think sometimes he struggles as well that he had this experience and it was a long time ago now but it was a big thing at the time, so I think that was my hope that it would help him a little bit just to feel normal because I guess he does feel different sometimes when he, I mean he doesn't get treated any different now but I just thought it would be nice for him to maybe meet some other people"*

Other participants talked about the impact of the child's cancer on the wider family and how important Candlelighters had been in supporting those members, both through volunteering and receiving Candlelighters support. It seemed that having experienced this far reaching impact, participants noticed a desire to offer support to all members of the families.

> Francis: *"there's also the grandparents day where erm, I know my mum and my mother in law they both went to one grandparents day. Because it doesn't just affect, it affects all the extended family as well."*

> Francis: *"I know like people would say, ohh how are you, how are you doing, and they never tended to ask my husband how he was doing, but we have tried to encourage it, it's not just for the mums to come, men will come as well, husbands will come. My husband came with me to, came to one of the meetings, unfortunately he works shift work so he can't always come, but yeah just, it's just like this connection now that you have with them"*

Ali described how changes in themselves and their outlook as a direct result of volunteering may also be of benefit to their family in the sense that they are more themself, 'more normal'. Within this comment, there is a suggestion that volunteering with Candlelighters may help to preserve the individuals' sense of self and the role and relationships they have with their family.

> Ali: *"because it's definitely helped me. And I'm sure with me being different, it helps me be more normal and myself, you know, and that shows in my family as well."*

Sub theme: "we do most of it as a family" (Shared Family Experiences)

The final aspect of the theme 'family' is the common occurrence of the experience of volunteering being a shared family venture. Many participants described how they

volunteered with other family members or close friends, all working towards a shared aim, creating a sense of teamwork and collaboration in the families' actions.

Francis: "*the 10k on the 10th June and my next door neighbour, she's actually running that for Candlelighter's and myself, and my husband, X my son and my mum, I've got lots of my family members we're all volunteering on that day, do you know, just like either we're going to be handing out water, or giving out medals from Candlelighters, just trying to promote Candlelighters the charity more, and make more awareness of it as well.*"

Jamie: "*both the charities that I volunteer for Candlelighters and the hospice, they know that I've got a family and they know… but then we do most of it as a family, we do everything sort of together where we can.*"

When describing family involvement with Candlelighters, participants conveyed a sense of pride and, as described in the theme of 'community', a feeling of joint venture and experience. Such pride may be brought about from the confirmation of shared values and beliefs, enabling a sense of similarity and cohesiveness between family members.

Francis: "*you know, I was really really proud of X when he said ' you know mum, I've worked at [alternative charity]' and he's got all his safeguarding and things like that, and he said 'how about me doing it as well', so erm we obviously emailed X, and they were delighted really because they said there's not a lot for siblings if you like, Candlelighters do these fun day workshop things and X has helped out at that, but there's not a lot for siblings I don't think.*"

It is of note that many of the quotes presented in these sub themes are from participants with lived experience of the charity. It was for these individuals that the concept of 'family' felt most poignant. Ashley and Jordan, both of whom did not express having lived experience of the charity, did not explicitly refer to the charity as a family.

However, Ashley did discuss how there were similarities and differences within some of their previous paid roles and this current volunteering position. Whilst Ashley discussed some previous roles where it felt more of a "city atmosphere", they seemed to compare Candlelighters to an alternative previous role in which they outlined the significance of working for a company run by a husband and wife, and the ability to speak to those who were influential in such a set up.

> Ashley: "*where I used to work which is a small[company] (illegible word) etc is owned by a husband and wife team if you like, and so I work directly for them if you like, so the ultimate decision about what goes on in the company, you could speak to the people who made the ultimate decision*"

It is also worth noting that the two participants who did not directly refer to Candlelighters as a family have been working at Candlelighters for the least amount of time. It may be that such a connection to the charity develops with time, and for these individuals, this relationship has not fully developed yet.

Summary of results

Overall, participants described their motivation for volunteering, what they gain from it and what they give, the role of previous loss or trauma, the impact on their identity and the way they contextualise their experiences in terms of community and family. In addition to this, participants reflected on how they cope with the demands of the role.

Participants noted what drew them to volunteering- some highlighting a desire to volunteer specifically for Candlelighters, others noting a more generic desire to volunteer for any charity. Additionally, participants reflected on the therapeutic impact of their volunteering role, in facilitating the process of grief and enabling feelings of

reward and excitement, whilst satisfying a desire to "give back" and use their experiences to help others. There was an emphasis placed on identity; both how volunteering and having the appropriate skills and resources fits with their values and sense of self *"That's it, it's me now" (Congruence),* but also the challenges that presented when there was a clash of values through difference between individuals responses. Differences also arose when participants described management of their emotional responses; some noting a sense of resilience, whilst others wanting to more actively protect themselves through techniques and strategies.

The focus of participants' discussions also broadened to wider parts of the system, such as their conceptualisation of their relationship with the charity as being like a family, and being part of a wider community or group. They described this both environmentally, in gaining a "sense of place" in which experiences of a safe base were eluded to, and emotionally in the sense of "belonging". Such inclusion led to participants having some "ownership" of the charity in that there was a sense of agency and responsibility for their involvement and the charity's outcomes. Interestingly, many of the participants' volunteering was not sporadic, and their connection and drive to volunteer for Candlelighters was spoken about in a more permanent way, leading to the sub theme "*Commitment*".

Chapter 4: Discussion

Introduction

Volunteers are becoming more important in society, and due to the limited resources within the NHS, volunteers in recent years have become integral to the health service (NHS England, 2017). Prior research tells us that serious childhood illness has a

significant impact on the child, and their family, but that supportive relationships can buffer some of this. Volunteers play a significant part in the support of such families, however despite this, there is little known about the experiences of volunteers, and more specifically, experiences of volunteers in emotionally challenging areas such as childhood cancer charities. The current study aimed to fill this gap in knowledge by exploring the experiences of volunteers working within a local childhood cancer charity.

Research aims:

- To gain an understanding of volunteers' experiences of working within a childhood cancer charity.

- To explore how volunteers manage the day to day expectations of the role, the relationships formed with families, and their own emotions and experiences of this.

- To identify important and shared aspects of such experiences and extract information that may inform the way this and other similar charities prepare and support volunteers in their work. More specifically, it is hoped the findings will support the development of the training programme that volunteers undergo within the Candlelighters charity, to ensure preparation for the role is as comprehensive as possible.

The study tried to meet the research aims through semi structured interviews carried out with seven volunteers working for Candlelighters childhood cancer charity. Interpretative phenomenological analysis (IPA) was used to analyse the data, producing six main themes. Each theme will be discussed individually and related to wider literature in order to consider implications for current understanding of volunteers and their experiences. Additionally the research aims were met through interpretation of these themes. Limitations and strengths will be discussed to evaluate the ecological

validity of the findings before considering the clinical implications and suggestions for future research.

Main Findings

Volunteers' experiences of working in a childhood cancer charity were interpreted within six main themes: *'Motivation', 'Identity and Roles', 'Coping', 'Community', and 'Family'*.

Overall, themes captured the process by which participants came to volunteer with Candlelighters and what motivates them to stay, whilst considering the influence of volunteering on the participant's sense of self and identity and how they cope with the new role. Themes also reflected the protective experiences of belonging to a community, and relationships with the charity being of such importance to many that they are conceptualised as being like a "second family". Individual themes, and how they fit with prior research will now be discussed.

Superordinate theme 1: Motivation

Participants discussed what motivated them to volunteer, and different aspects of the role that helped to maintain engagement. The theme was broken down into three sub themes; *"I did a google search for volunteering in Leeds", "there isn't nobody who can get it better than somebody who has been through it"* and *"It helps me"* (Emotional Impact). As discussed previously, Clary et al. (1998) suggested there were six functional aspects of motivation for volunteering. Namely these were the importance of the role being congruent with a person's values, increasing understanding, obtaining a social aspect (do something with friends/ do something socially favoured), furthering career, protective (reduce guilt over being more fortunate than others—protect ego from negative features of self) and enhancement (maintaining positive affect). Further

research has confirmed all the functions suggested by Clary et al. to be important motivators, and added three further motives; enjoyment, religiosity, and team building (Allison, Okun, & Dutridge, 2002). More recent research has further confirmed these findings with a range of populations from older adults to people who volunteer online by taking part in surveys (Yoshioka, Brown & Ashcraft, 2007; Vocino & Polonsky, 2011).

Many of these prior findings regarding motivation were mirrored in the current study. For example, "enhancement", in which it is suggested that positive emotions and affect are maintained through volunteering, was a part of the participant's experience reflected in the current study's sub theme "It helps me". Participants spoke about the emotional rewards they gained from doing the role, both in terms of "excitement" and the sense of accomplishment, but also in improving their mood. Notably, in the current study, the maintenance of positive affect was only part of this gain. For some individuals, volunteering took a therapeutic role, in which they were able to work through difficult emotions and processes such as "grieving", and provided a sense of "comfort" and containment. Whilst it could be suggested that this experience falls under the "protective" theme as outlined by Clary et al. there was a sense in this study that individuals are not protecting themselves *against* grieving, more that volunteering is facilitating this process.

In addition to facilitating grief, it could be suggested that such an experience may also allow a postponement of grieving. Stroebe and Schut (1999) suggest a dual process of mourning in which the individual fluctuates between loss orientation and restoration. Loss-oriented coping describes the process in which an individual attempts to deal with the loss through missing that person, and remembering them. Restoration-oriented coping can be used to describe when an individual begins to move forward, creates a

new life and identity which holds on to the loved one the individual has lost, but in a symbolic way, as opposed to physical way. It is suggested that the individual may fluctuate between these two different forms of coping, and eventually will achieve a balance of the two. It could be suggested that for such individuals in this study who commented on the importance of Candlelighters in their grieving process, that the emotional impact of volunteering and sense of family may refer to the times in which an individual is in the loss orientation stage, and being close to an organisation who provided support to their loved one and themselves during a traumatic time provides a sense of being closer to their loved one. The formation of new identities, boundaries and confidence may refer to the individual moving into restoration oriented coping.

In recent research exploring the experiences of volunteers in cancer charity roles, an "economy of giving" was found, in which volunteers gained from either repaying a debt or aiding the grieving process (Pourtau et al., 2016). This very closely mirrors the findings in this current study that volunteers want to give, or 'give back', and as previously mentioned, that this action is seen as beneficial to the volunteer through its facilitation of the grieving process. The study by Pourtau et al (2016) suggested that the impact on grieving seen in that study was due to the participants experiencing symbolic reward through volunteering. In the current study however, there was a sense that volunteering for Candlelighters helped the participants to feel as if they are in some way paying tribute to their child's memory. Whilst both studies found broadly similar findings and were both cancer charities with some volunteers with lived experience of cancer, there seemed to be subtle nuances in the way that involvement with the charity was conceptualised. For example, whilst the participants in the current study seemed to view their volunteering as a life-long involvement with the charity as described in the sub theme "commitment", the participants in the study by Pourtau et al (2016) made references to working out the "end of the debt", how the debt could be

"closed off", or the experience of finding it hard to do so. As such, this indicates that participants in the previous study viewed volunteering as a boundaried, time limited activity in which once the debt was repaid, involvement ceased.

Superordinate Theme 2: Identity and Roles

When talking about their involvement with Candlelighters and volunteering, participants in the present study referred to identity; both how volunteering and having the skills and resources to do so fit with their values and sense of self *"That's it, it's me now"* (Congruence) and "Competence and Confidence", but also how volunteering presented difficulties when either their sense of self, or their personal set of values was challenged through "difference", and how they managed such new identities and roles through personal boundaries.

This sense of identity and roles that was apparent in the current study mirrored the proposed motivations model by Clary et al. (1998) who identified congruency of the role with a person's values as one of the six main functions for volunteering. Turner (1978) discusses the concept of role identity in which depending on the level to which an individual adopts a role, and the pervasiveness of that role and behaviour across different situations, the person and the role may merge. Role identity theory suggests that how an individual conceptualises the self is related to the social role they assume (Grube & Piliavin, 2000). The more salient a role identity is for a person, the more likely this will form part of their identity and the more positive an impact the role will have on that person's wellbeing (Charng, Piliavin & Callero, 1988; Thoits, 2012). The participants in the current study identified with the role to varying degrees, some emphasised that being a volunteer felt integral to their sense of self, whereas others experienced volunteering as being one part of their identity, balanced with other roles and hobbies. Importantly, in the current study, when comparing participants who

referred to volunteering as being one part of them with participants who described the role as being central to their sense of self, there did not seem to be a significant different to the positive benefits either group felt. This may be due to the saliency of the role still being high for all individuals, therefore acting in a protective manner, and for some providing a restorative experience due to the level of confidence the participants experienced.

Notably, many of the participants in this study who described congruency with the role also currently volunteered for other charities. This finding differs from previous research which found that individuals who hold a strong role identity as a "volunteer" in general and a strong role identity as a volunteer for a specific charity experience emotional conflict due to not being able to fully satisfy either role identity. This is due to the latter role identity demanding maximum time and resources to the chosen charity, clashing with the time and resources needed when volunteering for a range of charities (Grube & Piliavin, 2000). It is of note that one of the volunteers in the current study who experienced congruency with the role described a sense of deeper congruence and authenticity because of volunteering elsewhere, as opposed to this causing the participant conflict; as did another participant who identified also working in another caring profession,. This is of interest as it might suggest that holding an identity as a volunteer in general and as a volunteer for Candlelighters does not cause conflict and instead provides a sense of acting in line with values and authenticity. It could be suggested that this is due in part to the flexibility that volunteering for Candlelighters allows, enabling participants to also be able to volunteer for alternative charities at the same time, whilst still aligning themselves fully to Candlelighters. Alternatively, participants may experience the role with Candlelighters to feel more natural and to be already aligned with their values, therefore requiring less adjustment to satisfy each role

identity. Whilst this is of interest, this experience was only present in two of the participants accounts, therefore it would be difficult to generalise further.

A new role can present challenges around managing expectations of behaviour and social interaction. Participants in this study reflected on boundaries as guiding principles for appropriateness and expectations of behaviour, however it was noticeable that these were reflected on in different ways by different participants. Some participants described a personal view that boundaries with families and other professionals were necessary and important, and a sense that this would help both themselves and the families they were supporting. Others were either more passive in their sense of boundaries, with these being encouraged externally, or experienced their relationship with the families as more of a friendship than a professional relationship. This is reflective of Merrell (2000)'s study which, although related to larger organisations than Candlelighters, found that for volunteers there was often uncertainty around self- disclosure and an inconsistency in individuals' opinions about how it should be utilised. In the current study, whether participants experienced their boundaries as internally or externally driven determined the degree of self-assurance around boundaries. Those who had more of an internal sense of their boundaries may have increased confidence and conviction in upholding the boundaries, whereas for those who perceive to have "been told [the] boundaries" may experience more confusion over where the boundaries lie and delineation of the role of a volunteer.

New roles and identities can have both positive and negative impacts on volunteers and the work they do, especially when the volunteer has lived experience of their own. Researchers have previously warned that volunteers with lived experience of cancer run the risk of viewing the experience of the individual they are supporting through their own perspective rather than through the eyes of that individual (Pourtau et

al, 2016). The risk outlined in Pourtau's study may draw parallels with the current study's sub theme "difference" as participants described finding differences in perspective, styles of coping or differences between volunteers' experiences difficult to manage at times. This may be due to a conflict in the individual's belief system in which their world view was challenged by supporting a family with a very different experience to them, or who responded to that experience in a way which challenged the volunteer's sense of wrong and right. For example, one participant noted shock at how accepting one of the families were of their child's illness. Additionally, it may be that exposure to another individual's experience may trigger an experience of survivor's guilt. Survivor's guilt refers to the sense of guilt that an individual experiences through being witness to others suffering when they believe that in a similar situation they had not suffered to the same extent. A phenomenon described in holocaust survivors (Niederland, 1981), these individuals can find it harder to accept enjoyment and continue with everyday routines- a phenomenon which is common for disaster volunteers (Pardess, 2005). A sense of guilt was experienced by some participants in the current study, whose child had recovered from their illness and the individual reported feeling guilt when hearing the experiences of fellow volunteers or the families they were supporting who had lost their child. Research investigating this phenomenon in disaster volunteers recommends that volunteers will benefit from a sense of belonging, support from the team, and a sense of agency to help to protect from burnout and survivor guilt (Pardess, 2005), all factors which have been found to be a source of protection for the individuals in the current study.

Superordinate theme 3: Coping
With the challenges discussed above in the sub theme "differences" in mind, participants were prompted to consider how they managed the emotional impact of the

role, especially when the participant had lived experience of their own. Such reflections on coping revealed two different types of experience. Some participants described what they felt was a natural resilience and being able to cope, with little awareness of how they did it, as portrayed in the sub theme "*Naturally happened "it were a feeling"*. Others, however, described actively managing emotions with conscious strategies, either through ensuring balance in their life, or avoidance of challenging conversations around bereavement and a focus on encouragement and positivity. This led to the sub theme "protecting the self". The latter theme of actively managing emotions replicates the findings of previous research with hospice volunteers which found that some volunteers cope with the emotional impact of the work through problem focused coping (such as seeking advice from others) and emotion focused coping (such as talking to others, pet therapy, avoidance and religious beliefs) (Brown, 2011).

However there was little research around how volunteers with lived experience manage the emotional impact of volunteering. Emotional contagion and levels of empathy that are found within authentic relationships at work have been found to increase the chances of burnout and emotional distress (Omdahl & O'Donnell, 1999; van Mol et al., 2015). In addition to this, Najjar, Davis, Beck-Coon and Doebbeling (2009) argue that there is a heightened risk of this in relationships in which there is opportunity for identification due to the different parties exhibiting similarities in lived experience. Despite this, whilst participants were able to reflect on the challenges associated with volunteering, there seemed to be little evidence of burnout or severe emotional distress in those interviewed. It should be noted however, that this study did not use standardised measures to directly measure this construct. It is also possible that individuals who volunteered for the interviews did so because they were not experiencing burnout and found volunteering to be beneficial, hence a desire to talk about their experiences. There was little literature on how volunteers with lived

experience manage the emotional impact of volunteering, specifically what strategies they employ, or what experiences enable them to cope with emotional demands. Rolland (1987) suggested that families which experience childhood illness, especially those illnesses with an acute onset, are required to develop skills to manage crises due to the period of processing and adjustment that is involved. He suggested that families who have an increased tolerance for high emotional arousal may demonstrate more resilience in this situation. More recent research has found no link between illness trajectory and specifics of the illness such as type and duration, further confirming that family process plays an important part in how a family moves through an illness trajectory (Cipolletta, Marchesin, & Benini, 2015). It may be that individuals from such families, who have developed efficient coping strategies in response to the onset of childhood illness, are those who choose to volunteer following such an experience, due to a higher level of resilience and tolerance for emotional arousal.

Additionally the sense this process being "natural" may become apparent through the protective functions of compassion satisfaction. Compassion satisfaction refers to the rewarding aspects of volunteering such as fulfilment and self –gratification (Weintraub, Geithner, Stroustrup, & Waldman, 2016). Studies have shown compassion fatigue, burnout and compassion satisfaction to be predictive of each other in individuals such as healthcare professionals and volunteers. More specifically, studies reported a negative relationship between compassion satisfaction and compassion fatigue/burnout (Conrad & Kellar-Guenther, 2006; Sorenson, Bolick, Wright, & Hamilton, 2016; Thieleman & Cacciatore, 2014). Therefore perhaps it is not surprising that there were themes of both *"emotional gains",* and *"coping"*, demonstrated by individuals reflecting on the experience of coping alongside gaining a sense of reward through volunteering. On the contrary, however, Lydon (2009) identified that compassion fatigue may be more prevalent in the voluntary sector due to lower levels of

training. Findings from the interviews in the current study showed that the participants felt well supported and all reported the training to be thorough, perhaps leading to a sense of certainty and a feeling of control. It may be that this increased level of training has served as a protective factor against compassion fatigue in this population.

Superordinate theme 4: Community

A seemingly important experience for participants within this study was the experience of being part of a wider community or group and experiencing a sense of togetherness. Participants described this both environmentally, in gaining a "sense of place", and emotionally in the sense of "belonging". Participants also talked about the charity in an active way indicating a sense of "ownership" with regards to the outcome and success of the charity and "commitment" as seen by participants' comments around long term dedication to the charity.

The bioecological model of human development (Bronfenbrenner, 1986) proposes that individuals can be thought of as part of multiple wider systems. An individual's micro system may include close family and friends, wider family or their school, whilst their macro system may include the organisation of a parent's workplace or alternatively the community they embed themselves in. The volunteers at Candlelighters described their experiences in relation to different systems. On the one hand they described Candlelighters as being part of a community, alluding to it forming part of their macrosystem. On the other hand, participant's talked about Candlelighters as if it also sat within their microsystem- an experience which will be discussed later in the theme "family". Later versions of the bioecological model of human development included the concept of time to capture the impact of historical events on an individual's development and current experience (Bronfenbrenner, 1995). In support of this, Neal and Neal (2013) proposed a 'social network model' in which the concept and focus of

an individual's different level of systems was similarly highlighted as important. In line with Bronfenbrenner's model, the 'social network model' highlights how different systems are inter-linked and how this pattern may change over time. This concept can be seen in the current study as the participants experienced Candlelighters as part of multiple systems.

Though much of the research into the experiences of "community" refer to an association with a particular location or geographical place, there are suggestions within the literature of community being a more psychological entity (Omoto & Snyder, 2002). McMillan and Chavis (1986) describe a sense of community as a feeling of belonging to a group and a confidence that their needs will be met through the group itself. This interaction with the physical group members and the resulting sense of community that the group provides demonstrates the different facets of "community".

We know that having a sense of community is a feeling in which an individual considers themselves to be a member of the group, to have influence over decisions and outcomes, and can use the group to get their needs met through shared emotional connections (McMillan & Chavis, 1986). This concept of a "sense of community" in volunteers is not new, and previous research has investigated the experience of a psychological sense of community within AIDS volunteers. Specifically, Omoto & Snyder (1999) (as cited in Omoto & Snyder, 2002). found that 81% of AIDS volunteers reported having friends through their volunteering work, and 21% reported having a significantly *close* friend through the AIDS service within 6 months of volunteering. More recently, studies on community participation (Talò, Mannarini & Rochira, 2014) and frequency of volunteering for small scale local sports events (Kerwin, Warner, Walker & Stevens, 2015) found a positive relationship between the psychological sense of community and volunteering participation. Further adding to this sense of

community, participants talked about a "belonging" to the community, facilitated through connection with others. Research on altruism reflected by altruistic kidney donation -in which a healthy individual donates an organ to an unknown recipient - has found two major themes in the donor's experiences. The first centred around difficult negotiations with family and friends due to health risks associated with the donation. However, the second theme of being "connected to others" suggested that individuals felt some alliance and a sense of being at one with those to whom they donated (Clarke, Mitchell & Abraham, 2014). This sense of connection is also seen in the current study, suggesting that the act of volunteering itself, and doing something for another individual, may produce experiences of connectedness and affiliation with others. Whilst the experiences between the participants in each study are very different due to level of contact with those they are helping, participants in both studies are exposing themselves to an emotionally challenging situation, within which it is clear that a sense of social connection is important. For those in the current study who directly support families, they may experience a more concrete connection in that they can physically meet with those they are supporting, and have a sense of who they are and their life experiences. The participants in the study on kidney donation however may never meet those they donate to. Except for the issue of anonymity, the latter experience may share attributes with the experience of the admin volunteers in the current study, who expressed a sense of connection and being able to impact families, despite not working directly with them. This is interesting for two reasons; it tells us that a sense of connection to those the charity aims to support is important, but perhaps more significantly that this sense of connection can be facilitated in volunteers who do not meet the families, but can still have a positive impact on their sense of "belonging" and overall experience of volunteering.

The "sense of place" that was also described was referred to as an attachment to the building and environment itself, often seen as creating a change in the participant's mood as they approached the Candlelighters building, and a sense of safety created by the staff team. The theory of place attachment refers to such a phenomenon in which individuals are emotionally and/ or culturally bonded to their physical environment. Such an attachment to a physical location or building can be shared across families, communities, and groups, and indeed may be impacted by such social relationships, due to the place itself representing the social relationships that the individual values (Low & Altman, 1992).

The findings of this theme so far have alluded to the importance of the attachment to the charity itself and the environment that is associated with Candlelighters, whilst emphasising the significance of a sense of community and belonging. Individuals may approach this relationship in different ways, either as a passive receiver or taking some "ownership" over the relationship and being more active in its shaping, for example through offering suggestions on recruitment of families for the family support groups. The latter was found to be true of the participants in the current study, in which the language they used tended to be more active, indicating a sense of agency and control in decision making and outcome of the charity. The positive impact of such agency is consistent with previous research that found perceived control in volunteers (measured using survey techniques) increased their sense of wellbeing (Mellor et al., 2008). Such quantitative techniques however restrict the participant's individual voice and subtle nuances of experience when trying to understand the influence of control and sense of ownership on experience of volunteering. The current study demonstrates individuals' experiences of being able to influence and hold some responsibility for the charity's outcomes. This was frequently

presented through pledges of allegiance to the charity and an acknowledgement of the impact of the volunteers' contribution whether seemingly large or small.

Linked to this idea of ownership was the overwhelming sense of "commitment" to the charity that participants' experienced. They often described their experience of volunteering to be a long term investment, a sense of wanting to commit to the charity and give for as long as they could. This is significant when thinking about the experiences of Candlelighters' volunteers as a whole as such long term commitment is typical of more traditional volunteering, as opposed to the more recent increase in episodic volunteering in which volunteers offer up their time more sporadically (Hustinx, Haski-Leventhal & Handy, 2008; Rochester, 2017). This perhaps suggests that creating such a strong sense of community and enabling the development of volunteer identities facilitates retention and dedication of volunteers.

Superordinate Theme 5: Family

As previously mentioned, the bioecological model of human development (Bronfenbrenner, 1986) also considers the effects of the microsystems on an individual and their experiences. Such microsystems may include an individual's close family and friends or wider family. In the current study, for some individuals, describing their relationship to Candlelighters as a community did not seem sufficient to capture the strength of their bond or fully capture the experience they had of Candlelighters, which in their words more closely resembled that of a family. Participants in this study often used the term 'family' when they talked about Candlelighters', sometimes metaphorically, in the sense that they felt part of a "Candlelighters family". This sense of relating to Candlelighters as their family, and the charity potentially exhibiting features of a family, indicates that Candlelighters for many individuals, form part of their microsystem as well as their macrosystem as described earlier in the theme

"community". On a different level some participants discussed how individually volunteering with Candlelighters benefitted their whole family reflecting on the systemic nature of the benefits of volunteering. Others reflected on their experience of volunteering for Candlelighters with their own family, and how this led to an experience of a family event. The different aspects of *"family"* were presented through the following sub themes; *"Team as family", "and that shows in my family as well"* (Benefit to participants family) and *"we do most of it as a family"* (whole family involvement).

As many of the participants had lived experience of cancer and this was experienced as a family event, such a strong relationship with healthcare professionals or third sector organisations in a supportive role such as Candlelighters is perhaps not surprising. As discussed previously, there is a wealth of literature emphasising the necessity of quality relationships between parents and medical staff when the child has a chronic or critical illness (Bry et al.,2016; Brooten et al., 2013; Gibson, 1995; Thorne & Robinson, 1988). Further to this, wider literature reports the necessity of a positive relationship between professionals and parents who are currently caring for a chronically ill child or in the grieving process (Snaman et al., 2016; Swallow & Jacoby, 2001). It may be that volunteers with lived experience of childhood cancer and for some, an experience of close relationships with medical staff that may have been found to be helpful, that these individuals may prioritise and experience close relationships with professionals to be the norm, and may be something they initiate or seek out. Additionally, research has shown that those with larger support networks experience less psychological distress in challenging times than those with smaller support networks, potentially due to having more people to turn to for support when required (Kazak, Reber & Carter, 1988; Umberson & Karas Montez, 2010). In the current study, participants described feeling

emotionally supported by the charity whilst volunteering, and it may be that such relationships have proved invaluable in the past, and therefore are sought out.

However, whilst this prior research demonstrates the importance of relationships when individuals are going through challenging times, it does not explore the continuation of these relationships when individuals volunteer, and the experience of such relationships - as the current study's findings revealed. The strength of the bond described suggests that relationships between some volunteers and Candlelighters were viewed in parallel to family relationships, suggesting a level of unconditional support and care as associated with families.

Participants experiences of volunteering involving family, and benefits from volunteering spreading to wider family members demonstrates the importance of family in participants' decisions whether to volunteer or not and potentially how long volunteers stay for. Such experiences are mirrored in previous research which found benefits of families volunteering together to include bringing the family members closer together, parents being able to role model helping behaviour to their children, and the practical experience of being more efficient as an individual family rather than an individual (Littlepage, Obergfell & Zanin, 2003).

Additionally, there are schools of thought such as bereavement models which may view the concept of 'family' in this setting as part of the grieving process. Bowlby (1980) identifies 4 phases of mourning; "Numbing", "Yearning and searching", "Disorganisation" and "Reorganisation". It could be suggested that individual's experience of Candlelighters as a family is a part of the participants searching and yearning for their loved one as suggested in the second stage of mourning, and that a closeness to the Candlelighters volunteers (who had supported the individual in the

past) creates a feeling of closeness to the individuals family member who had passed away.

Overall, it can be seen that family is an important part of participants' experience of volunteering for Candlelighters. On a more individual level, volunteers' individual experience of Candlelighters impacted the wider family therefore creating an experience of shared benefits. When families volunteered for the charity together, this shared experience extended to a family event in which volunteers and their families could experience working towards shared values. All of these different experiences of family are experienced within an overarching relationship with Candlelighters which has also been described as a familial relationship. The experience of familial relationships are felt at all layers of the system and may interact together to create secure relationships and a safe base for the volunteers. An experience which it could be suggested better mirrors experiences of being in a family rather than those of friendships, professional or wider community relationships.

It is of note, that when thinking about the superordinate theme of "family", I was uncertain about the use of the term "family" as a theme name due to this term having acquired a somewhat clichéd resonance within the wider literature and not wanting to put people's experiences into pre-defined boxes. Nonetheless, this was the language the participants used throughout the interviews to describe their own experiences. Notably, when participants referred to feeling part of the "Candlelighters family" they did not describe this experience to be *like* a family, but described their experience *as if they were* part of a family, further emphasising the significance of "family" as part of a participants' experience. To attempt to accurately capture the participants' experience, the term "Family" has been used to name this superordinate theme.

Strengths and Limitations

Strengths

This research offered a new and (as far as the researcher is aware) relatively

under researched perspective on volunteers' experiences within a childhood cancer

charity. Whilst previous research has investigated specific aspects of volunteering in

such a role, this has either used quantitative approaches or has focused on experiences

within an adult cancer charity.

Qualitative Methodology

Working in an emotionally challenging area such as childhood cancer inevitably brings

about complex and multifaceted experiences that could not be fully captured through a

quantitative approach. The use of qualitative methodology for this study enabled an

exploration of the volunteers meaning, and an opportunity to understand how

participants make sense of the world and their experiences in a sufficient level of depth

(Sofaer, 1999).

Strengths of IPA

IPA has been reported to be a particularly useful methodology for research that

aims to understand an ideographical understanding of a person's experiences and the

sense they make of such experiences (Smith, & Osborn, 2003). As IPA focuses on how

the individual experiences a phenomenon rather than reporting on the phenomenon

itself (Eatough & Smith, 2017), this helped to capture experiences specific to an

individual charity, understand these from the participants' perspective with past and

present life events in mind, and attempt to portray this in a way that stayed true to the

participants' experience. Whilst doing this however, the level of interpretation that IPA

enables allowed me to attempt to get a deeper understanding of the participants'

experience, and consider my own influence within the relationship between myself and

the interviewee. This process facilitated the use of psychological understanding in an attempt to deliver a more personal account of an individual's experiences (Eatough & Smith, 2017).

Contextual Factors

In order to build trust and better understand the context within which the participants were volunteering, I spent time with the charity, attended a generic Candlelighters' staff induction and held drop in sessions to allow participants to approach me on their terms if they wanted to better understand the aims of the study. From spending this time with the charity and understanding a bit about the nature of the charity's work, I was aware that the focus of the charity's work may be particularly distressing for individuals, which helped to shape my topic guide and led to an interest in initial questions such as why individuals volunteer.

Quality checks

Steps have been taken to facilitate the reader's understanding of my process of analysis; as outlined in Elliott et al., (1999). Quality checks I undertook included: situating the sample by giving some demographic details and providing pen portraits for each participant to allow the reader some insight into the context of each individual's experiences. Nonetheless, as outlined in the results section, due to the small size of the charity that the participants have been recruited from, I have limited the amount of detail that has been provided in the pen portraits to preserve anonymity to the best of my ability. In addition to this I fully immersed myself in the data through rereading the transcripts a number of times. I utilised supervision immediately following the initial interview to reflect on the quality of the interview, make any changes to the topic guide to ensure its effectiveness at eliciting rich data, and note any initial reflections.

Throughout the interview process, I shared my themes and selected anonymised extracts with my research supervisors to check whether or not my account of the interpretations was credible (Elliott, Fischer &Rennie, 1999; Larkin & Thompson, 2012).

Finally, I kept a reflective journal throughout the research process, and took part in a pre-data collection reflective interview to be more aware of any assumptions I may have had as an interviewer, which in turn may have impacted on how I interpreted the data (Elliott, Fischer &Rennie, 1999).

Limitations

Criticisms of the analysis

Whilst IPA has afforded this study many strengths in the reporting of individual experience, there are important criticisms of the approach that should be explored. Such criticisms suggest that it relies on the participants being able to articulate their experiences through language (Willig, 2001). For some of the participants in this study this may have been a difficulty as often they were unsure how to answer the questions, perhaps because the experience was difficult to put into words, for example one participant saying "ahh I don't know how to explain it" when describing what it feels like to support siblings of children who have cancer. However participants were able to talk about their experiences in a complex way, readily accessing the emotion, and providing links of sense making and meaning.

Homogeneity of the sample

Smith et al. (2009) stated that in order to produce themes that are representative of a group of people who share similar experiences, a sample should be as homogenous as possible. Initially the inclusion criteria of the study seemed to facilitate this sample selection as recruitment was from a small local charity in Leeds. Whilst the charity

reaches a wide geographical area due to the widespread need for support, individuals interviewed all work as volunteers within the Yorkshire area, and volunteer for the same charity. However, it is important to recognise that the volunteers interviewed held a range of different roles ranging from admin volunteers, and front of house to family network support volunteers, indicating a large range of experiences were covered. It is also important to recognise participants had different prior life experiences before beginning volunteering. Whilst in some ways the homogeneity of the sample may be compromised, this sample may capture the reality of the varying roles that volunteers can undertake, and the representational composition of a charity workforce.

It is important to note however, that the range of time spent volunteering with this charity spanned a significant range, from 3 months to 6 years. Such differences in amount of time spent at the charity will undoubtedly have an impact on the experiences these individuals had, and the sense they made from being a volunteer for a childhood cancer charity, subsequently compromising the homogeneity of the sample recruited.

Sample Bias

It should be noted that the sample is in some ways self-selecting, as whilst the charity do not have an expansive volunteer base, the response rate was not 100%. It may be that those who came forward to be interviewed did so because they experience benefits from volunteering and have more positive experiences of it, therefore producing a degree of bias. In addition to this, by interviewing those currently volunteering with a charity, we exclude those individuals who began volunteering but did not continue, or were approached to volunteer but felt it was not for them.

There is also the reality that all but one of the participants are still actively volunteering for Candlelighters, and some (by their request) were interviewed in the Candlelighter's building. This inevitably creates potential for bias due to individuals

being asked to explore their experiences of working with Candlelighters, whilst sat in the building they work in. There may be a desire to please the charity, or avoid the potential for conflict to maintain positive relationships with the charity. In addition to this, due to social desirability bias, participants want to present an image in keeping with social norms. Due to the sensitive nature of childhood cancer, participants may find it difficult to express negative experiences of working for a childhood cancer charity. This bias was reduced as much as possible by preserving anonymity and outlining confidentiality. However due to the small size of the charity, absolute anonymity could not be guaranteed. Additionally, as place attachment was found to be a significant experience for some of the individuals, being interviewed in the place they are attached to may have brought up different experiences to a scenario in which they were interviewed in an alternative building or over the phone.

All participants volunteered for the same charity. This was an intentional decision as it enabled comparison across individuals to obtain themes about working in such an area, however it limits the generalisability to other charities which also provide support for families with childhood illness. It may be that there are different milieu in different charities and it would be interesting to explore the impact of the different organisation set up and dynamics of different charities.

It is important to note that the gender split of the participants was heavily female oriented, with only one male coming forward to do an interview. This gender bias is reflective of the gender difference in types of volunteering roles with women being found to be considerably more likely to volunteer in a caring role (UK Civil Society Almanac, 2016). These statistics may suggest that women are more likely to volunteer for a charity such as Candlelighters in which the aim is to offer care and support to families with a child with cancer. Therefore the sample that I have recruited may

actually be representative of the gender split in childhood cancer charities such as Candlelighters.

Characteristics of the charity

Social desirability bias refers to the need of participants to present themselves in such a way that will be socially approved of by others (Crowne & Marlowe, 1960). Croson, Handy and Shang (2009) outline that social norms of giving can increase the amount of donations received by charities, suggesting that charitable donations given may be seen as a socially positive activity and that individuals are influenced by the awareness of such social norms. Due to the sensitive nature of the charity and the potential for social appraisal, it may be that participants felt unable to express negative experiences or attitudes towards a childhood cancer charity which they may have felt might have been disapproved of.

Researcher bias

As outlined in the method section, steps were taken to minimise any potential researcher bias such as keeping a reflective journal throughout the process, sustaining a reflective researcher position and noticing my own responses and reactions to the interviews. In addition to this, quality checks of the themes and sub themes were made by my research supervisors and verbatim extracts were provided to evidence these and increase transparency. Despite this however, as interpretative phenomenological analysis endorses, it is almost impossible to bracket our experiences entirely, and in this approach, nor should we do so. Therefore many of the themes that emerged from this data set may differ if another researcher were to analyse this data set.

Topic Guide and Interviewer Behaviour

It feels important to acknowledge my role of being a psychologist in clinical training. On the one hand, I feel that the skills associated with this role enabled me to

empathise and actively listen to the participants throughout the interview. However, I was also aware that at times I slipped into the clinician role instead of researcher role, perhaps paraphrasing and offering interpretations in the interview, as opposed to simply enquiring. Whilst I reflected on this in supervision, and actively tried to remain in the researcher role throughout additional interviews, it is to be noted that some of the data analysed may have been elicited in this way.

In addition to this, due to being a novice researcher the topic guide that was developed could be improved. Whilst the guide was revisited following each interview to allow for appropriate revisions, it may have been useful to include more experience based questions as part of the topic guide in order to elicit more of the participants experiences rather than fact based information.

Data Collection Method

Due to requests from participants and in order to increase access to the interviews, I extended the option of face to face interviews to include telephone interviews. Whilst this increased the number of volunteers who were able to take part, it is important to note that the different data collection methods have advantages and disadvantages. As a researcher it was difficult in the telephone interviews to convey active listening and empathy when participants were talking about emotional topics. In addition to this, I was also unable to access their non-verbal communication, for example their body language or facial expression.

On the contrary however, my experience was that participants appeared more relaxed in the telephone interviews, and were more able to access some of the challenging experiences of volunteering. It may have been that the telephone acted as a barrier that created a sense of safety.

Upon reflection of these data collection methods and the advantages and disadvantages of both, using a communication method such as Skype may have allowed for the convenience and sense of safety that telephone interviews provided, whilst still allowing access to non –verbal communication of both parties.

Implications

There are important wider implications of this study relating to the findings that we now have in our understanding of volunteers' experiences of working within a childhood cancer charity. Such information may suggest that in order for charities to retain volunteers, and to enhance their volunteers' mental wellbeing and satisfaction, implications might be that charities should focus on creating a sense of community and strong relationships with volunteers, whilst encouraging the sense of identity developed through the role. This research suggests that whilst volunteers may experience challenging situations and difficult emotions at times within this role, they are protected by the containing experience of the charity, the security of the relationship they have with them and the sense of purpose and agency gained from the role. It would be important for charities to consider the stage of grieving that the volunteers are in, and how best to support them through their time volunteering with the charity. Bereavement models could be used to help volunteers reflect on their experience of volunteering and promote wellbeing.

With regards to specific implications for the charity involved in this research, the findings imply that whilst most volunteers appear to manage the emotional challenges and boundaries for the role well, there may be a role for clinical supervision (either individual or group supervision) to help volunteers reflect on the impact of some of their past experiences and allow space for regular reflection. Such time for reflection could also facilitate individuals in their awareness and development of their own sense

of their personal boundaries, allowing for an increasing sense of certainty and role delineation.

In addition to this, it is clear that those volunteers with lived experience of cancer have a different experience to those without, as evidenced by the difference in initial motivation between the two groups, and volunteers with lived experience more prominently describing a long term commitment to the charity. It could be suggested that a person centred approach to roles within charities would be useful, both in planning of the job and in the specificities of support for the volunteer, taking into account their experiences before volunteering and how they conceptualise volunteering as part of their lives.

Future Research

The current study investigated the experiences of volunteers working within a childhood cancer charity. As previously outlined, volunteers as a group are relatively under studied, and the literature base would benefit from further research into this area. Volunteers contribute significantly to the economy and society, and there is the suggestion that volunteering as an activity can provide meaning and purpose, potentially decreasing the likelihood for mental health difficulties. This study found that whilst volunteers experience emotional challenges from their role, they appeared to be protected through role identity and a sense of connection, both on a community level and a familial level. As this study has only investigated volunteering in those who are currently still volunteering, it would be interesting to widen the inclusion criteria to individuals who began to volunteer but did not keep doing so, or were approached but decided it was not for them. This would allow exploration of the more challenging aspects of volunteering, and how these people or their experiences differ to those who have found it helpful.

Finally, as the data came from one charity within an emotionally sensitive area such as paediatric oncology- the implications that have been suggested might be targeted at similar charities. Further research may be needed to explore the effects of these protective aspects on volunteers within different charities.

Conclusions

The current study explored the experiences of volunteers working in a childhood cancer charity. It described five superordinate themes: Motivation, Identity and Roles, Coping, Community, and Family.

Overall, participants seemed to make sense of their experience by emphasising the importance of the role itself and the way in which this impacted their sense of self and subsequent confidence. Although participants reflected on the challenges that they faced, the relationship. Specifically, participants expressed a sense of being part of something wider and personally sharing the charity's aims. The ways in which these different aspects of the volunteering experience were thought about in the interviews emphasised emotional links between such aspects, which seemed to help the volunteers make sense of their experiences.

Whilst the importance of relationships, community and identity as potential benefits of volunteering are not surprising, the importance placed on this relationship by the participants is interesting. Organisations aspiring to be seen by employees as a family is arguably a modern cliché, but participants in the current study used this analogy in a genuine, reflective way. It is likely that such a relationship has a protective function in terms of the emotionally demanding nature of the volunteer role in this charity. In addition to this, as already noted, many of the volunteers in Candlelighters fit a similar

profile to the more 'traditional' style of volunteer in that they have a sense of long term commitment to the organisation (Hustinx, Haski-Leventhal & Handy, 2008; Rochester, 2017). At a time when episodic volunteering is on the rise (Hustinx, Haski-Leventhal & Handy, 2008; Rochester, 2017), this study provides evidence about the importance of attachment to the charity in retaining more long term volunteers, enabling the development of expertise, and the motivating aspects of a sense of community and role.

Volunteers are becoming increasingly important in society and the development of volunteer roles is actively encouraged in government policies emphasising community participation. With finite NHS resources and an increasing demand on health and social care due to an ageing population, the importance of volunteers in the healthcare service is ever increasing. Although psychologists are active in investigating the wellbeing of NHS staff and how best to support them, volunteers have received comparatively much less attention. This study focussed on what was presumed to be a particularly challenging area for volunteers - childhood cancer. Some of the findings were more predictable in that many of the volunteers had lived experience of cancer and so wanted to 'give something back'. Many had experienced significant loss, however, and their friends and family often expressed disbelief at how the participants 'did it', given their experience. This study found that whilst others may have expressed disbelief at their choice to volunteer, participants did not experience conflict, more accurately they experienced benefits from volunteering. Whilst some benefits were practical and more concrete, most notably participants were very clear in describing psychological and emotional benefits from volunteering. Despite volunteers recognising the challenges involved and contrary to what might be expected, the overarching experience is a positive one. The experiences described in this study offer a way in which we can better engage and incorporate volunteers in a healthcare setting and in particular

emotionally challenging areas such as childhood cancer, whilst supporting and

protecting their wellbeing.

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Appendix A. Information Sheet

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Participant Information Sheet

This is an invitation to take part in a research study; 'The experiences of volunteers working for a children's cancer charity'

What is the purpose of the research?
The aim is to better understand the experiences of volunteers, in particular those working with a children's cancer charity such as Candlelighters. In order to do this, I hope to carry out interviews with volunteers of Candlelighters about their experiences of being a volunteer.

Do I have to take part?
It is up to you to decide whether to take part or not. If you decide to participate you will be given this information sheet to keep and asked to sign a consent form. If you decide to take part you are free to withdraw at any point during the interview process and up until 72 hours post interview, as this is when the analysis stage will take place. Following this date, due to the anonymisation process, I will be unable to retrieve your individual data. You do not need to give a reason for withdrawing and a decision to withdraw or not to take part will not affect your position as a volunteer in any way. If you are interested in taking part I will answer any questions you may have.

What will I have to do if I take part?

Interview
You will be asked to attend an interview at the Candlelighters base (8 Woodhouse Square) with myself. The interview length will be guided by you and how much you would like to say within the interview, however on average they last between 20 minutes to 1 hour. I will utilise a topic guide for the interviews, however these are only general areas, and the interview content will ideally be guided by yourself, so please only speak about what you feel comfortable with.

Alternatively, if you are unable to attend an interview at the Candlelighters base, an interview can be offered over the phone.

Recording
The interviews (both face to face and telephone interviews) will be recorded with your permission. This is done so the interviews can be transcribed afterwards, preventing the need for me to take many notes within the interview. This will hopefully allow me to listen to you more and hear your experience better.

Are there any possible advantages of taking part?
Your involvement will aid understanding of volunteer's experience, and will help Candlelighters to prepare and organise their training and support for their volunteers. Finally, I hope the research process allows a chance for your story and experiences to be heard.

What happens to the information I provide?

Anonymity/ Confidentiality
All the information I obtain will be written up into a report that will be submitted as part of my doctorate degree. The report will be uploaded onto an online database, and may be submitted for publication. However at no point within the report will your information be

identifiable. When the information you provide is written up, to maintain confidentiality, identifying details such as your name will be removed. A pseudonym of your choice will be used throughout the report to anonymise your data. However, due to direct quotes being used verbatim within the report, complete anonymity cannot be guaranteed, and there is a small chance someone may be able to identify you. All transcripts will be stored on a secure setting on my personal university M: drive, which nobody else other than myself has access to. Following the write up of the study, the transcripts will be kept for 3 years to allow time to refer back to the original transcripts in case of publication.

If you agree to taking part in the research interview, I will ask you to sign a consent form to confirm that you have read this information sheet and have had an opportunity to talk through it, and ask any questions you may have.

What if I find the interview upsetting?
I do not intend for the interview to be distressing in anyway, however there may be certain topics or areas that feel more difficult for you to talk about. I would encourage you to be mindful of what you feel comfortable to talk about, take regular breaks if this feels helpful, and I will allow time for a debrief with myself following the interview, should you find this helpful. I will also signpost you to further sources of support, as outlined below.

Support sources:

Candlelighters   - Clair Smith or Carly Tordoff   Mind -   http://www.leedsmind.org.uk/
                  Tel: 0113 887 8333   Tel: 0113 305 5800

Potential breaches to confidentiality

It is to be noted that if the information you provide gives me cause for concern that yourself or another may be at risk of harm, I would need to breach confidentiality. This would entail informing Candlelighters of my concern so that they can follow their safeguarding protocol. If this were to be the case however, I would try to talk to you about it first if at all possible.

This project has sought approval from the School of Medicine Research Ethics Committee (SoMREC 16- 143)

Need further information or have any concerns?
If you would like further information about the project then please ask me in drop in sessions or contact me at the address below.

Rachel Eastaugh
Psychologist in Clinical Training
Clinical Psychology Programme, Leeds Institute of Health Sciences,
University of Leeds, Worsley Building – Level 10, Clarendon Way, Leeds LS2 9NL
umre@leeds.ac.uk

If you would like to speak to either of my thesis supervisors, please see the contact details below.

Gary Latchford	*Tom Cliffe*
Joint Programme Director	*Lecturer in Clinical Psychology*
Clinical psychology Training Programme	*Tel +44 (0)113 343 3407*
Tel: +44 (0)113 343 2736	
Leeds Institute of Health Sciences, University of Leeds,	
School of Medicine, Level 10, Worsley Building, Clarendon Way, Leeds, LS2 9NL.	

Appendix B. Ethical Approval

Faculty of Medicine and Health Research Office
School of Medicine Research Ethics Committee (SoMREC)

Room 9.29, level 9
Worsley Building
Clarendon Way
Leeds, LS2 9NL
United Kingdom

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11th September 2017

Rachel Eastaugh
Doctorate in Clinical Psychology Student
School of Medicine
Faculty of Medicine and Health
Leeds Institute of Health Sciences
University of Leeds
Level 10, Worsley Building
Clarendon Way
LEEDS   LS2 9NL

Dear Rachel

Ref no: **MREC16-143**

Title: **The experiences of volunteers working for a children's cancer charity**

Your research application has been reviewed by the School of Medicine Ethics Committee (SoMREC) and we can confirm that ethics approval is granted based on the following documentation received from you:

Document	Version	Date Submitted
ethics form Thesis v3 (1)	3.1	01/09/2017
email permission candlelighters	1.0	10/07/2017
Information sheet and consent form thesis v2	2.0	10/07/2017
risk assessment Thesis v2	2.0	01/09/2017
Topic Guide	1.0	10/07/2017
Transcriber Confidentiality Form	1.0	10/07/2017

Please notify the committee if you intend to make any amendments to the original research ethics application or documentation. All changes must receive ethics approval prior to implementation. Please contact the Faculty Research Ethics Administrator for further information (fmhuniethics@leeds.ac.uk)

Ethics approval does not infer you have the right of access to any member of staff or student or documents and the premises of the University of Leeds. Nor does it imply any right of access to the premises of any other organisation, including clinical areas. The committee takes no responsibility for you gaining access to staff, students and/or premises prior to, during or following your research activities.

Please note: *You are expected to keep a record of all your approved documentation, and all other documents relating to the study, including any risk assessments. These should be kept in your study file, which should be readily available for audit inspection purposes. You will be given a two week notice period if your project is to be audited.*

It is our policy to remind everyone that it is your responsibility to comply with Health and Safety, Data Protection and any other legal and/or professional guidelines there may be.

UNIVERSITY OF LEEDS

Faculty of Medicine and Health Research Office
School of Medicine Research Ethics Committee (SoMREC)

Room 9.29, Level 9
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Clarendon Way
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05 December 2017

Rachel Eastaugh
Doctorate in Clinical Psychology Student
School of Medicine
Faculty of Medicine and Health
Leeds Institute of Health Sciences
University of Leeds
Level 10, Worsley Building
Clarendon Way
LEEDS   LS2 9NL

Dear Rachel

Ref no: **MREC16-143 – Amendment 1**

Title: **The experiences of volunteers working for a children's cancer charity**

We are pleased to inform you that your amendment to your research ethics application has been reviewed by the School of Medicine Research Ethics Committee (SoMREC) and we can confirm that ethics approval is granted based on the following documents received from you:

Document	Version	Date submitted
Amendment_form_TC signed	1.0	06/11/2017
candlelighters email	1.0	06/11/2017
ethics form Thesis v3 (1)	3.1	06/11/2017
Information sheet and consent form thesis v3	3.0	06/11/2017

Please notify the committee if you intend to make any further amendments to the original research as submitted and approved to date. This includes recruitment methodology; all changes must receive ethical approval prior to implementation. Please contact the Faculty Research Ethics Administrator for further information (fmhuniethics@leeds.ac.uk)

Ethics approval does not infer you have the right of access to any member of staff or student or documents and the premises of the University of Leeds. Nor does it imply any right of access to the premises of any other organisation, including clinical areas. The committee takes no responsibility for you gaining access to staff, students and/or premises prior to, during or following your research activities.

Please note: You are expected to keep a record of all your approved documentation, as well as documents such as sample consent forms, risk assessments and other documents relating to the study. This should be kept in your study file, which should be readily available for audit purposes. You will be given a two week notice period if your project is to be audited.

It is our policy to remind everyone that it is your responsibility to comply with Health and Safety, Data Protection and any other legal and/or professional guidelines there may be.

We wish you continued success with the project.

Appendix C. Consent form

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UNIVERSITY OF LEEDS

Participant Consent Form for the Research Study
'The experiences of volunteers working for a children's cancer charity'

		Initials
I have read the participant information sheet (Version 3. 04/11/2017)	Y/N	
I have had the opportunity to ask any questions I may have	Y/N	
I am satisfied with the answers to my questions.	Y/N	
I have received enough information about this research project	Y/N	
I understand that I am free to withdraw my data from the research study at any point up until 72 hours post- interview, when the data will be anonymised and that I do not need to give a reason for this	Y/N	
I understand that if quotations are used in the write up of the study, anonymity will be preserved	Y/N	
I agree to take part in this research study.	Y/N	
I agree for the research interview to be recorded using a dictaphone, and understand that the recordings will be destroyed following transcription of the interviews	Y/N	
I would like to be sent a copy of the research study once completed.	Y/N	

Name of participant...

Signature...

Date...

Name of researcher...

Signature...

Date...

Appendix D. Topic Guide

- Setting the scene- How long volunteering for Candlelighters

- Why volunteer?

    Prompt- How did you come to volunteering?

- Experiences so far?

- What was the training like?

- Prior expectations of the role?/ volunteering

- How did the training reflect the day to day role?

- Management of own experiences and emotions

- Views around relationships

- If you could talk to yourself when you started volunteering, what advice would you give yourself?

Appendix E. Development of initial coding and development of themes using Jamie's transcript as an example

Extract	Initial noting	Superordinate theme (sub ordinate theme)
"just to give something back. For us, can is our charity now and it will be for the rest of our lives, so we've done the, well we still do the fundraising and we do what we can there, but this just felt like something different and it felt like it was something I really felt was missing"	Active volunteering/ not tokenistic/ part of something	Community (Ownership)
"I worked for [alternative charity] for years, the cancer charity and before I left there I worked in the volunteering section. I have always, I mean I worked for [alternative charity] prior to X being ill, I did loads of volunteering for them. Erm so I've volunteered for quite a long time and I've worked as like a volunteer coordinator before I left there. I feel like volunteering is a part, I'm a mum, I work part time but then I also volunteer for various… probably more for can now and I work for the local hospice. "	Already a volunteer elsewhere and prior to own lived experience of cancer/ volunteering is a part of her but also a mum	Identity and Roles (*"That's it, it's me now"* Congruence)
"There's always little X who was the dinner lady on the ward, she always came round with the sweet trolley, she's always at everything, erm she's like the ward mum, she's at everything"	Comparing Candlelighters staff to family members/ reflecting on frequency of seeing these individuals and consistency of contact	Family (Team as family)
"so sort of on the one part it is really helpful and therapeutic for you to be running these groups and you're gaining something from it as well as giving back"	Wanting to give back but also noticing therapeutic benefits for self	Motivation ("It helps me" Emotional Impact)

Appendix F. Example of initial coding from one page of Alex's transcript

Margin notes (left)	Line	Transcript	Margin notes (right)
Can see the value in the role / Charities work - faith in what support they do others	159 160 161 162	a Wednesday night at a family pub. So if families want to come, they can come with children to the ball pools or whatever and families can talk. So erm, I find that quite, I think that's going to be a big thing when that gets up and running properly so.	
lots of different roles	163	R: so that's sort of another hat you're wearing	
	164	P: yeah another hat. I have quite a few here! (both laugh)	
	165	R: so can you tell me a little bit more about the peer support group?	
Involved in development. trying to get established. ongoing development	166 167 168 169 170 171	P: erm, as I say its not really happened as such yet. We've done quite a few working groups to try and get it up and running. Erm we did have a family fun day here just to try and get people engaged with it and to try and get people to understand it a bit better. Erm so we had a facepainter in, I did some arts and crafts with families, erm we did some biscuits for the children to do and all different things all over the	Ability to influence
Challenges of recruitment. / high hopes for group.	172 173 174 175 176	building. Erm, and everyone seemed really engaged with it, but when we've gone out and sort of started organising the groups, they haven't taken it on as yet so its about discussing what's the next step, do we do more family groups where they can come to the square and everyone can come or it's a work in progress but I do think its really important	Active volunteering
different "journeys"	177 178 179	because although experts tell you what's going on and how its going. There isn't nobody who can understand it, although your journeys are different and no two journeys are the same, there isn't nobody who can	Journey
Value of own experience "gets it"	180 181 182	get better than somebody who has been through it, or done it or experienced it, so I think that's going to be really good when it gets going	Lived Experience
	183 184	R: yeah. Okay. And you said that you did some training for that? What was the training like?	
generic training information	185 186 187 188	P: erm, well we had a , quite a few of the mums who were on the bereavement group, so we had like a bit of a mini group, er and it were going through like your boundaries and your safeguarding, erm and you know all your general health and safety, your lifting and handling and	
Having enough information / preparation	189 190 191	that. But then it was saying if if, somebody has a break down then signposting them to the right places, and it was really covering our own backs so we knew what we had to deal with in any situation really. Erm	Preparation
knowing how to manage different scenarios? Not own boundaries?	192 193 194	and as I say mainly sort of setting the boundaries so you sort of don't overstep the mark, because they don't, although you are there to support them, you don't want to be their life line and you know them	
learning process → developed boundaries.	195 196 197	ringing you at midnight and saying 'oh I really need to talk to someone'. Erm so it was sort of learning how to set your boundaries with the group and the people that will be attending.	Boundaries

Appendix G. Table showing spread of themes across participants

Participant		Theme				
Participant	Pseudonym	Motivation	Identity and Roles	Protecting the self	Community	Family
1	Jamie	X	X	X	X	X
2	Alex	X	X	X	X	X
3	Charlie	X	X	X	X	X
4	Jordan	X	X	X	X	
5	Ali	X	X		X	X
6	Ashley	X	X		X	X
7	Francis	X		X	X	X