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# The Place of Volunteering in Palliative Care

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## 1. Introduction

This chapter discusses the place and development of volunteering in palliative care in the context of hospice service provision in the UK. It draws on recent qualitative research undertaken in a large hospice in England. The research explored a range of issues connected to the process and experience of voluntary work in this setting including who volunteers, what roles volunteers take up, how they are trained and supported and the ways in which role boundaries are established and maintained. The research revealed that hospice volunteering is rewarding but often emotionally challenging and is now highly routinised and closely monitored in ways paralleling practices in the paid labour market. Although volunteers freely give their time to the work of hospice, their activities are subject to significant management prescription, with hospices increasingly adopting sophisticated business models to underpin their operation and, in many cases, their expansion (Watts, 2010).

As noted above, the discussion of volunteering in palliative care takes as its theoretical starting point the positioning of volunteering as work and the first section of the chapter briefly outlines the nexus of paid commodified work and the informal non-commodified work of volunteers. This discussion is pivotal in informing understanding about the motivation and commitment that underpins voluntary work in the hospice sector and wider palliative care. The discussion then moves on to outline the development of hospice and palliative care services in the UK highlighting the juxtaposition of hospice as a 'built' enterprise alongside the focus of palliative care in the community. The essential contribution made by volunteers to UK hospice services is drawn out suggesting that many hospices would not be able to offer the diversity and level of service without the huge amount of time and energy given by volunteer workers. Some brief commentary about other models operating in such countries as India and South Africa is the subject of the next section and is included to specifically highlight how volunteering in palliative care is culturally produced with operational models highly context dependant. Details of the research design and method comprise the next section foregrounding how empirical research in this area is sensitive work framed by a sense that all those engaged in hospice work are potentially vulnerable actors (Liamputtong, 2007). The accounts of research participants are explored in the next four sections focusing on the themes of motivation, training and support, role diversity, management and accountability and the trend towards professionalisation of volunteering in this context. Integral to these aspects are considerations connected to role boundaries and ethical conduct. The chapter closes with brief commentary about future directions for volunteering in palliative care.

## 2. Intersection of voluntary and paid work

Work, as paid employment, has long been understood to contribute to individual identity, particularly masculine identity, with the ideology of the male breadwinner still the focus of contemporary debates about the sociology of work (Mooney, 2004; Edwards & Wajzman, 2005; Warren, 2007). Work has also been found to have spiritual properties with Howard and Welbourn (2004) reporting that work is an important element in people's sense of meaning and purpose, contributing significantly to their spirituality and sense of 'self' in the world. The paid work sector has a number of connecting points with voluntary work and MacDonald (1997) notes that working in a voluntary capacity can be a source of experience, skills development, networking and the route to paid employment. It also can be the vehicle for enabling people to have structure in their lives and is a source of job satisfaction and individual fulfilment as is the case for paid work.

The concept of work is thus multi-dimensional. In recent times work, as paid labour, has undergone significant transformation, particularly in Western societies that have seen a decrease in manufacturing, the disappearance of a 'job for life', a huge increase in women's employment and, with the onset of the internet, a rise in home and flexible working (Bolton & Houlihan, 2009). A further change has been the growth of the voluntary sector that is characterised by a variety of organisations from large professional bureaucracies to small neighbourhood-based community groups (Newman & Mooney, 2004). Noon and Blyton (2007) argue that one of the long term factors stimulating the growth of both the voluntary sector and volunteering has been the rising cost of buying in services from the formal economy, leading to a form of local self-provisioning within communities. The range of activities that constitute voluntary work is vast incorporating informal tasks such as acts of kindness (for example, doing an elderly neighbour's shopping), social exchange activities (such as a baby sitting circle) as well as work in the more formally oriented health and social care field (Noon & Blyton, 2007).

Voluntary work, as uncommodified work, can be distinguished from paid commodified work in that it is freely undertaken for no financial payment and is often motivated by altruism shaped by a sense of wanting to 'give back' to the community. Noon and Blyton (2007) further characterise voluntary work as normally undertaken outside the family in the community, with its key feature as that of 'gift work'. A core value of volunteering is working for the good of others, expecting nothing in return apart from the emotional satisfaction that such efforts may bring. Stebbins (1996) draws distinctions between types of volunteering: career and casual, formal and informal, and occupational and non-occupational. Gender is also a factor with men and women tending to volunteer for different types of work. Noon and Blyton (2007) argue that women are more likely to undertake voluntary work in schools, with social welfare groups and to engage in fundraising activities. Men, on the other hand, are disproportionately active in voluntary work involving sports groups and committee work. Fink (2004) draws attention to the relational features of much voluntary work that she argues can be emotionally demanding giving rise to emotional distress with the need to develop appropriate coping strategies. Rojek (2010: 27) develops this theme arguing that 'the management of emotional labour does not stop when one leaves the workplace' such that issues of competence and the maintenance of credibility continue as an ongoing project across the life-course, with the undertaking of voluntary work as one strategy for maintaining personal congruence.

Voluntary work is thus very diverse and evokes many different forms of commitment, identification and allegiance with the debate about its role centring on the concept of active citizenship that, it is argued, cements social networks and relationships as well as enhancing the greater social good (Newman & Mooney, 2004). The promotion of the idea of an active civil society by successive UK governments has led to the professionalisation of some voluntary work as the product of a partnership between the voluntary sector, government and business. Within the UK during the 1980's and early 1990's, the voluntary sector began to have a key role in the delivery of a whole range of care services as part of the Thatcherite 'care in the community' policy. The significance placed on providing care in the community continues not least because of the general increase in life expectancy and a larger proportion of the population living into very old age.

Historically, caring for the elderly, the sick and the young has represented a major aspect of voluntary activity and currently volunteers can be found working in schools, day care centres, 'after school' clubs, hospices and hospitals and in charity shops that are now a familiar feature of many UK local high streets. Some ideas presented in the literature position lay care of the vulnerable as a privilege and Sinclair (2007: 76) notes that "philanthropic and voluntary involvement in palliative care confirms the archetypal notion of care as a privilege or gift". This notwithstanding, much voluntary work in the health field and in other sectors, too, has become characterised by more standardised working practices. Thus semi-formalised aspects of voluntary work have changed the experience of volunteering because as Morrison (2000: 109) argues 'there is a particular and very significant tension between a professionalised managerial approach and a more traditional volunteering ethos'. Operating within the 'professional' discourse of quality, accountability and regulated practice, some voluntary work has been made closer to the experience of paid work. Noon and Blyton (2007) suggest that in the broad care sector this may be particularly the case and point to issues arising from the relationship between voluntary and paid work. One they highlight is the extent to which voluntary care activity undermines or dilutes the role and status of those performing care tasks within their paid employment both in professional and non-professional roles. A further point is whether the expansion of unpaid voluntary work in the diverse field of health care has restricted the growth of occupations in this area.

These debates provide an underpinning empirical and theoretical thread to the discussion below and are useful in guiding understanding about hospice development and operation in the UK that is considered next.

### **3. Hospice and palliative care services in the UK**

Much has been written about the development of the modern hospice movement, particularly the pioneering efforts of its founder, Cicely Saunders who formulated the vision of a haven where people could experience relief from pain and die with dignity within an atmosphere of calm and tranquillity. The services offered under the 'umbrella' of hospice now include day care, bereavement counselling, complementary therapies, day and night sitting services and terminal care both in the community and within the hospice for in-patients. This whole provision is seen as a 'high person, low technology and hardware system of health care' (De Spelder & Strickland, 2005) providing intimate care at scale. Its ultimate goal is the attainment of a 'good death' from the perspective of both the dying person and their family (Sandman, 2005), with the period before death characterised by the

best possible quality of life (Randall & Downie, 2006). Whilst space does not permit an extended discussion of this concept, it is important to note that the 'good death' is contested; it is socially produced with, in the developed world, death often taking place over time as people live with life-threatening illness or slow degenerative conditions (Holloway, 2007). Furthermore, 'social death' may occur before 'biological death' when some people, such as those with AIDS (see below), are socially ostracised because of their illness (Auger, 2007).

The establishment in 1967 of St Christopher's in South London, as the first modern research and teaching hospice to cater specifically for the needs of the dying, was instrumental in raising the profile of terminal care. Previously end of life care had been peripheral to the agenda of the medical profession, mainly due to associated discourses of death as failure. In-patient hospices are the original model of palliative care delivery and by the year 2000, Britain had 400 hospices and palliative care units helping to provide a new model of death (Jupp & Walter, 1999). By the year 2008 this number had risen to 716 (Watts, 2010) and Clark (1993) comments that, although hospice is often described as a philosophy rather than a place (particularly by US commentators), the drive to build more hospices and establish professionally led dedicated palliative care units is very striking. Sinclair (2007) argues that this is hardly surprising given the primacy of the institutional model in establishing status, authority and credibility within the medical mainstream.

The expansion in the number of hospices, although ad hoc (Field & Addington-Hall, 2000) and therefore unevenly geographically distributed, has been significant and widespread. Hospices are now well established in the UK as the principal site for the practice of specialist palliative care and have traditionally operated outside direct mainstream National Health Service (NHS) control with many constituted as charities dependant mainly on fundraising initiatives for their income. Although mainly charity-based, hospices now operate on a business model raising funds from corporate sponsors as well as from sales in their high street shops and individual donations. Despite the continuing drive to maintain some autonomy, the independent feature of their operation is gradually being eroded within a culture of audit and evidence-based practice, as hospices increasingly are expected to demonstrate the effectiveness of services as part of the NHS referral system (Randall & Downie, 2006).

The original ideal of hospice, as the setting for a good death, is the creation of an extended family (Howarth, 2007), to act as a refuge or safe retreat for the dying and those close to them. Patients are encouraged to pursue their interests and pleasures as they would in their own home and, with extensive visiting hours, to spend as much time as they wish with friends and family members. Extending this familial idea, hospices see the patient's family as an integral part of the unit of care, involving them in all aspects of decision-making. The importance of the family is a recurring theme in the literature on the culture of hospice care, offering insight into the ways in which these institutions approach support of the dying, as one aspect of the holistic approach they advocate. This familial feature is especially reproduced in hospices dedicated to the care of children and young people and in recent years a number of these have been established across the UK to respond to what has been perceived as the special needs of families looking after a child with a life-limiting condition. The organisation, Children's Hospices UK, reports that there are now forty-one children's hospices in the UK (Watts, 2010).

The staffing profile of hospices is centred on a multidisciplinary approach to care with nurses, doctors, health care assistants, social workers, physiotherapists, chaplains and a

range of complementary therapists working together to support the individual needs of patients. In addition, there is a growing emphasis on incorporating the skills of experienced managers to lead the hospice team as part of the ongoing drive for greater efficiency in all areas of service provision (Doyle, 2009). Alongside the paid and professional staff, hospices rely heavily on a significant volunteer workforce to help with the care of patients and their families both in the setting of the hospice and in the community with much care now taking place in patients' own homes (Armstrong-Coster, 2004; Howlett, 2009). Connor (2009), writing in the context of the USA, makes the further point that hospice and palliative care began there directly through the efforts of volunteers to create a new way of caring for dying people. Some of those efforts were inspired through religious belief and the development of the modern hospice movement has primarily been born out of a Christian tradition imbued with the principle of duty to others (Clark & Seymour, 1999). This sense of duty goes some way towards explaining the importance of the volunteer workforce to different aspects of hospice activities (Andersson & Ohlen, 2005) with Connor (2009: 117) pointing out that "the fact that people give of themselves to care for others has powerful significance to those who receive the care". He adds that people experience care given by professionals paid to deliver care differently than they experience the same care given by a volunteer arguing that the extra dimension of caring provided by volunteers has always been one of the unique features of hospice care.

The giving of self by the volunteer can result in the volunteer being the most significant person to the dying patient having devoted much one-to-one time to accompanying the patient as they face death. These interactions, supporting the work of paid staff, may be qualitatively different because of their 'gift nature' (see Noon & Blyton, 2007 above). The building of relationships between volunteers and users of hospice services is an important feature of high quality care and this is now seen as a characteristic of workforce excellence resulting in well-developed volunteer recruitment and training programmes. Given the ways in which specialist palliative care within hospices has evolved into a clinical set of disciplines whose emphasis is on pain control and symptom management in an approach similar to that found in mainstream clinical settings (Kellehear, 2005), the contribution of volunteers in 're-personalising' hospice care may be especially valuable. Sinclair (2007: 49), commenting on the pronounced voluntary staff component of most hospices, suggests that the population at large sees palliative care and the possibility of hospice support as a gift, and one to be both earned or repaid. This notwithstanding, volunteer work in this setting can be both stressful and emotionally demanding and can lead to 'burn-out' as may occur amongst members of the professional hospice workforce (Dein & Abbas, 2005). These and other aspects of the experience of being a hospice volunteer are explored more fully later in the chapter.

#### **4. Other models of hospice and palliative care**

Although the focus of the critique and research presented in this chapter is on hospice volunteering in the UK, there is merit in briefly considering some alternative models operating in other countries. The first of these is based in the state of Kerala in southern India and is characterised by Kumar (2009) as a neighbourhood network of palliative care. This network, that aims to develop a community-owned service, has grown out of pain clinics established as part of two cancer centres set up in 1990. The goal of the programme is the development of grass roots level sustainable and cost-effective care for patients with

terminal disease. Its underlying premise is community participation with local people encouraged to train as community volunteers to offer emotional support to patients and families as part of a home care programme. In this model the work of volunteers operates alongside the clinical expertise of specialist doctors and nurses and has resulted in a combined workforce of 5000 trained community volunteers, 50 palliative care physicians and 100 palliative care nurses (Kumar, 2009).

There are criteria for the recruitment of volunteer workers onto the programme; they must be available to spend more than two hours per week to care for the terminally ill in their village and be prepared to undertake the 15 hour structured training before becoming a member of the volunteer network. Training covers the basic palliative care precepts including communication skills, emotional support, basic nursing skills and organisational aspects of care. Prospective volunteers also make home visits as part of their training with these led by either a doctor or nurse. The result is a well-developed and highly skilled local community palliative care network with trained volunteers able to perform a wide range of tasks including initiating and running palliative care units locally, raising funds for the network, advocating for patients and the network through mobilising support from governmental and non-governmental agencies and performing a range of essential administrative tasks. Organising awareness and training programmes in the community with the local governments and agencies are particularly important components of the work of volunteers focused on future sustainability and end of life care policy-making. Their central role, however, is to provide one-to-one help to patients in their home offering emotional and practical support. This initiative has been highly successful not least because there is no charge for the use of services provided by the network that does not aim to replace professionally led health care. Its emphasis on psychosocial and spiritual support provided by volunteers connects well with local cultural and religious frameworks and privileges a collective rather than an individual approach to palliative care drawing on a social rather than a medical model of health and disease.

A second model of palliative care services that relies heavily on volunteer support is that of the South Coast Hospice (SCH) located in the province of Kwazulu-Natal in South Africa. The hospice provides palliative care to a highly disadvantaged and impoverished population where there is 70 per cent unemployment and where the prevalence of tuberculosis is 116 per 100, 000 (Defellippi & Mnguni, 2009). However, it is the scale of HIV/AIDS in the area that has been the key challenge, with the social and psychological trauma associated with the disease for both sufferers and their carers an overwhelming problem. With anti-retroviral medication only very recently becoming available in South Africa, the hospice had to plan services with the prospect of huge numbers of AIDS patients requiring palliative care.

In the early 1980s during the first phase of SCH's development, services were planned broadly adopting the UK model of collaborating with primary health care clinics to provide holistic care mainly to cancer patients living in outlying rural areas. Care delivered by professionally qualified nurses was the foundation of an outreach programme that formed the basis for the integrated community home care model developed from the mid 1990s in response to the escalating HIV/AIDS epidemic. Within this model hospice care teams (salaried professional staff) visit patients in their home approximately once a week with interim support provided by trained lay volunteers who usually live within walking

distance of the patients' homes. On average each volunteer is expected every week to visit about five patients and their families, and to make a report to the hospice's Voluntary Service Manager. This level of lay support has become necessary because the traditional care safety net of the extended family system in South Africa is being eroded by HIV/AIDS (Defellippi & Mnguni, 2009). Overburdened grandmothers, who are often frail and underfed, cannot cope with caring alone for their own sick adult children and young grandchildren, as well as inheriting the orphans many of whom are HIV positive.

The volunteer model of SCH is culturally located with some elements that differ from the community model of Kerala discussed above. In economically developed societies there is an assumption that volunteers work 'for free' and give their time with no expectation of financial remuneration. However, where people are living in impoverished circumstances, expectations may differ and motivations to volunteer can combine altruism and a sense of community service with hope that volunteering may lead to employment and be a vehicle to help alleviate their plight. These elements give rise to the concept of the 'paid volunteer' that is outside the traditional western model of voluntary work. Given the social context described above, SCH had to grapple with the issue of rewards for volunteers as part of a sustainable model of care delivery. Careful selection of volunteers is particularly important when payment of volunteers is involved especially in terms of identifying the motivation of any potential volunteer. SCH thus established a set of personal criteria for the recruitment of volunteers with most of these being in line with those adopted across all community palliative care programmes. Additional requirements were those seen as essential for the Southern African local context and include a track record of community involvement, an ability to communicate cross-culturally with sensitivity and respect and an ability to speak in an authoritative and compassionate manner about HIV/AIDS. The remuneration for this voluntary work ranges from financial stipends to food parcels, with the nature of the reward shaped by local conditions.

Nearly all the volunteers at SCH are women as it is women in African society who have the caring roles and responsibilities. Training, provided as induction to the volunteer role, incorporates a wide curriculum including behavioural conduct, psychosocial and spiritual support, pain and symptom control, paediatric AIDS and basic nursing skills that skill the volunteer to maintain basic hygiene and promote universal precautions in preventing the spread of infection as part of a health promotion approach. They also need to give sound nutritional advice to patients and families (Defellippi & Mnguni, 2009). This package of support can be understood as part of a wider programme of change that Kellehear (2005) sees as being intrinsically political, driving as it does, towards personal, local and, eventually, national change in particular behaviours.

A majority (60 per cent) of AIDS patients referred to the hospice are women who have contracted the virus from a male partner to whom they have been faithful, with the result that the skill level required by volunteers to initiate discussion about sexual health problems with both the infected person and their partner is very high. This is challenging work because, as Auger (2007) opines, HIV/AIDS is first and foremost a sociological issue with issues of stigma and social exclusion never far from view. Significant levels of supervision and mentorship are offered to volunteers in recognition of the stressful nature of this work. Evaluation and monitoring of the quality of support offered by volunteers is a feature of SCH's commitment to ensuring a high quality service drawing on the principle that feedback improves both practice and outcomes for service users. It also demonstrates to



volunteers that they are valued and that their work is important and enables the hospice to extend its services to reach large numbers of people in need.

## 5. The study

The research, on which much of this chapter draws, was conducted in a large well-established hospice in England. Qualitative methods were used to explore a range of topics centred on developing understanding of the experience of becoming and being a hospice volunteer. Particular issues considered included volunteer motivation, previous and current occupational and professional roles, training and support programmes, rewards and benefits of hospice voluntary work and challenges associated with the role. This was a small-scale pilot study undertaken to inform the design of a much larger research project involving a number of hospices across the UK.

Access to the work of the hospice was facilitated by my role as a university educator in the field of death and dying and the associated practice visits made to a wide range of palliative care settings, positioning me as an insider researcher (Watts, 2006). My earlier research into labour market issues had made me aware of the growing importance of voluntary work within the economy and in the context of health care generally and death and dying, in particular, it was becoming clear that this was an area ripe for research. Locating the research in one hospice underpinned a case study approach that Simons (2009) characterises as being context-specific whether in terms of organisation or individuals or collections of individuals. The design of the small scale study required careful planning given that volunteers' time is limited and taking their time away from input to patients is one of a number of ethical issues in palliative care research (Addington-Hall, 2007).

The decision to run a focus group centred on their use as "ideal for exploring people's talk, experiences, opinions, beliefs, wishes and concerns" (Kitzinger, 2005: 57) and agreement for the involvement of a small number of volunteers to form the group was given by the Voluntary Service Manager at the hospice. Having circulated information to the large number of regular volunteers, she forwarded me details of potential participants who had expressed an interest in contributing to the study. From seventeen positive responses, eight participants were recruited to the study with them agreeing to take part in a focus group. Usual consent procedures were followed with me confirming full confidentiality and anonymity. A room in which to run the focus group was provided by the hospice and the session ran for almost two hours. Participants ranged in age from 41 to 77 years and all the participants were women.

I used a topic guide to conduct the session (Bryman, 2004) to facilitate a semi-structured approach as a way of grouping topics for discussion that quickly developed into a lively exchange. All the participants knew each other and some had become friends during their years of volunteering at the hospice resulting in an informal and comfortable atmosphere for the discussion. Kitzinger (2004: 270), writing about the dynamics of the focus group method, comments that "the fact that participants provide an audience for each other encourages a greater variety of communication" and the element of performance was very much evident in the session. Also evident was a high level of sensitivity and tenderness of emotion amongst the group, particularly during discussion of how individuals had been drawn into this voluntary role, with a majority talking about the death of a loved one whilst under the care of the hospice.

Focus groups are not a natural event (Kitzinger, 2004); they are social process and are necessarily contrived being strongly influenced by the presence and person of the facilitator who in this case was also the researcher. Considerable care was taken not to give too much direction beyond setting the ground rules at the outset and noting the topics. Rounding a topic off as away of moving the discussion on to the next subject was necessary to keep the flow focused and on track. The session was digitally recorded and subsequently transcribed and then thematically analysed using the topic guide as a framework. A rich body of data was produced highlighting the breadth of views of participants about their experience of hospice volunteering.

There is considerable debate in the literature about the mechanics, authenticity and rigour of this qualitative data gathering method and space here does not permit a developed critique of the key arguments except to say that focus groups are always context-situated and subject to the interaction dynamics of the group, with this aspect particularly challenging to address as part of the analysis (Wilkinson, 2011). Focus group data are not more or less authentic than data generated by other qualitative methods and they are often used as one component of a project. This, as it turned out, was the case in this study as two volunteers, who were unwilling to join the focus group, expressed an interest in being interviewed individually. These two interviews each lasted for approximately ninety minutes and were subject to the same ethical processes as for the focus group. The topic guide used for the focus group acted as the semi-structured interview schedule to try and bring a measure of content uniformity across the two methods. The interviews were digitally recorded, with transcripts produced and then sent to the two respondents. The texts were thematically analysed as for the main data set drawing on some of the principles set out by Braun and Clarke (2006).

A number of themes emerged from the data and the discussion below focuses on those most useful for the current purpose namely motivation to become a hospice volunteer, training and support, experience in particular roles and lastly, challenges of the work that was felt to be increasingly demanding. Threaded through the thematic discussion of the study's findings are the voices of participants; using their language enables a data-focused approach rather than one that is literature focused and this style of reporting accords with the ethical frame of the research that was grounded in a collaborative participatory model (Birch & Miller, 2002).

## **6. Becoming a hospice volunteer**

Motivations to become a hospice volunteer are complex and varied and Howlett (2009) argues that there are almost as many motivations to volunteer, as there are volunteers. For participants in this research, however, volunteer motivations can be broadly characterised into the two categories of instrumental gain and altruism, with these not mutually exclusive. Howlett (2009) suggests that increasingly volunteers may expect to get something from their volunteering though, as demonstrated by this research, the rewards are very diverse and may well change over time.

In this context the concept of instrumental gain centres on fulfilling needs of the volunteer and for the older retired participants, the opportunity that volunteering affords to help organise time and give structure to weekly routines acted as a strong motivating force for

their commitment to the work of the hospice. Joyce, a member of the focus group comments: "my Tuesdays here are sacrosanct so I organise everything else around that and I wouldn't be without it now". Lesley spoke similarly highlighting how, as she put it, "volunteering here helps to break up the week and sometimes when they are short handed I come in and do extra time". The temporal dimension was taken up by Joan who, recently retired, wanted to ensure that she had a balance in the way she used her newly acquired leisure explaining "I want to feel that my retirement is useful and enjoyable and I want to be able to expect to do different things on different days and then I won't feel that each day is just a blank".

The opportunity to mix and have social interaction with like-minded people was identified as another important instrumental motivation and Beryl, a focus group participant, spoke about how her life had seemed so empty after the death of her husband and of the way in which working at the hospice helped to fill the vacuum. "I feel part of something here and it helps with the loneliness". Lesley saw her work at the hospice as an enhancement to her social well being commenting: "I have made quite a lot of friends here and sometimes we meet up for coffee and have a good old natter". Commenting on the social contacts developed by volunteers working in the hospice bereavement service, Eileen, one of the two interviewees, explained thus: "we go out to lunch about once every two months and sometimes we go round to each other's houses and have lunch; we call it our self support group". The extent to which the social contact sustained motivation rather than initiated it was difficult to judge but as Howlett (2009) notes, volunteer motivations do change over time and this can make it difficult for Voluntary Service Managers to identify and respond to motives as part of their recruitment activities.

Others in the group spoke about having something useful and worthwhile to do beyond family interests and, of feeling valued. Eileen put it very succinctly thus: "you see it's all about feeling valued and valued on a professional level because you have a real contribution to make". She also added: "I was a social worker and volunteering here has been one way of keeping up some of those skills". This sense of being valued appeared to be of instrumental importance equally to those with a professional occupational background as for those who had not been in paid employment having been at home raising their families. They spoke about how their ideas and concerns were generally listened to, making them feel part of the hospice team, giving them status and self-worth.

Another instrumental motivation emerged from the comments of the youngest member of the focus group, Linda. She took up volunteer work at the hospice to gain experience of palliative care hoping to enrol as a mature student on a qualifying social work programme at her local university. Having been, as she put it a "stay at home mum" for many years, she was using her hospice voluntary work as an opportunity to acquire new skills and experience that would be of benefit in her future professional role. Barbara Monroe, CEO St Christopher's Hospice in London, is clear that hospice volunteering can act as a route into paid work and education, citing an increasingly diverse volunteer profile that now includes people with learning disabilities and men and women on licence from prison (Monroe, ADEC conference, 2011).

Altruism, as the second category of motivation, was an underpinning theme of why participants had chosen to volunteer at the hospice. Half the participants had initially come into contact with the hospice because of the terminal illness of a loved one and all expressed in different ways how impressed they had been by the quality of care on offer. Giving something back was thus very significant in stimulating a regular commitment of time, skills and experience to a number of the hospice's services. Molly, one of the focus group

participants, spoke with emotion about her husband's care at the hospice and how she felt she wanted to make sure that others could have access to such high quality care and support. She said: "he was looked after so well and although it was awful, it somehow made it all bearable and now I feel ready to help out here so that all this fantastic work can go on and others can get help the way we did". Joyce also voiced a strong personal connection to the hospice saying: "my sister was in here, she died in here and they made it sort of peaceful and we all could come and go and be part of it....I didn't think I could work here but then I thought I could maybe manage working in the coffee shop and even that can make a difference can't it?". Other comments from Joyce further point to the ways in which giving something back to the community, as part of a sense of duty, is an important motivation; she says: "giving up my time is the least I can do".

Although the two types of motivation discussed above are clearly significant in hospices continuing to recruit volunteers to their workforce, it is important to emphasise that sometimes those who apply to join hospices in a voluntary capacity, may not have a particular motive or aim but do so out of curiosity and good, if not clearly defined, intention. Others may want to undertake this work as part of their own recovery from bereavement or with the goal of converting others to a faith before they die (Connor, 2009). This raises the important issue of suitability for this role and the need for careful scrutiny of applicants with Voluntary Service Managers having an ongoing responsibility to ensure that volunteers are both appropriately supported in this work and that any changes to their personal circumstances do not negatively impact on their work in this setting.

## 7. Training and support

Although volunteers will have different perceptions of their role in the hospice ranging from those who see this work as a semi-professional 'job' to those who see this not as a job but more as providing informal help, all hospice volunteers are expected to undergo a period of training and induction (Spencer-Gray, 2009). Discussion about the training and support offered to participants centred mainly on the nature and extent of provision with an emphasis on the need for regular updates that could incorporate new research findings. Several participants had been volunteering for a number of years evidencing what Hamilton (2009) terms as 'the volunteer career' that is likely to have a number of stages of development. These long-serving participants found it difficult to recall the detail of the training they had received on joining the hospice. However, those more recently joined talked about the different components of their initial training that variously included death education, personal death awareness, principles of palliative care, social and psychological reactions to death, grief and loss and working effectively as a member of the multidisciplinary team. Training that addressed ethical issues such as patient confidentiality and maintaining 'working' boundaries was only briefly referred to in the focus group. One of the two interviewees, however, gave greater emphasis to this element of the training explaining: "I know it is important not to talk about patients to people and to keep their details private and confidential. I feel it's part of upholding their dignity and we know that keeping things confidential is one of the cardinal rules here. It was made very clear in my training and after a while it almost becomes second nature".

The topics covered in the training of these volunteers is broadly in line with what Connor (2009: 97) calls the 'basics', at least in relation to the western model of palliative care. The training model used with volunteers in the South Coast Hospice in South Africa (discussed

above) also included basic nursing skills and knowledge about pain and symptom control such that they can, with supervision, administer prescribed medication. In the UK context, these skills are not expected of volunteers and there is a clear demarcation between the roles of professionally trained clinical staff and volunteers working alongside them. One of the reasons for this is the high level of regulation of health service provision to ensure clear lines of responsibility and accountability for those in professional practice.

In the focus group one of the prompts to develop discussion on the topic of training was the question "is there anything that you feel you would like more training on?". The areas of spirituality and diversity were identified as topics where there were knowledge gaps, particularly spirituality that seemed to present as a vague concept. Beryl, for example, commented: "I see spirituality as religion but these days a lot of people don't have a religion and so it is difficult to help people spiritually if you don't know how they see their spiritual needs. I suppose that is why we have the chaplain so he can look after the spirituality side of things". Directly following on, Joyce added: "yes, we could do with more training on spirituality so that we can be more confident about how to help people and understand what really matters to them". These points received general agreement amongst the group and both interviewees were also of the view that spiritual care was difficult to define and probably was best left to the chaplain.

The connection between spirituality, religion and cultural diversity was loosely made in the context of the gradually changing nature of the population in the locality of the hospice. Originally a white, prosperous middle class area, the population served by the hospice now included a growing south Asian population as well as a small but expanding eastern European community. The need for greater cultural awareness, particularly in relation to Hinduism and Islam was strongly articulated, with cultural competence seen as an important skill for volunteers working in the hospice. Diversity in palliative care, particularly in terms of access has long been debated (see, for example, Smaje and Field, 1997 and Firth, 2004) and participants' comments suggest that this still remains a deficit area.

Ongoing support for volunteers appeared to be organised according to their different roles but was mainly of two types: formal support from the hospice and informal peer support from fellow volunteers. Those working as part of the bereavement care team have a supervisor as well as a mentor with meetings with each on a monthly basis. In day care, support is provided by both the day care manager and the senior nurse who has responsibility for the organisation of activities and the overall care of patients. In day care there is a meeting between volunteers and the senior nurse before the start of each session to discuss any issues that may arise with particular patients and also to share updates that include information about patients who have died. Eileen comments: "we discuss who has died because that's upsetting because you make relationships in day care as you see them every week. Eventually the patients die and it is quite sad so you have to have somebody to discuss it with". These meetings are also the opportunity to discuss new patients coming into day care so that staff and volunteers can be fully prepared to welcome each new patient and meet their individual needs. It is this treating the patient as an individual that is the hallmark of specialist palliative care (Watts, 2010).

It was clear that volunteers who have the most contact with patients require the highest level of support because of the emotionally demanding nature of their work. Volunteers working in the coffee shop spoke about support that was mainly instrumental focusing on organisational matters such as work rosters and managing stock. Much of their contact is

with hospice staff, visitors and family members of patients using the hospice. They do have contact with patients, but the opportunity to get to know patients in a personal way is limited as the coffee shop is generally busy with people waiting to be served, drinks to be made and tables to be cleared. Support in this role appeared to be mainly of the peer variety as the policy at the hospice is for the coffee shop to be staffed by two or three volunteers at a time. Joyce, who works in the coffee shop two days each week, explained how she gradually came to feel comfortable working the till and the coffee machine, because of the friendly help of a co-volunteer. She commented: "I found it all a bit confusing at first what with the till and the coffee machine that I had never used before but Sally (co-volunteer) was patient and kept showing me what to do and I really enjoy it. I think I would really miss it if I wasn't here those two days".

## 8. Experiences as a hospice volunteer

A variety of volunteer roles was represented amongst the ten participants in the study; two worked in the coffee shop, one on the main reception desk, three in day care, three in bereavement support and one as a volunteer complementary therapist offering reflexology to patients. All spoke with considerable enthusiasm about their work, particularly valuing the social aspects of their volunteering that Howlett (2009) argues can often be pivotal in hospices retaining their volunteers. Fiona, one of the interviewees, characterised the pleasure she gained from working in day care helping with arts and crafts activities as a privilege. In her early fifties, Fiona had left a high-powered post as a corporate chief executive and felt that her work at the hospice was rewarding because of what she described as its "high people content". Further comments from Fiona highlighted just what she meant by privilege in this context: "patients and their families come to the hospice often at a very desperate time when they are staring death in the face and what they generally find is that people here care and can give them their whole attention. Being part of that is so special and so very different from the business world where time is money and people matter less than the bottom line on the balance sheet".

An underpinning theme of much of the discussion, both in the focus group and with the two interviewees, was the practice and approach of *caring about* patients and families who come to the hospice. Beryl, recounting a recent conversation with one of the patients in day care, spoke about the patient's appreciation for the support volunteers provide and how the patient saw this as volunteers caring about patients as individuals. The ethos of care appeared to extend across different types of voluntary roles including those not represented in the study, such as those of driver and fundraiser and these were commented on within the context of care and relationships. Eileen referred specifically to the important caring role of drivers explaining: "of course we have volunteer drivers that go and collect people to bring them into day care and those volunteers get very close to the patients. I remember that one of our ladies from day care who died recently, I went to her funeral and her driver was there and he was in tears. I wondered then, if they (the drivers) get the support they need".

The activity of fundraising is central to the running of many hospices in the UK with most now part of the registered charity sector. Managing fundraising is a key role usually involving the initiation and co-ordination of a range of ventures. Participants referred to fund-raising activities in connection with contributions they found themselves making to particular events, with this seen as part of their wider relationship to the palliative care

mission. Joyce commenting on a fundraising garden party, explained: "I don't know but I just seemed to get roped into helping. Joanna (fundraising manager at the hospice) was chatting to me one day and mentioned that they needed more help and asked me if I could help out. She is so nice and I didn't feel I could say no. It was fun, hard work, but fun and it took me a few days to get over it". This and other similar comments indicate that the work of volunteering at the hospice can be expanded beyond specifically assigned roles to take up a considerable chunk of time in volunteers' lives. The goodwill generated and reproduced through the highly valued care work of hospice is undoubtedly a resource for hospice managers. However, issues may arise about the extent to which the goodwill of volunteers can lead to their exploitation, with this as the unintended consequence of their deep and usually longstanding commitment to supporting this work.

## 9. Challenges

Hospice volunteering brings challenges both for volunteers and for Voluntary Service Managers. Data from the study reveal the concern of volunteers about maintaining appropriate functional and emotional boundaries, this despite the training and ongoing support they receive from professional staff. The emotional element of volunteer roles that involves close contact with patients was highlighted both in the focus group discussion and in the two interviews. The sensitive and potentially stressful nature of this work is illustrated by Fiona's comments: "we hear things that we don't quite understand or that we are not sure about and is this person telling you that they are going to commit suicide or are they not actually saying that and you think should I be telling someone or is it my job just to listen? Sometimes I wonder if I should have said more or something different but I am not a counsellor". Molly also talked about some of the boundary dilemmas she has had in her day care work: "sometimes I leave day care thinking what shall I do about this, did I ought to tell one of the managers and sometimes, though I don't take the patients' problems home with me, I do feel it and wonder if I did the right thing". Eileen was aware of the need to take responsibility for looking after herself emotionally and explained: "my theory about being a bereavement volunteer is that you have to have lots of empathy and lots of sympathy and love people but you have to have a hard centre. There has to be just that bit in the middle that they don't get through". These remarks demonstrate that careful management of emotions by volunteers is needed to prevent their negative impact and ensure this work does not spill over into other areas of life. In recognition of this, Dein and Abbas (2005) argue for more dedicated training on this topic for volunteers, with the aim of minimising the potential stress associated with the role.

Changes over time in the way in which volunteers are seen by the hospice management team was discussed within the focus group and attracted most comment from the longest serving volunteers. Eileen, for example, remarked: "when I was first here twenty years ago you couldn't stop hearing how much they needed us and what a difference we make. Now, though, you hardly ever hear that and I don't think it's because we are not valued, as I know we are, but it's just that everyone's so busy with paperwork and budgets and things like that. It all has got so formal somehow and maybe we matter less because of that". Connected to the issue of formalisation of procedures and bureaucracy is the sense of volunteering as a semi-professional role with an increased emphasis on continuity of care and the maintenance of high standards in all areas. Participants supported these

values but some identified a gradual shift in the attitudes of department managers in relation to a less flexible approach to making changes to the days of work and in connection to taking extended holiday, particularly over the summer when three of the participants wanted to devote time to spending with grandchildren. Howlett (2009: 17), commenting on the growing formalisation of volunteering in hospice and palliative care, argues that 'we are seeing the expansion of the workplace model, in which volunteering looks like paid work, but without the pay'. He suggests that the trend towards a more formal style of organising and managing volunteers stems from two causes. The first is the drive by successive UK governments for the delivery of public services by the voluntary sector and the second is the growing risk and fear of litigation in which organisations fear being exposed to risk as a result of not having adequate management systems in place.

Volunteering in palliative care as discussed above is shaped by different motivations, with altruism and a wish to contribute to a high quality care service, dominant motives. Thorough volunteer recruitment processes operate in the sector that tries hard to match the skills of potential volunteers with the needs of the service (Spencer-Gray, 2009). One participant explained how important this is both for the volunteer and the hospice; she comments: "if people get the right job they stay; if they fit into a job that they like and can do they stay like people here in the bereavement service, most of them have been here a long time". Sometimes, however, this match is not successful and one challenge for Voluntary Service Managers is the task of ensuring that a probation period is just that, with the necessary support and advice in place as part of assessment of suitability in role. Here, features of the employment model come into play and this is another area where more formal processes have been widely introduced. Despite this, the task of informing an enthusiastic volunteer that they may not be right for a particular role is a sensitive one that requires careful handling. Where volunteers are introduced to the hospice through personal networks within the hospice, this can be especially challenging. Dismissing a volunteer who has successfully completed probation but later oversteps guidelines and boundaries such as, for example, becoming over-involved with patients, can be particularly difficult. O'Brien and Wallace (2009) correctly assert that the interests of patients are pre-eminent and they suggest that one approach might be to counsel a volunteer to leave.

A further issue raised by one of the participants is that of 'retirement' of volunteers and Eileen's words demonstrate that this can be another sensitive issue for Voluntary Service Managers. She says: "when I first came here people were told that they had to leave when they were seventy. Well, that's stopped now and the thing that concerns me is now there is no cut off point so what do you do when people should retire? We have a counsellor here who has forgotten what her job is and comes in for her own sake. At some stage people are going to get too old to do the job and they've got to be told somehow that they are too old".

The final challenge that I want to address here is that raised by Sinclair (2007) concerning demarcation between professional and volunteer roles. Taking the concept of multidisciplinary that is a vital component of palliative care practice (Mitchell and Barclay, 2008), it is not difficult to see why on both a theoretical and practical level, volunteers should be treated as equal members of the multidisciplinary team. Sinclair (2007), however, drawing on Doyle (1995), asserts that the blurring of boundaries between professional and



lay workers is not appropriate within palliative care that has continuity, high quality communication and professional cohesion as key precepts. He makes the further point that in the case of the UK, because volunteers in the hospice sector are predominantly white, more affluent and mainly middle class, vestiges of an earlier philanthropic model are retained with recipients of care not seen as worthy of the best and by implication, expert care. This thinking does lean towards positioning palliative care as something that only specialists can do, with the implication that the extensive use of volunteers in roles that involve close contact with patients, might lead to the deprofessionalisation of care for dying people that Sinclair (2007: 76) notes are already a 'devalued class'. Despite some resistance from the specialist palliative care lobby this emphasis on professional exclusivity is now being contested in the literature because of the growing diversity of palliative care models beyond the original UK form. As discussed above in relation to palliative care programmes operating in India and South Africa, the blurring of professional and volunteer boundaries is sometimes necessary in some models of palliative care and seen by some (Kellehear, 2005, for example) as a positive attribute in aiding both personal and community understanding of death and dying.

## 10. Conclusion

The discussion of the nature, extent and experience of volunteering in palliative care has revealed both the importance and complexity of this work. Patients and hospices benefit from the work of volunteers and there is now a wide understanding that professionals and volunteers, working in partnership, provide patients with a safe, relaxed and unthreatening package of care (Doyle, 2009). However, voluntary work in palliative care, as in other sectors, is changing and is now subject to health and safety regulation as well as a range of other management practices, many of which draw on approaches in the paid labour market. O'Brien and Wallace (2009) point to specific practices from the employment model that they see as potentially useful for developing the capacity and status of hospice volunteers. Annual appraisals, satisfaction reviews that consider the extent to which volunteers are getting what they want from their work and an opportunity for training and education to develop practice are all elements that may become a standard feature of volunteering in palliative care in the future. Much of this investment in volunteers is resource dependent and, with the drastic cuts to health and social care budgets currently ongoing in the UK, these measures may have to be deferred. Whilst UK hospices operate outside the statutory sector because of their charity status, they are recipients of significant amounts of income from statutory health care budgets and this does make continuity of current levels of funding subject to some uncertainty. Alongside and more generally, the broad mission of palliative care may be increasingly difficult for voluntarily funded organisations to continue to pursue, especially when it cannot be justified in terms of easily measurable outcomes that have an increased focus as part of the evidence-based system of health care now operating in the UK (Holloway, 2007: 95).

Despite this uncertainty, the place of volunteering in palliative care within the hospice context looks set to continue, particularly as the recruitment of paid professional staff may have to be limited due to budget constraints. The roles undertaken by volunteers of emotional comforter, spiritual supporter, palliative caregiver and therapeutic healer appear

to play an important role in patients' psychosocial and emotional well being, with their work representing a division of 'healing' labour. Full recognition of these roles is proposed as a starting point for stronger collaboration between volunteer palliative care workers and professional clinical staff aimed at reducing patient and family distress. This notwithstanding, the extent of volunteers' contribution and the organisational value placed on their work will vary from hospice to hospice. Thus while the hospice setting for this research sees volunteers as essential to service provision, Sheldon (1997: 113) notes that in some palliative care settings volunteers are positioned 'as handmaidens to the professional team' and in some contexts are resented because of the substitution of volunteers for tasks previously done by professionals. In addition, broadening volunteering opportunities to draw in those from ethnic minority communities is a significant challenge for hospices to signal that hospice volunteering is not an elite activity practised by a privileged few. In an increasingly diverse society such as we have in the UK, it is important to have a volunteer workforce that caters for diverse local communities and client groups (Howlett, 2009). Dismantling the barriers that prevent those from diverse backgrounds seeking to become involved with hospice is a significant challenge within a culture that historically has managed to preserve a distinctly white middle-class image. Hospices are first and foremost care service providers but they are also employers, with responsibilities to promote anti-discriminatory policies and practices in all areas of their operation. Actively extending an inclusive approach to the recruitment of volunteers is an important initiative particularly for hospices located in inner city areas that have a culturally and ethnically rich and diverse population. Issues of diversity are now considered as part of the evaluation and audit of hospice services and the cultural profile of the volunteer workforce may in the future be incorporated within the overall picture of audited hospice activity in the way that patient diversity is currently.

All names have been changed to protect confidentiality

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