



Knowledge Exchange Seminar Series (KESS)

The role of the hospice volunteer in community settings

1. Introduction/abstract

In the UK, there are between 70,000 and 100,000 hospice volunteers, of whom half have direct patient contact. This seminar draws on a commissioned literature review that highlighted how 'volunteering is integral to voluntary action and often motivated by altruism.' The review concluded that hospice at home volunteers can help improve the quality of responsiveness of end of life care, improve access to care and can support care and death in the person's own home. Volunteers gain health and social benefits and personal growth from their volunteering and the patients and carers they support also gain benefits over and above the care they receive. Volunteers also bring benefits to the hospice as an organisation and to the local community, providing a link between the two and enabling the hospice to be more sensitive and responsive to local needs. The seminar will highlight further work that would seek to provide empirical, qualitative data on the role of the volunteer in two community settings, England and Northern Ireland, and would aim to explore the differences and similarities in these two community contexts.

For the purposes of this seminar the following definition of volunteering in end of life care is used:

'volunteering in end of life care is unpaid activity conducted for the benefit of others beyond close relatives provided in connection to an organisation that provides end of life care, support or services.' (Naylor et al. 2013, p.2).

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2. Context

2.1 National context

In recent years, Northern Ireland, Ireland, England, Scotland and Wales have all addressed issues relating to palliative and end of life care. This has been in recognition of, for example, an increasing older population, variable care at the end of life and the current economic downturn and instability. Each of the five nations recognise the need for care closer to home, including the need to deliver palliative and end of life care closer to home. They also recognise the role of the voluntary sector, especially hospices, as key partners in this provision. However, whilst national policy acknowledges that there is a preference to die at home (Department of Health 2008, Health Service Executive Ireland 2008, National Audit Office 2008, NHS Scotland 2008, Department for Health, Social Services and Public Safety 2010, Welsh Government 2013), Gomes et al. (2013) recognise that this ideal preference may not be met because circumstances 'may make this seem impossible' (p10). They go on to say that despite end of life care strategies being in place, and that the preference for care and death at home was well known, 'the majority of people still do not die at home' (p11). NICE concur, stating that up to 74% of people say they would prefer to die at home and yet currently 58% of people die in hospital (NICE, quality standard 13, 2011).

2.2 Regional context

Within Northern Ireland, there are a number of key documents shaping palliative and end of life care policy and which contain clear statements supporting the need for more responsive, community-based services.

In *Living Matters, Dying Matters*, the then Minister for Health, Social Services and Public Safety, Michael McGimpsey, stated 'I am ... mindful that families, carers and volunteers continue to be the crucial cornerstone of this care' (DHSSPSNI, 2010, p4). There is also reference to a 'robust infrastructure to bring patients, families and carers alongside public, independent, community and voluntary sectors and in so doing enable all organisations to work collaboratively to design, deliver and improve palliative and end of life care services' (DHSS&PSNI, 2010, p38). The document also highlights 'community based volunteers ... who ... can provide transport, help with cooking, washing and ironing and provide respite to carers as well as companionship and bereavement support (DHSSPSNI, 2010, p34).

To further support this approach, the review of the provision of health and social care services in Northern Ireland in 2011, which resulted in *Transforming Your Care*, highlighted a need for the integration of services at a local level, the provision of more community-based services and care for people at home when safe and appropriate to do so. It also identified the need to provide patient and client-centred care across a range of areas including long term conditions and palliative and end of life care. *Transforming Your Care* also asserts that 'services will regard home as the hub and be enabled to ensure that people can be cared for at home including at the end of life' (DHSSPSNI, 2011, p.7).

These policy documents are broadly aligned with those in England, Scotland, Wales and Ireland, all of which recognise the need for care to be brought closer to home, including end of life and palliative care, albeit using a range of different organisational approaches. They also acknowledge the role of the voluntary sector, particularly hospices, as key partners in this provision.

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2.3 *The contribution of volunteers*

Hospice care at home is delivery of care that meets an individual's end of life care needs, which will usually entail receiving care over and above that which is normally provided by community services in other circumstances. Furthermore, Calanzani et al. (2013) suggest that provision of 'hospice enabled' death will be needed in a range of settings – home, care home, community or acute hospital. It is recognised, however, that more volunteer support is needed to match the increased scope and size of provision that hospices will need to deliver now and in the future. Hospice volunteers are involved in all aspects of hospice life, in a wide variety of roles, and without their involvement hospices would not be able to operate effectively.

Currently, the numbers of volunteers providing *direct care* in the UK are low (NICE, quality standard 13, 2011 - updated October 2013). However, it has been suggested that hospice volunteers might provide more direct care to patients in the future and that the role will need to be integrated into the work of the clinical team (Help the Hospices, 2012). Wherever this care is located – home, hospital or elsewhere – it will require 'effective and collaborative, multidisciplinary working within and between generalist and specialist teams' (NICE, quality standard 13, 2011, p. 2). To enable home (including care homes) to be the primary place for palliative and end of life care, hospice at home staff, volunteers and other community staff will need to work together in a complementary way

2.4 *Strategic direction*

A Kings Fund report (Naylor et al 2013) *Volunteering in health and care. Securing a sustainable future* suggests that the new models of health, which emphasise a community response, will be reliant in many ways upon volunteer involvement. Similarly, the Volunteering Strategy for Northern Ireland (2011) identifies the need for a strategic approach to the promotion and expansion of volunteering in Northern Ireland. Its development is intended to produce a robust policy context which will provide the conditions that will 'enable volunteering to flourish and to ensure that its impact on life in Northern Ireland is maximised' (The Volunteering Strategy for Northern Ireland, 2011, p. 8). In the context of palliative and end of life care, a strategic approach to volunteer development and deployment is needed to meet the challenges of the future (HtHC, 2012).

In recognition of this increasing importance of the volunteer contribution, a literature review was undertaken by The Open University regarding the role of volunteers in the provision of palliative and end-of-life care in the community. The search comprised literature from 2000 to the present day, initially in the UK and Ireland and then expanded to include other countries primarily America and Canada. Policy literature and information from relevant charitable organisations was also searched in addition to a wide range of academic journals. The review sought to address a number of key questions concerning volunteering including the nature of activities undertaken by volunteers; the scope of their roles; how they are selected, inducted and trained; and the benefits of volunteering to the hospice, patients and carers, and to the volunteers themselves. It is these benefits that are explored in this seminar.

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3. Benefits to the hospice

Volunteers can be involved in all aspects of hospice life including house-keeping activities, assisting with personal care, shopping, transportation but only a minority in the UK are involved in direct patient care. Volunteers therefore provide a range of benefits to the hospice. Indeed many could not operate without volunteers (Davis Smith, 2004). Hospice volunteering should be driven by a genuine belief that volunteering brings benefits to the organisation (Naylor et al., 2013) and indeed there is some evidence to indicate they improve quality of care and also cost effectiveness (Calanzani, 2013). However, if cost saving is the principle motivation for involving volunteers, then it is unlikely that attempts to promote the role of volunteering will succeed (Naylor et al., 2013). In short, volunteering should be driven by a desire to improve quality, rather than reduce costs.

Volunteers provide diversity to the professional team and complement the work of paid staff and they are increasingly considered less as 'informal providers' and more commonly as core members of an interdisciplinary team (Guirguis-Younger et al., 2005). Volunteers therefore add capacity to the workforce but in doing so should not substitute or undermine paid roles. They can therefore provide a rich dimension to the hospice as an organisation, supporting and enabling hospice cultures.

There is also indication that volunteers in hospices provide strong reciprocal links to the community (Scott and Howlett, 2009). They bring local knowledge of the community and can act as 'bridges' between the hospice and its surrounding community, thereby promoting community cohesion (Naylor et al., 2013). The presence of volunteers therefore helps organisation to be more responsive to the needs of the local community, creating social identity and developing social capital (Seymour et al., 2011).

There is therefore significant evidence that volunteers bring value to the hospice as an organisation. However, supporting volunteers is not cost-free. Although they give freely of their time, to maximise their contribution there are costs associated to support, manage and coordinate volunteers (Department of Health, 2011). Volunteers need to be recruited and selected effectively, and then inducted and trained appropriately. They also need to be managed effectively and there is evidence to suggest that poor volunteer management services lead to unhappy volunteers (Bates, 2009). All these activities incur cost to the organisation. The concept of the Volunteer Value (HtH, 2006) is defined as the cost which a hospice would incur if it employed staff to do all the work done by volunteers. Help the Hospices (2006) estimates that the Volunteer Value of all UK independent hospices is £112 million, or 23% of a hospice's expenses. This pilot study indicated that for each £1 spend on supporting volunteers, hospices received a return of more than £11 suggesting that the economic value of volunteers to hospices was nearly equal to the contribution from the NHS.

4. Benefits to service users/carers

Volunteers are able to provide support to families to help care for their loved ones at home and to die at home. They are able to provide support across the illness trajectory, not just at the beginning, but also through to the bereavement stage too. In this regard, volunteers are able to help support the concept of hospice at home despite the fact that the evidence for patient and carer outcomes in hospice at home care is limited. In a recent systematic review of hospice at home care, increased patient and carer satisfaction was consistently reported as a benefit along with a decrease in general healthcare use (Candy et al., 2011). Those receiving care from volunteers felt that this care held great significance for them (Watts, 2012). The time freely given by the volunteer to support someone at the end of their life

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was highly valued and was considered different from the professional care experiences. The different types of support provided by volunteers include emotional, practical, informational, and spiritual (Claxton-Oldfield and Gosselin, 2011).

More generally, the literature demonstrates that hospice at home volunteers can help improve the quality and responsiveness of end of life care, help improve access to care and can support care and death in the person's own home.

5. Benefits to volunteers

The benefits of volunteering to individuals have been well researched and this work suggests volunteers receive health and social benefits, as well as personal growth from volunteering. These include, for example, increased self-esteem, well-being, social engagement, self-worth, and a sense of purpose (Warburton, 2006). Casiday et al. (2008) suggest that volunteering is shown to decrease mortality, improve self-rated health and mental health, improve life satisfaction, improve the ability to carry out activities of daily living, support health behaviours and improve the ability to cope with one's own illness. Volunteer satisfaction is associated with the experience of fulfilling their volunteer goals and feeling accepted as part of the hospice family (Andersson and Ohlen, 2005). Volunteers also report valuing education and training as part of their volunteering role.

These benefits and the satisfaction that comes with hospice volunteering are also closely linked to the motivations for volunteering. The literature identifies a range of reasons that motivate people to volunteer in hospice settings. These include personal experiences of death, a desire to help, a desire to learn about palliative care and end of life, wanting to give something back to the service or community, or in response to an active recruitment campaign (Starnes and Wymer, 1999, Watts, 2012). Volunteering therefore has enduring appeal and consequently recruiting to volunteer roles does not appear to be difficult. In addition to these benefits however, volunteers report that it can be challenging citing, for example, poor communication and lack of emotional support (Morris et al., 2012), feeling undervalued, emotional stress (Payne, 2001) and burn out (Huynh et al., 2012). These challenges reinforce the need for effective training, support and management of volunteers.

6. Conclusion

We have seen that volunteer involvement is an increasingly important aspect of community life in general and in palliative and end of life care in particular. There is evidence of benefits of volunteering to care providers, to service users and carers. In addition, volunteers themselves have been seen to benefit. However, the evidence to date is not evenly spread with apparently more evidence of benefit to organisations and patients than there is to carers and volunteers. Having explored the policy and research in the area, we conclude that volunteer care needs to become a more developed and more supported area of palliative and end of life care in Northern Ireland.

We have noted several policy documents and local strategies that already support the development of volunteer engagement and this goes beyond striving for cost-effective care. Northern Ireland and Ireland explicitly acknowledge the central role of patients, carers, families, communities and volunteers in the provision of palliative and end of life care, especially in the community. They also recognise the need for education and training for these groups to ensure appropriate quality care is provided which is essential if they are to provide direct patient care and be integrated within clinical teams. Our 'shift-left' policy to increase the capacity of the service to support people at home or in their own community dovetails with the volunteering agenda.

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DHSSPSNI (2010) have commented that as more palliative and end of life care is provided in the community it is crucial to recognise carers, families, communities and volunteers as essential partners in caring and it is vital that they 'have the confidence and competence to take on these roles and responsibilities (p34).

In addition, Northern Ireland has a strong tradition of volunteering. There is also a strong network of end-of-life care providers with organisations that already have volunteers on the workforce, in many and varied roles. These include [Foyle Hospice](#) providing care across community; [Southern Area Hospice at Newry](#); hospices around Belfast; [Northern Ireland Hospice](#) (including Northern Ireland Children's Hospice and Horizon West in Fermanagh) and [Marie Curie Hospice](#) (here in Belfast), which is part of the UK network of Marie Cure Hospices. The hospice network here extends south in partnership with the [All Ireland Institute for Hospice and Palliative Care](#). These networks of care providers and partners are powerful engines to drive practice development and explore gaps in our knowledge.

As yet, it is unclear how best to involve volunteers in palliative and end of life care and the work reported here has highlighted a number of questions including

- What exactly can volunteers do
- How to avoid tension between volunteers and paid staff
- How to provide culturally sensitive care with volunteers
- What training and support is needed
- What is the impact of volunteering on volunteers
- How to maximise the benefits and minimise the challenges
- What is the impact of previous bereavement on volunteering practice

In a number of ways, volunteers occupy 'boundary spaces', between the public, the patient and paid staff and further research is needed to better understand how these boundaries can be navigated.

By combining a rigorous literature review with a detailed understanding across the Island – North and South – we hope to begin to address some of these gaps in knowledge and subsequently make recommendations to enhance the patient/carer/volunteer experience. In our partnership approach between academia and palliative care providers, we aim to undertake further research to examine these issues, so that the potential of volunteers can be realised for organisations, patients, carers and volunteers themselves in palliative and end-of-life care settings.

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Jan Draper, The Open University

George Kernohan, the University of Ulster

Aine MacNamara, The Open University

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