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Abstract

This paper is based on on-going doctoral research designed to investigate the lived experiences of hospice volunteers and the institutional processes that are shaping that experience. The research is being carried out in a hospice using ethnographic techniques including observation, interviews and an unconventional approach in hospice research based on the principles of LEGO® Serious Play® (LSP). LSP involves group sessions, in which the research participants have the opportunity to think and express themselves as they create using the medium of Lego models. Drawing on the experience of the researcher and data collected so far, the paper provides a critique of LSP and argues that it can be an effective technique for exploring sensitive and complex topics, as well as facilitating organisational development through the research process. As such it has the potential for wider use in research within hospices and other organisations within the voluntary sector.

(Word count 148)

Introduction

The world’s first modern hospice, St Christopher's, was founded in London in 1967. A network of independent hospices was subsequently established across the UK, to provide holistic, palliative care to people in the final stages of life. Palliative care has since developed into a complex medical specialism in its own right and today’s hospices employ highly trained, professional specialists in medical, clinical and non-clinical areas. Operating within the charitable sector, their workforce has always included both volunteers and paid staff within all aspects of the service they provide. £1.6 million is spent on hospice care every day, with only around one third of the costs met by the government. With a UK volunteer workforce of approximately 70,000 in adult hospices, the economic value of volunteers to independent charitable hospices in the UK is estimated to be over £112 million (Help the Hospices 2014). Whilst there are seemingly obvious financial benefits to hospices in the continued use of volunteers, other benefits are more difficult to quantify.
The hospice at the centre of this research is situated in the north of England. Opened in 1981 it comprises an in-patient and a day care unit where volunteers are involved directly with staff and patients, undertaking a variety of roles. Volunteers also contribute to the hospice within the local community in charity shops and fundraising activities. The hospice provides a range of highly specialised palliative care and offers support and advice to other clinicians, health practitioners, care providers and members of the public. There are currently 492 volunteers registered with the hospice. A questionnaire sent out to volunteers by the hospice showed that in total 66,420 volunteering hours were given each year with an equivalent salary cost, based on the minimum wage, of half a million pounds per year. Palliative care in a hospice is provided by an inter-disciplinary team including paid clinical and non-clinical staff, and volunteers are integral to those teams. As hospice services look to expand in response to an increasing demand for palliative care, in order to provide and sustain that service, volunteers are likely to play an increasingly important role in both clinical and community settings.

**Methodology**

The research is a small-scale, ethnographic case study. Ethnographers study the lived experiences, daily activities, and social/political context of everyday life from the perspectives of those being studied; typically the researcher immerses [herself ]in the natural setting for long periods of time to gain a deeper understanding of people’s lives. (Buch and Staller 2013). Within the hospice, volunteers work independently and alongside paid staff in all areas of the setting, including: in-patient and day care, reception duties, fundraising and the board of trustees. The key research questions for the study are:

- What contribution do volunteers make within a hospice?
- How is the volunteer role perceived by volunteers and by paid staff?
- What is the nature of the relationship between paid staff and volunteers?

The researcher is herself a trustee of the hospice and has been a volunteer in various capacities for over 30 years. Trustees are responsible for strategic management, major policy decisions and upholding the vision and ethos of the organisation. The role requires trustees to have a degree of distance from the everyday running of the hospice; operational decisions rest with the Senior Management Team, all of whom are paid and include both clinical and non-clinical professionals. As such, the researcher’s decision to undertake an ethnography within the institution sees her quite literally positioned in close proximity to staff and
volunteers in a way that trustees would not normally be seen within a hospice. The researcher has a pre-conceived notion of the work of volunteers based on her knowledge and experience as a trustee but the ethnography enables her to see things as those involved see things and ‘to grasp the native’s point of view’ (Denscombe 2007:63). The research, whilst seeking to find out about the lived experiences of individual volunteers through an ethnographic approach, is also seeking to understand the institutional and cultural processes which shape that experience. In addition to the ‘skills-set’ of volunteers, are there institutional practices or assumptions which limit or encourage the contribution of volunteers? The methodology has characteristics of an Institutional Ethnography, described metaphorically by Smith (2006) as a small heroic figure standing at the bottom peers into the ruling relations that tower above her. The exploration starts where the small hero stands. In this case that metaphor represents the individual volunteers and their experiences, as well as the researcher and her enquiry.

**Participatory research**

The hospice has no history of research, but there is an aspiration to become research active in order to inform practice and policy and to disseminate expert knowledge practice and expertise beyond the immediate confines of the hospice. Whilst there is enthusiasm amongst individual staff and trustees, to date research and education is embryonic within the institution. This is not unusual in hospices and resonates with research by Payne, Preston, Turner and Rolls (2013) who looked in detail at research capacity in hospices, and identified substantial barriers such as: hospices being small independent institutions having no research culture, a lack of infrastructure, expertise and resources, and do not benefit from research partnerships with the NHS or university sectors. Despite these barriers they concluded that it was essential that hospices do contribute to research in the future. Regulation of health care provision and commissioning of services are increasingly combined with the requirement that providers demonstrate evidence-based practice. Hospices also need to understand and question what they do in order to disseminate knowledge and expertise more widely amongst other providers of palliative care. This study involves participatory research: the participants are actively involved in shaping the direction and focus and involved with the researcher, in a joint process of knowledge-production (Bergold and Thomas 2012). From the outset the researcher has sought to involve staff and volunteers in the research process, seeking out their ideas on key issues they considered should be included within the research. Actively involving the hospice staff and volunteers attempts to democratise the research.
process, flatten some of the traditional hierarchies (Henn, Weinstein and Foard 2009) and make the research process more collaborative and emancipatory. The impact of participation in the research process will help to develop the embryonic research culture at the hospice, enhance the research skills and experience of individuals and develop volunteer strategies and practice.

The experience of this ethnography is enabling the researcher to see examples of the work of volunteers and staff at first hand, and is already helping to shape her strategic thinking and consider the impact of management decisions on the people they affect. This highlights the importance of managers, policy makers and those who have responsibility for strategic decisions spending time with others to experience first-hand the ‘work’ they do. Whilst some might question the validity of research carried out within one’s own organization the researcher feels privileged to be able to spend time seeing and hearing about the work people do and the stories they tell within the hospice. It is perhaps something which others in managerial and strategic roles might usefully undertake in their organisations to better understand individual roles and to give voice to subordinates within an institutional hierarchy. The ethos and values underpinning this methodology resonate with the researcher’s personal approach to research practice: it is an attempt to make the research process more collaborative and emancipatory, providing an opportunity for shared participation between researcher and participants.

**LEGO® Serious Play® as a research method**

Previous studies of hospice volunteers have made use of traditional data collection methods such as interviews, focus groups and questionnaires to collect qualitative data. A review of research methods commonly used in end of life care research, commissioned by the National Institute for Health Research (NIHR) and carried out by Goodman, Froggatt and Mathie (2012), concluded that research in this field using creative, representational methods to enable self-expression is underdeveloped.

Whilst this research has involved traditional ethnographic techniques for collecting data including interviews, observation and work-shadowing, it has also made use of visual research methods (Mitchell 2011) and specifically metaphorical modelling (Gauntlett 2007, 2011) based on the principles of LEGO® Serious Play® (LSP). Initially designed as a problem-solving tool in the Lego company, the principles of LSP are being applied in this research to capture data both individually and jointly from groups of staff and volunteers. Metaphorical modelling using LSP involves participants coming together in a group of 4-6 participants and building models using
the medium of Lego models which represent concepts and ideas. Whilst not making any claim that this technique is essentially preferable to other methods, in this research it has shown itself to complement those other approaches and in some cases afforded some notable advantages which are discussed within this paper. The process allows for an informal and unstructured exchange of ideas as opposed to a highly structured and one-way extraction of information as might be more akin to individual interviews (Henn, Weinstein & Foard 2006:189). In this study the models are used by participants as a focus for conversation and discussion and to explore together the nature of the volunteer role and relationships of volunteers and paid staff in the hospice. This approach has been valuable to both the researcher and participants in jointly: exploring some potentially complex ideas; avoiding ‘top of the head’ responses; and, combining the benefits of individual responses as one would seek to achieve in an interview with group interactions characteristic of focus groups. Social research often requires participants to produce instant descriptions of their views, opinions or responses, in language and most people can’t really provide accurate descriptions of why they do things as soon as you ask them. (Gauntlett and Holzwarth 2006). The process of building and explaining a Lego model which represent a concept metaphorically allows participants more latitude to shape the conversation with the researcher, talk about the subject in their own terms and provides more scope for exploring relatively unchartered terrain. It has also been useful in exploring potentially sensitive and complex areas such as participants’ relationships, learning, and emotions within their work with death and dying.

Given that LSP is a relatively novel approach which volunteers and staff are unlikely to be familiar with, finding participants for the group sessions was challenging. It soon became apparent that face to face contact with groups of staff and volunteers would be required to explain and justify the approach and to answer questions before individuals might agree to participate. Groups of volunteers have monthly meetings with some paid staff and these events have been a useful gateway and an opportunity to publicise the research. They have also given the researcher the opportunity to explain the research in person and talk to the volunteers and staff about the project more fully than could be achieved in a written information sheet. The researcher was able to answer questions and these exchanges resulted in volunteers offering to participate in interviews, shadowing and the Lego modelling events. To help with the explanation the researcher took photos to the meetings, of sessions done previously in other contexts, including images of the Lego models and some of the participants from those sessions. The photos were carefully chosen to
give a good representation, matching some of the ‘profile’ of the participants (eg older adults and younger individuals and groups) and trying to convey the ‘fun’, informality and participatory nature of the sessions. It turned out that taking the pictures along was very effective in generating interest and discussion about the project and involving individuals as participants.

The aim of the LSP sessions is for participants to use Lego pieces to build a metaphorical model which represents a concept, an idea or their perception of something, for example: the volunteer role or the relationship between the volunteer and the paid staff. In the process of building, participants formulate their ideas and reframe their thinking helping them to think and express themselves as they create. Using their model as a focal point or a point of reference they then share that thinking with the researcher and others in the group. It affords opportunities for sharing of ideas within the group but unlike a focus group the key points are not determined by individuals who may then influence the direction of the discussion. That said individual contributions will still be influenced by the group dynamic and the presence of others. Taking time to make something, using the hands, gives people the opportunity to clarify thoughts or feelings, and having an image or physical object enables them to communicate and connect with other people more directly (Gauntlett 2011:4).

The researcher assumes the role for the facilitator, and participants are encouraged to explain their models, the choices they make in terms of the metaphors they have used and the structure and components of the models they have built. The researcher can also ask participants how they might change their metaphorical model in some way to develop their thinking further eg ‘if that represents your relationship with a paid member of staff, what would an ideal relationship look like?’ That then prompts conversations about professional relationships, the role of volunteers, the expectations of staff and the perceived boundaries which might exist. In the process of building the models the participants have ‘private conversations’ with themselves. However, an important part of the process is the collaboration which follows when they explain their models and start to put their thinking into words so making their private thoughts public, often leading to reflective conversations with other participants and the researcher. Moving from thoughts to words can be difficult, and ‘stuttering interpretations’ are common. Participants need to be reassured that their stuttering interpretations are a valued and often essential part of the process and that ‘fledging thoughts’ are as important as fully formed ideas and opinions.
Metaphors and emerging themes

The metaphors used provide useful insights into participants’ thinking and help to identify common or contrasting themes. LSP sessions and other data indicated the symbiotic relationships between volunteers and paid staff. Metaphors such as ‘gems’, ‘gifts’ ‘backbone’ and ‘treasure’ were commonly used. Staff described volunteers at the hospice as:

“A tower of strength supporting us and bringing time and generosity. They want to come…they’re a right tonic.” (Volunteer Co-ordinator)

“It’s the little things …you don’t realise how good they are until they’re not there….they do such a good job so when they’re not there…they’re just part of what’s normal…and they do give you a lift.’ (IPU Nurse)

Staff and volunteers felt that volunteers free up aspects of the paid workers’ role especially where time was a factor. One of the nurses talked about the volunteer drivers who transport patients to and from the Day Hospice. She described how paid staff and volunteers work together and the complexity of the role of a volunteer driver:

“We [paid staff] never go to the patient’s home anymore. So they [the volunteers] see things we don’t see. And you know, sit in that car for that journey and they’re sharing so much more. What we do is support volunteers more, particularly if they’re bereaved because they probably feel grief as well. They [the volunteers] probably know a lot more than sometimes that patient shares with us and also we’ve had a few where, you know, they’re going to the home situation, it’s a bit of a crisis point, because our patients are poorly …… a bit of a 999 situation. So it’s reassuring the volunteers we’re there. But they’re fantastic, couldn’t do without them. (Day Hospice nurse)

Staff often felt supported by volunteers and encouraged in their work; the metaphor of ‘family’ was a word often used by both staff and volunteers.

‘I think both the staff and the volunteers benefit, its like a mutual, a bit of like, …..symbiosis, that we, you know, we’re all connected, really to every department as well, you know, no matter what role you do, particularly within
the hospice, you know, that you’re really all interconnected and you work as part of a team. ……. I just love, I love the place.’ (Volunteer, Finance Department)

Staff often saw it as part of their role to support and care for volunteers, representing this with bridges, towers and hearts in their models and individual volunteers have also spoken of such instances. That care for volunteers on an individual basis was seen by some of the staff as an extension of the caring role they have for patients and their carers. There were examples when volunteers required care and support whilst they were still experiencing bereavement, but other examples where volunteers were perceived as having thrived and developed as a consequence of their volunteering.

‘It’s our responsibility that we are seen to be supportive ………it is your family isn’t it?…….There’s nothing more satisfying than seeing a volunteer striding round the hospice like it’s their home….like they belong here. What a difference the hospice can make to them and how they flourish. We see such a massive change in some volunteers.’ (IPU Staff nurse)

‘I mean I think it rescued me in a way, and I think, you know, I think it does for a lot of people. But oh yeah, I mean they’ll have to take me out in my box, you know, but yeah, if I can keep trundling in.’ (Volunteer Receptionist)

Metaphors also highlighted challenging or negative aspects of the relationships between staff and volunteers, notably: sharks; models with prickles and spikes; weighing scales representative of a fine balancing act led into discussion about management of individuals and groups of volunteers.

‘Occasionally we do have some volunteers that need more managing than others….Sometimes they want to get too involved …management side of things and want to know a bit too much.. so I do find some volunteers challenging, same as staff really.’ (Day Hospice nurse)

The challenges staff identified relating to volunteers often relate to management within the organisation. Volunteers, unlike paid staff can to an extent ‘work’ on their own terms in relation to: availability; time; ways of working; and can say ‘no’. For example fitting volunteering in with other commitments such as: holidays, family and
work which in some cases take priority. Volunteers can have agency and arguably be more difficult to 'control' which requires sensitivity, tolerance and more creative approaches to management from individual staff and managers who cannot naturally assume conformity and performativity from volunteers.

As well as building individual models, during LSP sessions participants have built joint models representative of their vision of volunteer development, incorporating perceived barriers and opportunities within that vision. Barriers which were identified in expanding volunteer involvement, especially in clinical and community services, included: safeguarding, damaging the hospice’s reputation, finance and regulation. However, in discussing one such shared model, the group came to a consensus that the perceived danger and limitations of using volunteers in a wider role was attributable more to perceived rather than actual risk. With the evolution of this hospice, over time there has been increasing professionalisation in that, like other hospices, it is recognised as a centre of highly specialised practice and expertise and at the same time is increasingly subjected to the same regulatory and inspection processes as NHS and other providers of health and care. To meet the expectations of inspection and commissioning bodies, explicit policies and procedures are put in place, often mirroring those of public and private sector organisations. Paine, Ockenden and Stuart (2010) explore changes in third sector organisations and suggest that standardisation and formality are replacing more 'homegrown', less bureaucratic approaches. They argue that despite an overwhelming drive towards professionalisation and formalisation, some organisations have resisted it and kept the spirit of volunteering alive and central to its ethos and the centrality of volunteers in an organisation stops it slipping further into hybridity. With its roots and ethos firmly in the charitable ‘third’ sector, increasing complexity, changes to funding and with a greater emphasis on accountability and management have seen a blurring of boundaries and more influence from both the public and private sectors. With the increasing influence of adjacent sectors there is a danger of the potential loss of independence and possible mission creep, where voluntary organisations ‘lose their soul’ (Billis 2010:10) In the early stages of the data collection, this is showing itself to be an interesting aspect to explore.

The group activity within the LSP sessions were well received by participants who welcomed the opportunity to discuss aspects of the research questions together, especially when it enabled them to consider future development of the hospice.
Limitations

There have been some limitations and points to consider in using LSP as a research tool. The sessions last a minimum of one hour and finding sufficient time and space for staff and volunteers to participate within a workplace setting in a small organisation is challenging. There is a danger that ‘style and the look’ of the model may take precedence over content and meaning when participants build their models, and the concept of metaphor can sometimes be difficult to grasp. On occasions during the sessions it has been necessary to manage the emotional response of some participants arising from some of the issues discussed or conversations triggering memories of previous events or on-going issues associated with the participants’ individual roles or workload. It would be naïve to claim that these methods allow some sort of privileged access to the participants’ ‘inner self’ (Buckingham 2009) and it will not be a panacea for all. Some participants who saw themselves as ‘not creative’ were constrained by the method in the early stages of a session, and this needed to be managed sensitively with a high degree of support and some humour; the group dynamic was important in this regard. Some participants found the activity challenging but the same could be said for research participants in interviews or focus groups who can similarly be overawed and uncomfortable.

However, most participants enjoyed the ‘return to childhood’ and the opportunity to ‘play’ with ideas, which was significant given the nature of the hospice workplace. This project and the use of LSP specifically has involved hospice staff and volunteers in research and facilitated organisational development through the research process, enabling staff to experience a technique which might be used more widely as a method of communication and inquiry in the hospice.

“The researcher enters into give-and-take conversations with the people of the community. Moreover, the people of the community are not ‘subjects’ at all; they are active collaborators in the research effort.” (Angrosino, 2007:12).

Conclusion

Hospice work is by its very nature, challenging, demanding and emotionally laden. Many of the volunteers’ roles such as reception duties, providing refreshments, gardening and driving, could be seen as basic and low status. Indeed one of the recurring themes when speaking with volunteers is: ‘I’m only a volunteer’. Whilst recognising some of the benefits they bring to the hospice, some describe their own
position within the organisation as below that of paid members of staff. Some of the more visible aspects of volunteers’ work is made explicit within formal induction, role descriptors and training provided within a hospice. Aside from those clearly defined aspects of work however, there are less visible and arguably complex aspects of the volunteer role which are associated with enculturation of the hospice. As part of the hospice team, volunteers acquire culturally transmitted knowledge about death and dying and find themselves needing to learn about palliative care, forming relationships and dealing with the unexpected. This learning is situated and contingent upon the culture which exists within the hospice setting. The nature of that experience is complex and difficult to classify but this ethnography is enabling the researcher to see examples of ‘invisible work’ at first hand. The use of LSP alongside other more traditional research methods is helping to illuminate some of the complexities of volunteer experiences in a professional workplace. Allen (2014) argues that so-called simple tasks of gerontological nursing are actually highly complex but made to look simple, because of the expertise of nurses, and this study suggests that the same can be said for the volunteers’ activity within the hospice.

(Word count 4032)

REFERENCES


