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Title: Hospice volunteers as facilitators of public engagement in palliative care priority setting research

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Short title: Hospice volunteers facilitating public engagement

Key Statements

- Hospice shop volunteers could be key facilitators of public engagement in palliative care research
- Hospice shop volunteers captured public priorities for palliative care research and relayed their experiences of involvement
- Hospice volunteers can support public engagement and palliative care research, but approaches to their involvement require further development

Introduction

In England, volunteering in palliative care is well established, with the largest numbers of volunteers per 1,000 inhabitants in Europe(1). The role of palliative care volunteers can vary considerably, from hospice-based roles (e.g. acting as ‘go-between’ connecting patients/family and paid staff) to more public-facing responsibilities (e.g. fundraising and community work). This pilot project explored a novel method for involving volunteers in public engagement research. Hospice shop volunteers surveyed members of the public about their perspectives on priorities for palliative care research.

Methods

St Gemma’s Hospice, Leeds, is one of the largest hospices in the UK, with an Academic Unit of Palliative Care (AUPC) and a network of 22 high street shops that generate funding through the sale of donated items. Ten shop volunteers attended a training workshop at the AUPC. Volunteers were given a series of short presentations about AUPC research and asked to comment on a survey designed for visitors to hospice shops. The project was linked to a national project identifying research priorities in palliative care (Palliative and end of life care Priority Setting Partnership (PeolcPSP): <http://www.palliativecarepsp.org.uk/>). Two questions from the PeolcPSP were included in the survey to capture a public dimension on research priorities, with remaining questions refined through volunteer feedback. Volunteers used a finalised survey to approach shop visitors. Two evaluation forms were completed by volunteers; one following the workshop event and another on completing surveys with shop visitors. All workshop attendees were invited to attend a dissemination event in March 2014 to provide additional feedback on their experience of participating in the project and to comment on the data captured. Members of the North Trent Cancer Research Network Consumer Research Panel were also invited to the dissemination event to comment on the project and its findings.

Results

Nine volunteers reported the initial workshop as improving understanding and confidence about using the survey with members of the public. This in turn increased confidence to approach members of the public, and volunteers looked forward to conducting the survey. Volunteers suggested that i) the workshop could have better exploited the infrequent opportunity for volunteers from different shops to talk with one another; ii) materials outlining what involvement in the project entailed could have been more explicit; and iii) volunteers would have valued researchers spending time familiarising themselves with the hospice shop environment during project planning.

Volunteers completed surveys with shop visitors (n=67) between November and December 2013, collecting pilot data on the priorities and perceived value of research taking place in palliative care. Volunteers reported mixed experiences of participation. Enjoyment was reported from engaging with the shop visitors with the survey. However, volunteers reported tension between conducting the survey and carrying out their routine volunteering role, some resistance to the survey from shop visitors, and issues with content of the survey in terms of the appropriateness of questions regarding end of life and their clarity.

Of the shop visitors completing the survey, the majority were members of the public with an interest in palliative care (57%), although there were individuals who were currently or previously a caregiver or close acquaintance of someone at the end of their life (28%). The remainder were people working with those at end of life (4%) or other (11%). Volunteers reported that most shop visitors were receptive to the survey and its content. However, unexpected reactions from respondents were encountered. For example, a respondent took home a copy of the survey and returned it with a 4-page detailed description of her experience of palliative care during the final months of her husband's life-limiting illness, reporting that completing the survey alleviated some remaining anger that she felt about her own experience. Four volunteers attended a dissemination event and were joined by three representatives from North Trent Consumer Panel who were providing additional reflections on the data and volunteer experiences. This discussion, along with lessons learned throughout the project, have been summarised in Table 1.

Table 1: Summary of key findings to inform future volunteer involvement in palliative care research

Key recommendations in public engagement work with volunteers
<ul style="list-style-type: none">• Ensure recruitment materials are explicit about the expectations on volunteers. Where possible, explain how involvement in a research project might change routine roles of volunteers• Establish a lay panel to screen materials for volunteers (e.g. those used in workshops, information sheets) to ensure ease of understanding for research naive individuals (including clarification of all scientific terms). A lay panel can also screen the content of any survey to be used with the public to ensure that questions are acceptable• Develop an understanding of the demographic and activities of the environment in which volunteers are based (e.g. times of increased visitor numbers in hospice shops, staffing patterns)• Ensure formal infrastructure is in place to support management of confidential information• Consider how clear processes of support can be established and accessed for volunteers or survey respondents who may be upset or distressed from involvement in the research• Ensure the boundaries of flexibility to the research approach are discussed with shop volunteers. For example, in this project volunteers enabled some shop visitors to take home the survey and return it at a later date. Such approaches could be encouraged if shop volunteers are aware of what is appropriate for the particular study• Consider how events can be used as networking and discussion between volunteers that may not usually have such opportunities to communicate with one another• Explore ways of gauging whether volunteers are confident in the approach being taken to public engagement prior to commencing activities

Discussion

This project explored the involvement of shop volunteers in public engagement research in palliative care and identified areas for improvement. This represents an early and evolving approach to accessing the views of members of the public that utilises the skills and strengths of volunteers. The existing and changing roles of volunteers are currently being explored with the recent formation of a European Association of Palliative Care Task Force on Volunteering in Hospice and Palliative Care. Hospice volunteers are well placed to facilitate public engagement, which may form part of their varied role across the UK(2), Europe(1) and Middle East(3). Gauging volunteers' perspectives is essential to ensure that role expectations are acceptable.

Acknowledgements

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