

Peer education for advance care planning: volunteers' perspectives on training and community engagement activities

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Abstract

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Background Peer education by volunteers may aid attitudinal change, but there is little understanding of factors assisting the preparation of peer educators. This study contributes to conceptual understandings of how volunteers may be prepared to work as peer educators by drawing on an evaluation of a training programme for peer education for advance care planning (ACP).

Objectives To report on volunteers' perspectives on the peer education training programme, their feelings about assuming the role of volunteer peer educators and the community engagement activities with which they engaged during the year after training. To examine broader implications for peer education.

Design Participatory action research employing mixed methods of data collection.

Participants Twenty-four older volunteers and eight health and social care staff.

Data collection methods Evaluative data were gathered from information provided during and at the end of training, a follow-up survey 4 months post-training; interviews and focus groups 6 and 12 months post-training.

Findings Volunteers' personal aims ranged from working within their communities to using what they had learnt within their own families. The personal impact of peer education was considerable. Two-thirds of volunteers reported community peer education activities 1 year after the training. Those who identified strongly with a community group had the most success.

Conclusion We reflect on the extent to which the programme aided the development of 'critical consciousness' among the volunteers: a key factor in successful peer education programmes. More research is needed about the impact on uptake of ACP in communities.

Introduction

The rise in chronic long-term conditions means that it is often difficult to ascertain the onset of 'dying': as a result that there may be a lack of discussion of end-of-life care decisions and a delayed transition to palliative care.¹ 'Advance care planning' (ACP) is defined here as a process of discussion and review enabling individuals to express and, if they wish, to record views, values and specific treatment choices to inform their future care.² It has been widely promoted as one means of improving end-of-life care, but uptake is low, even among older adults who make up most of those with chronic disease.³ It is acknowledged that increasing uptake depends on raising public awareness of ACP⁴ and enabling people to think about its applicability to their own life situation. Given the host of complex cultural issues associated with death and its anticipation, there is also a need to initiate community led processes of change by enabling knowledge and discussion of a wider range of issues surrounding end-of-life care.⁵⁻⁷

Initiatives to raise public awareness of ACP reported in the international literature focus on the distribution of leaflets and similar materials to encourage completion of advance directives,⁸ although there are also a few reports from North America of community-based outreach projects encouraging the uptake of advance directives through a range of public education activities.^{9,10} In the UK, the government funded 'Expert Patient Programme' (EPP) includes an ACP component which focuses on a short introduction to advance directives.¹¹ Findings from an evaluation of this element of the EPP reveal that a significant weakness was the lack of consideration of any broader aspects of ACP which may be of more relevance to the biographical situations of participants.¹²

In this study, we draw on an evaluation of a 3-day training programme to prepare volunteers to undertake community-based peer education for advance care planning and associated

end-of-life care issues. The training programme was developed as a part of a larger community-based study exploring end-of-life concerns and educational needs among older adults and their care providers. We report volunteers' perspectives on the peer education training programme, their feelings about assuming the role of volunteer peer educators, and the community engagement activities with which they engaged during the year after training. The project involved 32 volunteers who were mainly older adults, who all participated in the earlier phase of the larger study involving focus groups, the findings of which are reported elsewhere.¹³

In reporting this evaluation, we seek to add to conceptual understandings of how volunteers may be prepared to work as peer educators for health promotion within their own communities and, specifically, to provide insights into how peer educators engage actively with new knowledge and then shape a role in peer education according to their own aims and contexts. In so doing, we build on existing observations that processes of dialogue and contextual influences^{14,15} underpin community participation in health and draw on insights provided by Campbell and Macphail¹⁶ who highlight the importance of these processes in the development of 'critical consciousness' in the peer education context.

Background

Our work in this area is part of a programme of research¹⁷⁻²⁰ aimed at understanding the perspectives of older people on end-of-life care. This shows that many older people value the opportunity to exchange stories about end-of-life care with people who belong to their community group or who are of a similar age to them or with whom similar experiences are shared. Within this latter research, the topic of ACP has been perceived by older people as potentially enabling participation in end-of-life care decision making or helping their families to make decisions on their behalf. However, older

people also associate ACP with a number of problems including questions about possible links between ACP and euthanasia, the possibility that preferences for care may change, and difficulties in thinking about and discussing death and dying.¹⁹ Our direction has subsequently been targeted at finding approaches to enabling public understanding and engagement with these topics.

The 3-day peer education programme reported in the following paragraphs builds on an earlier pilot project in which we worked with five older people to co-write a booklet about ACP and end-of-life care subsequently published by a UK charity.²¹ We provided a structured 3-day peer education training programme²² to the five older volunteers from one locality to enable them to use the booklet to co-facilitate a series of community-based workshops.¹⁷ This training programme covered issues of bereavement and loss, group dynamics and facilitation, palliative care, and ethical and legal issues.

We subsequently gained funding for a larger community-based study with two elements: first, a series of focus groups to explore end-of-life concerns; and second, a revision of the training programme so that we could train a larger number of volunteers from diverse groups and localities.

Peer education

Peer education, defined here as: 'sharing experiences and learning among people with something in common'²³ has been advocated as one way of enhancing awareness about health issues among older adults.^{24–26} Peer education is most commonly associated with projects involving young people and relating to sexual behaviour, drug use or smoking.²⁷ 'Peerness' has been noted to relate to a multiplicity of identities rather than to one key demographic factor, such as age or ethnicity.²³ Moreover, there is a wide range of conceptualizations about what might be considered activities in 'peer education', from the

highly structured delivery of a set education package, to more informal, unstructured activities.²⁸

Peer education may provide either an alternative or a complement to 'expert' led education.²⁹ Peel and Warburton³⁰ suggest that peer education supports interactions that many people prefer, strengthens a sense of identity and encourages attitude change by role modelling. In essence, all peer education projects value lay experience, with many conceptualizing peer education as having the potential to generate self-knowledge among peer educators.³¹

Peer education has been called 'a method in search of a theory',²⁸ because there is little understanding of how the role of peer educator is shaped and enacted in community contexts or what lessons can be transferred from such initiatives to other contexts. In seeking to address this dearth of understanding, Campbell and Macphail¹⁶ report a critical case study of a schools-based peer education programme in South Africa employing three concepts to explain the processes by which peer educators are prepared to promote safe sexual behaviour. First, 'social identity', which refers to the significance of group membership and the collective negotiation of beliefs, norms and behaviours. Second, and of primary emphasis in their work, the importance of the development of 'critical consciousness' characterized by interactive and reflexive engagement with new knowledge and development of insights into practical ways to initiate change.³¹ Third, Campbell and Macphail¹⁶ explore the utility of 'social capital' as an explanatory tool, likening this to a social or community context that enables the development of social identity and critical consciousness and supports a sense that individuals can 'make a difference' through their own efforts.

The peer education training programme

In refining the pilot training programme, we worked with the five original peer educators to look at its content, suitability and scheduling,

and at sources describing participatory research with older adults.^{32,33} Training was directed at enabling volunteers to develop understanding of key aspects of ACP and how it related to end-of-life care; understanding of what peer education means and to help them to think about the role they wished to take as a peer educator and how and from where they would access support to enable this role. In addition, we sought to help them to develop:

1. awareness of issues about loss and communication and how these influence peer education;
2. skills to prepare them to facilitate peer group or one-to-one discussions to raise awareness of ACP in their communities;
3. awareness of appropriate resources to provide information to others about ACP and related end-of-life care issues.

We aimed to run the peer education programme in a participatory and non-didactic manner, with small group work and opportunities for debate and discussion. We also sought to provide a safe and enjoyable environment for participants to air concerns, identify goals and develop new knowledge and plans for action. Training took place over 3 days, with each day involving attendance of between 5 and 6 h. Box 1 presents a summary of the programme.

Box 1 Content of the volunteer peer educator training programme

Topics

- a. Palliative and end-of-life care: introducing key issues.
- b. Understanding loss, grief and bereavement.
- c. Advance care planning and other legal/ethical issues.

Approach

- a. Peer education: what does it mean? What does it involve? Examples of peer education in action.
- b. Supporting ourselves and others: moving on; ways to manage, using reflective diaries.
- c. Working with your peers: Action Planning.

Techniques

- a. Group work: dynamics, facilitating groups.
- b. Communication skills.

Days 1 and 2 were delivered consecutively. Day 3 took place 3 weeks after the first days, to allow time for individual reflection.

Methods

An approach known as ‘participatory action research’³⁴ was employed as a methodological framework. This draws upon different fields of influence including critical thinking and feminism.³⁵ Participatory action research aims to produce usable outcomes and knowledge of direct relevance and applicability to the issues being studied. It aims to engage participants in dialogue throughout the study process³⁶ and to adjust the conduct of the project in response to feedback. Studies employing participatory action research typically involve cycles of action and critical reflection and cast researchers as co learners, rather than ‘experts’.³⁴ Ethical committee approval for the research project was gained through the UK National Research Ethics Service.

Recruitment of volunteer peer educators

We accessed volunteers primarily from members of five community groups who participated in focus groups as part of the larger study.¹³ Four of the original volunteer peer educators also took part, taking the role of mentors to the new volunteers. The groups were as follows:

1. A ‘Crossroads’ Cancer and Palliative Team and their Bereavement Support Group in a city in the Midlands of England
2. An umbrella organization comprising several self-help groups operating across a city in the Midlands of England
3. An African Caribbean Community Association in a city in Northern England
4. A network of lesbian, gay and bisexual (LGB) older people living in various parts of England
5. A Seniors Forum in the North East of England.

Box 2 Summary of evaluative methods and stages

1. Immediate evaluative activities during and at the end of each training day (all 32 participants).
2. Postal survey administered 4 months after training (24 respondents).
3. Focus groups at a follow-up workshop 6 months after training (22 participants in four focus groups).
4. Interviews (either single or group) between 12 and 18 months after the training (25 participants in 12 interviews).

In addition to these five community groups, we recruited volunteers from a senior learners group at a University in North West England, who had expressed interest in the project. A small number of health and social care staff also underwent the peer education training and were recruited from the related focus group study.

Demographic characteristics of volunteers

Thirty-two people participated in the training programme: 24 older people and eight care staff,

Table 1 Demographic characteristics of volunteer peer educators

Gender	
Male	10
Female	22
Type of participant	
Older volunteer	24
Care staff volunteer	8
Age bracket	
< 55	8
55–64	8
65–74	9
75 and over	3
Missing	4
Self-reported ethnicity	
White British	26
Black British	2
Missing	4
Self-reported health status	
Excellent or good	17
Fair or poor	7
Missing	8
Current or last occupation	
Professional, managerial or 'white collar'	17
Skilled workers or care workers	5
Missing	10

including community nurses, care home assistants and social care workers. Twenty-two women and ten men took part. Table 1 summarizes participants' demographic characteristics.

Evaluation of the programme: an overview of data collection methods

Box 2 summarizes the methods employed to evaluate the peer education training programme, the stages of the evaluation and the numbers of participants in each stage.

As well as a range of ongoing evaluative activities during the 3-day course, a summative evaluation form was completed by volunteers at the end of day three (see box 3 for the evaluative questions).

Box 3 Evaluative questions at the end of the 3-day peer educator training programme

1. Closed questions: respondents indicated (√) whether they strongly agree, agree, disagree or strongly disagree to the statements.
 - a. The training programme was well organised.
 - b. The content was relevant to my needs.
 - c. The presentations were interesting and helpful.
 - d. Opportunities for participation were appropriate.
 - e. I felt able to contribute to group work.
 - f. The booklet material was easy to understand.
 - g. The booklet and handouts stimulated discussion.
 - h. The day was worthwhile.
 - i. The venue was suitable.
 - j. The catering arrangements were satisfactory.
2. Open-ended questions
 - a. What have you most enjoyed about the overall experience of the training programme?
 - b. What is the most significant thing that you have learnt as a result of the overall experience?
 - c. Is there anything you think about differently as a consequence of the overall experience?
 - d. Having now attended the Peer Education training programme, do you plan to become a peer educator in relation to end of life care, either with friends and/or family, with groups based in your area, or a mixture of all three?
- e. Additional comments.

Four months after the training, a postal questionnaire to gain information on volunteers' views about the training and their subsequent experiences was distributed (see Box 4 for the questions addressed).

Box 4 Survey questions administered at 4 months to volunteer peer educators

Respondents indicated (✓) whether they strongly agree, agree, disagree or strongly disagree to the statements and were also invited to provide written comments

For you personally, do you feel that the 3 day programme:

1. Enabled you to share and further develop understanding of key issues in end of life care?
2. Enhanced your awareness of issues about loss and communication?
3. Enabled you to facilitate peer group or one to one discussions about end of life care issues?
4. Enabled you to identify and use appropriate resources to provide information about end of life care to others?

Do you feel that the programme involved:

5. The sharing and valuing of each other's knowledge and beliefs in a supportive environment for learning?
6. Examining how experiences of bereavement and loss may influence the ways in which we listen to others?
7. Time for reflecting on different experiences of communication?
8. The development of your skills to facilitate discussions about end of life care with greater confidence?
9. Sharing and reviewing of examples of resources that may help discussions about end of life care?

The following topic areas were looked at during the programme (five topics listed):

10. Which of the topic areas do you feel you have learnt the most about?
11. Which of the topic areas did you find most interesting?
12. Do you feel you are still unclear about, or lack confidence in any of the topic areas? If so, which?

Style of the programme

13. Do you feel that contributions relating to your personal experiences were welcomed by the research team and other participants?
14. Do you feel that contributions relating to your personal experiences were valued by the research team?
15. Do you feel that the programme was run in an informal style?

Supportive environment

16. Do you feel the programme provided you with enough space to think about these issues in a safe environment and did you feel supported?

17. During the 3 days of the programme, did you feel the need for support?

18. If you felt in need of some support, did you speak with a member of the research team or with another person on the programme?

Privacy and Confidentiality

19. Did you feel people's privacy and confidentiality was respected by everyone and at all times?

Expenses

20. Did you claim expenses and the allowance for attending the programme?

21. Do you feel that the allowance paid was appropriate and sufficient?

22. Did you have any difficulties in completing the paperwork for your claim or getting your payments?

23. If so, did the difficulties get resolved?

After the programme:

24. Were you contacted by the person nominated as your supporter?

25. Did you contact your nominated member of the research team for further support?

26. Did you contact, or were you contacted by, anyone else from the university team?

27. Since the programme, have you been in touch with any other people who attended the programme?

Twenty-four people responded, providing qualitative and quantitative data. We used the results of this questionnaire to inform an aide memoire employed in four focus groups attended by 20 peer educators held 6 months after the end of training. Twenty-five volunteers were subsequently followed up between 1 year and 18 months after the training, taking part in either single or group interviews, conducted by a member of the project team who had not taken part in the delivery of the training. Four older peer educators were not followed up because of illness or bereavement and we were unable to contact three staff members. The focus groups and interviews addressed how volunteers perceived 'peer education', what peer education activities they had engaged in since the completion of training and what impact these had upon them and how they sought support.

The data gathered as a result of these evaluative activities were analysed in three ways. The quantitative data were analysed to produce descriptive statistics. Textual data from evaluative activities

and from the postal questionnaire were subject to content analysis. Interviews were transcribed and analysed qualitatively with the aid of the qualitative data analysis package, NVIVO™.

Findings

In presenting the findings of the evaluation, we show how a sense of social identity was developed by the volunteers alongside the growth of ‘critical consciousness’ which comprised the emergence of a new understanding among volunteers about advance care planning and end-of-life care issues, and an associated sense of how they could shape their role as a peer educator. We draw attention to tentative observations that those volunteers who were able to sustain their peer education activities had been able to access ‘social capital’ to nurture their personal efforts. We present the findings in relation to the different stages of the evaluation process.

Sharing concerns, anxieties and hopes for a peer education role

Most preliminary concerns expressed at the outset of training involved anxieties about personal abilities, or participating and speaking in groups. Some were also nervous about discussion of a ‘taboo’ topic, while those who had been bereaved were concerned that the training may upset them. Concerns were also expressed about whether the role of peer educator would ever be something that they could usefully and feasibly adopt. Personal aims included enhancing communication skills; gaining confidence in both practical and emotional terms; gaining knowledge and understanding about the subject matter and helping others become more aware of the issues at hand. Many people expressed wishes to find ways of listening and relating to others, particularly those experiencing bereavement.

Developing new understanding and emergent plans for peer education

At the end of the 3 days, most participants reported increased knowledge of advance care planning issues and greater awareness and

comfort with associated issues relating to death, dying and bereavement. Thus, one person noted that ‘death is not something to be afraid of’, while others reported gaining a new understanding of loss, as not only to do with bereavement though death, but also to do with ongoing change or with illness. Most reported gaining new insights into how to support those who had been bereaved and some reported gaining insight into the ways in which people might experience or think about end-of-life care issues. In a minority of cases, people reported heightened anxiety rather than increased comfort, or a greater appreciation of complexity, which deterred them from taking the role of peer educator any further. In relation to understandings and perceptions of the role of peer education, a range of views were expressed, which capture the diverse stances we had encouraged the volunteers to consider. Box 5 summarizes these views.

Box 5 Views and understandings immediately after the training programme: examples of volunteers’ written comments

Evaluative comments

Meeting like minded people who all wanted to help other people- even though some obviously had difficult times themselves.

Enjoyed meeting a wide variety of people- hearing different points of view.

The camaraderie and very useful information for all- much food for thought indeed!

Reflections on learning about end of life care issues

The diverse ways and extent to which other people think about end of life issues- I have learnt a lot.

That there are many ways in which we might use this information for ourselves and also with others.

Dying sounds a bit more complicated than I thought!!!

I appreciate how people experience death and dying differently

Understandings and perceptions of the role of peer education

Involves people with something in common learning together.

Is about exchange of information and a participatory learning process.

Can be done with individuals and with groups, as informal and as formal discussions.

Information was gathered from the volunteers about any peer education activities they planned. Some wished to primarily work in their own locality or as part of their existing community group network. In contrast, some anticipated using what they had learnt to engender greater discussion of the issues within their own families. Those volunteers who were ‘staff’ anticipated using peer education both in their work and in their personal lives, although the balance between these varied. Box 6 summarizes these plans

Box 6 Immediate plans for implementing peer education for end of life care: examples of volunteers’ written comments

Working with a community group

I plan to meet as part of a group to discuss the way forward.

I hope to use what I have learnt and go forward with (community group).

I would like to participate within groups in my local area.

Finding a way forward

I would like to go away and re-read the information, think about the subject and look at how I can pass on information.

I wish to find a way of working that matches my strengths and (more importantly) is judged reasonably effective.

Using it with family and friends

I hope to use it in my personal life, put it to family and friends.

I will talk about the process of my dying with my family.

Personal and emotional implications of being a peer educator: volunteers’ reflections in the year after training

Data from the 4-month follow-up questionnaire and the follow-up focus groups and interviews revealed the development of a much deeper level of engagement with the topics, with some volunteers emphasizing how participation in the programme had led to change or growth, either within themselves or in their relationships with others. For example, one older man reflected on how he felt that he had changed his ‘style’ during the year following the programme, becoming more empathetic and compassionate:

It is obviously a very delicate area and it gave me compassion ... a re-education as far as I was concerned because in my working life I was the person giving orders ... so it did educate me on getting down the people’s level; I’m not up here talking down to them if anything I’m down here talking up to them and the training taught me to be more sympathetic with more compassion and I am very thankful for that (Male older volunteer, 12 months after the programme).

A younger woman who had participated as a staff volunteer, reflected on how the training had enabled her to think about a personal bereavement and to relate what she had learnt to issues within her own family:

Where the course kicked in for me was because of the personal level ... we had the knowledge that we could apply and we were aware emotionally how to be around the family ... It opened a lot of boxes but the way the course was organized gave you a sense of security to be able to talk about whatever (Female staff volunteer, 12 months after the programme).

Similarly, an older woman, who was in poor health and who had no immediate family, reflected on the personal impact of undertaking the training:

... on a personal note, I too have taken notice of what I’ve learned from here, and I’ve made all my arrangements, such as if I have to go. As I progressively get worse I might later on, hopefully a lot later on, have to go in a home because I don’t have next of kin. And I have been out to talk, write down exactly what I want to know, [how] I want it done, so that for me has been a good thing as well, because I wouldn’t know nothing about it had I not come here.... All I’ve got to do now is grow old gracefully (Female older volunteer, six months after the programme).

Another staff volunteer noted her improved confidence and comfort with the topic, which had helped both at work and at home:

Before it always felt like a major topic, you know ‘Oh how am I going to raise this?’ ... it [has] made it seem like something more natural to talk about, not to feel so awkward about discussing end-of-life matters and decisions ... so that was really helpful (Female staff volunteer, 12 months after the programme).

Community engagement activities reported by the volunteer peer educators in the year following peer education training: the importance of attachment to a community group

Four months after the training programme, 21 people who responded to a survey questionnaire indicated that they had initiated a one-to-one discussion about ACP or end-of-life care, with someone in their community or in their workplace; seven reported that they had either given, or planned to give, a talk or presentation of some sort to others; two reported that they had worked together to arrange what they named an 'information day' in their local area, where they invited members of the public to come and listen to presentations and question local stakeholders (policy makers, staff in influential positions in health and social care) about end-of-life care issues. In addition, fourteen people had sought out other relevant workshops or presentations to learn more about the issues.

In the follow-up focus groups and interviews, we found that those people who were well embedded in a community group, or who had undertaken the training as a staff volunteer, were more likely to report success with shaping a role as peer educator. For example the senior learners group reported how they had had an idea for a personal resource portfolio for advance care planning and how they had been able to gain funding to develop this:

We've got a great long list, really quickly. And we wanted to take our training out into the community. So we thought the first thing we would do is prepare this portfolio ourselves, and just see how it felt and what issues it raised and what we learned from that doing that before we tried it out on anybody else. And then we realized that if we were going to do anything in the community, there would be some costs... we realized that the PCT [Primary Health Care Trust] was giving out grants, and we got nearly £10,000 (Older female volunteer, six months after the programme).

At 12 months, they described how they had subsequently worked together to develop this idea and then tested it out in two community-based workshops in partnership with their local PCT, as part of a drive to raise public aware-

ness of end-of-life care issues locally and nationally.

The older people who represented a network of LGB elders also reported a range of activities, which involved the participation of friends and relatives, their local support group, as well as regional activities such as provision of training about end-of-life care to health and social care staff and giving presentations at regional events. This group has subsequently won a regional award for the community impact of their activities in this area. One of the participants in this latter network, who suffered ill health, explained how she had taken part in the training because she saw it as an opportunity to develop her voluntary work with her local forum for LGB people. In turn, she had gained encouragement and support because of the wider national interest in LGB issues and end-of-life care expressed by two national charities for older people in the UK:

Well I certainly wouldn't have done the course if I wasn't involved with (LGB local group). But again that's the input from Help the Aged and Age Concern, the work they're doing, I'm very interested in what they do. I don't know what really, I don't think I'd be where I am now really (Female older volunteer, 12 months after the training).

Similarly, those older people who belonged to an active seniors' forum reported success in engaging with local stakeholders in their health-care trust, partly because of the direction of national policy, which was encouraging local health-care organizations to develop new ways of engaging the local community in strategic plans for end-of-life care, with a particular emphasis on advance care planning. These volunteers persuaded a number of stakeholders to put on a public education day, involving the distribution of leaflets, talks and opportunities for questions and discussions. Six months after the training course, this event had been in the planning stages; by 12 months they could reflect on the work involved:

I'll be quite frank, I certainly wouldn't have got as involved as I am if I hadn't have done it (the training). See, I mean, last year we organized an information day ... after the last training day we

had a meeting we said well okay we'll go and meet these people and see what they're doing ... one thing we found was who knows what is out there as far as care provision. Who provides it, how is it provided, how do you latch onto it? So we went and saw the hospice. We went and saw the PCT [Primary Health Care Trust]. We went and saw the Council. ... We literally pressed our PCT to get an (end-of-life care) strategy together because we went and saw them and we said okay we're going to hold an information day and we will invite them to come and talk. So it pressurized them into having to have something ready (Older volunteer, male, 12 months after the programme).

Other peer educators reported plans for involvement in the national and local activities of a new National Coalition for Raising Awareness of death, dying and bereavement: 'Dying Matters: Let's Talk About It',³⁷ with some reporting networking with large national charities such as the National Council for Palliative Care and Age UK. Their role in these organizations is highly valued according to anecdotal reports (personal communication).

In contrast, those people who were less well embedded in their community groups, or who were operating as a sole volunteer or in pairs, found sustaining a role in peer education much more difficult. As noted earlier, we were unable to follow up seven volunteers and conclude from this that these individuals were unlikely to have undertaken any peer education activities, although we cannot be certain that this is the case. Also, some individuals experienced illness and bereavement during the follow-up period, which constrained their activities.

Discussion

In this project, we were interested in how volunteers who were committed to raising awareness among their peers of advance care planning experienced a training programme to enable them to become peer educators and how they enacted this role over the following 12- to 18-month period. Unlike some peer education programmes, which see peer education as a means to deliver a set and tightly controlled programme of education activities,³⁸ we did not seek to impose a fixed mode of peer education

upon the volunteers, rather we wanted to help them to develop knowledge about advance care planning and end-of-life care in their own terms (at the same time ensuring that the sources from which they gained this knowledge were reliable and accurate) and to develop a mode of peer education that worked for them and fitted with their particular situation. Here, we were influenced by perspectives on peer education as affected by the extent of personal engagement of peer educators and their social conditions, i.e. as an 'intervention in context'.³⁹

The findings provide insight into how the 'interested' public⁴⁰ engage with a new health care technology through a process of mutual learning involving integration of personal, emotional and experiential reflection with acquisition of 'objective' knowledge about technocratic elements.⁴¹ Following Campbell and Macphail,¹⁶ we have shown how volunteers were prepared to take on new knowledge by responding to the opportunities provided to share worries and concerns and to set out feasible personal plans for a peer educator role. In the months that followed, many volunteers reported many aspects of a development of 'critical consciousness' that enabled them to engage in action.³¹ This included changes in personal style; becoming aware of new ways of learning and sharing learning with others; perceiving new opportunities for coming to terms with personal bereavement or new ways of thinking about death and dying, and finding positive impacts in private and work lives. A strong relationship between effective diffusion of new information by peers and the degree to which they have some personal 'ownership' of the latter has been observed.⁴² In addition, in this project, the synergy between volunteers' personal experiences of loss and end-of-life care and their motivation to provide support or advocacy to others who wished to know more about these issues has been very clear.

We found that those people who were well connected with a local community group or who were able to form a distinct 'sub group' of peer educators in their locality reported the most success in encouraging and sustaining interest in

the issues locally. Some of these were able, in addition, to build alliances with wider local or national activities that were taking place, as a result of the direction of national policy in end-of-life care.⁶ To this extent, the volunteers were able to 'catch' an important historical moment. Sustainability of the peer education role has been found to be more likely where volunteers are embedded in a wider community-based programme of change or action.^{26,43} The importance of building such alliances has been observed in other contexts,³⁹ and is a clear example of the importance of access to 'social capital' to nurture and sustain voluntary peer education activity.

In contrast, those who were less well embedded, or who faced illness and bereavement, were less likely to have sustained a role in community peer education. This finding resonates with the wider research on peer education, which shows that the ability to sustain being a 'peer' is tightly related to a social identity nurtured by group connections and membership.²³ In addition, it has been previously shown in the literature that older adults can be among the most highly committed community-based volunteers; they may have more time to be involved and more motivation to find new ways of drawing of their past experiences.³⁰ Some of the peer educators were part of communities or networks who might be seen as marginalized (here we are referring to the African Caribbean community association and the network of LGB elders): to this extent we are able to tentatively conclude that this approach to sharing information has enabled outreach to people who it may be more difficult to access using more traditional modes of education or engagement.

Limitations

This project recruited a self-selected group of volunteers to undertake training in peer education for ACP and related issues. We expected to solely recruit older adults, but in keeping with the participatory philosophy of the wider project, also involved eight health and social care staff who had taken part in an earlier phase of

the project. The evaluation of the programme presented depends on self-report data and does not provide insight into the effectiveness or recipients' perceptions of the volunteers' peer education activities within their localities. The degree of personal and emotional impact on the volunteers and the need for appropriate support to be provided during the training programme must be emphasized.

Conclusion

This study has contributed, building on existing research about peer education, to the development of conceptual understandings of how volunteers may be prepared to work as peer educators for health promotion in their own communities. It has shared some lessons learnt about the successful design and implementation of a peer education training programme in advance care planning and related end-of-life care issues and demonstrated the potential for engaging participants from a wide range of backgrounds in an innovative approach to a potentially difficult and sensitive subject to address a key strategic goal of contemporary end-of-life care policy.

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