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# Supporting family carers in home-based end-of-life care: using participatory action research to develop a training programme for support workers and volunteers

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## ABSTRACT

**Background** Family carers are crucial in enabling dying people to stay at home, but are often not prepared for their caring role, receiving little support from formal health and social care services. It is increasingly likely that any help or support family carers receive will be provided by a third sector organisation on either a voluntary basis or by untrained carer support workers.

**Objectives** To produce a training programme designed to equip carer support workers and volunteers with the basic skills and knowledge needed to support family carers.

**Process of development** Participatory action research, a collaborative form of working in which those who are affected by an issue take a lead role in the research, was used. Bereaved carers acting as research partners, support workers and representatives of third sector organisations took an active part in designing, developing, piloting and refining the programme in a number of interlinked stages. During development, the programme was piloted on four occasions and evaluated by 36 trainees and 3 trainers.

**Final training programme** The outcome of the project is an innovative, 1-day training programme, offering an introduction to supporting family carers who are looking after someone approaching the end of life. The use of participatory action research methods enabled the development of a programme that addresses support needs identified by bereaved carers and training needs identified by carer support workers.

The finished programme includes all the materials necessary to run a training day for support workers and volunteers: facilitator's notes, trainee workbook, slides, promotional poster and pre-course reading for trainees.

Knowledge of issues involved in end-of-life and palliative care is not required, although some experience in delivering training is advisable.

**Conclusion** The programme evaluated well during development, but further research is required to examine the transfer of learning into the workplace.

## INTRODUCTION

Most people in England die in hospital, but spend most of their final months of life in their usual place of residence,<sup>1</sup> which may be a care home, although many people continue to live in their own homes.<sup>2</sup> For those living at home, many of their care needs are met by family members, which often represents a new experience for family carers, who may not feel ready to occupy such a role.<sup>3-5</sup> Looking after someone approaching the end of life can have a huge impact on family carers, who may find it stressful, exhausting and lonely.<sup>3-6-9</sup> In this paper, the term 'family carer' refers to a person who takes on the responsibility of looking after someone approaching the end of life who needs support and assistance. The family carer gives such help without being paid and tends to come into the role through their personal relationship with the dying individual; such a relationship may be one of friendship, rather than kinship, and the term family carer is intended to encompass all such relationships.<sup>9</sup>

Individuals caring for a family member or friend who is dying at home often believe that they are only doing what might be expected; this means that the nature and extent of the caring they do is



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obscured from the outside world.<sup>9</sup> In addition, end-of-life care within families is often carried out with little formal support from health and social care services with reliance instead on informal support offered by the extended family, friends and neighbours.<sup>10</sup> Given the context of such care and the lack of support for carers, it is unsurprising that looking after someone who is dying can be an emotionally and physically demanding role to take on.<sup>10</sup>

The importance of the work that carers do is acknowledged among those working in the statutory services, but it remains the case that carers may have many unmet practical and emotional needs.<sup>6</sup> The unmet needs will vary between individuals, but may include a need for information, for emotional and psychological support, for relationship support or practical support.<sup>6 11</sup> Research exploring the support needs of carers has identified such needs as falling into two categories, namely support that allows the family carer to provide good care for their relative who is dying and support that relates directly to the carer's own health and well-being.<sup>6</sup>

In the current UK social and political context, it is increasingly likely that any help or support family carers receive will be provided by a third sector organisation on either a voluntary basis or by untrained carer support workers, rather than by statutory services.<sup>10 12</sup> The training needs of volunteers and support workers have not been well researched, although a number of studies have examined the implementation of training programmes for professionals who are caring for people at the end of life in institutional settings, with a particular emphasis on the utility of train-the-trainer approaches.<sup>13–15</sup> Family carers' own need for training in end-of-life care issues forms the theme of another strand of research.<sup>14 16</sup> The aim of one study was to develop a training pack for community workers whose role included supporting families caring for sick children. The content of the pack was developed by experts with the assistance of the community workers, and the pack was evaluated by community workers and carers. Care was taken to ensure that content was culturally appropriate, with the telling of stories as a key training resource, which evaluated well.<sup>17</sup>

This article reports on a participatory action research project that was designed to address the lack of training for volunteers and support workers who offer support for family carers in home-based end-of-life care. The aims of the project were twofold: first, to develop and pilot a training programme for volunteers and support workers who help family carers; and second, to develop a resource pack for family carers. Participatory action research was used in the belief that people who had looked after a dying relative at home would best know what support they needed, whether they had received it or not. In addition, workers and volunteers whose roles could potentially encompass supporting family carers of people who are dying at

home would know what prior training and experience they had in relation to this type of supporting role.

The research, therefore, drew on the expertise of a range of stakeholders, including bereaved carers, carer support workers and third sector organisations such as Carers Federation, a Nottingham-based carer support agency, and Age UK Nottingham and Nottinghamshire.<sup>18–20</sup> It also drew on two prior research projects. In one, a tool called the Carer Support Needs Assessment Tool (CSNAT) was developed, using focus groups and interviews with carers recruited through hospice at home care services. The CSNAT, which comprises 14 domains of support, provided a framework for work on the training programme.<sup>6</sup> The second project was a peer education project on advance care planning, which offered a model for this programme at the outset.<sup>21</sup> Ethical approval was obtained from the Faculty of Medicine and Health Sciences Research Ethics Committee, for the inclusion of healthy volunteers.

## PARTICIPATORY ACTION RESEARCH

Participatory action research (PAR) is conducted in a collaborative fashion and has been used in a variety of fields, including healthcare,<sup>22</sup> care of older people,<sup>23</sup> education<sup>24</sup> and in organisational and management research.<sup>25</sup> The idea of PAR is that individuals and groups for whom the issue is important should have a genuine role in research and should be the ones to drive the focus and planning of the work. The rationale is that they are the people who know how their lives are affected and who have an interest in making improvements, with research providing evidence of how to do this. At its best, a PAR project will be driven at all stages of development, conduct and implementation by the interests of the participant group, with professional researchers assisting in the process. In practice, it is rarely straightforward and it is unlikely that there will be equality of power and influence in the design and conduct of a participatory research project.<sup>26</sup> Lay people are unlikely to have the same level of knowledge about research and its techniques that academics have, and the drive to carry out research will often come from universities or other research-focused institutions.<sup>27</sup>

Notwithstanding the potential difficulties with regard to power, for this project, using PAR meant that those to whom the issue of support for family carers in home-based end-of-life care was important were key players and were involved in all stages of the research process.<sup>28</sup> The project was led by university-employed researchers in collaboration with the Carers Federation, some of whose support workers took part in the early stages of shaping the training programme. Three bereaved carers, who had looked after their respective spouses towards the end of their lives, were co-applicants on the funding bid to carry out the research. They stayed with the project throughout as members

of the advisory group, and they were participants at different stages, depending on their preferred level of involvement. All three had been involved with at least one research project previously, and all had been co-authors on a briefing paper about involvement in research.<sup>29</sup> They were also members of an active patient and public involvement network based at the University of Sheffield. During the project, and in this paper, they are known as research partners.

## METHODS

This section of the article describes the process of development of the programme. The project began with a meeting of the advisory group, comprising academics, research partners and representatives from the Carers Federation. We agreed that our aim was to produce a training programme that would be published so that it could be free at the point of use, and that it would be suitable for trainers to use with groups of varying sizes. The finished programme includes all the materials necessary to run a training day for support workers and volunteers: facilitator's notes, trainee workbook, slides, promotional poster and pre-course reading for trainees. Knowledge of issues involved in end-of-life and palliative care is not required, although some experience in delivering training is advisable.

We developed, piloted and refined the training programme over a period of 2.5 years, and this involved a number of interlinked stages, which are described below. Although described in a linear fashion, the process was an iterative one that required different programme elements to be revisited and refined a number of times.

### Resource pack development

The first part of the programme to be developed was a resource pack for family carers. The pack comprises leaflets, booklets and websites that provide advice or information, which may be useful for family carers of people who are dying at home.

The resources selected were available as a mix of web-based and hard copy. This was deliberate, as some people do not use the internet and some prefer their reading to be on paper; two of our research partners were not online at the time of the project.<sup>30</sup> An initial list of 43 resources were reviewed by research partners and carer support workers in terms of content, title, appearance, utility and ease of reading. A final list of 10 was put together and incorporated into the training programme.

### Training needs analysis

To establish what should be included in the training programme, we held two workshops in collaboration with Carers Federation, a third sector organisation 'dedicated to supporting carers of all ages' and collaborator in the research (<https://www.carersfederation.co.uk/>). A form of purposive sampling was used to

## Box 1 Feedback from workshop two.

Issues for research team to consider in taking the programme forward: Issues for research team to consider in taking the programme forward:

- ▶ The kinds of situations in which contacts with carers in end-of-life contexts might occur
- ▶ Recruiting and identifying carers to be supported
- ▶ The term 'carer' and how to promote services
- ▶ Wider terminology, and how to work with carers when their own needs might not be a priority
- ▶ The amount of materials we expect to be downloaded in order to deliver the course
- ▶ Exit strategies in the programme
- ▶ Can we deliver the course over 1 day?
- ▶ Our vision for the supporter role
- ▶ Word the course title so that our audience is clear
- ▶ Empowering carers, increasing their confidence, legitimising their concerns and problems, giving them tips and strategies to manage their situation
- ▶ The limits of their supporters' own knowledge and role, and signpost on as appropriate

select workshop participants, to ensure that all had knowledge and experience relevant to the topic.<sup>31</sup> The first workshop comprised five carer support workers, who responded to an invitation to participate circulated by the organisation's training manager. Vignettes were used to focus discussions on the training needs of carer support workers.<sup>32</sup>

Work then began on the training programme, identifying core topics to be included and mapping out a broad timetable. The second workshop involved four workers from three organisations; researchers distributed invitations to existing and developing networks. This workshop focused on the expertise and knowledge already available in the represented organisations, and participants offered informal feedback on the proposed programme content. A key response was that the programme was too long at 2 days. Box 1 illustrates some of the feedback provided by participants in workshop two.

### Developing the training programme

Following the second workshop, the training programme was refined into a 1-day programme. Extra activities and information were added so that trainers could decide how they wished to use the programme and tailor it to their trainee group and particular institutional circumstances. The programme incorporated the 10 resources for carers, and the Carers Support Needs Assessment Tool (CSNAT) was used to provide structure.<sup>33</sup> A range of different approaches to the delivery of teaching materials was built into the programme, including activities and discussions, case studies, taught elements, audio clips and video clips of bereaved carers talking about their experiences. The video clips included one from Healthtalk.org

**Box 2 Principles of supporting.**

The principles:

- ▶ The supporter is someone who will listen
- ▶ The supporter will have an awareness of the palliative approach to care.
- ▶ The supporter appreciates the wider context of 'caring' and recognises that carers may have a variety of responsibilities.
- ▶ The supporter understands that they are part of a larger team of people involved in supporting the carer and the person being cared for.
- ▶ The supporter will be aware of his or her own knowledge and skills.
- ▶ The supporter and carers are clear about the supporter's role and that the relationship is constrained by professional boundaries and contractual obligations.
- ▶ The supporter will work within the scope of their own organisation's policies and procedures.

(<http://www.healthtalk.org/home>), while others were filmed specifically for the programme and involved two research partners sharing their experiences and insights. The use of film enabled us to present culturally appropriate stories that made sense to trainees and could facilitate their learning.<sup>17</sup>

We developed each section of the programme separately, in consultation between members of the research team and the advisory group. The session on the principles of supporting offers an example that illustrates how the process worked.

Developing the principles of supporting session

The terms support and support work are commonly used in relation to social care services, but there is little clarity regarding what being a support worker involves, and little sense of this as a role involving a group of workers with common aims and objectives.<sup>34</sup> Despite this, employment in a role that requires

working with potentially vulnerable individuals must be underpinned by the principles of good practice, which acknowledge the rights and responsibilities of both the supported person and the supporter. The research team, therefore, developed a series of principles for discussion during the training, with the intention of engaging trainees in reflection about their role and how it should be carried out. In this way, we followed the advice of workshop two participants, who suggested that we should include our vision for the role of carer support worker.

These principles were mapped against the NICE *Quality Standard for End of Life Care* and the *Common Core Competences and Principles for Health and Social Care Workers Working with Adults at the End of Life*.<sup>35 36</sup> Debate among the research team refined the principles and honed the wording, but discussions at workshop two were also key in identifying the principles underpinning the role. **Box 2** presents the final set of principles.

**Piloting and evaluation**

Each session of the training programme was developed in a similar way and thereafter followed an iterative process of piloting, evaluating and refining the programme. The programme was piloted on four separate occasions; **table 1** shows the stages of the piloting process and the methods of evaluation used.

As the intention of evaluation was to improve the programme, we used a formative model based on that of Weston *et al.*<sup>37 38</sup> This involved different evaluation techniques for the different pilots of the programme, although one method common to each was feedback from trainees. Feedback forms included a short questionnaire and a number of open questions, inviting trainees to reflect on the day. **Table 2** shows some of the evaluative comments made after the first three pilots of the programme.

**Table 1** Piloting and evaluation process

|   | No of trainees           | Trainers  | Form of evaluation  | Involving   |
|---|--------------------------|---|---|---|
| Pilot 1<br>January 2014<br>Nottingham   | 12, from 6 organisations | Members of research team  | Evaluation forms at end of day<br>Evaluator taking notes<br>Follow-up discussions | Trainees<br>Observer from research team<br>Trainees with members of research team |
| Pilot 2<br>September 2014<br>Nottingham | 12 from 7 organisations  | Age UK trainer  | Evaluation forms at end of day<br>Evaluator taking notes<br>Phone interview       | Trainees<br>Another observer from research team<br>Trainer                        |
| Pilot 3<br>December 2014<br>Torquay     | 7 from 4 organisations   | 2 Hospice trainers  | Evaluation forms at end of day<br>Phone interview                                 | Trainees<br>Trainers  |
| Pilot 4<br>March 2015<br>Manchester     | 5 from 2 organisations   | Trainees as trainers—took turns to deliver the training and to receive training | Evaluation forms  | Trainees/trainers   |



**Table 2** Sample of evaluative comments

|         |  |
|---------|--|
| Pilot 1 | Very informative   |
|         | Resources will be useful   |
|         | Recognition of things we do well and value of support we give  |
|         | Would have liked more time to discuss—sometimes felt a little rushed                                       |
|         | Sometimes felt a bit too general, more specifics would have been helpful                                   |
|         | Informative discussions and ability to share best practice   |
|         | Opportunity to discuss difficult topic in appropriate manner without being too sad/upsetting               |
| Pilot 2 | Opportunity to think about emotional impact of caring in EOL situations                                    |
|         | Presented in a way that did not leave you emotionally drained  |
|         | Whole day has been interesting and informative   |
|         | More time for talking about how issues may affect people and make it more difficult to support people      |
|         | The principles were a little confusing to get your head round  |
|         | Information on websites brill!   |
|         | Reflecting on case studies and networking with participants  |
| Pilot 3 | Thoroughly stimulating day, which excellently supported underpinning knowledge of end-of-life carer issues |
|         | This would be perfect for carer support workers and dementia advisors in particular                        |
|         | The way the workbook was set out was clear   |
|         | Possibly address carers in a residential setting as well   |

EOL, End of Life.

After each pilot and evaluation, the programme was refined. By March 2015, we felt that the programme was approaching completion. It was then sent to four critical readers, who included one of the trainees from the first pilot and three people with specific expertise and knowledge in end-of-life care, for final comments. Researchers then liaised with the School of Health Sciences' education and technology team, who produced a version of the training programme that was suitable for publishing online.

#### Dissemination event

In February 2015, a dissemination event was attended by 32 interested individuals, representatives of organisations and stakeholders. We gave a presentation about the training programme and its development, and then round table discussions were held to gather suggestions about the way forward and how the programme should be published. The research partners took a leading role in the discussions, which were facilitated by the research team.

## RESULTS

The final product is an innovative, introductory training programme for those who support carers providing home-based end-of-life care. Table 3 shows the outline content for a 1-day programme. It is designed to allow as much flexibility in delivery as possible so that trainers can adapt to local needs.

**Table 3** Outline content

|             |  |
|-------------|--|
| 09:30–10:00 | Session one<br>Introduction and welcome                              |
| 10:00–11:00 | Session two<br>Caring and being cared for                            |
| 11:00–11:15 | <i>Coffee</i>  |
| 11:15–12:00 | Session three<br>Supporting in practice                              |
| 12:00–12:45 | <i>Lunch</i>   |
| 12:45–13:45 | Session four<br>Being a safe supporter                               |
| 13:45–13:50 | <i>Comfort break</i>   |
| 13:50–14:20 | Session five<br>The principles of supporting in end-of-life contexts |
| 14:20–14:50 | Session six<br>Boundaries and exit strategies                        |
| 14:50–15:00 | <i>Comfort break</i>   |
| 15:00–15:50 | Session seven<br>Ongoing learning and development                    |
| 15:50–16:00 | Evaluation   |

The programme, 'Supporting carers in end of life care: an introductory programme', was published on 8 September 2015 and is now freely available for use ([http://www.nottingham.ac.uk/helm/dev/end\\_of\\_life/](http://www.nottingham.ac.uk/helm/dev/end_of_life/)).

Those who wish to view or use the programme are asked to complete a short registration form first; during the first year, 444 people signed up to access the programme.

## PARTICIPATORY ACTION REVISITED

The aim of this project was to develop a training programme to equip those supporting family carers providing home-based end-of-life care with the basic skills and knowledge necessary to take on such support with confidence. The intention was to do so through a collaborative participatory action research project, involving bereaved carers, individuals and organisations who may be involved in supporting family carers.

As other researchers have discovered, it is not necessarily straightforward to secure the participation of individuals who are not accustomed to research involvement, and that a degree of background work is required, for example, in terms of building new networks and consolidating existing ones.<sup>22 25</sup> Our collaborators were busy people with many other calls on their time. In addition, as Waterman *et al* discovered in their work exploring the diffusion of innovations in healthcare practice, when the likely outcomes of research are unknown at the start, it is difficult to be sure what partners and collaborators are being asked to sign up to.<sup>22</sup>

As a research team, we believed that it is important for all voices to be heard in the research process and have input into the finished product.<sup>22</sup> That this happened in our project is testament to the level of commitment from our research partners, carer support workers and third sector organisations. Research partners gave

us key insights into the support that was available to them at the time they were providing care for a family member, and more importantly, with hindsight they recognised the kinds of support that were unavailable to them at the time but which would have been beneficial. Carer support workers and their organisations were able to provide insight on the training already available for workers, and how best workers could be prepared for supporting family carers in end-of-life contexts.

## CONCLUSION

In line with other work, we found that the inclusion of culturally relevant stories and the involvement of workers in developing the content, produced a programme that trainees found accessible.<sup>17</sup> The research partners were active in the project at all stages, but it was still the case that the research was led by academics and that the impetus came from the research team at the university.<sup>27 28</sup>

The result of the project is a training programme that is published online and is freely available for individuals and organisations to use. The programme evaluated well as a training session, but this tells us little about the use that trainees make of their new learning after the training day has ended. This highlights the main limitation to the study, which is that we have no way of knowing how effective the programme will be in terms of improving support for family carers providing care for someone who is dying at home. Future research is therefore needed, including an implementation study to explore whether and how trainees take the learning from the classroom and transfer it into practice. Further work is also required to explore how carers experience the support they receive once their supporter has undergone the training.

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