

Pearson BTEC Level 3 Nationals Diploma, Extended Diploma

January 2020

Monitored hours: 6 hours

Paper Reference **31494H**

Health and Social Care

Unit 4: Enquiries into Current Research in Health and Social Care

Part A

You do not need any other materials.

Instructions

- **Part A** contains material for the completion of the preparatory work for the set task.
- **Part A** is given to learners four weeks before **Part B** is taken under formal supervision as scheduled by Pearson.
- **Part A** must be given to learners on the specified date so that learners can prepare as directed and monitored.
- **Part A** is specific to each series and this material must only be issued to learners who have been entered to undertake the task in that series.
- **Part B** contains unseen material and is issued to learners at the start of the specified formal supervised assessment session on the timetabled date specified by Pearson.

Turn over ►

W64090A

©2020 Pearson Education Ltd.

1/1/1/1



Pearson

Instructions to Teachers/Tutors

This set task has a preparatory period. **Part A** sets out how learners should prepare for the completion of the unseen task in **Part B** under supervised conditions.

Part A should be issued to learners four weeks prior to undertaking **Part B** of the assessment.

Learners should be provided with the opportunity to conduct independent research in order to select and read secondary source materials such as articles and journals. Centres may need to make facilities available to learners to support independent work. Learners are advised to spend approximately **8 hours** on selecting and reading their secondary sources and that spending any longer on this is unlikely to advantage them. Learners may bring their research, such as copies of articles, into the monitored sessions, and these will be subject to monitoring by the teacher/tutor.

Learners should be monitored in **6 hours** provided by the centre to compile notes on their secondary research. During this time they may only have access to:

- the internet to carry out searches and to access secondary sources in relation to their research
- outcomes of independent research such as sources that they have selected.

Learners must work independently and must not be given guidance or feedback on the completion of the preparatory work. Learners must not prepare potential responses.

Learners may take up to four A4 sides of notes into the supervised assessment. Learner notes are the outcome of independent preparation and support learners in responding to the additional information and activities presented only in **Part B**.

The notes may be handwritten, or typed in a 12 point size font. Learner notes can only include:

- facts, figures and data relating to secondary sources covering the article's area of research
- the research methods used in the learner's own secondary research.

Other content is not permitted.

In addition to the four pages of notes, learners should use the monitored sessions to prepare a list of sources that they have used to take into the supervised assessment.

Teachers/tutors should note that:

- learner notes produced under monitored conditions must be checked to ensure that they comply with the limitations
- learner notes should be retained by the centre between the monitored sessions and the formal supervised assessment
- learner notes should be retained by the centre after the completion of assessment and may be requested by Pearson.

Part B is a supervised assessment and uses the **Part B** booklet. This is a task book.

This supervised assessment will take place in a timetabled slot. A supervised rest break is permitted.

The supervised assessment is a formal external assessment and must be conducted with reference to the instructions in this task booklet and the Instructions for Conducting External Assessments (ICEA) document.

Instructions for Learners

Read the set task information carefully.

In **Part B** you will be asked to carry out specific written activities using the information in this **Part A** booklet and your own research on this topic.

In your preparation for **Part B**, using this **Part A** booklet you may prepare notes to refer to when completing the set task. Your notes may be up to four sides and may be handwritten or typed in a 12 point size font. Your notes can only include:

- facts, figures and data relating to secondary sources covering the article's area of research
- the research methods used in your own secondary research.

Other content is not permitted.

You will complete **Part B** under supervised conditions.

You must work independently and should not share your work with other learners.

Your teacher will provide a schedule for the **6 hours** of monitored preparation.

Your teacher cannot give you feedback during the preparation period.

Set Task Information

You are required to use your understanding of research methodologies and associated issues related to a piece of current research on a health and social care issue, and to use your own skills in carrying out secondary research around the issue.

You must choose **one** of the two articles covering an aspect of recent research in the health and social care sector to base your secondary research on.

To prepare for the set task in **Part B** you must carry out the following:

1. Analyse the article.
2. Carry out your own independent research using secondary sources.
3. Prepare the following for your final supervised assessment:
 - a list of your secondary sources
 - notes on your secondary research – you can take in no more than four A4 pages of notes.

During the supervised time for **Part B** you will have access to this material. You will be required to address questions based on your chosen article and your own secondary research. You will have **3 hours** under supervised conditions in which to complete your final assessment.

Part A of Set Task

Select **EITHER** Article 1 **OR** Article 2.

You are provided with the following information:

Article 1: Health research: Video game-based 'brain training' may help people with schizophrenia, pages 7 to 9.

Article 2: Social care research: Supporting family carers in homebased end-of-life care: using participatory action research to develop a training programme for support workers and volunteers, pages 10 to 16.

Article 1: Health Research

Video game-based 'brain training' may help people with schizophrenia

Monday 12 February 2018

"People with schizophrenia can be trained by playing a video game to control the part of the brain linked to verbal hallucinations," BBC News reports. Verbal or auditory hallucinations, which typically take the form of "hearing voices", can be one of the most distressing aspects of schizophrenia. The voices are often abusive, rude or critical, and around 1 in 3 people's symptoms don't respond to conventional drug treatment.

This small proof-of-concept study involved 12 people. Researchers used a functional MRI scanner (fMRI) to provide a real-time analysis of brain activity based on changes in blood flow inside the brain. In turn, the fMRI output was linked to a simple computer game that involved landing a rocket.

Participants were asked to try to land the rocket using their own mental strategies. They weren't given any explicit instructions on how to do this. Successfully landing the rocket involved reducing activity in the part of their brain associated with speech perception (the superior temporal gyrus). The researchers thought this would also reduce verbal hallucinations.

Participants' mental health was monitored using questionnaires and two different scales to measure the severity of their hallucinations. After playing the game, people showed no worsening of symptoms on one scale, and an improvement on the other. There was also a detectable decrease in brain activity in the speech-perceiving regions during the training process.

The findings suggest this is a worthy area for continued investigation in a larger group of people. But at this stage it's far too soon, and too small a sample of people, to say whether or not this treatment will ever be suitable for use in clinical practice.

Where did the story come from?

The study was carried out by researchers from King's College London and the University of Roehampton, and was funded by the UK's Medical Research Council. It was published in the peer-reviewed journal *Translational Psychiatry*. The research was described well by BBC and Sky News, although the headlines overstated the findings – it's not possible to draw any firm conclusions from the results of a study of this size and type.

What kind of research was this?

This was a proof-of-concept study, which means that the researchers invited a small number of people to take part to see if their study design was feasible before they started a full-sized study. This is a very sensible approach as it means that, if there are any problems, these can be identified and fixed early on. But any results that come out of a study like this are usually limited, as only a small number of people take part. In this case, the researchers didn't use a control group, which would be needed in subsequent studies to see if the treatment really was effective.

What did the research involve?

The 12 people invited to participate in the study all had diagnosed schizophrenia, which had been treated with stable doses of antipsychotic medicine for at least months. They all experienced auditory hallucinations as defined by a standard tool called the Positive and Negative Syndrome Scale (PANSS). Those who'd misused alcohol or substances in the previous 6 months were excluded from the study.

People attended the research centre for 5 appointments. The first was for their condition to be assessed, and the next 4 sessions were for the intervention over the course of a 2-week period. At each visit, their mental health was monitored using questionnaires and tools designed to look at the severity of hallucinations, including the PANSS and the Psychotic Rating Symptom Scale (PsyRats). PsyRats is similar to PANSS, but takes a more focused look at the impact of hallucinations and delusions on quality of life.

Their brain activity was monitored by fMRI, which detected the part of the person's brain that's active during perception of speech (the superior temporal gyrus, or STG). By process of a feedback loop, activity in the STG was outputted to the computer game program. This meant that if the person was able to somehow reduce activity in that part of their brain, the game would respond with a visual representation of this (an image of a rocket landing on the ground). There was no long-term follow-up to see if any changes lasted over time.

What were the basic results?

One person moved around too much in the MRI scanner and couldn't be included in the analysis, so the final results were based on 11 people. There was no worsening of auditory hallucinations before and after the intervention as assessed using the PANSS. But improvements in symptoms were detected by the PsyRats tool. Total scores decreased on average after the intervention compared with what they were before. Further analysis suggested this was a reduction on scales measuring the intensity of patients' distress and their beliefs about the origin of the voices they heard. The researchers also noted that levels of activity in the speech perception regions of the brain decreased after playing the game.

How did the researchers interpret the results?

The researchers noted that their initial findings were consistent with previous research on reduced brain activity in the speech-sensitive regions of the brain, leading to an improvement in auditory hallucinations in some cases. But the way the study was designed meant that the placebo effect couldn't be ruled out, as there was no control group or dummy intervention to compare the treatment with. They now plan to carry out a larger randomised controlled trial to investigate this treatment further. They also speculated that, if successful, this could be part of a wider range of novel therapies that could help people with schizophrenia.

Conclusion

This study showed some promising initial findings for a new way of managing auditory hallucinations in people with schizophrenia. It may be possible for people to be able to learn how to better control and cope with the sounds they hear by using a process of computer feedback. But this was only a pilot study and wasn't designed to fully evaluate the effectiveness of the treatment.

To do this would require:

- A much larger number of participants to see whether the effects could be consistently detected and not down to chance.
- A control group. It may be helpful to compare the results with a sham fMRI scan-computer intervention to see whether this wasn't just a placebo effect. It would then be helpful to move on to compare the findings with a control group of patients who received a more conventional range of support and treatment.
- Longer follow-up of the participants to see whether the effects of undertaking this training could be maintained over time.
- Whether the effects of the intervention make a meaningful difference to the person's daily life and functioning.

- Whether the effects vary by the type of symptoms the person has – for example, whether it's different in people who get other types of hallucinations, not just hearing voices.
- Making sure the intervention didn't have any potential harms.

This study is a good starting point for the researchers to continue their investigations. But it's far too early to be able to tell whether this intervention will ever be introduced into clinical practice in the future.

Analysis by Bazian
Edited by NHS Choices

Links to the science

Orlov ND, Giampietro V, O'Daly O, et al. Real-time fMRI neurofeedback to down-regulate superior temporal gyrus activity in patients with schizophrenia and auditory hallucinations: a proof-of-concept study. *Translational Psychiatry*. Published online 12 February 2018

(Source: © Crown copyright)



OPEN ACCESS

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

Glenys Caswell,¹ Beth Hardy,² Gail Ewing,³ Sheila Kennedy,⁴ Jane Seymour⁵

¹School of Health Sciences, University of Nottingham, Nottingham, UK

²Department of Health Sciences, University of York, York, North Yorkshire, UK

³Centre for Family Research, University of Cambridge, Cambridge, UK

⁴School of Health and Related Research, University of Sheffield, Sheffield, UK

⁵School of Nursing and Midwifery, University of Sheffield, Sheffield, UK

Correspondence to

Dr Glenys Caswell, NCARE, School of Health Sciences, University of Nottingham, Queen's Medical Centre, Nottingham, NG7 2HA, UK; glenys.caswell@nottingham.ac.uk

Received 23 January 2017

Revised 2 June 2017

Accepted 7 June 2017

Published Online First

2 August 2017

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,¹ which may be a care home, although many people continue to live in their own homes.² 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.³⁻⁵ Looking after someone approaching the end of life can have a huge impact on family carers, who may find it stressful, exhausting and lonely.³⁻⁹ 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.⁹

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



To cite: Caswell G, Hardy B, Ewing G, et al. *BMJ Supportive & Palliative Care* 2019;**9**:e4.

obscured from the outside world.⁹ 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.¹⁰ 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.¹⁰

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.⁶ 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.^{6,11} 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.⁶

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.^{10,12} 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.¹³⁻¹⁵ Family carers' own need for training in end-of-life care issues forms the theme of another strand of research.^{14,16} 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.¹⁷

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.¹⁸⁻²⁰ 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.⁶ The second project was a peer education project on advance care planning, which offered a model for this programme at the outset.²¹ 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,²² care of older people,²³ education²⁴ and in organisational and management research.²⁵ 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.²⁶ 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.²⁷

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.²⁸ 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.²⁹ 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.³⁰ 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.³¹ 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.³²

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.³³ 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.¹⁷

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.³⁴ Despite this, employment in a role that requires

working with potentially vulnerable individuals must be underpinned by the principles of good practice, which acknowledged 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*.^{35 36} 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.*^{37 38} 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 January 2014 Nottingham	12, from 6 organisations	Members of research team	Evaluation forms at end of day Evaluator taking notes Follow-up discussions	Trainees Observer from research team Trainees with members of research team
Pilot 2 September 2014 Nottingham	12 from 7 organisations	Age UK trainer	Evaluation forms at end of day Evaluator taking notes Phone interview	Trainees Another observer from research team Trainer
Pilot 3 December 2014 Torquay	7 from 4 organisations	2 Hospice trainers	Evaluation forms at end of day Phone interview	Trainees Trainers
Pilot 4 March 2015 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 brilliant!
	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 Introduction and welcome
10:00–11:00	Session two Caring and being cared for
11:00–11:15	<i>Coffee</i>
11:15–12:00	Session three Supporting in practice
12:00–12:45	<i>Lunch</i>
12:45–13:45	Session four Being a safe supporter
13:45–13:50	<i>Comfort break</i>
13:50–14:20	Session five The principles of supporting in end-of-life contexts
14:20–14:50	Session six Boundaries and exit strategies
14:50–15:00	<i>Comfort break</i>
15:00–15:50	Session seven 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/).

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.^{22–25} 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.²²

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.²² 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.¹⁷ 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.^{27 28}

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.

Acknowledgements The authors thank the research partners, advisory group, trainers in pilots, trainees and critical readers.

Contributors All named authors contributed to the project and to the writing of the paper. All authors approved the final version. GC worked as a researcher on the project, liaising with research partners, developing and piloting the training programme. She took the lead in drafting this paper, approved the version to be published and agreed to be accountable for the work. BH worked as a researcher on the project, liaising with research partners, developing and piloting the training programme. She has revised the paper, approved the version to be published and agreed to be accountable for the work. GE made a substantial contribution to the design of the project and worked on the development and piloting of the programme. She has revised the paper, approved the version to be published and agreed to be accountable for the work. SK made a substantial contribution to the design of the project and worked on the development and piloting of the programme. She has revised the paper, approved the version to be published and agreed to be accountable for the work. JS made a substantial contribution to the design of the project and worked on the development and piloting of the programme. She has revised the paper, approved the version to be published and agreed to be accountable for the work.

Funding This work was supported by the Dimpleby Marie Curie Grants Scheme, grant DCMC-RF-12-08.

Competing interests None declared.

Ethics approval University of Nottingham, Faculty of Medicine and Health Sciences Research Ethics Committee.

Provenance and peer review Not commissioned; externally peer reviewed.

Open access This is an open access article distributed in accordance with the Creative Commons Attribution Non Commercial (CC BY-NC 4.0) license, which permits others to distribute, remix, adapt, build upon this work non-commercially, and license their derivative works on different terms, provided the original work is properly cited and the use is non-commercial. See: <http://creativecommons.org/licenses/by-nc/4.0/>

© Article author(s) (or their employer(s) unless otherwise stated in the text of the article) 2019. All rights reserved. No commercial use is permitted unless otherwise expressly granted.

REFERENCES

- 1 National End of Life Care Intelligence Network *what we know now in 2014*. London: Public Health England, 2015. http://www.endoflifecare-intelligence.org.uk/resources/publications/what_we_know_now_2014 (accessed Dec 2016).
- 2 Robinson J, Gott M, Ingleton C. Patient and family experiences of palliative care in hospital: what do we know? An integrative review. *Palliat Med* 2014;28:18–33.
- 3 Kristjanson LJ, Aoun S. Palliative care for families: remembering the hidden patients. *Can J Psychiatry* 2004;49:359–65.
- 4 Harrop E, Byrne A, Nelson A. "It's alright to ask for help": findings from a qualitative study exploring the information and support needs of family carers at the end of life. *BMC Palliat Care* 2014;13.
- 5 Holm M, Carlander I, Fürst CJ, *et al*. Delivering and participating in a psycho-educational intervention for family caregivers during palliative home care: a qualitative study from the perspectives of health professionals and family caregivers. *BMC Palliat Care* 2015;14:16.
- 6 Ewing G, Grande G; National Association for Hospice at Home. Development of a Carer Support Needs Assessment Tool (CSNAT) for end-of-life care practice at home: a qualitative study. *Palliat Med* 2013;27:244–56.
- 7 Carduff E, Finucane A, Kendall M, *et al*. Understanding the barriers to identifying carers of people with advanced illness in primary care: triangulating three data sources. *BMC Fam Pract* 2014;15:48 <http://www.biomedcentral.com/1471-2296/15/48>
- 8 Morris SM, King C, Turner M, *et al*. Family carers providing support to a person dying in the home setting: a narrative literature review. *Palliat Med* 2015;29:487–95.
- 9 Knowles S, Combs R, Kirk S, *et al*. Hidden caring, hidden carers? Exploring the experience of carers for people with long-term conditions. *Health Soc Care Community* 2016;24:203–13.
- 10 Williams AM, Wang L, Kitchen P. Impacts of care-giving and sources of support: a comparison of end-of-life and non-end-of-life caregivers in Canada. *Health Soc Care Community* 2016;24:214–24.
- 11 Lambert SD, Harrison JD, Smith E, *et al*. The unmet needs of partners and caregivers of adults diagnosed with cancer: a systematic review. *BMJ Support Palliat Care* 2012;2:224–30.
- 12 Moriarty J, Manthorpe J, Cornes M, *et al*. *Social care practice with carers: what social care support is provided to family carers? What support do family carers want?* NIHR School for Social Care Research, 2014. <https://www.kcl.ac.uk/sspp/policy->

- institute/scwru/pubs/2014/reports/NIHR-SSCR-Research-Findings-Carers-Nov-2014.pdf
- 13 Ersek M, Kraybill BM, Hansen NR. Evaluation of a train-the-trainer program to enhance hospice and palliative care in nursing homes. *Journal of Hospice & Palliative Nursing* 2006;8:42–9.
 - 14 Kwak J, Salmon JR, Acquaviva KD, *et al.* Benefits of training family caregivers on experiences of closure during end-of-life care. *J Pain Symptom Manage* 2007;33:434–45.
 - 15 Mayrhofer A, Goodman C, Smeeton N, *et al.* The feasibility of a train-the-trainer approach to end of life care training in care homes: an evaluation. *BMC Palliat Care* 2016;15:11.
 - 16 Harding R, List S, Epiphaniou E, *et al.* How can informal caregivers in cancer and palliative care be supported? An updated systematic literature review of interventions and their effectiveness. *Palliat Med* 2012;26:7–22.
 - 17 Naicker SN, Richter L, Stein A, *et al.* Development and pilot evaluation of a home-based palliative care training and support package for young children in southern Africa. *BMC Palliat Care* 2016;15:41.
 - 18 Kindon S, Pain R, Kesby M, *Participatory research approaches and methods*. Abingdon: Routledge, 2007.
 - 19 Bergold J, Thomas S. Participatory research methods: a methodological approach in motion. *Forum: Qualitative Social Research* 2012;13 <http://www.qualitative-research.net/index.php/fqs/article/view/1801/3334>
 - 20 Larkin M, Richardson E-L, Tabreman J. New partnerships in health and social care for an era of public spending cuts. *Health and Social Care in the community* 2012; 20: 199–207. [10.1111/j.1365-2524.01031.x](https://doi.org/10.1111/j.1365-2524.01031.x).
 - 21 Seymour JE, Almack K, Kennedy S, *et al.* Peer education for advance care planning: volunteers' perspectives on training and community engagement activities. *Health Expect* 2013;16.
 - 22 Waterman H, Marshall M, Noble J, *et al.* The role of action research in the investigation and diffusion of innovations in health care: the PRIDE project. *Qual Health Res* 2007;17:373–81.
 - 23 Hanson E, Magnusson L, Nolan J, Nolan M. Developing a model of participatory research involving researchers, practitioners, older people and their family carers: an international collaboration. *Journal of Research in Nursing* 2006;11:325–42.
 - 24 Sanders C, Seymour J, Clarke A, *et al.* Development of a peer education programme for advance end-of-life care planning. *Int J Palliat Nurs* 2006;12:216–23.
 - 25 Burns D, Hyde P, Killeit A, *et al.* Participatory organizational research: examining voice in the co-production of knowledge. *Br J Manag* 2014;25:133–44.
 - 26 Singh AA, Richmond K, Burnes TR. Feminist participatory action research with transgender communities: fostering the practice of ethical and empowering research designs. *Int J Transgend* 2013;14:93–104.
 - 27 Kesby M, Kindon S, Pain R. Participation as a form of power. In: Kindon S, Pain R, Kesby M, eds. *Participatory research approaches and methods*. Abingdon: Routledge, 2007:19–25.
 - 28 Whyte WF. Introduction. In: Whyte WF, ed. *Participatory action research*. Sage: Newbury Park, CA, 1991:7–15.
 - 29 Kennedy S, Allcroft J, Allen-Perry D, *et al.* Older carers and involvement in research: why, what and when? <https://www.healthtalk.org/research/groups/srcr/documents/projects/srcrproject-report-caring-older-carers.pdf>
 - 30 Age UK. Later life in the United Kingdom, 2016. <http://www.ageuk.org.uk/latest-news/archive/internet-use-amongst-older-people-shows-northsouth-divide/>(accessed Dec 2016).
 - 31 Mason J. *Qualitative researching*. 2nd ed. London: Sage, 2002.
 - 32 Spalding NJ, Phillips T. Exploring the use of vignettes: from validity to trustworthiness. *Qual Health Res* 2007;17:954–62.
 - 33 Ewing G, Brundle C, Payne S, *et al.* The Carer Support Needs Assessment Tool (CSNAT) for use in palliative and end-of-life care at home: a validation study. *J Pain Symptom Manage* 2013;46:395–405.
 - 34 Manthorpe J, Martineau S. *Support workers: their role and tasks. A scoping review*. London: Department of Health, 2008.
 - 35 NICE. End of life care for adults (QS13), 2011. <https://www.nice.org.uk/guidance/qs13>(accessed Dec 2016).
 - 36 NHS. *Common core competences and principles for health and social care workers working with adults at the end of life*. 2nd ed. Bristol: Skills for Care, 2014.
 - 37 Weston C, McAlpine L, Bordonaro T. A model for understanding formative evaluation in instructional design. *Educational Technology Research and Development* 1995;43:29–48.
 - 38 Brown KG, Gerhardt MW. Formative evaluation: an integrative practice model and case study. *Pers Psychol* 2002;55:951–83.

BLANK PAGE

Acknowledgements:

NHS. Video game-based 'brain training' may help people with schizophrenia. Source: <https://www.nhs.uk/news/mental-health/video-game-based-brain-training-may-help-people-schizophrenia/>

Caswell G, Hardy B, Ewing G, et al. BMJ Supportive & Palliative Care Published Online First: [25.11.18]
doi:10.1136/bmjspcare-2017001317

Please check the examination details below before entering your candidate information

Candidate surname

Other names

Centre Number

Learner Registration Number

Pearson BTEC
Level 3 Nationals
Diploma, Extended
Diploma

--	--	--	--	--	--	--

--	--	--	--	--	--	--	--	--	--

Wednesday 8 January 2020

Supervised hours: 3 hours

Paper Reference **31494H**

Health and Social Care

Unit 4: Enquiries into Current Research in Health and Social Care

Part B

You will need notes prepared in Part A.

Total Marks

Instructions

- Use **black** ink or ball-point pen.
- **Fill in the boxes** at the top of this page with your name, centre number and learner registration number.
- Answer **all** activities.
- Answer the activities in the spaces provided – *there may be more space than you need.*
- **Part A** will need to have been used in preparation for completion of **Part B**.
- **Part B** booklet must be issued to learners as defined by Pearson and should be kept securely.
- **Part B** booklet must be issued to learners on the specified date.
- **Part B** is specific to each series and this material must only be issued to learners who have been entered to undertake the task in that series.
- **Part B** should be kept securely until the start of the supervised assessment periods.

Information

- The total mark for this paper is 65.
- The marks for **each** activity are shown in brackets – *use this as a guide as to how much time to spend on each activity.*

Advice

- Read each activity carefully before you start to answer it.
- Try to answer every activity.
- Check your answers if you have time at the end.

Turn over ►

P64091A

©2020 Pearson Education Ltd.

1/1/1/1




Pearson

Instructions to Teachers/Tutors

Part B set task is undertaken under supervision in a single session of **3 hours** in the timetabled session. Centres may schedule a supervised rest break during the session.

Part B set task requires learners to apply research. Learners should bring in notes as defined in **Part A**. The teacher/tutor needs to ensure that notes comply with the requirements.

Learners must complete the set task using this task and answer booklet.

The set task is a formal external assessment and must be conducted with reference to the instructions in this task booklet and the *Instructions for Conducting External Assessments* (ICEA) document to ensure that the supervised assessment is conducted correctly and that learners submit evidence that is their own work.

Learners must not bring anything into the supervised environment or take anything out without your approval.

Centres are responsible for putting in place appropriate checks to ensure that only permitted material is introduced into the supervised environment.

Maintaining security during supervised assessment sessions

- The assessment areas must only be accessible to the individual learner and to named members of staff.
- Learners can only access their work under supervision.
- Any work learners produce under supervision must be kept secure.
- Only permitted materials for the set task can be brought into the supervised environment.
- During any permitted break and at the end of the session materials must be kept securely and no items removed from the supervised environment.
- Learners are not permitted to have access to the internet or other resources during the supervised assessment period.
- Learner notes related to **Part A** must be checked to ensure length and/or contents meet limitations.
- Learner notes will be retained securely by the centre after **Part B** and may be requested by Pearson if there is suspected malpractice.

After the session the teacher/tutor or invigilator will confirm that all learner work had been completed independently as part of the authentication submitted to Pearson.

Outcomes for Submission

One document will need to be submitted by each learner.

- A completed taskbook.

Each learner must complete an authentication sheet.

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA



Instructions for Learners

This session is of **3 hours**. Your teacher/tutor will tell you if there is a supervised break. Plan your time carefully.

Read the set task information carefully.

Complete all your work in this taskbook in the spaces provided.

You have prepared for the set task given in this **Part B** booklet. Use your notes prepared during **Part A** if relevant. Attempt all of **Part B**.

You will complete this set task under supervision and your work will be kept securely during any breaks taken.

You must work independently throughout the supervised assessment period and should not share your work with other learners.

Outcomes for Submission

You will need to submit one document on completion of the supervised assessment period.

- A completed taskbook.

You must complete a declaration that the work you submit is your own.

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA



Set Task Information

Select **EITHER** Section 1 beginning on page 6 **OR** Section 2 beginning on page 24 and answer the questions in the spaces provided.

You will need to refer to Article 1 on pages 41–43 **or** Article 2 on pages 44–50 and the notes of any research completed in **Part A**.

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA



DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

BLANK PAGE

SECTION 1: HEALTH RESEARCH BEGINS ON THE NEXT PAGE.



SECTION 1: Health Research

Activity 1

How have different research methods been used in this research?

In your answer, you should consider the:

- suitability of research methods referred to in the article
- reliability and validity of the research methods.

(15)

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA



DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

Large writing area with horizontal dotted lines.



Lined writing area with horizontal dashed lines.

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA



DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

Handwriting practice area with 20 horizontal dotted lines.

(Total for Activity 1 = 15 marks)



Activity 2

How does secondary research support the importance of research into this issue?

In your answer, you should consider:

- secondary research and its relationship to the issue
- an analysis of the effects on individuals, practitioners and/or wider society.

(15)

A series of horizontal dotted lines for writing the answer to the question above.

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA



DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

Large writing area with horizontal dotted lines.



Handwriting practice area with 20 horizontal dotted lines.

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA



DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

Handwriting practice area with 20 horizontal dotted lines.

(Total for Activity 2 = 15 marks)



Activity 3

How could this research affect the provision of health services for people living with schizophrenia?

In your answer, you should consider:

- the effect on provision and/or practice
- recommendations for change in future provision and/or practice
- secondary research findings.

(20)

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA



DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

Large writing area with horizontal dotted lines.



Handwriting practice area with 20 horizontal dotted lines.

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA



DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

Large writing area with horizontal dotted lines.



Handwriting practice area with 20 sets of horizontal dotted lines.

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

(Total for Activity 3 = 20 marks)



Activity 4

Helen is a psychiatrist who works for the NHS to support patients in her local area to deal with symptoms of schizophrenia. She works closely with a multidisciplinary team to support patients to manage their symptoms through medication and therapy.

Helen wants to investigate the link between brain training and reducing auditory hallucinations to improve the patients' ability to function in everyday life. She is planning to undertake research with her patients and a control group to compare findings. The research will use a range of brain training techniques including reading exercises and listening to music, alongside the patients' prescribed medication.

The research will involve a scientific experiment over a six-month period using MRI scans to assess brain activity changes when using the brain training techniques.

The first scans will be at the start of the research to get baseline measurements of the auditory hallucinations. These scans will be repeated each month to record any changes in brain activity. Interviews and relevant questionnaires will also be used during the research.

What should Helen and her team consider when undertaking this research?

You should include judgements on:

- planning considerations
- ethical issues
- research methodologies
- research skills required to explore the issue.

(15)

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....



Lined writing area with horizontal dashed lines.

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA



DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

Large writing area with horizontal dotted lines.



DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

Lined writing area with horizontal dotted lines.

(Total for Activity 4 = 15 marks)

TOTAL FOR PAPER = 65 MARKS



DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

BLANK PAGE

SECTION 2: SOCIAL CARE RESEARCH BEGINS ON THE NEXT PAGE.



DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

Large writing area with horizontal dotted lines.



Handwriting practice area with 20 horizontal dotted lines.

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA



DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

Large writing area with horizontal dotted lines.

(Total for Activity 1 = 15 marks)



DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

Large writing area with horizontal dotted lines.



Handwriting practice area with 20 sets of horizontal dotted lines.

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA



DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

Handwriting practice area with 20 horizontal dotted lines.

(Total for Activity 2 = 15 marks)



DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

Large writing area with horizontal dotted lines.



Handwriting practice area with 20 sets of horizontal dotted lines.

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA



DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

Large writing area with horizontal dotted lines.



Handwriting practice area with 20 sets of horizontal dotted lines.

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

(Total for Activity 3 = 20 marks)



Activity 4

Cameron works for the National Council for Palliative Care. His job requires him to undertake research and suggest improvements to the care and support provided for those requiring end-of-life care and their families. He works closely with several charitable organisations.

He has been asked to evaluate the effectiveness of the recent implementation of training for carer support staff in providing support to families. He has decided to give questionnaires to the families who have received support. He will investigate the effectiveness of the training.

In addition, Cameron will hold a focus group with delegates from several charity organisations who attended the training events. The focus group will consider the benefits of the training and further improvements needed.

What should Cameron consider when undertaking this research?

You should include judgements on:

- planning considerations
- ethical issues
- research methodologies that could be used
- research skills required to explore the issue.

(15)

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....



Handwriting practice area with 20 sets of horizontal dotted lines.

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA



DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

Large writing area with horizontal dotted lines.



DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

(Total for Activity 4 = 15 marks)

TOTAL FOR PAPER = 65 MARKS



Article 1: Health Research

Video game-based 'brain training' may help people with schizophrenia

Monday 12 February 2018

"People with schizophrenia can be trained by playing a video game to control the part of the brain linked to verbal hallucinations," BBC News reports. Verbal or auditory hallucinations, which typically take the form of "hearing voices", can be one of the most distressing aspects of schizophrenia. The voices are often abusive, rude or critical, and around 1 in 3 people's symptoms don't respond to conventional drug treatment.

This small proof-of-concept study involved 12 people. Researchers used a functional MRI scanner (fMRI) to provide a real-time analysis of brain activity based on changes in blood flow inside the brain. In turn, the fMRI output was linked to a simple computer game that involved landing a rocket.

Participants were asked to try to land the rocket using their own mental strategies. They weren't given any explicit instructions on how to do this. Successfully landing the rocket involved reducing activity in the part of their brain associated with speech perception (the superior temporal gyrus). The researchers thought this would also reduce verbal hallucinations.

Participants' mental health was monitored using questionnaires and two different scales to measure the severity of their hallucinations. After playing the game, people showed no worsening of symptoms on one scale, and an improvement on the other. There was also a detectable decrease in brain activity in the speech-perceiving regions during the training process.

The findings suggest this is a worthy area for continued investigation in a larger group of people. But at this stage it's far too soon, and too small a sample of people, to say whether or not this treatment will ever be suitable for use in clinical practice.

Where did the story come from?

The study was carried out by researchers from King's College London and the University of Roehampton, and was funded by the UK's Medical Research Council. It was published in the peer-reviewed journal *Translational Psychiatry*. The research was described well by BBC and Sky News, although the headlines overstated the findings – it's not possible to draw any firm conclusions from the results of a study of this size and type.

What kind of research was this?

This was a proof-of-concept study, which means that the researchers invited a small number of people to take part to see if their study design was feasible before they started a full-sized study. This is a very sensible approach as it means that, if there are any problems, these can be identified and fixed early on. But any results that come out of a study like this are usually limited, as only a small number of people take part. In this case, the researchers didn't use a control group, which would be needed in subsequent studies to see if the treatment really was effective.

What did the research involve?

The 12 people invited to participate in the study all had diagnosed schizophrenia, which had been treated with stable doses of antipsychotic medicine for at least 3 months. They



DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

all experienced auditory hallucinations as defined by a standard tool called the Positive and Negative Syndrome Scale (PANSS). Those who'd misused alcohol or substances in the previous 6 months were excluded from the study.

People attended the research centre for 5 appointments. The first was for their condition to be assessed, and the next 4 sessions were for the intervention over the course of a 2-week period. At each visit, their mental health was monitored using questionnaires and tools designed to look at the severity of hallucinations, including the PANSS and the Psychotic Rating Symptom Scale (PsyRats). PsyRats is similar to PANNS, but takes a more focused look at the impact of hallucinations and delusions on quality of life.

Their brain activity was monitored by fMRI, which detected the part of the person's brain that's active during perception of speech (the superior temporal gyrus, or STG). By process of a feedback loop, activity in the STG was outputted to the computer game program. This meant that if the person was able to somehow reduce activity in that part of their brain, the game would respond with a visual representation of this (an image of a rocket landing on the ground). There was no long-term follow-up to see if any changes lasted over time.

What were the basic results?

One person moved around too much in the MRI scanner and couldn't be included in the analysis, so the final results were based on 11 people. There was no worsening of auditory hallucinations before and after the intervention as assessed using the PANSS. But improvements in symptoms were detected by the PsyRats tool. Total scores decreased on average after the intervention compared with what they were before. Further analysis suggested this was a reduction on scales measuring the intensity of patients' distress and their beliefs about the origin of the voices they heard. The researchers also noted that levels of activity in the speech perception regions of the brain decreased after playing the game.

How did the researchers interpret the results?

The researchers noted that their initial findings were consistent with previous research on reduced brain activity in the speech-sensitive regions of the brain, leading to an improvement in auditory hallucinations in some cases. But the way the study was designed meant that the placebo effect couldn't be ruled out, as there was no control group or dummy intervention to compare the treatment with. They now plan to carry out a larger randomised controlled trial to investigate this treatment further. They also speculated that, if successful, this could be part of a wider range of novel therapies that could help people with schizophrenia.

Conclusion

This study showed some promising initial findings for a new way of managing auditory hallucinations in people with schizophrenia. It may be possible for people to be able to learn how to better control and cope with the sounds they hear by using a process of computer feedback. But this was only a pilot study and wasn't designed to fully evaluate the effectiveness of the treatment.

To do this would require:

- A much larger number of participants to see whether the effects could be consistently detected and not down to chance.

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA



- A control group. It may be helpful to compare the results with a sham fMRI scan-computer intervention to see whether this wasn't just a placebo effect. It would then be helpful to move on to compare the findings with a control group of patients who received a more conventional range of support and treatment.
- Longer follow-up of the participants to see whether the effects of undertaking this training could be maintained over time.
- Whether the effects of the intervention make a meaningful difference to the person's daily life and functioning.
- Whether the effects vary by the type of symptoms the person has – for example, whether it's different in people who get other types of hallucinations, not just hearing voices.
- Making sure the intervention didn't have any potential harms.

This study is a good starting point for the researchers to continue their investigations. But it's far too early to be able to tell whether this intervention will ever be introduced into clinical practice in the future.

*Analysis by Bazian
Edited by NHS Choices*

Links to the science

Orlov ND, Giampietro V, O'Daly O, et al. Real-time fMRI neurofeedback to down-regulate superior temporal gyrus activity in patients with schizophrenia and auditory hallucinations: a proof-of-concept study. *Translational Psychiatry*. Published online 12 February 2018

(Source: © Crown Copyright)



P 6 4 0 9 1 A 0 4 3 5 2



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

Glenys Caswell,¹ Beth Hardy,² Gail Ewing,³ Sheila Kennedy,⁴ Jane Seymour⁵

¹School of Health Sciences, University of Nottingham, Nottingham, UK
²Department of Health Sciences, University of York, York, North Yorkshire, UK
³Centre for Family Research, University of Cambridge, Cambridge, UK
⁴School of Health and Related Research, University of Sheffield, Sheffield, UK
⁵School of Nursing and Midwifery, University of Sheffield, Sheffield, UK

Correspondence to
 Dr Glenys Caswell, NCARE, School of Health Sciences, University of Nottingham, Queen's Medical Centre, Nottingham, NG7 2HA, UK; glenys.caswell@nottingham.ac.uk

Received 23 January 2017
 Revised 2 June 2017
 Accepted 7 June 2017
 Published Online First 2 August 2017



To cite: Caswell G, Hardy B, Ewing G, et al. *BMJ Supportive & Palliative Care* 2019;9:e4.

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,¹ which may be a care home, although many people continue to live in their own homes.² 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.³⁻⁵ Looking after someone approaching the end of life can have a huge impact on family carers, who may find it stressful, exhausting and lonely.³⁻⁹ 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.⁹

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



Education

obscured from the outside world.⁹ 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.¹⁰ 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.¹⁰

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.⁶ 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.^{6 11} 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.⁶

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.^{10 12} 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.¹³⁻¹⁵ Family carers' own need for training in end-of-life care issues forms the theme of another strand of research.^{14 16} 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.¹⁷

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.¹⁸⁻²⁰ 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.⁶ The second project was a peer education project on advance care planning, which offered a model for this programme at the outset.²¹ 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,²² care of older people,²³ education²⁴ and in organisational and management research.²⁵ 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.²⁶ 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.²⁷

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.²⁸ 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



DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

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.²⁹ 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.³⁰ 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.³¹ 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.³²

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.³³ 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



Education

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.¹⁷

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.³⁴ 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*.^{35 36} 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.*^{37 38} 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 January 2014 Nottingham	12, from 6 organisations	Members of research team	Evaluation forms at end of day Evaluator taking notes Follow-up discussions	Trainees Observer from research team Trainees with members of research team
Pilot 2 September 2014 Nottingham	12 from 7 organisations	Age UK trainer	Evaluation forms at end of day Evaluator taking notes Phone interview	Trainees Another observer from research team Trainer
Pilot 3 December 2014 Torquay	7 from 4 organisations	2 Hospice trainers	Evaluation forms at end of day Phone interview	Trainees Trainers
Pilot 4 March 2015 Manchester	5 from 2 organisations	Trainees as trainers—took turns to deliver the training and to receive training	Evaluation forms	Trainees/trainers



DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

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

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.^{22 23} 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.²²

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.²² 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



Education

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.¹⁷ 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.^{27 28}

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.

Acknowledgements The authors thank the research partners, advisory group, trainers in pilots, trainees and critical readers.

Contributors All named authors contributed to the project and to the writing of the paper. All authors approved the final version. GC worked as a researcher on the project, liaising with research partners, developing and piloting the training programme. She took the lead in drafting this paper, approved the version to be published and agreed to be accountable for the work. BH worked as a researcher on the project, liaising with research partners, developing and piloting the training programme. She has revised the paper, approved the version to be published and agreed to be accountable for the work. GE made a substantial contribution to the design of the project and worked on the development and piloting of the programme. She has revised the paper, approved the version to be published and agreed to be accountable for the work. SK made a substantial contribution to the design of the project and worked on the development and piloting of the programme. She has revised the paper, approved the version to be published and agreed to be accountable for the work. JS made a substantial contribution to the design of the project and worked on the development and piloting of the programme. She has revised the paper, approved the version to be published and agreed to be accountable for the work.

Funding This work was supported by the Dimpleby Marie Curie Grants Scheme, grant DCMC-RF-12-08.

Competing interests None declared.

Ethics approval University of Nottingham, Faculty of Medicine and Health Sciences Research Ethics Committee.

Provenance and peer review Not commissioned; externally peer reviewed.

Open access This is an open access article distributed in accordance with the Creative Commons Attribution Non Commercial (CC BY-NC 4.0) license, which permits others to distribute, remix, adapt, build upon this work non-commercially, and license their derivative works on different terms, provided the original work is properly cited and the use is non-commercial. See: <http://creativecommons.org/licenses/by-nc/4.0/>

© Article author(s) (or their employer(s) unless otherwise stated in the text of the article) 2019. All rights reserved. No commercial use is permitted unless otherwise expressly granted.

REFERENCES

- 1 National End of Life Care Intelligence Network *what we know now in 2014*. London: Public Health England, 2015. http://www.endoflifecare-intelligence.org.uk/resources/publications/what_we_know_now_2014(accessed Dec 2016).
- 2 Robinson J, Gott M, Ingleton C. Patient and family experiences of palliative care in hospital: what do we know? An integrative review. *Palliat Med* 2014;28:18–33.
- 3 Kristjanson LJ, Aoun S. Palliative care for families: remembering the hidden patients. *Can J Psychiatry* 2004;49:359–65.
- 4 Harrop E, Byrne A, Nelson A. “It’s alright to ask for help”: findings from a qualitative study exploring the information and support needs of family carers at the end of life. *BMC Palliat Care* 2014;13.
- 5 Holm M, Carlander I, Fürst CJ, *et al*. Delivering and participating in a psycho-educational intervention for family caregivers during palliative home care: a qualitative study from the perspectives of health professionals and family caregivers. *BMC Palliat Care* 2015;14:16.
- 6 Ewing G, Grande G; National Association for Hospice at Home. Development of a Carer Support Needs Assessment Tool (CSNAT) for end-of-life care practice at home: a qualitative study. *Palliat Med* 2013;27:244–56.
- 7 Carduff E, Finucane A, Kendall M, *et al*. Understanding the barriers to identifying carers of people with advanced illness in primary care: triangulating three data sources. *BMC Fam Pract* 2014;15:48 <http://www.biomedcentral.com/1471-2296/15/48>
- 8 Morris SM, King C, Turner M, *et al*. Family carers providing support to a person dying in the home setting: a narrative literature review. *Palliat Med* 2015;29:487–95.
- 9 Knowles S, Combs R, Kirk S, *et al*. Hidden caring, hidden carers? Exploring the experience of carers for people with long-term conditions. *Health Soc Care Community* 2016;24:203–13.
- 10 Williams AM, Wang L, Kitchen P. Impacts of care-giving and sources of support: a comparison of end-of-life and non-end-of-life caregivers in Canada. *Health Soc Care Community* 2016;24:214–24.
- 11 Lambert SD, Harrison JD, Smith E, *et al*. The unmet needs of partners and caregivers of adults diagnosed with cancer: a systematic review. *BMJ Support Palliat Care* 2012;2:224–30.
- 12 Moriarty J, Manthorpe J, Cornes M, *et al*. *Social care practice with carers: what social care support is provided to family carers? What support do family carers want?* NIHR School for Social Care Research, 2014. <https://www.kcl.ac.uk/sspp/policy->



- institute/scwru/pubs/2014/reports/NIHR-SSCR-Research-Findings-Carers-Nov-2014.pdf
- 13 Ersek M, Kraybill BM, Hansen NR. Evaluation of a train-the-trainer program to enhance hospice and palliative care in nursing homes. *Journal of Hospice & Palliative Nursing* 2006;8:42–9.
 - 14 Kwak J, Salmon JR, Acquaviva KD, *et al.* Benefits of training family caregivers on experiences of closure during end-of-life care. *J Pain Symptom Manage* 2007;33:434–45.
 - 15 Mayrhofer A, Goodman C, Smeeton N, *et al.* The feasibility of a train-the-trainer approach to end of life care training in care homes: an evaluation. *BMC Palliat Care* 2016;15:11.
 - 16 Harding R, List S, Epiphaniou E, *et al.* How can informal caregivers in cancer and palliative care be supported? An updated systematic literature review of interventions and their effectiveness. *Palliat Med* 2012;26:7–22.
 - 17 Naicker SN, Richter L, Stein A, *et al.* Development and pilot evaluation of a home-based palliative care training and support package for young children in southern Africa. *BMC Palliat Care* 2016;15:41.
 - 18 Kindon S, Pain R, Kesby M, *Participatory research approaches and methods*. Abingdon: Routledge, 2007.
 - 19 Bergold J, Thomas S. Participatory research methods: a methodological approach in motion. *Forum: Qualitative Social Research* 2012;13 <http://www.qualitative-research.net/index.php/fqs/article/view/1801/3334>
 - 20 Larkin M, Richardson E-L, Tabreman J. New partnerships in health and social care for an era of public spending cuts. *Health and Social Care in the community* 2012; 20: 199–207.10.1111/j.2011.1365–2524.01031.x.
 - 21 Seymour JE, Almack K, Kennedy S, *et al.* Peer education for advance care planning: volunteers' perspectives on training and community engagement activities. *Health Expect* 2013;16.
 - 22 Waterman H, Marshall M, Noble J, *et al.* The role of action research in the investigation and diffusion of innovations in health care: the PRIDE project. *Qual Health Res* 2007;17:373–81.
 - 23 Hanson E, Magnusson L, Nolan J, Nolan M. Developing a model of participatory research involving researchers, practitioners, older people and their family carers: an international collaboration. *Journal of Research in Nursing* 2006;11:325–42.
 - 24 Sanders C, Seymour J, Clarke A, *et al.* Development of a peer education programme for advance end-of-life care planning. *Int J Palliat Nurs* 2006;12:216–23.
 - 25 Burns D, Hyde P, Killett A, *et al.* Participatory organizational research: examining voice in the co-production of knowledge. *Br J Manag* 2014;25:133–44.
 - 26 Singh AA, Richmond K, Burnes TR. Feminist participatory action research with transgender communities: fostering the practice of ethical and empowering research designs. *Int J Transgend* 2013;14:93–104.
 - 27 Kesby M, Kindon S, Pain R. Participation as a form of power. In: Kindon S, Pain R, Kesby M, eds. *Participatory research approaches and methods*. Abingdon: Routledge, 2007:19–25.
 - 28 Whyte WF. Introduction. In: Whyte WF, ed. *Participatory action research*. Sage: Newbury Park, CA, 1991:7–15.
 - 29 Kennedy S, Allcroft J, Allen-Perry D, *et al.* Older carers and involvement in research: why, what and when? <https://www.healthtalk.org/research/groups/srcc/documents/projects/srccproject-report-caring-older-carers.pdf>
 - 30 Age UK. Later life in the United Kingdom, 2016. [http://www.ageuk.org.uk/latest-news/archive/internet-use-amongst-older-people-shows-northsouth-divide/\(accessed Dec 2016\)](http://www.ageuk.org.uk/latest-news/archive/internet-use-amongst-older-people-shows-northsouth-divide/(accessed Dec 2016)).
 - 31 Mason J. *Qualitative researching*. 2nd ed. London: Sage, 2002.
 - 32 Spalding NJ, Phillips T. Exploring the use of vignettes: from validity to trustworthiness. *Qual Health Res* 2007;17:954–62.
 - 33 Ewing G, Brundle C, Payne S, *et al.* The Carer Support Needs Assessment Tool (CSNAT) for use in palliative and end-of-life care at home: a validation study. *J Pain Symptom Manage* 2013;46:395–405.
 - 34 Manthorpe J, Martineau S. *Support workers: their role and tasks. A scoping review*. London: Department of Health, 2008.
 - 35 NICE. End of life care for adults (QS13), 2011. <https://www.nice.org.uk/guidance/qs13> (accessed Dec 2016).
 - 36 NHS. *Common core competences and principles for health and social care workers working with adults at the end of life*. 2nd ed. Bristol: Skills for Care, 2014.
 - 37 Weston C, McAlpine L, Bordonaro T. A model for understanding formative evaluation in instructional design. *Educational Technology Research and Development* 1995;43:29–48.
 - 38 Brown KG, Gerhardt MW. Formative evaluation: an integrative practice model and case study. *Pers Psychol* 2002;55:951–83.



DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

BLANK PAGE



P 6 4 0 9 1 A 0 5 1 5 2

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

DO NOT WRITE IN THIS AREA

BLANK PAGE

Acknowledgements:

NHS. Video game-based 'brain training' may help people with schizophrenia. Source. <https://www.nhs.uk/news/mental-health/video-game-based-brain-training-may-help-people-schizophrenia/>

Caswell G, Hardy B, Ewing G, et al. BMJ Supportive & Palliative Care Published Online First: [25.11.18]
doi:10.1136/bmjspcare-2017001317

