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Helping patients prepare their dependent children for parental death: mixed-methods evaluation of a codeveloped training programme for palliative and allied healthcare professionals in the UK

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ABSTRACT

Objectives To evaluate how the codesigned training programme, 'No conversation too tough', can help cancer, palliative and wider healthcare professionals support patients to communicate with their dependent children when a parent is dying. We examined perceptions of learning provided by the training, its contribution to confidence in communicating with families when a parent is dying, and subjective experience of, and reactions to, the training. We also explored potential changes in practice behaviours.

Design Pre–post, convergent, parallel, mixed-methods study. Motivations for practice change were measured quantitatively, and qualitatively through semi-structured interviews. Non-parametric analysis was conducted for self-efficacy and outcome expectancy measures; descriptive statistics examined perceptions of usefulness; intentions to use learning in practice and reactions to the training. Semi-structured interviews examined motivations and perceptions of learning in depth. A 6-week, practice log recorded immediate practice effects and reflections.

Setting 1-day training delivered 3 times, total delegates 36: online December 2021, February 2022, face-to-face March 2022. Questionnaires delivered correspondingly in online or paper formats, semi-structured interviews online.

Participants Pre–post: palliative care professionals (n=14/12), acute cancer clinical nurse specialists (n=16/11), other healthcare professionals (n=5/5).

Results Positive changes were observed in self-efficacy (17 of 19 dimensions p<0.003) and outcome expectancies (3 of 14 beliefs p<0.036). Perceptions of usefulness and intentions to use learning in practice mean scores were 82–94 (scales 0=low to 100=high). There was high affirmation for sharing learning and influencing change in the workplace and wider practice. Content, style and delivery were positively endorsed. Further elements to be included in the training were identified.

Conclusions The training programme has the potential to effect change in practice behaviours. A large-scale study will evaluate the roll-out of the training delivered to individual professionals and whole teams across the UK. It will provide longer-term feedback to understand practice

behaviour and mediators of change across professional roles.

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ This was a convergent, mixed-methods, parallel design whereby data were analysed independently, integrated, and interpreted.
⇒ The Kirkpatrick's model of evaluation was employed to frame the methods and data analysis in terms of healthcare professionals' reactions, learning and behaviour.
⇒ Kirkpatrick level 4, the impact of change on patient outcomes, was not included in the design of this initial evaluation.
⇒ This was a single-arm study, without a control group.

INTRODUCTION

When a parent is dying from a life-limiting condition, open and honest communication between parents and their children is vital for children's well-being and their future emotional, behavioural and educational development.[1 2] Children wish to be informed about their parent's illness and prognosis and can be resilient if given age-appropriate information and support to grieve.[3–5] Nevertheless, parents often feel anxious and ill prepared to hold honest conversations at this time and can be at odds with their partners and wider family over what is best for their children; some avoid telling their children how ill their parent is until death is imminent.[6] In this difficult end-of-life period, parents want timely help from healthcare professionals so that they can support and communicate with their dependent children, and prepare them for their parent's death.[7]

Palliative care professionals are well placed to provide this support to parents, but services provided to help parents support their children through bereavement vary. Across UK hospice and community palliative care services, the number and types of services available to parents and children are uniformly greater after a parent's death than before.[8] Their focus is more on supporting children's challenges after bereavement than on preventing them before a parent dies.[8] Fundamental to these gaps in provision are healthcare professionals' stated low confidence in their skills, fear of making a situation worse, uncertainty over parents' and children's needs, and fear of the emotional labour required to provide support. Despite evidence that healthcare professionals welcome and benefit from educational training to support parents and families with advanced cancer, ultimately there remains an absence of training specifically related to supporting dying patients who have dependent children.[9–11]

To address the need for support, a training programme 'No conversation too tough', was codeveloped with cancer and palliative care professionals, children's bereavement specialists (therapists and bereavement charity representatives), those with lived experience of parental bereavement (both bereaved partners and adults bereaved as children), healthcare educators and academic researchers, and representatives from the Ruth Strauss Foundation, a specialist UK cancer charity. The training was designed to provide cancer, palliative care and wider healthcare professionals with knowledge, skills, and confidence to help families prepare for parental death, manage their own emotions around providing support, and to build networks with peers to enhance support for one another both in the workplace and in wider practice. This evaluation aimed to understand delegates' perception of learning provided by the training, the contribution it made to their confidence in communicating with families when a parent is dying, and their subjective experience of the training. Potential changes in practice behaviours were assessed, and recommendations for future roll-out of the programme were developed.

METHODS

Design

We conducted a pre–post, convergent, parallel, mixed-methods study.[12] Quantitative and qualitative data were collected in the week before and immediately after training, and a practice log was completed for the following 6 weeks. Data were triangulated: quantitative and qualitative data were analysed independently, integrated and interpreted (online supplemental material 1).

We used Kirkpatrick's Model of Evaluation to frame the methods and data analysis.[13] This model is widely applied across many sectors, including palliative care and nursing.[14–19] It measures effectiveness of training across four levels: (1) an individual's reaction to the training, (2) learning from the training, (3) changes in behaviour

and (4) patient outcomes. This evaluation presents data across levels 1–3.

Reporting followed the Criteria for Describing and Evaluating Training Interventions in Healthcare Professions Checklist.[20]

The training

The programme comprised 1 day of training which ran twice online and once face to face. 15 places were available for each occasion across which 36 delegates took part in total. Facilitators were registered health and/or social care professionals: the lead was an expert in communications skills training; the second facilitator for the first course was a registered play therapist specialised in working with children; for the second and third course, the second facilitator was a specialist practitioner in preparing families for loss. 'No conversation too tough' is described in table 1.[21]

Participant recruitment

Healthcare professionals were invited to take part in the course by the supporting UK cancer charity. This took place on a convenience basis via the charity's existing networks and word of mouth. 15 places were available on each of three courses. Invitations were accepted until all the places were filled. At course registration on the supporting charity's website, delegates gave their permission for their contact details to be passed to the evaluation team at the University. Informed consent to participate in the evaluation research was then conducted independently via email and telephone by the University. Consent to take part in the questionnaires was a requirement of participation; consent to also take part in the interviews and/or keep a reflective practice log for up to 6 weeks, was optional. Interview participants were selected on participant availability and to ensure a range of job roles and work settings. A pragmatic approach to sample size was adopted given the limited size of the delegate population in this instance.

Quantitative data collection

To assess the potential effect of the training on behaviour change, we included a measure of self-efficacy (the perceived capability to perform a target behaviour).[22–24] The measure asked participants to rate their confidence on a scale of 0–100, where 0 represented no confidence and 100 represented full confidence. 19 items across three domains were assessed: confidence in skills learnt, confidence in managing own emotions and confidence in discussing topics learnt about with patients (online supplemental material 2). According to social cognitive theory, self-efficacy is a precursor to a person's motivation to engage in a specific behaviour. More recent theories have gone further to propose self-efficacy-as-motivation, including it as one of a range of behavioural motives that predict behaviour change.[25] Reflecting on this, we included further measures to understand participants'

Table 1	'No conversation too tough' training features
Item	**Description**
Development	The codesign group included cancer and palliative care professionals, children's bereavement specialists (therapists and bereavement charity representatives), those with lived experience of parental bereavement (both bereaved partners and adults bereaved as children), healthcare educators and academic researchers, and representatives from the supporting UK cancer charity. The group met five times, facilitated by an expert in healthcare education and training.
Aims	To provide course delegates with information and education to (1) enable them to assess and influence families' readiness to address the needs of their dependent children; (2) improve their confidence, knowledge and skills to provide or signpost parents to available resources/tools to help with preparing children for parental death from cancer; (3) provide them with the knowledge and skills to recognise and manage their own emotions when dealing with families facing the death of a parent and (4) empower them to network with peers to acknowledge the difficulties of supporting patients with dependent children, and to enhance support for one another.
Course delivery	Three iterations of the training course ran between December 2021 and March 2022 with 15 places designated for each course. The first two courses were delivered online through video conferencing to reflect pandemic restrictions. The third course was delivered face to face at a UK city-centre venue.
Intended delegates	Cancer clinical nurse specialists and palliative care nurses working in community, hospice or acute settings, who care for people whose cancer cannot be cured.
Training recruitment	Potential delegates were contacted via personal and email approaches through the supporting UK cancer charity and the codesign team's networks.
Course content	Informed orientation and background evidence, theoretical foundations, developing skill sets and fostering supportive processes (both peer-to-peer and organisational). Specifically, this included presentation of the evidence for the programme, models of grief, ages and stages of children's development, understanding of family dynamics and structures, documenting the presence of children, putting knowledge into action, awareness of available resources, skills-based sessions and 'caring for yourself'.
Teaching methods	Student-centred, experiential and interactive methods comprising lectures and discussion, case studies, videos, small groups, actor-facilitated role-play, facilitated reflection on practice, supportive and theoretical resources.
Structure	One-day session
Facilitation	The lead was an expert in providing advanced communications skills training, and an established lecturer with a research profile in supportive cancer care at a UK university and a nursing background. The second facilitator for the December 2021 course was a registered play therapist and a senior lecturer at a UK university with a background in nursing and counselling. For the February and March 2022 courses, the second facilitator was a specialist practitioner in preparing families for loss.
Adverse event	Should delegates have needed help with difficult issues they wished to discuss, contact details for a Ruth Strauss Foundation practitioner were given in the course introduction. The facilitators monitored responses throughout the session and were prepared to support delegates if required.
Costs	Free to delegates

motivations to translate learning from the course into their practice.

The anticipated consequences of engaging in practice behaviour change were assessed with an outcome expectancies measure; beliefs were rated on a scale of 1–9, where participants were asked across 14 items to rate '*How likely is it that …*' where 1 represented 'very likely' and 9 represented 'very unlikely' (online supplemental material 3). Both self-efficacy and outcome expectancy measures were adapted from those used in Sage and Thyme communication skills training in palliative care. Although unvalidated in previous studies, they were developed based on previous research that reported good content and face validity.[15 26 27] The measures in our research were tailored to reflect the factors affecting cancer, palliative and wider healthcare professionals' approaches to having conversations with patients to help them support their dependent children.

We assessed motivation for behaviour change further through an author-generated questionnaire with closed and open questions. We asked about perceptions of usefulness and intention to use learning, both rated on a scale of 0 (low) to 100 (high); attitudes to change in practice and reactions to the training in respect of contents, teaching and learning styles were each measured on a 5-point Likert scale from strongly agree to strongly disagree. Before the training, we assessed participant characteristics, working practices, reasons and expectations for attending the course (online supplemental materials 4 and 5).

For the first two courses, pre and post questionnaires were administered online via the Qualtrics platform

(Qualtrics December 2021/February 2022 USA). For the third, held face to face, paper questionnaires were distributed and collected on the day.

Qualitative data collection

Repeated pre–post training, semi-structured interviews were planned with five participants from each training day. JEG, a postdoctoral research fellow with training and experience in qualitative and mixed-methods research, conducted the interviews via video conferencing; interviews lasted 30–40 min each. Pre-training interviews explored motivations, hopes, expectations and past experiences. Post-training interviews covered reactions to the course, perceived changes in skills and confidence, managing one's own emotions, intentions to use learning in practice, perceptions of making a difference, barriers and facilitators to translating learning into practice and support required in the workplace (online supplemental materials 6 and 7).

To understand the immediate effect of the training on practice behaviours, participants were asked to keep a post-training practice log for up to 6 weeks. The log asked participants to choose one example of caring for a patient with dependent children, to think about the situation, how they felt, what they did, what they used from the training, and what they would do again or differently next time.

Data analysis

Questionnaire data were downloaded in SPSS from the Qualtrics platform (IBM SPSS Statistics V.28). Responses to self-efficacy and outcome expectancy measures were analysed to identify changes between pre-assessment and post-assessment using a Wilcoxon signed-rank test. Descriptive statistics were used to assess reactions to the training and intended behaviour change.

Interviews were audio recorded, transcribed, entered into NVivo V.12 and analysed using framework analysis.[28] Framework analysis was chosen to enable the data to be compared and contrasted across the range of healthcare professional roles and specialities that characterise this study population. At the same time, its accessible matrix output aided understanding of the breadth and depth of individual participant responses.[29] JEG, JC-H and ER read/re-read the transcripts from the first course, identified, discussed and agreed the major themes. JEG applied a coding frame developed from the initial data to the remainder of the transcripts, Free-text responses from the questionnaires were coded separately and subsequently integrated into the coding frame, accounting for duplications (ie, a participant highlighting the same point in both the questionnaire and interview) to avoid 'double counting'. Themes were compared within and across cases. To examine intended and actual integration of learning into practice, practice log entries were separately analysed with a framework approach.[28]

The data were triangulated to identify convergent and divergent themes across the datasets.[30]

Patient and public involvement

Individuals with lived experience of parental bereavement (both bereaved partners and adults bereaved as children) were integral members of the codesign team that developed the training programme; they also contributed to the design of the research and the dissemination plans.

RESULTS

Sample size and characteristics

35 delegates consented to take part in the research and completed the pre-training questionnaires; 28 completed pre-training and post-training questionnaires. 16 participants were interviewed before the training; 14 attended a second interview after the training. 11 participants completed and returned the practice log.

Pre-training and post-training, respectively, n=16/11 were acute oncology clinical nurse specialists, n=14/12 were palliative care professionals, and 5/5 were allied healthcare professionals working in cancer support (n=4) or as a lead research nurse (n=1). Pre and post the majority of participants were female (n=31; 89%: n=25; 89%), over 45 years (n=19; 54%: n=15; 54%) or parents (n=27; 77%: n=20; 72%). A minority had higher education qualifications past undergraduate (n=8; 23%: n=7; 25%), or indicated an ethnic/cultural minority background (n=5; 15%: n=4; 16%). In respect of professional status, pre–post, the majority had been registered over 20 years (n=20; 57%: n=17; 60%) and had been in their current specialism for 5 years or more (n=20; 57%: n=15; 54%) (online supplemental materials 8).

Quantitative outcomes

Self-efficacy

A Wilcoxon signed-rank test revealed significant positive change after the training on 17 of the 19 items assessed across three domains (z=−2.956 to −4.458 p<0.003, effect size r=−0.40 to −0.61). Participants had more confidence following the training in starting, encouraging and closing conversations, listening, responding, supporting patients empathetically, and discussing relevant issues. Similarly, they felt more confident in managing their own feelings during and after having conversations. The observed change in skills to create a comfortable setting to speak openly did not reach significance; and no change was observed in skills to ask a patient if they have dependent children (table 2).

Outcome expectancies

Wilcoxon signed-rank tests revealed significant positive change between pre-training and post-training on three items: participants were less likely to believe (1) they would get too close to a parent if they asked them about their feelings or concerns for their children (Z=−2.524, p=0.012, r=0.34), (2) it would damage the way the patient copes (Z=−2.207, p=0.027, r=−0.30) and (3) that a patient would raise their concerns without being asked (Z=−2.097, p=0.036, r=−0.29) (table 3).

Table 2 Self-efficacy pre–post training: Wilcoxon signed-rank test

Variables: total scores 0–100	N	Premedian (IQR)		Post median (IQR)		Test statistic Z	P value	Effect size R
How certain are you that you have the skills to:								
Create a comfortable setting in which a patient can speak openly about their family?	27	71	(58–90)	90	(64–95)	−1.873	0.061	−0.26
Initiate a discussion with a patient about their family circumstances?	27	81	(60–93)	99	(90–100)	−3.296	0.001	−0.45
Ask a patient directly if they have dependent children?	26*	100	(90–100)	100	(95–100)	−1.29	0.197	−0.18
Ask questions to encourage a patient to talk about how their children are feeling and coping?	27	80	(64–90)	90	(80–94)	−2.956	0.003	−0.40
Ask questions that will encourage a patient to talk about their concerns for their children?	27	74	(53–90)	90	(80–95)	−3.236	0.001	−0.44
Close a conversation with a patient who has concerns about their children?	27	60	(50–80)	80	(65–95)	−4.189	<0.001	−0.57
Listen and respond in a way that will encourage a patient to talk about their feelings in respect of their children?	27	70	(50–85)	90	(80–97)	−4.145	<0.001	−0.56
Use empathic supportive comments with a patient when talking about their children?	27	67	(53–80)	90	(80–100)	−4.294	<0.001	−0.58
Encourage a patient to tell you if they would like help to support their children?	27	75	(50–90)	90	(85–100)	−3.838	<0.001	−0.52
Support a patient if they get upset while talking about their children?	27	74	(58–82)	90	(80–100)	−4.106	<0.001	−0.56
How certain are you that you can manage your own emotions:								
About initiating a conversation with a patient about their children's well-being?	27	71	(50–80)	90	(80–92)	−4.231	<0.001	−0.58
While having a conversation with a patient about their children?	27	75	(52–89)	90	(80–94)	−3.144	0.002	−0.43
While having a conversation with a patient about the need to talk openly with their children about death and dying?	27	70	(50–83)	87	(80–95)	−3.306	<0.001	−0.45
When you are off duty, having previously had a conversation with a patient about their children?	27	72	(50–85)	80	(70–95)	−3.748	<0.001	−0.51
How certain are you that you can discuss with a patient:								
How children can be affected by losing a parent through cancer that can't be cured?	27	50	(21–70)	80	(67–90)	−4.349	<0.001	−0.59
How children's needs for information and support vary depending on their age?	27	56	(35–75)	90	(69–95)	−4.392	<0.001	−0.60
The problems faced by parents with dependent children when a parent is dying?	27	50	(26–60)	80	(70–94)	−4.458	<0.001	−0.61
The best time for a parent to receive help to support their children?	27	50	(35–70)	89	(74–95)	−4.063	<0.001	−0.55
Information resources that might help a parent to support their children?	27	60	(30–81)	90	(80–95)	−4.024	**<0.001**	−0.55

*Missing data in paper format.

Perceptions of usefulness, intentions to use learning

Participants felt the training would leave them more satisfied in their work with parents (scale mean 82/100); it would encourage them to seek out more knowledge and understanding about working with patients with dependent children (scale mean 92/100), and it would be highly useful for supporting patients (scale mean 93/100). There were strong intentions to use learning in practice (scale mean 94/100).

Attitudes to change in practice

The majority of participants agreed/strongly agreed that they would share their learning with colleagues and contacts (26/28, 90%), and that they would be able to

Table 3 Outcome expectations pre–post training: Wilcoxon signed-rank test

Variables: total scores 1–9: 1=very likely, 2=very unlikely	N	Pre-median (IQR)		Post-median (IQR)		Test statistic Z	P value	Effect size r
How likely is it that …								
You would be helping a patient if you talk to them about their children?	27	2	(1–3)	1	(1–2)	−1.676	0.094	−0.23
You will keep control of the conversation if a patient becomes upset while talking about their children?	27	3	(2–5)	3	(2–5)	−0.201	0.840	−0.03
Asking a patient about their concerns will help you identify what may be helpful?	27	1	(1–2)	1	(1–2)	−0.741	0.459	−0.10
You will have colleagues who you can go to if you need emotional support after talking to a patient about their children?	27	2	(1–4)	1	(1–2)	−0.431	0.666	−0.06
A patient will become distressed and upset if you ask about their children?*	27	2	(1–3)	2	(1–5)	−1.781	0.075	−0.24
You will get too close to a patient if you ask about their feelings or concerns for their children?*	27	8	(5–8)	8	(7–9)	−2.524	0.012	−0.34
It will damage the way a patient copes if you ask them about their children?*	27	7	(5–8)	7	(7–9)	−2.207	0.027	−0.30
Your workload will become unmanageable if you ask a patient about their children?*	26†	8	(7–9)	8.5	(6.75–9)	0.000	1.000	0.00
You will be criticised by your colleagues if a patient becomes upset when you talk to them about their children?*	27	9	(8–9)	9	(8–9)	−0.718	0.473	−0.10
You could say something that will make matters worse for your patient if you try to talk to them about their children?*	26†	7	(5–8)	8	(6.75–9)	−1.954	0.051	−0.27
A patient will raise concerns/feelings about their children without you asking?*	26†	5	(3–6)	5	(4.75–6)	−2.097	0.036	−0.29
If a patient shows strong emotions when talking about their children, it will be overwhelming for you?*	27	7	(6–8)	8	(6–9)	−1.243	0.214	−0.17
You will feel down if you ask a patient about their children?*	27	7	(5–9)	8	(6–9)	−1.675	0.094	−0.23
There will not be enough support available to you if you need to reflect on the difficulties you experience when talking with a patient about their children?*	27	7	(6–9)	8	(5–9)	−0.802	0.423	−0.11

*Negatively worded variables.
†Missing data in paper format.

influence change in their workplace (25/28 participants, 89%). Nearly three-quarters (20/28, 71%) thought they could change or influence wider practice.

Reactions to the training

Participants were consistently positive about the course. All 28 agreed/strongly agreed that the facilitators worked well together and were knowledgeable, and the topics covered were relevant to them. For the second and third course, we asked about response to the role-play; all 21 participants agreed/strongly agree that the role-play actor performed authentically, and the scenario depicted was realistic. Two provided negative feedback relating to clarity of the training objectives, time available, support materials and role-play (online supplemental material 9).

Qualitative findings

Two overarching themes were identified and explained motivations: (1) transferring learning into practice and (2) reactions to the training. Verbatims are provided in table 4.

Transferring learning into practice
Intentions to use learning

The interviews immediately post-training revealed that due to the shortness of time passed, participants had not had an opportunity to apply their learning, but they spoke of intentions to do so. They were aware of the optimal timing to initiate conversations and aimed to enquire more about patients' children, how 'children are doing', explore patient cues to assess readiness for conversation, use listening skills, and 'be alongside' patients as they navigate their 'palliative journey'. They intended in future to look more consciously through clinic notes to establish children's presence, make efforts to document this, allocate follow-up appointments with patients, ensure they had enough time to ask parents questions about their

Table 4 Participant verbatim quotes

Transferring learning into practice

Intentions to use learning	(…) it has made me make more of an effort to consciously go through their notes to remind myself what their family setup is and whether it looks like it might be appropriate to start engaging in that conversation, which is something I wasn't necessarily making a concerted effort to do before the training. Breast CNS
Intentions to improve organisational practice	So (…) I'm really looking forward to our next [monthly nurse meeting] so I can share with the whole team what happened in the training day and just share some of the resources as well because I think there is an awful lot out there that we maybe haven't been so aware of (…) I want to just try and make the other nurses (…) who are a bit more junior feel a bit more empowered to be able to initiate some of these conversations. Breast CNS One of my roles here (…) was with the development of our computer (…) and it's made me realise we don't have anything on there. Although we do family trees and we might write about the fact that people have children, we don't have any reportable box on there that says 'does this person have children under 18?' or anything like that, so I'm now going to discuss that with the team and I'm going to take that away and say, 'Right, this is something we need. Community PCNS
Barriers to implementing learning	So we have had [ethnic minority] patients that have died and they really do not accept death and dying, they really a lot of the time do not accept withdrawal. So that was very complex. If the parents and the adults aren't accepting it, they (…) aren't going to start preparing the children and the young people. Hospital PCNS (Pre-training) I know that if I need to have those conversations that's going to be really difficult for me to do realistically and in terms of privacy it's related to space in the cancer centre and how many rooms we have. Lung CNS (Pre-training) There is a bit about, at the moment, lots of changes going through the team, a bit of a lack of staffing level, so it is a bit sad but all the projects are on hold. So at the moment, the barrier would be that it's not the right timing. Hospital PCNS
Learning into practice	The training enhanced the courage of my convictions to talk with [the patient] about her family and her daughter. It would have been so easy to shy away from this as it was just too painful. In the end, instead of being painful, it was probably the most meaningful, tender and most beautiful moment of my nursing career. Breast CNS (practice log extract)

Reactions to the training

Contents and style	(…) it definitely suited me. I do like (…) that style of learning. I don't want to be sat and talked to all the time with information, I want to participate and want to join in. Breast CNS I think just giving you the (…) overall background that this is something that's really important and that you do need to plan for it and you do need the confidence to be able to go in and start conversations with people and not be sort of fearful about how things might go wrong. Community PCNS From the information delivered [and] from the learning from the day, I certainly feel (…) I can do better and (…) I can now also share practice with other colleagues and feel more confident, maybe in challenging others on how they approach supporting patients with children and become a better advocate (…) for services to improve and being available. Breast CNS
Interactive training	Just little tips from other people and case studies and scenarios and just how people manage different situations. (…) Yes, just learning from others really. It's silly but it's little things like, "Oh I say this to my patients," and you think, oh yes, that's a really good thing. Hospital Research Nurse I think actually [*the mix of professional backgrounds*] really complemented it because I got to see things from (*Hospital CNSs'*) perspectives and how hard their conversations are. Because we know that our patients have been given that information in clinics, sometimes a few weeks, sometimes a few years ago, it varies massively, but I hadn't really heard first hand from those nurses around how that feels for them and how the conversations sometimes go and the complications that can come up as well. Community PCNS
Role-play	One of the CNSs doing the role-play at one point said (…) '*How can I tell the child?*' and she said, '*Can I just ask* [the patient] *how did you tell* [your son] *when you had your cancer diagnosis?*' I thought, that's quite powerful because almost what she was saying was 'You've done this before, you've broken bad news to your children before'. That's why the learning from your peers (when observing role-play) is quite often so powerful as well. Hospital PCNS I certainly didn't feel that I managed it well at all, I really felt myself floundering (…) and that really disconcerted me actually (…) I would say probably for the rest of the day. Community PCNS
Resources and additional learning	So all the resources that were shared on the day were great and actually has made me think that I could improve the information I give to my patients and the support that they may get as well. Breast CNS I know there were some resources laid out, some booklets for children, bereavement support, but really we were not being explained the differences between them, they were only left on the table to have a look at and I was hoping that we would have had more explanation about what is what and how to use it as well. Hospital PCNS
Talking to children	I think also a lot has been said about convincing or helping a parent understanding what is important to talk to their children, but we have not got down to the practicality of what words do you use, what do you say based on their age. Hospital Palliative Care Clinical Nurse Specialist

children, and compile resources for patients on communicating with their children.

Intentions to improve organisational practice

Some participants had shared the training resources with colleagues; several had plans to do so. Some had started to think about changes that could be made to procedures to improve their organisation's practice; these included reviewing and updating patient documentation systems, building stronger networks with other professionals and developing workshops to be offered to parents.

Barriers to implementing learning

Professional settings and roles influenced participants' perceptions of the support they could provide families. Those working in acute settings faced challenges including heavy caseloads, limited time and scarce resources that hindered their ability to develop relationships and engage in proactive conversations with parents. Some participants only met patients in their final days of life and felt unable to build meaningful rapport in the way achieved by those who worked with patients longer term. These factors constrained how learning from the training could be implemented. Participants discussed their lack of control over the environment in which to hold conversations; community-based participants were dependent on the home situation they visited, whereas hospital-based participants often found it difficult to find quiet and private spaces for sensitive discussions.

Putting learning into practice

Where post-training, participants had encountered patients with dependent children, practice log entries supported their increased awareness of the importance of engaging parents in conversations around death and dying, and their greater confidence in initiating these conversations. Participants also discussed how the training had reiterated the importance of being open and non-judgemental (eg, in situations where patients were reluctant to discuss their family/children). They recognised the importance of mirroring the patient's energy, pausing, listening, and providing cues and responses at appropriate times, and had employed these strategies in conversations. After the training, some felt more confident with signposting and liaising with other professionals and organisations.

Reactions to the training
Content and style

Face-to-face training encouraged more networking, enquiry and support. Across both delivery formats, awareness of the importance of having conversations around parental death, and enhanced confidence to initiate such conversations were felt to have increased. Despite levels of experience, all those interviewed found the training suitable for their personal needs; junior participants alluded to knowledge and skills acquisition, more experienced participants referenced validation, updating and expansion of existing knowledge.

Interactive training

The range of delegates' professional backgrounds was deemed especially beneficial; sharing experiences and learning from others was invaluable. Participants found it useful to learn about practice within other settings and get advice and ideas on innovations to implement in their own practice. Hearing others' stories validated personal experiences of working with patients with dependent children.

Reality and authenticity

Role-play was one of the most appreciated elements of the training: the professional actor added to the realism and authenticity of scenarios. Whether participating or observing, participants discovered new practice insights and approaches to be used in conversations with parents. Despite positive response to the role-play, the similarity of a scenario to a recent patient experience caused upset for one delegate; another indicated that the role-play strengthened feelings of inadequacy. It was suggested that role-play would work better in a face-to-face context, where appropriate in-person support can be offered.

Resources and additional learning

Participants welcomed being introduced to grief and childhood development theory, and support resources for preparing parents to communicate with their children about parental death, although some would have liked more practical guidance on how to work with these in practice. Many explained how they worked with a diverse range of patient populations that varied in their responses to illness, and the care and support provided by healthcare professionals. It was highlighted that in some cultures, the concepts of death and dying are not accepted and/or openly spoken about. Diversity and inclusivity across cultures and social groups were considered essential to reflect in resources and materials. Similarly, while not a main component of the training, multiple participants would have liked to receive guidance on how to talk to children directly, using age-appropriate language.

Integrating data

Data converged to develop understanding in relation to participants' intentions to incorporate their learning into their practice and more widely, and to provide guidance for the development and design of the training. These themes are illustrated in table 5 and interpretation is presented in the next section.

DISCUSSION

These evaluation outcomes determined that the 'No conversation too tough' training was principally effective in meeting intended aims. After the training delegates felt more empowered to hold conversations with parents about supporting their dependent children. Confidence in skills and the ability to discuss sensitive issues increased, and clear intentions to build empathetic and supportive

Table 5 Convergent themes

Quantitative	Qualitative	
	Theme: Transferring learning into practice	**Over-riding themes**
Confidence (p<0.003) Increases in: Skills to have conversations; managing own emotions, being able to discuss relevant issues.	Feelings of confidence to hold conversations. Improved confidence in practice to signpost and liaise with other professionals and organisations.	Empowerment
Expectations and beliefs Less concerned about: Getting too close to a patient. (p=0.012) Talking to them would damage how they cope. (p=0.027) Making matters worse. (p=0.051) Less likely to believe that: A patient would raise concerns on their own. (p=0.036)	Greater awareness of the importance of being non-judgemental, especially where patients were reluctant to engage. Appreciation of the importance of mirroring the patient's energy, pausing, listening, providing cues and responses at appropriate times, and readiness to employ these strategies in conversations.	Tolerance and open-mindedness Increased sensitivity
Perceptions of usefulness and intentions (Scale mean. Total=100) More satisfied. Mean=82 Motivated to seek more knowledge. Mean=92 More able to support parents. Mean=93 Intension to use. Mean=94	Strong intentions to use learning in practice. More awareness of timing, questions to ask, the need to check in with patients, explore cues, use listening skills, 'be alongside' and to use resources. Consciously looking at patient notes to identify children, greater efforts to document presence of children, ensuring time for talking and resources.	Determination Changing personal practice
Attitudes to influencing change in practice % Participants Sharing learning with colleagues. (90%) Influence change in the workplace. (89%) Influence wider practice. (71%)	Sharing learning and making organisational changes—reviewing and updating documentation systems, building stronger networks with other professionals, developing workshops to be offered to parents. Support provided is influenced by settings and roles. In acute settings: heavy caseloads, limited time and scarce resources hindered relationships and proactive conversations/finding a quiet space for sensitive discussions. Difficult to build rapport when only contact is in a patient's final days of life. In community-based settings: lack of control over context and conversation flow.	Influencing wider practice Barriers/challenges to implementing learning
	Theme: Reactions to the training experience	
Participants consistently positive. N=28/28 agreed/strongly agreed the facilitators worked well together and were knowledgeable, and the topics covered were relevant to them. N=21/28 agreed/strongly agreed that role-play was authentic and realistic. N=2/28 provided negative feedback—not clear about the objective, not enough time, support materials not helpful, role-play not comfortable.	Delivery style and range of content were appreciated and relevant. Training considered suitable for all levels of roles and experience. Face-to-face format facilitated relationship building and support.	Content and style
	Opportunities to share experience invaluable, new ideas, validated experiences. Learning together with mixed professional backgrounds brings other perspectives and expands knowledge and understanding.	Interactive training
	Role-play with a professional actor brings realism/authenticity. New insights experienced whether engaged in role-play or observing. Risk of evoking recent experiences, generating emotional responses and increasing feelings of inadequacy. Suggestions that role-play might be better when face to face so that appropriate support can be offered.	Realism and authenticity
	Resources introduced were welcomed and useful, but more practical guidance on how to work with these in practice is required. Understanding diversity in response to illness, death and dying across different patient populations. How to talk to children directly.	Resources and additional learning

relationships with patients were displayed. More open-minded beliefs in the consequences of engaging with patients about their dependent children were evident; this is an important element for behaviour change that can increase as experiences of new behaviours progress over time, and new practice is normalised through peer group and external feedback.[31] Delegates also revealed determination to use their new learning in practice by being proactive in starting conversations, and making greater use of, and improving, organisational procedures to identify and record the presence of children. These results reflect outcomes of communication skills training developed and researched in palliative care more broadly.[15 26]

A pertinent finding in this evaluation is that delegates were enthusiastic and exhibited strong intentions to share their learning with colleagues. They welcomed the opportunity during the course to interact with other professionals, and subsequently to build strong networks and influence wider practice. The mix of professionals attending the training offered delegates new perspectives and facilitated learning about, and from, others. Delegates were working across roles and settings and recognised the influence that working contexts had on relationships built with patients; length of time (days/months/years) available to build relationships with patients, the duration of conversations staff time affords, and environments in which these take place, all varied strikingly. To maximise learning, the training needs to take account of, and explore, best practice across professional roles and settings.[32] The challenges that exist in today's healthcare environments, evidenced in this research by concerns over heavy caseloads, limited time and resources, and lack of privacy and space for conversations to build and continue relationships with patients, all impact on scale and scope of possible enhancements in patient support. Provider organisations are crucial in facilitating conducive cultures and environments, not only for ensuring changes in practice behaviours, but also for supporting the emotional well-being of their staff.[11]

The benefits of face-to-face versus virtual delivery of the training were apparent. The focus of the training is highly sensitive and evoked strong emotions, particularly during role-play. Delegates welcomed the more cohesive face-to-face environment over virtual delivery, as it enabled greater opportunity to share experiences, develop new ideas from others and build supportive relationships with the facilitators and other delegates. There has been an increase in virtual learning since the pandemic and the opportunities this affords for health education are apparent.[33] However, in this context, where delegates' sensitives, experiences and individual responses can require support, a face-to-face format, potentially in conjunction with virtual learning, appeared to offer greater opportunity; it can impart knowledge and skills in a comfortable, supportive, nurturing environment where individuals are less likely to get 'lost' without recourse to in-the-moment support.

Further training needs became apparent during the research. Congruent with other research,[34 35] several delegates indicated how they were often introduced to children within the care setting, but their own lack of understanding of how to communicate according to children's ages and levels of development was a significant deterrent to establishing relationships with children, or with their parents when the child was the focus. Delegates also called for a greater focus in the training on the diversity of the families they care for, and delivery of culturally appropriate care. Difference in ethnocultural background, socioeconomic status, and family structure influence patients' responses to illness, their care needs, and their willingness to talk about death and dying. These have an impact on the nature of the conversation to be had (eg, need for cultural sensitivity, focus on legalities and guardianship in the case of single parenthood). Hitherto, the needs of dependent children and diverse families have been lacking in palliative care policy and guidance, but there are now clear elements set out in the UK Ambitions for Palliative and End of Life Care: A national framework for local action 2021–2026.[36]

This evaluation of the training programme has limitations. It was a small-scale study, not powered to detect change, nor to assess changes in practice behaviours or their sustainability. Furthermore, it was not designed to assess the impacts of such changes on patient outcomes. In the context of National Health Service (NHS) staff shortages and potential burnout,[37] there is a need to ensure training is effective and time efficient, and that evaluation is straightforward and brief enough to capture what is needed. Furthermore, the techniques and advice imparted need to be easily implemented in busy NHS environments. Longer-term, large-scale evaluation is now required.

CONCLUSIONS AND NEXT STEPS

'No conversation too tough' is the first training programme codeveloped and tested specifically for cancer, palliative care and wider healthcare professionals to help dying parents support their dependent children.[11 38] These evaluation findings have shown that training such as 'No conversation too tough' has the ability to impart healthcare professionals with the skills, knowledge and confidence to empower them to start conversations about death and dying, progress supportive patient relationships, and in turn, to help their patients to communicate with and support their children.

The findings have supported course refinement, and the training is to be rolled out on a national basis. It will comprise pre-course e-learning, (including an extra module to address cultural and religious diversities in attitudes to death and dying), and a subsequent 1-day face-to-face interactive session. Individual professionals and whole teams will take part across healthcare providers and higher education. Large-scale evaluation will provide feedback to understand behaviour change, what works

for whom (which professionals benefit most), and why (mediators of change). In light of demand, a masterclass for communicating directly with children is planned. Future evaluation steps will include sensitive assessment of the impact of the training on family and children's outcomes.

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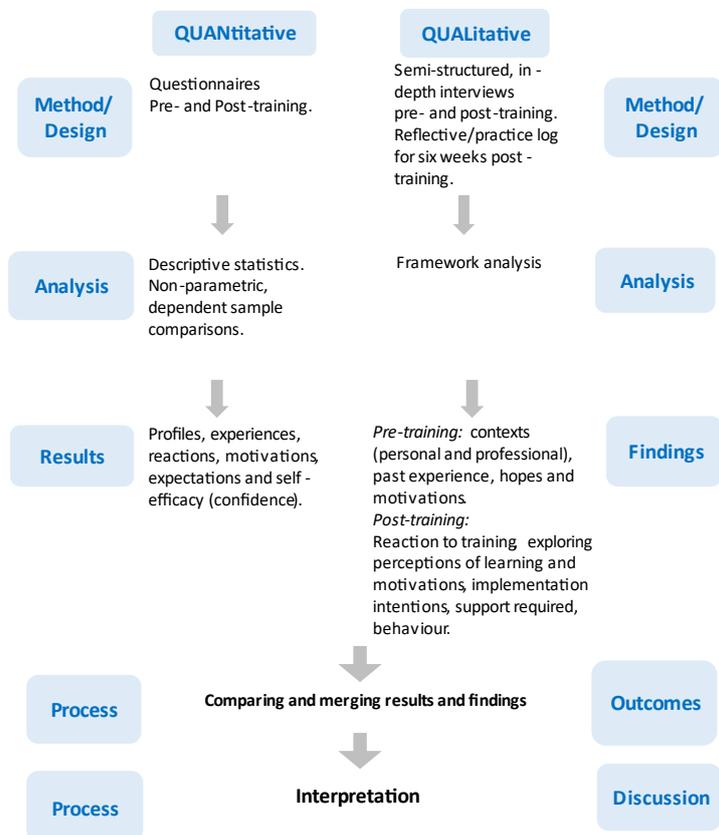## REFERENCES

1 Luecken LJ, Roubinov DS. Pathways to LifeSpan health following childhood parental death. *Soc Personal Psychol Compass* 2012;6:243–57.
2 Niemelä M, Paananen R, Hakko H, *et al*. Mental disorder diagnoses of offspring affected by parental cancer before early adulthood: the 1987 Finnish birth cohort study. *Psychooncology* 2016;25:1477–84.
3 Bergersen EB, Larsson M, Olsson C. Children and adolescents' preferences for support when living with a dying parent - an integrative review. *Nurs Open* 2022;9:1536–55.
4 Bylund-Grenklo T, Kreicbergs U, Uggla C, *et al*. Teenagers want to be told when a parent's death is near: a nationwide study of cancer-bereaved youths' opinions and experiences. *Acta Oncologica* 2015;54:944–50.
5 Marshall S, Fearnley R, Bristowe K, *et al*. The perspectives of children and young people affected by parental life-limiting illness: an integrative review and thematic synthesis. *Palliat Med* 2021;35:246–60.
6 Hanna JR, McCaughan E, Semple CJ. Challenges and support needs of parents and children when a parent is at end of life: a systematic review. *Palliat Med* 2019;33:1017–44.
7 Fearnley R, Boland JW. Communication and support from healthcare professionals to families, with dependent children, following the diagnosis of parental life-limiting illness: a systematic review. *Palliat Med* 2017;31:212–22.
8 Cockle-Hearne J, Reed E, Todd J, *et al*. The dying parent and dependent children: a nationwide survey of Hospice and community palliative care support services. *BMJ Support Palliat Care* 2022;12:e696–704.
9 Grant L, Sangha A, Lister S, *et al*. Cancer and the family: assessment, communication and brief interventions—the development of an educational programme for healthcare professionals when a parent has cancer. *BMJ Support Palliat Care* 2016;6:493–9.
10 Turner J, Clavarino A, Butow P, *et al*. Enhancing the capacity of oncology nurses to provide supportive care for parents with advanced cancer: evaluation of an educational intervention. *Eur J Cancer* 2009;45:1798–806.
11 Franklin P, Arber A, Reed L, *et al*. Health and scoial care professionals' experiences of supporting parents and their dependent children during and following the death of a parent: a qualitataive review and thematic synthesis. *Palliat Med* 2019;33:49–65.
12 Creswell JW, Plano Clark VL. *Designing and Conducting Mixed Methods Research, 3rd ed*. SAGE Publications Ltd, 2017.
13 Kirkpatrick D, Kirkpatrick J. *Evaluating Training Programs: The Four Levels*. Berrett-Koehler Publishers, 2006.
14 Artioli G, Bedini G, Bertocchi E, *et al*. Palliative care training addressed to hospital healthcare professionals by palliative care specialists: a mixed-method evaluation. *BMC Palliat Care* 2019;18:88.
15 Connolly M, Thomas JM, Orford JA, *et al*. The impact of the SAGE & THYME foundation level workshop on factors influencing communication skills in health care professionals. *J Contin Educ Health Prof* 2014;34:37–46.
16 King O, West E, Lee S, *et al*. Research education and training for nurses and allied health professionals: a systematic scoping review. *BMC Med Educ* 2022;22:385.
17 Officer E, Johnson M, Blickwedel J, *et al*. Evaluation of the training in early detection for early intervention (TEDEI) E-learning course using Kirkpatrick's method. *BMC Med Educ* 2023;23:129.
18 DeSilets LD. An update on Kirkpatrick's model of evaluation: part two. *J Contin Educ Nurs* 2018;49:292–3.
19 Kirkpatrick JD, Kirkpatrick WK. *Kirkpatrick's Four Levels of Training Evaluation*. Association for Talent Development, 2016.
20 Van Hecke A, Duprez V, Pype P, *et al*. Criteria for describing and evaluating training interventions in healthcare professions–CRE-DEPTH. *Nurse Educ Today* 2020;84:104254.
21 Brighton LJ, Koffman J, Hawkins A, *et al*. A systematic review of end-of-life care communication skills training for generalist palliative care providers: research quality and reporting guidance. *J Pain Symptom Manage* 2017;54:417–25.
22 Bandura A. *Social Foundations of Thought and Action: A Cognitive Social Theory*. Englewood-Cliffs, NJ: Prentice-Hall, 1986.
23 Bandura A. Health promotion by social cognitive means. *Health Educ Behav* 2004;31:143–64.
24 Bandura A, Freeman WH, Lightsey R. Self-efficacy: the exercise of control. *J Cogn Psychother* 1999;13:158–66.
25 Williams DM, Rhodes RE. The confounded self-efficacy construct: conceptual analysis and recommendations for future research. *Health Psychol Rev* 2016;10:113–28.
26 Griffiths J, Wilson C, Ewing G, *et al*. Improving communication with palliative care cancer patients at home–A pilot study of SAGE & THYME communication skills model. *Eur J Oncol Nurs* 2015;19:465–72.
27 Parle M, Maguire P, Heaven C. The development of a training model to improve health professionals' skills, self-efficacy and outcome expectancies when communicating with cancer patients. *Soc Sci Med* 1997;44:231–40.
28 Spencer L, Ritchie J, Ormston R, *et al*. Analysis: principles and processes. In: Richie J, Lewis J, McNaughton Nicholls C, eds. *Qualitataive Research Practice*. Sage, 2014.

29 Gale NK, Heath G, Cameron E, *et al*. Using the framework method for the analysis of qualitataive data in multi-disciplinary health research. *BMC Med Res Methodol* 2013;13:117.

30 Östlund U, Kidd L, Wengström Y, *et al*. Combining qualitative and quantitative research within mixed method research designs: a methodological review. *Int J Nurs Stud* 2011;48:369–83.

31 Johnson MJ, May CR. Promoting professional behaviour change in healthcare: what interventions work, and why? A theory-led overview of systematic reviews. *BMJ Open* 2015;5:e008592.

32 Kirkpatrick AJ, Donesky D, Kitko LA. A systematic review of Interprofessional palliative care education programs. *J Pain Symptom Manage* 2023;65:e439–66.

33 Frenk J, Chen LC, Chandran L, *et al*. Challenges and opportunities for educating health professionals after the COVID-19 pandemic. *Lancet* 2022;400:1539–56.

34 Viftrup DT, Voetmann SS. Caring existentially and spiritually for young children and close grandchildren of life-threatened cancer patients in secularized Denmark. *Semin Oncol Nurs* 2023;39:151484.

35 Wickramasinghe LM, Yeo ZZ, Chong PH, *et al*. Communicating with young children who have a parent dying of a life-limiting illness: a qualitative systematic review of the experiences and impact on Healthcare, social and spiritual care professionals. *BMC Palliat Care* 2022;21:125.

36 National Palliative and End of Life Care. Ambitions for palliative and end of life care: a national framework for local action 2021-2026. n.d. Available: https://acpopccsporguk/system/files/documents/2021-05/FINAL_Ambitions-for-Palliative-and-End-of-Life-Care_2nd_editionpdf

37 Waters A. NHS staff survey underlines need for national workforce strategy. *BMJ* 2022;o871.

38 Hanna JR, McCaughan E, Beck ER, *et al*. Providing care to parents dying from cancer with dependent children: health and social care professionals' experience. *Psycho-Oncology* 2021;30:331–9.

Supplemental material

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Supplemental Material 1.   Convergent, parallel, mixed methods design

Description of convergent parallel mixed -methods design used adapted from Creswell and Plano Clark 2017

Supplemental Material 2.

'No Conversation Too Tough'

Self-Efficacy Questionnaire

Thinking about patients whose cancer cannot be cured, and who have a poor or uncertain prognosis, or whose life expectancy is short.

Below are statements about how certain you are that you can successfully provide support. Please rate your response on a scale of 0-100, with 0 being Very uncertain and 100 being Very certain.

```
0   10   20   30   40   50   60   70   80   90  100

Very Uncertain                    Very Certain

                    54
         ⬤
```

Please write down a number (0-100) in the table below.

Thinking specifically about *having a conversation* with a patient who has dependent children.

How certain are you that you have the skills to …	Response (0 = Very uncertain, 100 = Very certain)
… create a comfortable setting in which a patient can speak openly about their family.	
… initiate a discussion with a patient about their family circumstances?	
… ask a patient directly if they have dependent children?	
… ask questions that will encourage a patient to talk about how their children are feeling and coping?	
… ask questions that will encourage a patient to talk to you about their concerns for their children?	
… close a conversation with a patient who has concerns about their children?	

Thinking now about *responding* to what a patient has told you about their dependent children.

How certain are you that you have the skills to …	Response (0 = Very uncertain, 100 = Very certain)
… listen and respond in a way that will encourage a patient to talk about their feelings in respect of their children?	
… use empathic supportive comments (not sympathy) with a patient when talking about their children?	
… encourage a patient to tell you if they would like help to support their children?	
… support a patient if they get upset while talking about their children?	

Now thinking about *managing your own emotions* when talking to a patient about their dependent children.

How certain are you that you can manage your own emotions …	Response (0 = Very uncertain, 100 = Very certain)
… about initiating a conversation with a patient about their children's well-being?	
… while having a conversation with a patient about their children?	
… while having a conversation with a patient about the need to talk openly with their children about death and dying?	
… when you are off duty, having previously had a conversation with a patient about their children?	

Finally, thinking about the *knowledge* you have about patients and their dependent children.

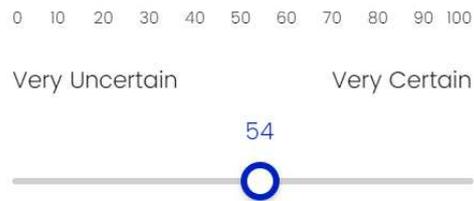| How certain are you that you can discuss with a patient ...	Response (0 = Very uncertain, 100 = Very certain)
... how children can be affected by losing a parent through cancer that can't be cured?	
... how children's needs for information and support vary depending on their age?	
...the problems faced by parents with dependent children when a parent is dying?	
...the best time for a parent to receive help to support their children?	
... information resources that might help a parent to support their children?	

Supplemental Material 3.

'No Conversation Too Tough'

Outcome Expectancies Questionnaire

Thinking about patients whose cancer cannot be cured, and who have a poor or uncertain prognosis, or whose life expectancy is short.

We'd like to know what you think might be the outcome of having a conversation with a patient about their dependent children.

The following pages contain statements about your expectations.

For each, please circle your response on a score of 1 to 9 where:

1 = Very likely and 9 = Very unlikely.

Please note: this scale runs in the opposite direction to that in the previous questionnaire.

How likely is it that ...
... you would be helping a patient if you talk to them about their children? *Very likely* - 1   2   3   4   5   6   7   8   9 - *Very unlikely*
... a patient will become distressed and upset if you ask about their children? *Very likely* - 1   2   3   4   5   6   7   8   9 - *Very unlikely*
... it will damage the way a patient copes if you ask them about their children? *Very likely* - 1   2   3   4   5   6   7   8   9 - *Very unlikely*
... you will get too close to a patient if you ask about their feelings or concerns for their children? *Very likely* - 1   2   3   4   5   6   7   8   9 - *Very unlikely*
... your workload will become unmanageable if you ask a patient about their children? *Very likely* - 1   2   3   4   5   6   7   8   9 - *Very unlikely*
... you will be criticised by your colleagues if a patient becomes upset when you talk to them about their children? *Very likely* - 1   2   3   4   5   6   7   8   9 - *Very unlikely*
... you will keep control of the conversation if a patient becomes upset whilst talking about their children? *Very likely* - 1   2   3   4   5   6   7   8   9 - *Very unlikely*

… you could say something that will make matters worse for your patient if you try to talk to them about their children? *Very likely* - 1 2 3 4 5 6 7 8 9 - *Very unlikely*
… asking a patient about their concerns will help you identify what may be helpful? *Very likely* - 1 2 3 4 5 6 7 8 9 - *Very unlikely*
… a patient will raise concerns/feeling about their children without you asking? *Very likely* - 1 2 3 4 5 6 7 8 9 - *Very unlikely*
… if a patient shows strong emotions when talking about their children, it will be overwhelming for you? *Very likely* - 1 2 3 4 5 6 7 8 9 - *Very unlikely*
… you will feel down if you ask a patient about their children? *Very likely* - 1 2 3 4 5 6 7 8 9 - *Very unlikely*
… there will not be enough support available to you if you need to reflect on the difficulties you experience when talking with a patient about their children? *Very likely* - 1 2 3 4 5 6 7 8 9 - *Very unlikely*
… you will have colleagues who you can go to if you need emotional support after talking to a patient about their children? *Very likely* - 1 2 3 4 5 6 7 8 9 - *Very unlikely*

THANK YOU VERY MUCH FOR COMPLETING THE PRE-TRAINING QUESTIONNAIRES

Supplemental Material 4.

'No Conversation Too Tough'

Pre-training Main Questionnaire.

Thank you for taking part in this evaluation of the Ruth Strauss Foundation Pilot Training Programme.

To start, please could you tell us a little about yourself?

In which type of health care do you currently work?

○ Acute Care

○ Hospital Palliative Care

○ Hospice

○ Community

○ Other, please describe: _____

What is your current job title? *Please write down:*

_____

And what is the year of your professional registration?

_____

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Could you tell us your current specialism? *Please write down:*

_____

And, how long have you worked in this specialism?

○ Less than a year

○ 1-2 years

○ 3-4 years

○ 5 or more years

Which of the following qualifications have you completed? *Please check all that apply.*

☐ Diploma

☐ Undergraduate Degree

☐ Master's Degree

☐ MPhil

☐ PhD

☐ Post-registration training specific to palliative care.

Please describe: _____

Please could you indicate how you describe your ethnic or cultural background? On the next page are the categories used by the NHS. Please select one category. *This question is optional.*

○ White British

○ White Irish

○ White - any other White background

○ Asian Bangladeshi or Bangladeshi British

○ Asian Indian or Indian British

○ Asian Pakistani or Pakistani British

○ Asian - any other Asian background

2

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○ Chinese

○ Mixed Black Caribbean + White

○ Mixed Black African + White

○ Mixed Asian + White

○ Mixed - any other Mixed background

○ Black Caribbean or Black Caribbean British

○ Black African or Black African British

○ Black - any other Black background

○ Any other ethnic group

○ Prefer not to answer

With which gender do you most identify?

○ Female

○ Male

○ Non-binary

○ Prefer to self-describe _____

○ Prefer not to answer

In which age group are you?

○ 18-24 years

○ 25-34 years

○ 35-44 years

○ 45-54 years

○ 55-64 years

○ Over 65 years

○ Prefer not to answer

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3

And finally, please could you tell us which of the statements below best describes your family situation? *Please select one statement.*

○ I have a dependent child (or children) under the age of 18 years.

○ All my children are over 18 years.

○ Neither of the above apply to me.

○ Prefer not to answer.

In this next section, we would like you to think about the patients who you care for in your workplace.

When we refer to patients, we mean *patients whose cancer cannot be cured, and who have a poor or uncertain prognosis, or whose life expectancy is short.*

How often do you encounter patients with dependent children? *Please check one option below.*

○ Regularly (at least weekly)

○ Occasionally (once a month)

○ Rarely (once every six months or so)

○ Hardly ever (once a year)

○ Never

How frequently do you provide support for patients with dependent children?

○ Very frequently

○ Quite frequently

○ Sometimes

○ Hardly ever

○ Never

What <u>types</u> of support have you provided to patients with dependent children? *Please select all that apply.*

4

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☐   Emotional support.

☐   Written literature/information.

☐   Conduct Holistic Needs Assessment and care plan.

☐   Signposting - please describe:_____

☐   Referral to specialist services - please describe:_____

☐   Other - please describe: _____

Below are names/descriptions of sources of support that patients/parents with dependent children might find helpful.

We'd like you to tell us which ones you are aware of and how often you have used them.

Which of the following charitable organisations that support parents/children are you aware of and, <u>if aware</u>, how frequently have you used them when supporting patients with dependent children?

	Not aware	Aware	*Used often*	*Used occasionally*	*Never used*
Winston's Wish	○	○	○	○	○
Child Bereavement UK	○	○	○	○	○
Grief Encounter	○	○	○	○	○
RipRap for Teenagers	○	○	○	○	○
Teenage Grief Sucks	○	○	○	○	○

Other than those we listed on the previous page, are you aware of any other charitable organisations that support parents/children? *If so, please write names below.*

_____

And have you ever used any of these?

_____

Which of the following books, booklets and resources that support parents/children are you aware of, and, if aware, how frequently have you used these when supporting patients with dependent children?

	Not aware	Aware	*Used often*	*Used sometimes*	*Never used*
Badger's Parting Gift by Susan Varley	○	○	○	○	○
The Invisible String by Patricia Karst	○	○	○	○	○
What Does Dead Mean? A book for young children to help explain death and dying by Caroline Jay and Jenni Thomas	○	○	○	○	○
The Little C Club	○	○	○	○	○
The Secret C by Julia Stokes (Winston's Wish)	○	○	○	○	○
Pip's Kit by Fruit Fly Collective	○	○	○	○	○
No Matter What by Debi Gliori	○	○	○	○	○
Macmillan Cancer Support Booklet on preparing a child for loss	○	○	○	○	○
Talking to Children and Teenagers When an Adult has Cancer by Macmillan Cancer Support	○	○	○	○	○
As Big As It Gets from Winston's Wish	○	○	○	○	○

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Other than those we listed on the previous page, are you aware of any other books, booklets or resources for supporting parents/children? *If so, please describe/write names below:*

_____

Have you ever used any of these?

_____

Now, we'd like you to think about your workplace.

Please could you tell us about the processes your workplace has, if any, for gathering information about whether a patient has dependent children? *Please select one option below that most accurately describes what happens in your workplace.*

- ○ We ask at admission or first community visit and enter in a patient's records.

- ○ We ask at admission or first community visit, but we do not enter in a patient's records.

- ○ We ask informally during a patient's stay or subsequent visits and enter in their records.

- ○ We ask informally during a patient's stay or subsequent visits, but we do not enter in their records.

- ○ We have no consistent procedure.

- ○ We do not ask or record at any time.

- ○ Don't know.

If you have indicated that your organisation gathers information about whether a patient has dependent children, please could you tell us if this information is ever gathered through Holistic Needs Assessment? *Please select one of the options below.*

- ○ Yes, information about dependent children is gathered through Holistic Needs Assessment.

- ○ No, Holistic Needs Assessment is not used to gather information about dependent children.

- ○ Don't know.

Is there anything else you'd like to tell us about asking patients if they have dependent children?

_____

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Thinking now about being supported to have conversations with patients.

Can you tell us which of the following best describes the support provided in your workplace for having conversations with patients about their dependent children? *Please select all that apply.*

☐ Practical support (facilities to have a conversation, directory of resources etc).

☐ Formal support from managers (supervision, debrief time).

☐ Informal support from colleagues/peer support.

☐ Training in holding sensitive conversations.

☐ Regular group/individual meetings with a counsellor/therapist/clinical supervisor.

☐ Talking with a family support or well-being team.

☐ Chaplin support/service.

☐ No support is available.

☐ We have to seek our own support if we need it.

☐ Other, please describe: _____

Can you tell us more about the support provided in your organisation, if any, for having conversations with patients about their dependent children?

_____

In this last section, we'd like to ask you about your previous training experience and how you feel about coming on this course.

What previous training courses, if any, have you attended? *Please select all that apply.*

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☐ Advanced Communication Skills Training

☐ Intermediate or Foundation Level Communication Skills Training

☐ Level 2 Psychology

☐ Sage & Thyme

☐ None

☐ Other, please describe:_____

Could you please tell us the reasons why you decided to come on this course? *Please check up to three reasons.*

☐ To get more confidence in working with patients who have dependent children.

☐ To learn more about the effects on children of losing a parent to cancer.

☐ To improve my communication skills with patients who have dependent children.

☐ To network.

☐ To help me control my emotions when I have conversations with patients who have dependent children.

☐ Because I was asked to attend.

☐ To fulfil my CPD requirement.

☐ Other, please describe: _____

Please could you tell us a little about what you hope to achieve by attending this course?

_____

How likely do you think it is it that you can influence or bring about change in practice in your workplace?

9

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○ Extremely unlikely.

○ Unlikely.

○ Somewhat likely.

○ Very likely.

○ Extremely likely

Is there anything more you would like to tell us about the likelihood that you can, or cannot, influence or change practice in your workplace?

_____

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Supplemental Material 5.

'No Conversation Too Tough'

Post-training Main Questionnaire.

Now that you have taken part in the Ruth Strauss Foundation Training Programme we'd like you to complete some further questionnaires to help us evaluate the course.

In this first section, we ask how you think the training was organised and delivered.

	Strongly Agree	Agree	Somewhat Agree	Disagree	Strongly Disagree
1. The pre-course communication and joining instructions were clear.	○	○	○	○	○
2. The training objectives were clearly defined.	○	○	○	○	○
3. The content was organised well and easy to follow.	○	○	○	○	○
4. The topics covered were relevant to me.	○	○	○	○	○
5. There was enough time given to each of the topic areas.	○	○	○	○	○
6. The facilitators were knowledgeable about the topics covered.	○	○	○	○	○
7. The facilitators	○	○	○	○	○

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were well prepared.					
8. The facilitators worked well together.	○	○	○	○	○
9. The training support materials helped increase my knowledge and skills.	○	○	○	○	○
10. The range of training support materials was about right.	○	○	○	○	○
11. There was enough time allocated for the training as a whole.	○	○	○	○	○
12. The training objectives were met.	○	○	○	○	○
13. The roleplay scenario depicted felt realistic.	○	○	○	○	○
14. The roleplay actor performed authentically.	○	○	○	○	○
15. The roleplay activity created a comfortable space to practise my	○	○	○	○	○

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2

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communication skills.					

Thinking about the venue where the training was held. How comfortable did you find it? *Please select one option below.*

○   Not at all comfortable

○   Slightly comfortable

○   Moderately comfortable

○   Very comfortable

○   Extremely comfortable

How would you rate the number of participants on the course? Were there about the right number, too many or not enough? *Please select one option.*

○   About the right number

○   Too many

○   Not enough

How did you find the amount of rest periods built into the course? *Please select one option.*

○   About the right number

○   Too many

○   Not enough

How useful did you find the breakout sessions? *Please select one option.*

○   Not at all useful

○   Slightly useful

○   Moderately useful

○   Very useful

○   Extremely useful

How did you find the opportunity to meet and get to know other participants? Was this very poor, poor, fair, good, or excellent? *Please select one option.*

○ Very poor

○ Poor

○ Fair

○ Good

○ Excellent

We'd now like to find out what you thought of the course content.

Can you tell us how satisfied you were with the content of the course? *Please select one option.*

○ Not at all satisfied

○ Slightly satisfied

○ Moderately satisfied

○ Very satisfied

○ Extremely satisfied

Thinking about the topics covered, how relevant were they to the training objectives? *Please select one option.*

○ Extremely relevant

○ Very relevant

○ Moderately relevant

○ Slightly relevant

○ Not at all relevant

Were there any other topics you would have liked included?

○ No

○ Yes, please describe. _____

Were there any topics you would suggest leaving out in future?

○ No

○ Yes, please describe. _____

Did you learn as much as you expected? *Please select one option below that describes your expectation.*

○ Did not meet my expectation

○ Fell below my expectation

○ Met my expectation

○ Was above my expectation

○ Far exceeded my expectation

Training courses can be taught with different styles and methods to meet different learning needs.

Can you tell us if the style of teaching and learning in the Ruth Strauss Foundation Training Programme was comfortable for your needs? *Please select one option below.*

The methods of teaching and learning in the course were:

○ … just right for me.

○ … mostly right for me.

○ … not right for me.

Please explain your answer:

_____

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5

Thinking about supporting patients whose cancer cannot be cured and who have dependent children.

Below are some questions about the strength of your intentions and feelings as a result of the training.

For each question below, please indicate your response from 0 (low) to 100 (high):

	Response (write down a number from 0-100):
How strong is your intention to use what you have learned through the training in your practice?	
How strongly do you feel that the training will be useful for supporting patients?	
How strongly do you feel that the training will leave you more satisfied in the work you do with patients?	
How strongly do you feel that the training has encouraged you to seek out more knowledge and understanding about working with patients with dependent children?	

Last in this section, can you tell us what you will do differently in your practice from now on?

_____

On the next page are some questions about recommending the training and influencing practice.

Which of the following professional health care groups do you think would most benefit from the training course? *Select as many as you prefer.*

- ☐ Tumour-specific CNSs

- ☐ Palliative Care CNSs/Nurses

- ☐ Lead Nurses

- ☐ Chemotherapy Nurses

- ☐ District Nurses

- ☐ Oncologists, Consultants

- ☐ Allied Health Care Professionals

- ☐ Community Nurses

- ☐ Social workers

- ☐ Educators

- ☐ Other, please describe. _____

- ☐ None of these

How likely are you to recommend the course? *Please select one option.*

- ○ Very unlikely

- ○ Unlikely

- ○ Not sure

- ○ Quite likely

- ○ Very likely

Below are some statements about attitudes to change.

Please can you tell us how much you agree or disagree with each?

	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
I will share my learning from the training with other colleagues and contacts.	○	○	○	○	○
Now that I have completed the training, I will be able to change or influence practice in my workplace.	○	○	○	○	○
Now that I have completed the training, I will be able to change or influence wider practice.	○	○	○	○	○

Did your organisation support your attendance on the course?

○   Yes, please explain how: _____

○   No

The following statements refer to being supported to have conversations with patients about the needs of their dependent children.

How much do you agree or disagree with each?

	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
There is enough support available within my workplace to help me reflect on these conversations.	○	○	○	○	○
It would be helpful to me if there was a community of peers that I could engage with for support in respect of these conversations.	○	○	○	○	○
I like to deal with my feelings about these conversations in private.	○	○	○	○	○

We'd like to get your thoughts on the course overall, and if you wish, you can take the opportunity to elaborate on your previous answers.

Could you tell us what aspects of the course *worked well* for you?

_____

And, please could you tell us what aspects *worked less well* for you?

_____

Are there any ways you think the course could be improved?

_____

Is there anything else you would like to tell us about the training course?

_____

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Supplemental Material 6.

'No Conversation Too Tough'

Before training interview questions

General questions about participant:

1. Firstly, can you tell me a bit about yourself?
   - What is your job role, and can you describe some of your day-to-day activities within this role?
2. Can you tell me a bit more about your training background, pre- and post-registration?
   - As you know, The RSF training programme focuses specifically on helping patients whose cancer cannot be cured to communicate with and support their dependent children. Were there any elements, broad or specific, within your previous training, pre- or post-registration, that you believe have positively influenced your ability to help patients in this sense?
   - And do you think there were any gaps in your training in relation to this? *[if so, what were these?]*

Questions about motivations, hopes and expectations in relation to RSF training programme:

3. How did you come to hear about this training programme and what were your initial thoughts regarding, for instance, the name 'No conversation too tough' and the training description provided by RSF?
4. What made you sign up for this training programme?
5. What are the most important things that you hope to get out of the training programme? Why is this important to you?
   - How do you expect the training to help you in supporting patients and their children?
   - Regarding this, are there any specific elements that you hope to see in the training, which will help you support patients? How do you think these may help you?
   - Is there anything else that you would like to add regarding your expectations in relation to the training programme?

Questions about experience:

6. Can you tell me a bit more about the kinds of patients you work with on a regular basis and to what extent you tend to be aware of these patients' family situations and/or have conversations with patients about their family situations? *[further probing based on response, e.g. How do you usually become aware of this? Is this through formal or informal conversation/volunteered by patient/asked/does it come up in holistic needs assessment? If participant mentions they do not regularly have these conversations, ask why they think this is]*
7. How often do you encounter patients whose cancer cannot be cured and who have dependent children in practice?

8. What are your experiences in relation to communicating with these patients about their children/discussing support for their children/communication with their children directly? *[further probing based on response]*
- How do you feel about this? (in terms of, for instance, your confidence, skills and managing your own emotions)?
- Can you think of any specific examples where you feel that you were able to support these patients and their children effectively? What made this effective, and how did you feel in this situation?
- Can you think of any specific examples where you found supporting these patients and their children more challenging? What made it challenging, and how did you feel in this situation?

9. To what extent do you believe you can personally influence change in your workplace in general, and specifically when it comes to helping patients communicate with and support their children? *[further probing based on response, e.g. what do you see as constraints in relation to this?]*

10. In your workplace, do you receive any support for having conversations with these patients and their children*? [further probing based on response – If yes: What kind of support? Do you find this to be helpful? If no: why do you think no support is currently being offered? Do you think this will change in the future?*]

11. Because we are aware that personal context can be important for perspectives in relation to children's needs, may I ask if you have any children that you are a parent or guardian to or that you are in any other way responsible for? How old are they?

12. Does anything from your own life influence your response to these patients, and/or your approach to communicating with and supporting these patients and their children?

13. That's all my questions. Is there anything that we haven't covered and that you would like to share before we finish?

Supplemental Material 7.

'No Conversation Too Tough'

After training interview questions

1. First of all, can you tell me what your overall thoughts on the training programme were?
   - Was there anything that worked particularly well for you? Why do you think this worked well for you?
   - Was there anything that worked less well for you? Why do you think this did not work so well for you? How do you think this can be improved in the future?
2. What did you think of the communication about the training beforehand? Was it clear enough to you in advance when and in what format the training would take place?
3. You previously told me that your main reasons for signing up to the training programme were *[…]*. To what extent do you believe the training programme has met your expectations in relation to this? Why/why not? *[If expectations met: Which elements of the training did you find particularly helpful in relation to this? If not: Why do you think the training programme did not meet these expectations?]*
4. Were there any surprises in the training programme? Can you explain what these were and why it was surprising to you?
5. Was there anything missing in the training programme? *[If so: why is that important? How do you think this could/should be included in the future?]*
6. We are aware that the training day was quite full, with a lot of information and components. Do you think it would be possible to move some elements into pre-course work, for participants to do *before* the course, to free up time on the day for other things? If so, which elements and how do you think this could be done?
7. What did you think of the role play and the actor who carried out the role play? What, if anything, did you get out of this?
8. Thinking about your previous training background, and where you currently are in your career, how did you feel about the suitability of the level of the training programme?
9. Do you believe the training has made a difference to how you feel in terms of your skills and confidence in relation to helping patients whose cancer cannot be cured communicate with and support their dependent children? *[Why and in what way?/Why not?]*
10. And has the training made any difference to how you feel in relation to managing your own emotions and feeling supported?
11. Which elements of the training, if any, do you aim to implement in your practice? How do you intend to do this? What do you think will be the timeline for doing this?
12. Do you think implementing these elements will make a difference to patients? *[If so: how and why? If not: why not?]*
13. What do you believe to be the main barriers and facilitators to implementing your learning from the training in practice/in your workplace? *[In relation to any barriers: do you think these can be overcome? How?]*
14. What support do you need in your workplace to implement learning from the training in your practice? Is this support available? *[If not: what might be most helpful?]*
15. In the training programme, the intention to build a community of practice has been discussed
    - What are your thoughts on this?

- What might you like to get out of a community of practice that will follow on from this? training programme? *Would this include seeking support from the other training participants? How likely do you think you are to stay in touch with the other participants and contact them? Do you think you would benefit from RSF keeping you connected? How? SHOW SLIDE ABOUT COMMUNITY OF PRACTICE AND ASK WHAT THEY THINK OF THIS*

16. In addition to further improving the training programme, we also aim to improve the way in which we are conducting this evaluation research for the next round of participants. In relation to this, do you have any comments on the questionnaires, these interviews and the reflective log document we are sending out?

17. Is there anything else that you would like to share before we finish?

Supplemental Material 8. Evaluation Sample Characteristics

	Pre-Training N = 35		Post-Training N = 28	
	n	%*	n	%*
Demographics:				
Gender Identity				
Female	**31**	*89*	**25**	*89*
Male	**4**	*11*	**3**	*11*
Total^b	**35**		**28**	
Age Group				
18-24 years	**1**	*3*	**1**	*3*
25-34 years	**7**	*20*	**7**	*25*
35-44 years	**8**	*23*	**5**	*18*
45-54 years	**11**	*31*	**8**	*29*
55-64 years	**8**	*23*	**7**	*25*
Total^b	**35**		**28**	
Ethnic/Cultural Background				
White British	**24**	*69*	**19**	*68*
White Irish	**1**	*3*	**1**	*4*
White Other	**5**	*14*	**4**	*14*
Asian	**2**	*6*	**1**	*4*
Mixed background	**1**	*3*	**1**	*4*
Black Caribbean/Black Caribbean British	**1**	*3*	**1**	*4*
Black African or Black African British	**1**	*3*	**1**	*4*
Total^b	**35**		**28**	
Presence of Children				
Under 18 years	**18**	*51*	**12**	*43*
All children over 18 years.	**9**	*26*	**8**	*29*
No children	**8**	*23*	**8**	*29*
Total^b	**35**		**28**	
Professional Status:				
Registration Year				
1980-1989	**6**	*17*	**5**	*18*
1990-1999	**9**	*26*	**6**	*21*
2000-2009	**9**	*26*	**6**	*21*
2010-2020	**11**	*31*	**11**	*39*
Total^b	**35**		**28**	

	Pre-Training N = 35		Post-Training N = 28	
	n	%*	n	%*
Time in current specialism				
Less than a year	**4**	*11*	**4**	*14*
1-2 years	**6**	*17*	**5**	*18*
3-4 years	**5**	*14*	**4**	*14*
5 or more years	**20**	*57*	**15**	*54*
Total^b	**35**		**35**	
Qualifications				
Diploma	**14**	*40*	**10**	*36*
Undergraduate Degree	**24**	*69*	**20**	*71*
Master's Degree	**8**	*23*	**7**	*25*
Post Registration Training specific to Palliative care	**16**	*46*	**15**	*53*
Totals exceed sample sizes				
Professional Roles:				
Acute Care Clinical Nurse Specialists	**16**	*46*	**11**	*39*
Breast Cancer n =	5		5	
Haematology	2			
Lung Cancer	2		1	
Colorectal	1		1	
Gynaecology Oncology	1		1	
Myeloma and Plasma	1			
Oncology	1		1	
Oesophageal/Gastroenterology	1			
Neuro-Oncology	1		1	
Sarcoma	1		1	
Palliative Care	**14**	*40*	**12**	*43*
Hospital Palliative Care Nurse	8		7	
Hospice Community Care Nurse	3		2	
NHS Trust Community Palliative Care Nurse	1		1	
Clinical Practice Educator for Palliative Care	1		1	
Hospital Palliative Care Social Worker	1		1	
Cancer Support	**4**	*11*	**4**	*14*
Support/Information Specialist	3		3	
Support Services Manager	1		1	
Lead Research Nurse	**1**	*3*	**1**	*4*
Total^b	**35**		**28**	

a Percentages rounded.
b Some totals exceed 100% due to rounding.
Seven participants were lost to quantitative post-training assessment, two of whom were also lost to qualitative post-training interviews. Reasons given were, lack of time due to busy practice, issues with staffing levels, and personal reasons (leave, illness).

Supplemental Material 9.   Reactions to the Training