

Mixed-methods evaluation of a face-to-face educational intervention for health and social care professionals to deliver family-centred cancer supportive care when a parent with dependent children is at end of life

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#### **ORIGINAL ARTICLE**





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# Mixed-methods evaluation of a face-to-face educational intervention for health and social care professionals to deliver family-centred cancer supportive care when a parent with dependent children is at end of life

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#### **Abstract**

**Objective:** To deliver and evaluate an educational intervention to equip health and social care professionals (professionals) on how best to support parents at end of life with cancer concerning their dependent children (<18).

Methods: An evidence-based and theory-driven face-to-face educational intervention was developed and evaluated using three levels of Kirkpatrick's Model of Evaluation. Pre-test, post-test surveys were completed immediately before-andafter the intervention using a validated self-efficacy scale and single-item questions evaluating perceived usefulness and relevance (levels one/two). Qualitative interviews ≥ 3-months post-intervention explored if, and how the intervention impacted professionals' practice (level three). Fourteen sessions were delivered at oncology settings to 347 professionals between 2021 and 2023. Two hundred seventy four professionals completed the pre-test survey, with 239 completing the post-test survey. Fourteen professionals were interviewed between three-and 19-months post-intervention.

Results: Quantitative findings demonstrated a statistically significant improvement in self-efficacy post-educational intervention (p < 0.001). Qualitative data high-lighted professionals gained new approaches to progress end of life conversations with parents, despite some familial resistance to sharing the reality of the situation with children. Positive intervention content shaping clinical practice included the bereaved parent's lived experience, communication framework and roleplay videos. Some professionals considered a booster session and opportunities to practice conversations necessary to further consolidate learning into practice.

Conclusions: Evidence and theory-driven education can positively impact professionals' provision of family-centred cancer care. Future studies should explore the impact of this educational intervention on familial outcomes. Alongside a sustainable delivery of this intervention, advanced communication skills programmes should incorporate parent-child end of life conversations.

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#### KEYWORDS

cancer, children, educational intervention, end of life, family, family-centred care, healthcare professionals, Kirkpatrick Model of Evaluation, mixed methods, oncology, parents, social care professionals, support

#### INTRODUCTION

Families impacted by parental cancer often feel uncertain about how best to prepare children (<18 years) for the end of life experience.1 'End of life' is defined as the last 12 months of life.2 It is estimated that 26,900 parents die in the UK each year leaving behind 46,300 children,<sup>3</sup> and one-in-13 children in the United States experience the death of a parent before adulthood.<sup>4</sup> Sadly, many children are not prepared for the death of a parent when it is expected, 1,5 and are at greater risk of adverse outcomes in bereavement and later life.<sup>6</sup> This includes issues in maintaining and sustaining trusting relationships, a decline in education, and greater involvement with psychiatry.<sup>6,7</sup> Aligned to Family Resilience Theory,8 the benefits of honest communication at end of life are clear in maintaining and sustaining parent-child relationships, and mediating for adverse outcomes. 9,10

Health and social care professionals (professionals) are ideally placed to support parents at end of life regarding their children. 11,12 Consistently, professionals highlight a lack of knowledge, skills and confidence to provide this important aspect of familycentred cancer supportive care, necessitating a need for training. 11-14 A recent systematic review identified there is a dearth of evidence-based educational interventions available for professionals to equip them with the skills and strategies to support families at end of life. 15 Developing robust educational interventions that equip professionals with the skills, strategies and confidence on how best to support parents at end of life could lead to better mental and physical health outcomes for the whole family at end of life and bereavement. 15,16

#### 1.1 | Aims and objectives

The aim of this study was to deliver and evaluate a face-to-face, evidence-based, and theory-driven educational intervention to equip professionals to provide family-centred cancer supportive care when a parent with children (<18) is at end of life. The objectives are:

- 1. to determine if the intervention was relevant and improved professionals' knowledge about the support needs of families at end of
- 2. to determine if the intervention improved professionals' selfefficacy towards supporting parents at end of life,
- 3. to explore the perceived impact of the intervention on professionals' practice towards supporting parents at end of life.

#### **METHODS**

#### **Educational intervention**

The educational intervention was grounded in Social Cognitive Theory, with self-efficacy identified as the primary outcome. <sup>17</sup> Aligned to Bandura's Theory of Motivation, self-efficacy was considered the most appropriate outcome for the educational intervention. Selfefficacy, in addition to perceived confidence provides an understanding of a professional's beliefs and capacity to provide a certain aspect of clinical care and support. 18

The content for the two-hour face-to-face educational intervention was derived from the research team's empirical evidence on the impact of parental cancer at end of life. 1,11,16,19,20 The research findings are grounded in Family Resilience Theory, which highlights nine processes that can help families cope whilst navigating an adverse event, and promote psychological and emotional adaptation for the family.<sup>8</sup> These include: (1) normalising the adverse situation within the home, (2) maintaining connected to each other, (3) having opportunities to share emotions openly, and (4) clear communication within the home regarding the situation.8

Seven short co-produced educational videos were developed by the research team, alongside a creative learning educationalist, professional actors and a bereaved parent were integrated into the intervention. The educational videos ranged between 1 and 3 min, roleplaying good practice surrounding key end of life conversations. These included: (1) the importance of providing parents with honest information regarding the poor prognosis, (2) guidance on sharing the poor prognosis with the children, (3) planning for the future, (4) honest information that death is expected soon, and (5) preparing the parents and children for the dying experience. Two further videos provided (a) insight of parents struggling at home after receiving the news of the poor prognosis, and (b) glimpses of family life in the final weeks of life.

A step-by-step communication framework ('Talking, Telling, Sharing Framework: End of Life) was integrated within the educational intervention.<sup>21</sup> The framework provides professionals with: (1) prompts on how to open the conversation with parents regarding their readiness, beliefs and attitudes on sharing the poor prognosis with the children, and (2) guidance on how to equip parents about how and when to communicate with the children about the poor cancer prognosis.<sup>21</sup> During the intervention, a bereaved parent shared her lived-experience as a mum, wife and carer in the last year of life, entitled 'Walking in my Shoes'.

Between September 2021 and September 2023, the two authors of this paper, who are expert academic nurses in family-centred

cancer care facilitated fourteen, face-to-face, two-hour sessions across the five Health and Social Care Trusts in Northern Ireland, with 347 professionals participating. A gatekeeper was identified within each Health and Social Care Trust who helped to coordinate the session and share the one-page flyer to promote participation at least 8-weeks before the session. The flyer provided details on the purpose and learning outcomes of the session, as well as the time, date, location and contact details of how to register (email address of the appropriate gatekeeper). The flyer was widely shared with relevant professionals working in generalist and specialist roles across acute and community sectors of the Healthcare Trust.

#### 2.2 | Research design

Mixed-methods approach using Kirkpatrick's four levels of evaluation framework.<sup>22</sup> The Kirkpatrick Model of Evaluation was considered appropriate as it is a useful tool to evaluate the effectiveness of educational interventions.<sup>23</sup> For the purpose of this study, evaluation will focus on the first three levels: reaction, learning and behaviour. Quantitative pre-test, post-test surveys were conducted immediately before and after the intervention (levels one and two). Qualitative interviews were conducted at least 3-months post-intervention to explore the perceived impact of the intervention on professionals' practice (level three).

#### 2.3 | Participants

Of the 347 professionals that participated in the intervention, 274 completed the pre-test survey, with 239 completing the post-test survey. A total of 216 professionals completed both pre-test and post-test surveys.

A total of 14 professionals were interviewed between 3- and 19-months post-intervention (mAvg = 9 months).

#### 2.4 Data collection

#### 2.4.1 | Pre-test survey

Professionals were invited to take part in the study by scanning a QR code at the beginning of the session, which provided them with an information sheet on Qualtrics about the reasons why the study was being conducted, what their involvement would be, and relevant ethical considerations such as how data would be stored and used. Interested and willing professionals completed the consent form attached to the information sheet. Participants then selected a link to complete the survey on another Qualtrics file.

Participants completed a modified version of the SE-12 scale for measuring clinical communication skills on a Likert scale of 0 (very uncertain) to 10 (very certain) for 12 questions (see Supporting Information S1 for modified questionnaire).<sup>24</sup> The maximum

score was 120 which reflects high self-efficacy.<sup>24</sup> Appropriate demographic questions were included to capture details about the sample.

#### 2.4.2 | Post-test survey

Participants scanned another QR code to complete the post-test survey immediately after the intervention. This survey included the same modified version of the SE-12 scale as the pre-test survey.<sup>24</sup> Alongside this, participants completed single-item questions to evaluate the session's usefulness and relevance on a five-point Likert scale from 1 (strongly disagree) to five (strongly agree). Participants were invited to submit their email address in an unlinked part of the survey if they were interested in being contacted for further research opportunities related to the topic.

#### 2.4.3 | Qualitative interviews

A total of 142 email addresses were provided from participants who completed the post-test survey up until June 2023. These individuals were emailed at least 3-months post-intervention and were provided with a participant information sheet and consent form by the first author (JRH). Of note, 12 individuals replied stating they were no longer interested in being involved in the research study, thirty-four out-of-office replies were received with no further response, and nine replied stating they had no opportunity to put into practice the learning from the session.

Semi-structured interviews were conducted between March and October 2023. A topic guide was developed by the research team, guided by level three of Kirkpatrick's Model of evaluation (behaviour) and relevant literature (see Table 1). Interviews were completed when no further categories were identified within the data. Interviews were conducted on Microsoft Teams, audio-recorded and lasted between 18 and 57-min (mAvg = 31.1 min). Interviews were conducted by the first author (JRH) who had no prior relationships with the participants and has a wealth of experience in conducting sensitive interviews on cancer care at end of life.

#### TABLE 1 Semi-structured topic guide.

Key topics included:

- Explore professionals' motivations and reasons for taking part in a session.
- 2. Explore professionals' experience of taking part in a session.
- 3. Explore key components of the session with professions.
- 4. Explore what impact the session has had on professionals' practice.
- Explore obstacles (if applicable) to the provision of family-centred cancer care in practice, post-intervention.
- Explore what impact professionals perceive the session has/could have on health systems.
- 7. Explore professionals' perceptions of training needs.
- 8. Anything else relevant.

#### 2.5 | Data analysis

#### 2.5.1 | Quantitative data

Data was downloaded from Qualtrics to SPSS v.29 and analysed using descriptive and inferential statistics.

#### 2.5.2 | Qualitative data

Qualitative analysis was completed by both authors who are registered nurses and have a wealth of experience of analysing qualitative data. First, transcripts were taken from Microsoft Teams and verified by listening back to the audio-recording by the first author (JRH). Qualitative data were analysed using Braun and Clarke's reflexive thematic analysis framework.<sup>25</sup> To promote rigour, transparency and credibility of the data, the transcripts were independently read by the two authors (JRH + CJS), who made independent reflexive notes on each transcript.<sup>26</sup> Independent codes were also made on the transcripts by the first author (JRH) by marking similar phrases or words in the participants' narratives.<sup>27</sup> Also, JRH identified where the codes merged together into themes.<sup>25</sup> JRH + CJS subsequently met to discuss independent notes, alongside the codes and themes identified by JRH. Themes were verified and refined through critical discussion as a research team.<sup>25</sup>

#### 2.6 | Ethical considerations

Professionals were not coerced to take part in the study and were informed that non-participation would not impact on their ability to attend the educational session, or any relationship with the researchers or Healthcare Trust. Due to the emotive nature of the topic, a nominated professional was identified as a point of contact within each Trust for professionals to contact if they had any concerns post-intervention. A support pack was provided to participants who took part in the interview. Unique codes were used to match the pre-test and post-survey; participant's first initial and date of birth in format of ddmmyy. Participants who provided an email address were only contacted once to take part in an interview to respect possible wishes of non-participation. Transcripts were anonymised using pseudonyms. Although consent was only captured in the pre-test survey, 23 professionals only completed the posttest survey. Given that these individuals volunteered to complete the survey by scanning the QR, a decision was made by the research team to include their data evaluating the course usefulness and relevance. It was not appropriate to use their responses to the SE-12 scale, as there was no baseline data from the pre-test survey. Data protection procedures were observed, and assurances of confidentiality were given. Ethical approval was obtained from Ulster University's Research Ethics Committee for the

quantitative phase by CJS in 2021 (Ref: FCNUR-21-078), and the qualitative phase by JRH in 2023 (Ref: FCNUR-23-009).

#### 3 | RESULTS

Of the 274 professionals that completed the pre-test survey, this included registered nurses (n=171), medical professionals (n=23), social workers (n=10) and others (n=70). Full sample characteristics are provided in Table 2. Demographic questions were only asked in the pre-test survey. Consequently, it is unclear what the sample characteristics are of 23 participants that only completed the post-test survey.

#### 3.1 Level one: Reaction—Quantitative findings

In general, professionals perceived that the objectives of the training were clear (mean = 4.66; max = 5), the course content was relevant for their practice (mean = 4.58; max = 5), and was delivered at a suitable pace (mean = 4.67; max = 5). Participants considered the training will positively impact their practice (mean = 4.64; max = 5). Of the 239 participants that answered the question, 233 'agreed' or 'strongly agreed' that they would recommend the training to a colleague working in cancer care. See Table 3.

#### 3.2 | Level two: Learning—Quantitative findings

Professionals considered the workshop increased their knowledge (mean = 4.65; max = 5) and was detailed enough to meet their training needs (mean = 4.56; max = 5). Alongside this, participants considered that the 'Talking, Telling, Sharing Framework: End of Life' would be helpful for professionals to engage in conversations with parents with cancer to empower them to share their poor prognosis with the children (mean = 4.67; max = 5), and said they would use it in their practice (mean = 4.60; max = 5). See Table 3.

#### 3.2.1 | Measurement of self-efficacy

A total of 216 participants completed the SE-12 scale before and after the session, with no missing data. Prior to taking part in the educational intervention, participants reported a low mean score regarding their perceived self-efficacy to successfully communicate with parents concerning their children when they had incurable cancer (mean score = 45.68). After the session, participants mean score increased by 51.18 (see Table 4). One-way repeated measures ANOVA identified there were statistically significant improvements in participant's self-efficacy after the educational intervention in their certainty to successfully communicate with parents concerning

### **TABLE 2** Sample characteristics of participants who completed the pre-test survey.

U	impleted the pre-test survey.		
Professional role n			
	Registered nurse	171	
	Medical professional	23	
	Social worker	10	
	Physiotherapist	8	
	Cancer support worker	13	
	Complementary therapist	1	
	Counsellor	7	
	Healthcare assistant	3	
	Health and wellbeing manager	3	
	Improvement manager	2	
	Information and support	3	
	Cancer services manager	1	
	Chaplain	5	
	Occupational therapist	11	
	Palliative care facilitator	1	
	Pharmacist	2	
	Radiographer	3	
	Speech and language therapist	2	
	Student nurse	2	
	Midwife	1	
	Paramedic	2	
Υ	Years' experience caring for people with cancer		

Paramedic	2
Years' experience caring for people with cancer	
0-5 years	85
6-11 years	55
12-20 years	68
21+ years	38
Missing	28

Formal training on supporting parents with incurable cancer to communicate with and manage their children

Yes -	39
Type of formal training	
Advanced communication training ( $n = 12$ )	

CLIMB programme (n = 6)

Cancer charities (n = 8)

Bereavement charities (n = 3)

Postgraduate studies (n = 6)

Hospice (n = 4)

No	222
Missing	13

#### TABLE 2 (Continued)

Parent of dependent children (<18 years old)		
Yes	150	
No	122	
Missing	2	

their children when a parent is at end of life with cancer [F (1,215) = 2481, p = <0.001].

## 3.2.2 | Effect of previous formal training on self-efficacy

A total of 39 participants reported having previous formal training on supporting parents with incurable cancer to communicate with and manage their children. Two hundred and twenty two participants reported no formal training. At baseline, tests of between-subjects effects were statistically significant: F(1,203) = 9.734, p = 0.002). Pairwise comparisons identified a mark difference overall that those with previous formal training scored higher on self-efficacy (mean score = 78.78) compared to those without any training (mean score = 70.430) (see Table 5). However, while those with previous training reported a higher mean score of self-efficacy (mean score = 57.667) compared to those who did not report any previous training (43.837) at time one, both groups were similar after training (mean score = 97.023 and mean score = 99.909) (see Table 6).

There were no significant differences across professional job role in relation to scores of self-efficacy over time (p = 0.492), years' of clinical experience (p = 0.319), or having children (<18 years) living at home (p = 0.864).

#### 3.3 Level three: Behaviour—Qualitative findings

Of the 14 professionals interviewed, 13 were female. Participants were reflective of the five Health and Social Care Trusts in Northern Ireland, and included nurses (n=7), medical professionals (n=4) and professionals working in other clinical roles (n=3). See Table 7 for sample characteristics.

Findings are presented under two themes: (1) impact of the educational intervention on practice, and (2) how to consolidate family-centred end of life cancer care in practice.

## 3.3.1 | Theme one: Impact of the educational intervention on practice

Professionals felt they lacked the knowledge and self-efficacy on how and when best to provide meaningful support to parents at end of life

Question	Mean	Std. deviation
'The workshop objectives were clear' $(n = 239)$	4.66	0.82
'The workshop was delivered at a suitable pace' ( $n = 239$ )	4.67	0.78
'The course content was relevant to my practice' ( $n = 239$ )	4.58	0.84
'The course content increased my knowledge level' (n = 239)	4.65	0.77
'The course content will positively influence my practice' ( $n = 239$ )	4.64	0.76
'The course content was detailed enough to meet my training needs' ( $n = 239$ )	4.56	0.60
'I would recommend this training workshop to a colleague working on cancer care' $(n = 239)$	4.80	0.55
'The framework would be helpful for healthcare professionals to empower parents with cancer to share their poor prognosis with the children' $(n = 239)$	4.67	0.60
'I will use the framework provided in my practice when supporting parents with incurable cancer to share their poor prognosis with the children' ( $n = 239$ )	4.60	0.70

TABLE 4 Pre-test and post-test mean score of self-efficacy.

Survey	Mean	Std. error
Pre-test	45.68	1.16
Post-test	96.86	1.08

**TABLE 5** Pairwise comparisons on mean score of self-efficacy for professionals with previous formal training compared to professionals with no previous training.

Question: Have you had any formal training on supporting parents with incurable cancer to communicate with and manage their children?	Mean score of self-efficacy	Std. Error
Yes	78.8	2.45
No	70.4	1.07

**TABLE 6** Previous training pre and post-test scores of self-efficacy.

Question: Have you had any formal training on supporting parents with incurable cancer to communicate with and manage their children?	Pre-test mean score of self-efficacy	Post-test mean score of self-efficacy
Yes	57.67	99.91
No	43.84	97.02

regarding the children, often highlighting this as a key motivation to taking part in a session. Other key reasons to participating included perceptions of an increase in parents at end of life with dependent children within clinical caseloads, and the desire to 'want to get it right' for the whole family. Most professionals highlighted examples from their own clinical practice of caring for parents pre-intervention, often describing how parental resistance to telling the children the reality of the situation presented them with a moral dilemma

TABLE 7 Sample characteristics of 14 professionals interviewed.

	Professional role	Ν
	Clinical nurse specialist—Oncology (gynae, lung, skin, breast)	4
	Clinical nurse specialist—Palliative care	1
	Consultant—Oncology	3
	Consultant—Palliative care	1
	Improvement manager—Bereavement	1
	Health and wellbeing manager—Oncology	1
	Registered staff nurse—Oncology (ward based)	1
	Registered staff nurse—Oncology (community)	1
	Occupational therapist	1
	Location of professionals	
	Belfast Health and Social Care Trust	3
	Northern Health and Trust	2
	Southern Health and Social Care Trust	3
	South Eastern Health and Social Care Trust	1
	Western Health and Social Care Trust	5
	Gender	
	Female	13
	Male	1
	Years' experience of supporting people with cancer	
	0-5 years	1
	6-11 years	4
	12-20 years	6
	21+ years	3
- 6		

regarding what they (professionals) believed was best for the children. Other professionals reported they perceived their provision of supportive care to parents before taking part in the educational

7 of 11

intervention was 'adequate and done well'. On reflection, these professionals felt they 'overestimated' their knowledge and confidence to this important aspect of family-centred cancer care at end of life.

> I have worked in oncology for 17-years and to be honest I thought I was doing an alright job at this. But this was one of the most valuable courses I have attended. It was excellent. I do feel this past 5 years I have cared for more young parents than previous years and I feel more equipped in supporting young patients, families and children during this heart-breaking time.

> > [Oncology clinical nurse specialist]

Post-educational intervention, professionals emphasised their heightened awareness of the necessity of parents being provided with open and honest information regarding the reality of a poor prognosis. Professional highlighted how this was the 'building blocks' for other important conversations and decisions throughout the end of life experience for parents, and between parents and professionals. Some professionals reflected on how clinical situations could have been better navigated if they had this training earlier in their career.

> Maybe I was over-protecting, or I did not give the news as clear as I intended to, so the parent didn't get to make the preparations they needed to before it was too late. It's something I've thought about since, and I am consciously mindful of the language I am now using when delivering bad news.

> > [Oncology consultant]

One participant described a situation where they 'challenged' another professional regarding the provision of delivering a poor prognosis, and reflected this would not have happened before the session.

> I had a quiet word with Patrick [oncologist] before the appointment, and I gently challenged him in that the lady needed to know that her time is limited, so she can make the necessary preparations. I told him [oncologist] 'I'm happy to have further conversations with her, but you need to start that with an honest prognosis'.

> > [Oncology clinical nurse specialist]

Professionals felt they gained new approaches and tools from the educational intervention on how to progress supportive cancer conversations with parents considered as 'emotionally not ready' to tell the children the reality of the situation. Many participants stated that prior to the session they would have 'ended the conversation' if parents were resistant to telling the children. Other professionals highlighted how they often thought it was important for parents to tell the children, but would not have encouraged parents to do so.

I quickly learnt some parents may never get there and need gently encouraged.

[Occupational therapist]

Professionals felt they gained a sense of permission to 'nudge' conversations with parents about the importance of sharing the poor prognosis with the children. The 'Talking, Telling, Sharing Framework: End of Life' was considered helpful by professionals to provide a rationale and reassure parents that children: (1) will suspect something is wrong, (2) want to know what is happening, and (3) cope better in bereavement and later life when they are involved in the end of life experience. Alongside this, professionals often considered it helpful to reassure parents of the importance and protective nature of involving children in end of life conversations was evidencebased, rather than the professionals' personal beliefs.

> Now, I could be wrong, but I have noticed that framing it as 'I've been on a course and the research evidence tells us that children cope better' rather than 'I believe children cope better', parents seem to be less defensive and more open to exploring with me how to tell the children.

> > [Palliative care clinical nurse specialist]

Alongside this, the 'Talking, Telling, Sharing Framework: End of life' was viewed as helpful by professionals in providing them with structure and the language that is appropriate to equip parents, as they prepare to share the poor prognosis with their children. Some professionals reported returning to the framework 'to prepare themselves' prior to a clinical encounter with a patient of a parenting age who has a poor cancer prognosis. This was especially important for those clinicians who had fewer clinical interactions with parents in routine practice.

> Encouraging the use of the word 'cancer'-I wouldn't have done that before, but I now understand the rationale that children may get confused otherwise. [Palliative care consultant]

The educational video resources were considered by professionals as instrumental to understanding how important conversations at end of life could be embedded into routine practice. Professionals working in acute settings often highlighted how certain videos were useful to providing new insights of situations they often do not see as part of their practice, such as the parents struggling with the news of a poor prognosis at home, or the final weeks and days of life at home. While some professionals reported re-watching the videos to remind them of the content, other professionals shared the videos with colleagues who were unable to attend a session.

> It's been ten months, but the memory of those videos has stuck with me. I've watched them a few times since. In fact, I had a mum who was in the dying phase

a few weeks ago, and I re-watched that video just to remind myself of what it was I needed to tell dad. The videos are so impactful and poignant, and very reflective of what we are seeing in practice. They are so well done.

[Oncology clinical nurse specialist]

Overwhelmingly, professionals highlighted the importance of listening to the bereaved parent's story to 'bridging the gap' between the research findings and a real-life encounter. Alongside this, the bereaved parent's story was considered by participants as motivational to ensuring future families receive a better end of life experience.

> I mean, you can't argue with someone's lived experience. Lisa's story was so raw and yet so real. Lisa really had to pick up the pieces, and had to find out a lot of support for herself. And that's not right. I've no doubt there's plenty of parents out there like Lisa. Hearing the real-life example makes you want to change your practice and make things better for future parents. It highlighted to me just how important our role is as healthcare professionals. And we can do something about it.

> > [Oncology consultant]

#### 3.3.2 | Theme two: How to consolidate familycentred end of life cancer care in practice

Participants felt there was a need for all professionals to have access to evidence-based training on this aspect of family-centred care. Professionals considered this pertinent as they acknowledged supportive care for parents is required throughout the end of life experience. Based on professionals' experiences and perceptions of care provided, it seemed that some parents benefitted from repeated parent-child supportive care conversations, especially those who were resistant to telling the children. Often professionals highlighted the necessity for a 'whole systems approach' to supporting parents at end of life to promote consistency and continuity in care, and ensure the best possible outcome for the children. Some professionals clearly noted that team members who did not have the opportunity to attend a session would have benefited from the training.

> So many [professionals] are avoiding these conversations because do they do not know how to have them. I suppose you could say I feel brave now to have these conversations with parents. But everyone needs to have this training to really create change and impact for families.

> > [Oncology clinical nurse specialist]

There was a sense from some professionals that despite increasing their knowledge on how best to support families at end of life, there was a still a gap in their confidence to starting these important end of life conversations with parents. These participants felt they needed an opportunity to 'rehearse' some of the emotive conversations to promote their confidence in practice. Other professionals felt they would need a booster session to remind them of the content, especially if they have less frequent interactions with parents in their clinical role

> I do feel like I would need a booster session. It's now been 11-months since the training, and while I do remember a lot of it, am not seeing parents all the time. So, I'm not 'practising' these conversations enough. And you can forget it. I just feel like I need something to return to.

> > [Ward based registered staff nurse]

While professionals were positive about educational videos, some felt they would have benefited from learning from examples where conversations 'had gone wrong'. This included if parents did not respond well to the advice and guidance on telling the children about the poor prognosis, or if a child had 'acted out' to the news.

#### **DISCUSSION**

There was a statistically significant increase in professionals' perceived self-efficacy in supporting parents at end of life with cancer in the post-test survey. Professionals with previous formal training reported higher self-efficacy that those with no previous training in the pre-test survey. However, both groups reported similar scores in the post-test survey, suggesting that this intervention increased self-efficacy. It could be argued from the findings that those with previous training miscalculated their perceived selfefficacy in the pre-test survey, overestimating their ability by considering this aspect of care as done 'well' in practice. Coined as Dunning-Kruger effect, overestimation of one's ability in pre-test scores is a well reported phenomenon.<sup>28,29</sup> Supported by the qualitative findings, training can improve an individual's ability to enhance confidence, and aid recognition of a miscalculation of initial selfimpressions.<sup>28,30,31</sup> While there were a number of experienced professionals who took part in this face-to-face educational intervention, there were no differences in scores of self-efficacy across years' of total cancer care experience, or motivations for participation. Akin to other studies, effective communication skills and confidence in delivering this aspect of cancer care is not an inevitable by-product of clinical experience alone, but acquisition of confidence and knowledge through evidence-based training. 32,33

While findings highlight a clear need and benefit for evidencebased educational interventions to promote-family centred end of life cancer care in practice, a recent systematic review identified a dearth (n = 2) of existing interventions.<sup>15</sup> Unfortunately,

professionals often report a lack of training opportunities leads to a failing to engage in parent-child end of life discussions. 11,12,14 This places parents and children at risk of adverse psychosocial outcomes, to include an increased risk among children for psychotropic medication when not prepared for the death of a parent.<sup>6,7</sup> This lack of support from professionals is disconcerting, as it is well-established that honest and open communication between adults and children at end of life can promote a better end of life experience for the family and mediate for adverse outcomes in bereavement and later life. Alongside this, international policies highlight the necessity of professionals to provide patients with clear information regarding a poor prognosis and guidance on how best to navigate the end of life period with significant others. 34-36 Of note, these policies do not refer to professional support for significant others, such as the 'wellparent', despite the fact they are often leading significant conversations with the children alone at end of life. 16

There are no clear standards for appropriate measurement of clinician-patient communication training in cancer or end of life care. <sup>37–39</sup> A systematic review of educational interventions to promote professionals' end of life communication skills highlighted professionals' self-reporting of self-efficacy was predominately the primary outcome measured. <sup>40</sup> Literature highlights that the appropriate outcome should be: (1) closely aligned to the content of the communication skills intervention, and (2) measured using a validated scale. <sup>41,42</sup> Consequently, the SE-12 was considered as the most appropriate outcome measure for this study. <sup>24</sup>

Kirkpatrick's Model of Evaluation was a useful systematic approach for this study to measure learners': (1) reactions or perceived value of the educational intervention, (2) learning in perceived knowledge and self-efficacy, and (3) behaviour in their capability to apply learning with self-reported changes to their clinical practice. <sup>22,23</sup> To evaluate level four (results) of Kirkpatrick's Model of Evaluation, <sup>22</sup> it is necessary to explore the impact of the educational intervention from parent level data. It is the authors' intention in a further planned qualitative study to obtain parent-level outcomes, to include parents' perceptions of clinicians' communication and satisfaction with family-centred supportive cancer care at end of life. This is imperative to evaluate if an improvement in professionals' self-efficacy and cognitive understanding of beneficial communication behaviours positively impacts on supportive end of life care for parents. <sup>43</sup>

#### 4.1 | Clinical implications

To date there has been inadequate funding, lack of training, and insufficient clinical supervision to support family-centred end of life supportive conversations. 15,44 Aligned with international policy recommendations, there is a need to improve access to training (undergraduate and postgraduate) on how to initiate and deliver transparent, realistic and sensitive end of life discussions across professional disciplines. 34,45 Undergraduate and postgraduate curriculum programmes should continue to design their interventions according to current evidence and base them on a solid theoretical

framework.<sup>46</sup> Furthermore, to progress accessibility of educational interventions in this area, a self-directed eLearning resource would provide greater access to training on a global scale, be cost-effective and available on-demand for professionals when faced with clinical situations of a parent who is at end of life with cancer.<sup>47,48</sup> eLearning has the potential to promote the reach and significance of this education, promoting equitable end of life care and support on a global scale. Within these educational interventions, discussion of death and dying should be destigmatised and normalised.<sup>49</sup>

End of life communication when a parent is dying is often a high learning priority amongst professionals, who continue to have discomfort in facilitating end of life discussions, fearing worsening an emotionally fraught situation. <sup>11,14,50</sup> There is an evident need for this aspect of training to be integrated within advanced communication skills training, so that these important conversations are not 'too little, too late, and not great'. <sup>51</sup> Such a reform in accessible education has the potential to improve professionals' confidence in the provision of family-centred cancer care at end of life and promote patent-child communication. <sup>11</sup> This could also help professionals stave off compassion fatigue and burnout, improving their perceptions of a clinical role as rewarding and meaningful. <sup>52-54</sup>

#### 4.2 | Strengths and limitations of the study

A rigorous approach was taken to developing the content of the educational intervention, alongside data collection and analysis processes. There was significant PPI representation in this study, to include a bereaved parent who shared their personal experience during the educational intervention. There is a need to collect demographic survey data in both pre-and-post-test surveys to have a comprehensive understanding of the participants involved in all aspects of the study. It is important to note the potential methodological limitation of the uncontrolled pre-test, post-test designs, which may overestimate effects due to concurrent co-interventions and maturation effects.<sup>54</sup> Longitudinal data of the quantitative findings may have provided more balanced scores of self-efficacy overtime. Although there were only 14 professionals recruited to the qualitative study, the authors have presented and reflected the data within the broader literature. Alongside this, directions for future research have been outlined to further understand the impact of the educational intervention on familial experiences at end of life.

#### 4.3 | Conclusion

Evidence and theory-driven education can positively impact professionals' provision of family-centred end of life cancer care. Given the clear need to improve access to such training, ardent efforts are required to improve educational opportunities. This should include a more sustainable delivery format of this educational intervention and incorporating it within advanced communication skills programmes. Upskilling professionals on family-centred supportive care has the

potential to promote a better end of life experience for the family and mediate for adverse outcomes in bereavement and later life.

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#### CONFLICT OF INTEREST STATEMENT

The authors declare that they have no conflicts of interest.

#### DATA AVAILABILITY STATEMENT

The data that supports the findings of this study are available at the Ulster University Repository and available on request from the first author. The data are not publicly available due to privacy and ethical restrictions. The study passed ethical committee review [FCNUR-21-078 and FCNUR-23-0091.

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#### SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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