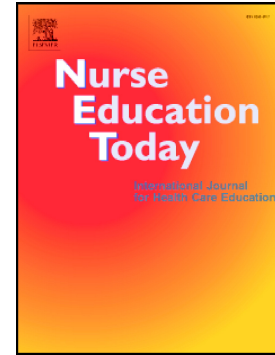


Educational needs and preferred learning approaches of the PAEDIATRIC palliative care workforce: A qualitative exploratory study

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EDUCATIONAL NEEDS AND PREFERRED LEARNING APPROACHES OF THE PAEDIATRIC PALLIATIVE CARE WORKFORCE: A QUALITATIVE EXPLORATORY STUDY

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Declaration of conflicts of interest

The Authors declare that there is no conflict of interest with respect to the research, authorship and/or publication of this article.

Ethical Approval

This study was carried out in accordance with The Code of Ethics of the World Medical Association (Declaration of Helsinki) for experiments involving humans. Ethical approval to undertake this work was secured from Edinburgh Napier University's School of Health and Social Care Research Ethics Committee (SHSC3/FHLSS 2017-18). Participants gave written informed consent prior to taking part in the focus groups.

INTRODUCTION AND BACKGROUND

Palliative care for children¹ with life shortening conditions (LSCs) refers to *“an active and total approach to care, from the point of diagnosis or recognition, throughout the child’s life and death. It embraces physical, emotional, social, and spiritual elements, and focuses on enhancement of quality of life for the child and support for the family.”* (Chambers 2018, p.9) The number of children with LSCs is growing with the latest evidence estimating that worldwide there are over 21 million children with conditions that would benefit from palliative care input and more than eight million children with a requirement for specialised palliative care (Connor et al., 2017). In addition to an increase in numbers, the complexity of care required by these children continues to progress and is often required over prolonged periods.

Children’s palliative care is no longer considered solely as a speciality area but rather becoming ‘everyone’s business’ as children with palliative care requirements access a wide range of services and are supported by a diverse workforce within health, social care, education and the voluntary sector (Chambers 2018). There is international acknowledgement that education in this area is essential to ensure the workforce is competent, capable and equipped with appropriate knowledge, skills and attitudes to provide high quality and effective palliative care to children and their families (Liben et al., 2008; Gamondi et al., 2013; Downing et al., 2014). Moreover, embedding education in undergraduate and postgraduate nursing and medical curricula and clinical practice to enable improvements in children’s palliative care is a documented priority (Liben et al. 2008; Gamondi et al. 2013). The existing evidence base, however, indicates there are continuing challenges in addressing educational requirements for those delivering palliative care (Liben et al., 2008; Gillan et al. 2014; Downing et al. 2014). Documented challenges in providing palliative care education include, but are not limited to, how to best teach the values, beliefs and ethics associated with children’s palliative

¹ The term children’s palliative care is used throughout this paper with the understanding that it is inclusive of neonates, infants, children and young people.

care, a lack of recognition or accreditation of courses, limited individuals with experience to teach courses, a requirement for development of interdisciplinary thinking and collaboration, and a need for the transfer of theory learning to practice situations (Downing et al. 2014). Moreover, the infrequency in which some professionals are exposed to children with palliative care needs can pose a challenge to education as there is a lack of sufficient opportunity or incentive for all professionals to seek further training and education in palliative care.

Moving forward, it is important to acknowledge the inherent challenges and complexities associated with children's palliative care and identify innovative and effective approaches to meet the learning needs of the current and future workforce both within the UK and beyond. In order to achieve this, further evidence surrounding the specific learning needs of this workforce would be of value to inform the development of targeted education strategies. The current study set out to address this gap in the evidence by exploring the educational needs and preferred learning approaches of professionals responsible for delivering palliative care to children in Scotland.

RESEARCH QUESTION

What are the learning and development needs of nurses, doctors and the wider interdisciplinary team responsible for delivering palliative care to children and which educational approaches would they find most effective to address these needs?

METHODS

Employing a qualitative exploratory design, the perspectives and experiences of education in palliative care and perceived learning and development requirements of those providing children's palliative care across a range of settings and services were explored through focus group discussions.

Sample

Acknowledging the importance of an integrated and collaborative approach to delivering children's palliative care across Scotland, purposive sampling was employed to achieve a balanced sample of professionals responsible for supporting children with palliative care needs. The aim was to ensure representation from a range of staff groupings who could each share their unique perspectives on education and learning related to children's palliative care. It was important to recruit individuals working in a variety of care settings including hospitals, children's hospices and in the community as well as ensuring those with different levels of experience were included with a balance of junior and more experienced staff.

Diana Children's Nurses (DCNs) work alongside a range of services to provide clinical leadership and support in the planning and delivery of children's palliative care and were ideally placed to inform the recruitment process. There are three DCNs currently in Scotland, one covering the north of the country, one in the east and one in the west. The DCNs played a valuable role in generating key informant lists for their area and the plan was to conduct a focus group in each of the north, east and west of the country. However, given the large and expansive geographical area of the north, two separate focus groups were arranged for this area. A lead representative for each of the two children's hospices in Scotland was responsible for identifying potential participants to include representation from a selection of the various volunteer and staff groupings within the hospice. This resulted in a total of six planned focus group discussions.

Initial contact with potential participants was made through an email invitation which introduced the purpose of the project and provided detailed information. Following consideration of this information, potential participants were asked to return an 'Agreement to Participate' form to the project team should they wish to take part. The project team then made contact with participants to provide them with details on the date, time and venue for the focus groups. Figure 1 illustrates the recruitment and retention process for the focus groups.

Data Collection

Focus groups were facilitated by a member of the project team and a second member recorded field notes. Ground rules for the session, including issues of confidentiality, anonymity and sensitivity, were discussed and each participant was required to sign a consent form prior to the discussions commencing.

Participants were asked to consider their past education and learning experiences, perceived unmet learning needs, and educational initiatives which would support them in caring for children with palliative care needs and their families. The discussion was guided by broad topics (table I) which emerged after the authors undertook a scoping review of the current evidence base surrounding education in children's palliative care. Competent and experienced facilitation allowed for an in-depth exploration of the participants' experiences and perspectives on education and encouraged discussion and debate.

Analysis

Focus groups were digitally recorded, transcribed verbatim and the transcripts uploaded into the data management software, QSR NVivo 11 (QSR International Pty Ltd., Victoria, Australia).

Qualitative thematic analysis was undertaken using Braun and Clarke's (2006) six phase approach which involved a systematic process of familiarisation with the focus group transcripts and field notes, generating initial codes from the data, searching for themes, reviewing, defining and naming themes, finalising the analysis and writing the report. Two members of the research team independently conducted the initial analysis to identify emerging themes and topics. The researchers reviewed the final themes in collaboration to allow for consensus to be reached in the thematic mapping of the data, thus enhancing rigour and trustworthiness.

Ethical Considerations

Ethics approval was granted by the School of Health and Social Care Research Integrity Committee, Edinburgh Napier University. Written consent was obtained from participants prior to undertaking the focus groups and return of the completed anonymous survey implied consent.

RESULTS

Six focus groups were conducted during March and April 2018 with a total of 61 participants.

Representation from a wide range of services and care providers including acute and community health services, children's hospices, the voluntary sector, social care and education was achieved (table II). Focus groups ranged from four to 14 participants in size and discussions lasted a minimum of 66 minutes and a maximum of 110 minutes.

The focus groups yielded very productive and engaging discussions. A strong sense of enthusiasm for and commitment to the topic of education, learning and continuing professional development was evident across participants regardless of role. Following thematic analysis of the focus group transcripts (n=6), the data was categorised into four principal themes: learning and support needs, preferred learning approaches, challenges in paediatric palliative care education, and building capacity and capability for paediatric palliative care through education.

Learning and support needs

The perceived learning and support needs identified by participants could be grouped into eight sub-themes: advance care planning, provision of end of life care and bereavement support, complex symptom management, self-care, spirituality, faith and culturally sensitive care, ethics and ethical decision making, communication skills, and managing parental expectations. Table III provides exemplary quotes for each sub-theme. Learning and support needs were comparable for all participants regardless of the setting in which they worked. The data indicated that not only do specialist palliative care staff have unmet learning needs, but generalist staff and those working in supportive and volunteer roles share similar learning needs.

The emotional impact of caring for children and families and the resultant importance of self-care was a prominent theme that resulted in extensive discussion during the focus groups. Whilst a number of support measures are in place, including but not limited to, clinical supervision, debriefing and resilience building, there was concern amongst participants that access to support measures is not consistent across all settings. Moreover, anyone in contact with children and families with palliative care needs would benefit from self-care including support staff and volunteers.

Preferred learning approaches

Participants identified a range of learning approaches with the five most preferred methods being experiential learning, simulated practice, technology enhanced learning, inter-disciplinary learning and learning from the stories and experiences of children and families.

Participants valued experiential learning or learning in practice through exposure to different clinical situations more than traditional classroom-based learning. It is through learning in practice and importantly sharing that learning with colleagues that can help develop and nurture expertise:

'I'm just looking back on what I have in my own head about learning, where I learned palliative care...it's on the job and whether you've had one case where you learned a lot from or 20 cases, but the focus is about sharing those experiences and when you're going through, say, a terminal phase of a child's illness, it's actually learning from your peers as well who've got that experience.' (Focus

Group 2; Participant 2)

'It's the opportunity to practice I think as well isn't it that makes a huge difference. You can talk and talk about it but it's doing it isn't it.' (Focus Group 4; Participant 6)

Participants placed an emphasis on the value of learning from families' experiences and suggested ways to achieve this. The family's story needs to be captured and shared in a learning environment.

Where participants had experiences of reflecting on and learning from a family's story, this was suggested to be a powerful and effective approach:

'This is the most powerful thing...getting a family's personal story about what they've been through and then reflecting on it.' (Focus Group 2; Participant 8)

Participants also recognised the importance of ensuring the child's voice is heard:

'I think we're all saying parents, but we need to listen to children as well because they have a lot to tell us and we need to listen to what they say.' (Focus Group 5; Participant 2)

The merit of interdisciplinary learning was clearly articulated. Participants valued the opportunity to 'learn together' with colleagues across disciplines, suggesting this is embedded within education alongside discipline-specific learning.

Challenges in paediatric palliative care education

Participants reported palliative and end of life care to be both complex and challenging. Many children present with rare and complex LSCs which require very specific, specialised and individualised care. Moreover, the rarity of the conditions means there are often significant lapses in time before caring for another child with the same or similar condition and thus an attrition in certain skills. Children's hospice staff noted that this rarity of LSCs and complexity of care poses ongoing and changing learning requirements:

'It changes here every day...we can have six different children on two different days with different needs and so we have different educational needs, it's quite hard. It's not standardised education for us, it jumps about.' (Focus Group 1; Participant 10)

Similarly, nurses and doctors working in acute hospitals commented on the limited exposure they have to children with palliative care needs. This results in them either not seeing the relevance of education because that won't need to apply the learning to their regular practice or in the cases where they do undertake learning related to palliative care, the infrequency in which they actually

provide palliative and end of life care to children means they have difficulty in maintaining the relevant knowledge and skills:

'If you're not regularly using those skills how do you maintain them, and that is the tricky part. I think the more exposure you get to it, to providing palliative care wherever that may be, you retain it and you learn from that and you progress, but if you're not being exposed to it regularly how do you maintain the clinical side of things? And again, every time you're faced with it it's different. So, I don't know how you would?' (Focus Group 2, Participant 4)

Participants recognised paediatric palliative care as being a relatively small, yet distinct field with limited opportunities for learning and continuing professional development. A number of recommendations were put forward to encourage individuals working in palliative care together to share learning and best practice. These included secondment opportunities, shadowing palliative care experts in different practice settings, and utilising technology to encourage learning and develop communities of practice.

Building capacity and capability for paediatric palliative care through education

The ability for education to build capacity and capability was clearly identified by participants who articulated a need for the principles and philosophy of paediatric palliative care to be embedded in undergraduate education for all health and social care professions. Other initiatives included integrated palliative care education through joint posts, rotations and exchanges between children's hospices, hospitals and community services:

'But there's an opportunity to work together. How do we retain people? We create posts where you're not stuck in the one place. You can do six months in a children's hospice, you can then come to ITU, you can then be part of the community team and we build skills and people will find places they want to work. It should be something that there's succession, that there's new people moving through, and a rotational post would really help with that.' (Focus Group 3; Participant 4)

Within the focus group attended by children's hospice staff and volunteers, participants acknowledged organisation has a role to play in education and where possible should be supporting others to learn. This offers potential benefits in terms of succession planning and building future capacity. There was also some discussion around the need for greater education of the wider health and social care workforce in order to enhance children's palliative care as described in the following quote:

'In children's hospices we wouldn't see palliative care just being for end of life. We see it as a journey over a number of years, whereas sometimes hospital staff will say 'oh they're not at end of life yet so they don't need palliative care' and so sometimes the terminology and the common understanding of what it means can be a barrier as well.' (Focus Group 1; Participant 8)

This perception of palliative care equating to end of life care also resonated within the focus groups attended by those external to children's hospices. Participants recognised the need to ensure that all care providers who come into contact with children with palliative care needs, regardless of role or discipline, have a basic education and understanding of palliative care. The terminology used around palliative care was identified as challenge and suggestions to 'rebrand' palliative care with an alternative term such as 'supportive care':

'Partly I think it's a branding thing. I mean as soon as you say the word palliative then people assume that means end of life care and going somewhere to die. Say the words palliative care and that's what everyone jumps to, as opposed to symptom relief and optimisation of quality of life that is not location specific.' (Focus Group 4; Participant 7)

DISCUSSION

The underlying importance of education in enhancing the quality of care delivered to children with palliative care needs, from the perspective of those working in the field, was compelling. Moving forward, educational initiatives should be targeted at all individuals who have contact with children

and families with palliative care needs, including those working in support roles and volunteers (Swinney et al., 2007; Gamondi et al. 2013; Chambers 2018). The level and scope of education should be dependent on an individual's role and responsibilities (Downing et al., 2014).

A number of unmet learning needs were identified and may inform future learning in paediatric palliative care. Whilst existing evidence highlights similar learning needs amongst palliative care providers in a number of countries, particularly symptom management (Amery & Lapwood, 2004; Amery et al., 2010; Peng et al., 2013; Quinn & Hillis, 2015; Lee et al., 2016), planning end of life care (McCabe et al., 2008; Botwinski, 2010; Gallagher et al., 2012; Quinn & Hillis 2015), communication skills (Amery & Lapwood, 2004; Amery et al., 2010; Botwinski, 2010; Peng et al., 2013; Quinn & Hillis, 2015; Lee et al., 2016) and ethical decision making (Gallagher et al., 2012; Peng et al., 2013; Lee et al., 2016), the studies focused largely on single disciplines of which hospital doctors and nurses were predominant. The current study makes a valuable addition to the evidence base as it includes perspectives from the wide range of disciplines contributing to an integrated approach to delivering paediatric palliative care. Moreover, there was consensus amongst these diverse disciplines in terms of the priority areas for future education.

A recurrent theme running through the focus group discussions was the essential requirement for self-care. The emotional impact of working within the field of palliative care was acknowledged and the need for an educational framework for self-care where individuals can discuss, reflect and learn from their experiences in practice was clear. There is growing evidence surrounding the need for self-care and personal coping strategies within paediatric palliative care (Amery & Lapwood, 2004; Browning et al., 2006; Swinney et al., 2007; Downing et al., 2013; Taylor & Aldridge, 2017). In order to best support individuals in their capacity to provide quality and compassionate palliative care, self-care needs should be included as part of a well-rounded curriculum. Through evidence based educational approaches, the concepts of self-care, self-awareness and resilience can be explored to aid the paediatric palliative care workforce in managing the emotional dimension of their roles.

Preferred learning approaches were also consistent amongst our participants. The merit of 'learning on the job' was emphasised and favoured over more traditional 'classroom' learning. Our findings advocate that where possible, paediatric palliative care should be integrated into everyday practice.

This would allow for maximising opportunities for learning as they arise, an important tactic as exposure to different aspects of paediatric palliative care can be sporadic in many settings.

Embedding education into practice was considered to be a valuable learning approach in a number of papers (Sahler et al., 2000; Baker et al., 2007; Liben et al., 2008; Mancini et al., 2013). Sahler and colleagues (2000) emphasise the importance of taking advantages of 'teachable moments' which include those spontaneous opportunities that arise in day to day care of patients. Experiential learning is an effective way of individuals being able to learn and see palliative care 'in action' through exposure to the clinical situation and role modelling and thus should form an essential part of any training programme (Downing et al., 2013).

Our participants support an inter-disciplinary approach to learning. Within the field of paediatric palliative care, there is value in engaging in inter-disciplinary education as this is reflective of the way care is delivered to children and families. There is evidence to support the implementation of inter-professional approaches to paediatric palliative care education (Browning & Solomon, 2005; Solomon et al., 2010; Wager et al., 2013; Nicholl et al., 2016). Whilst there will be aspects of the curriculum specific to certain professions or groups, much of the core knowledge, skills and attitudes can, and should where opportunity allows, be taught to an inter-disciplinary group (Downing et al., 2013). As noted in the literature, and articulated by our participants, it is important to maintain a balance. Inter-disciplinary education is beneficial, but it is equally important to have education within disciplines to ensure the distinct needs of each group is addressed.

As advocated in a number of international studies (Browning & Solomon, 2006; McNeilly et al., 2008; Schiffman et al., 2008; Solomon et al., 2010; Carter & Swan, 2012; Adams et al., 2013; Spalding & Yardley, 2016; Snaman et al., 2017), our participants recommend involving children and families in

the education process by learning from their stories and experiences. Browning and Solomon (2006) support what they have termed 'relational learning across boundaries' where education is grounded within the context of relationships between children, families and practitioners. They encourage the involvement of children and families in education and prioritise those approaches to learning that ensure the voice of the child and family is heard.

This study has both strengths and limitations. It was conducted in one European country thus it may be argued that generalisability of the results is somewhat limited. However, findings with respect to perceived learning needs and preferred learning approaches corroborate strongly with the wider international evidence base on children's palliative care education. The project team are confident that data saturation was reached within the focus groups. Whilst efforts were made to ensure a diverse sample with differing experience levels, geographical location of practice and range of settings or services, they cannot represent the entire palliative workforce, and this is acknowledged.

Findings from this study add further evidence to the requirement for children's palliative care education to ensure the current and future workforce are prepared to meet the complex and ever-changing care needs of children with LSCs. A significant opportunity exists to implement the preferred approaches to learning identified in this study and the wider evidence base after which the impact of these approaches should be measured through well-designed research.

CONCLUSION

Those responsible for the care of children with LSCs require education and support in palliative care regardless of the discipline or setting within they work in. This study has generated further evidence on educational needs and preferred learning approaches from the perspective of a wide range of generalist and specialist palliative care providers working across different settings. Self-care must be included within palliative care education to enable individuals to identify their specific emotional support needs and ensure they have measures in place to respond to them. The findings from this study indicate opportunity for development of collaborative initiatives which promote a consistent

and standardised approach to addressing educational needs of all those who come into contact with children with palliative care needs.

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Table 1. Summary of broad areas for discussion during focus groups.

Experience of education in paediatric palliative care <ul style="list-style-type: none">• Past educational experiences• What works well and what doesn't
Perceived learning and development needs <ul style="list-style-type: none">• What are the priority areas/topics for education and why are they important• Gaps in education and training in paediatric palliative care
Preferred learning methods or approaches <ul style="list-style-type: none">• What works well and what doesn't
Ideas about the future <ul style="list-style-type: none">• Ways to influence paediatric palliative care through education• Ways to build capacity and a future workforce in paediatric palliative care

Table II. Focus group participant roles ($n=61$)

Job Role	Number of Participants (<i>n</i>)
Nursing	19
Medicine	6
Social Work	4
Children's hospice staff	24
Representative from Charity Organisation*	4
Educator	4

*Charity organisations were associated with palliative, end of life and/or bereavement care

Table III. Learning and support needs

Learning and support needs	Participant Quotes
Advance care planning (ACP)	<i>'How we initiate discussions with families about their wishes and ensure these are clearly documented in ACP documents.'</i> (Focus Group 6; Participant 4)
Provision of end of life care and bereavement support	<p><i>'We need to learn more about end of life...We don't see end of life situations as often as you might think.'</i> (Focus Group 2; Participant 5)</p> <p><i>'There is little focus on bereavement support which can be difficult to pick up on the job. It would be better to have some underpinning knowledge first then gain experience and confidence in providing this to ensure we are offering the best possible service.'</i> (Focus Group 3; Participant 11)</p>
Complex symptom management	<i>'A common area that we hear people asking for education or learning is about symptom control, for example, the common symptoms in palliative or end of life care.'</i> (Focus Group 3; Participant 9)
Self-care and support needs	<p><i>'I think staff struggle with accepting that they're struggling with things and I think that's an inbred thing that as nurses we're fine. We're fine, we're fine, we're fine....but actually what I've seen is more and more staff coming to me and telling me that they're not fine, and that's a big change.'</i> (Focus Group 6; Participant 1)</p> <p><i>'I think that's [self-care] big at the moment. One of our members of staff actually left because of an experience in end of life care and we supported her the best we could, however, she couldn't go through that again.'</i> (Focus Group 1; Participant 7)</p>
Spirituality, faith and culturally sensitive care	<i>'There needs to be some education around listening to family's needs even if it is against your cultural beliefs about death...We need to have an awareness of death and dying practices to support families.'</i> (Focus Group 1; Participant 3)
Ethics and ethical decision making	<i>'I think what makes that [communication] even more important is the culture that we're all working in today...really, really tricky ethical situations that I don't</i>

	<i>think we're equipped for. Part of that is about these difficult conversations and about being honest about what we can and can't provide or what we will or won't do. We all need to be more knowledgeable, more proactive, more upskilled.'</i> (Focus Group 4; Participant 9)
Communication skills	<p><i>'Communication has to be an absolute key part of any training at all different levels because often that's where it falls down, and you don't have to facilitate a difficult discussion but you just have to know how to listen to that family and then seek appropriate advice or speak to the person who will be responsible for facilitating that discussion. So communication has to be in there.'</i> (Focus Group 1; Participant 6)</p> <p><i>'I think there needs to be communication for all staff. We need to get communication right because that is the crux of what we do.'</i> (Focus Group 5; Participant 5)</p>
Managing parental expectations	<i>'And I think a lot, we probably all need it, a lot of guidance about parental expectations. So I've seen lots in the papers recently about parents' expectations about their babies and what we should be doing and I think that's going to become more and more, you know, even in oncology we have parents pushing for any type of treatment that might be available...that might prolong life for a bit and I think that is really hard for all teams to deal with...and I think from a palliative care perspective if we're thinking about training, I think we need a lot about how to manage parents' expectations.'</i> (Focus Group 3; Participant 10)

Table IV. Learning and support needs

Learning and support needs	Participant Quotes
Advance care planning	<i>'Advance care planning (ACP)....knowing when to introduce an ACP and how.'</i> (Survey participant)
Provision of end of life care and bereavement support	<p><i>'We need to learn more about end of life... We don't see end of life situations as often as you might think.'</i> (Focus group participant)</p> <p><i>'There is little focus on bereavement support which can be difficult to pick up on the job. It would be better to have some underpinning knowledge first then gain experience and confidence in providing this to ensure we are offering the best possible service.'</i> (Focus group participant)</p>
Complex symptom management	<p><i>'Symptom support...to cater for the physical needs of the child, such as pain relief.'</i> (Survey participant)</p> <p><i>'A common area that we hear people asking for education or learning is about symptom control, for example, the common symptoms in palliative or end of life care.'</i> (Focus group participant)</p>
Self-care and support needs of staff and volunteers	<p><i>'I think staff struggle with accepting that they're struggling with things and I think that's an inbred thing that as nurses we're fine. We're fine, we're fine, we're fine....but actually what I've seen is more and more staff coming to me and telling me that they're not fine, and that's a big change.'</i> (Focus group participant)</p> <p><i>'I think that's [self-care] big at the moment. One of our members of staff actually left because of an experience in end of life care and we supported her the best we could, however, she couldn't go through that again.'</i> (Focus group participant)</p>
Spirituality, faith and culturally sensitive care	<i>'There needs to be some education around listening to family's needs even if it is against your cultural beliefs about death... We need to have an awareness of death and dying practices to support families.'</i> (Focus group participant)
Ethics and ethical decision making	<i>'I think what makes that [communication] even more important is the culture that we're all working in today...really, really tricky ethical situations that I don't think we're equipped for. Part of that is about these difficult conversations and about being honest about what we can and can't provide or what we will or won't</i>

	<p><i>do. We all need to be more knowledgeable, more proactive, more upskilled.'</i> (Focus group participant)</p> <p><i>'Ethics...how do you practically manage difficult ethical situations which I think are only going to increase.'</i> (Survey participant)</p>
Communication skills	<p><i>'Communication has to be an absolute key part of any training at all different levels because often that's where it falls down, and you don't have to facilitate a difficult discussion but you just have to know how to listen to that family and then seek appropriate advice or speak to the person who will be responsible for facilitating that discussion. So communication has to be in there.'</i> (Focus group participant)</p> <p><i>'Managing difficult conversations as communications are key to providing good care.'</i> (Survey participant)</p> <p><i>'I think there needs to be communication for all staff. We need to get communication right because that is the crux of what we do.'</i> (Focus group participant)</p>
Managing parental expectations	<p><i>'And I think a lot, we probably all need it, a lot of guidance about parental expectations. So I've seen lots in the papers recently about parents' expectations about their babies and what we should be doing and I think that's going to become more and more, you know, even in oncology we have parents pushing for any type of treatment that might be available...that might prolong life for a bit and I think that is really hard for all teams to deal with...and I think from a palliative care perspective if we're thinking about training, I think we need a lot about how to manage parents' expectations.'</i> (Focus group participant)</p>

Figure I. Flowchart outlining recruitment process for focus groups.

Author Contribution Statement

There were two main investigators and subsequent authors. Both contributed to the conception and design and subsequently conducted the study. CM led the data analysis and DM contributed to the analysis. CM prepared the draft manuscript and DM critically reviewed each version. Both authors approved the final version of the manuscript prior to submission.

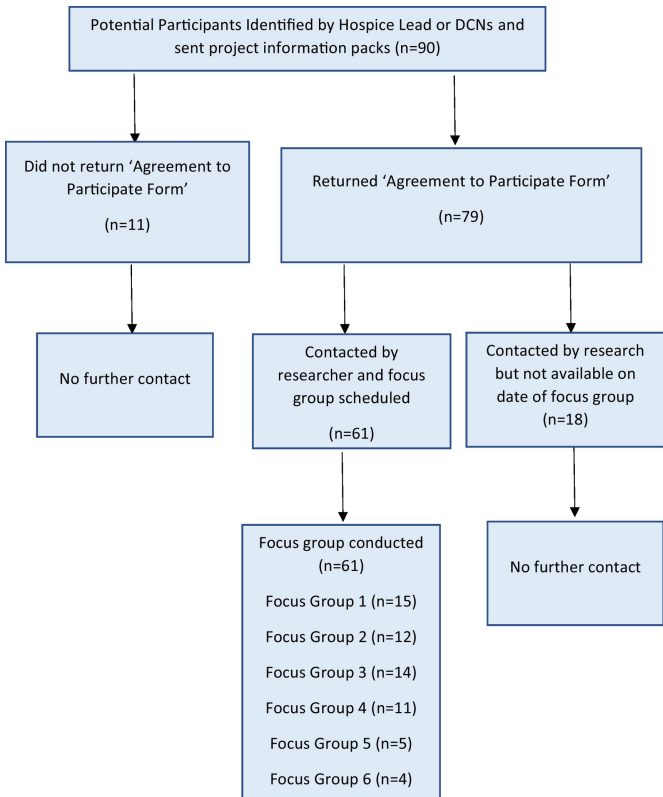


Figure 1