

School of Health and Social Care

Scoping exercise to inform the development of an education strategy for Children's Hospices Across Scotland (CHAS)



Children's Hospices Across Scotland



Acknowledgements

The project team would like to thank all those who participated, either through attending a focus group discussion or completing the online survey. The commitment and enthusiasm of these individuals to improving education, learning and development in the field of children's palliative care was clearly evident across a range of disciplines and regions.

We also wish to thank members of the Project Steering Group for their expert guidance throughout the study. Their time, contributions and invaluable comments were much appreciated by the project team.

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Executive Summary

Background

Children's palliative care¹ continues to grow as a speciality in Scotland with sustained increases in the prevalence and complexity of life-limiting conditions. Education is an integral component of children's palliative care to ensure the workforce is capable and equipped with the required knowledge, skills and attitudes to deliver high quality and effective care. Policy makers and professional bodies recognise the need for and support educational initiatives within children's palliative care (Scottish Children and Young People's Executive (SCYPPEX) 2012; Scottish Government 2015; NES/SSSC 2017). This report presents findings from a scoping project examining current evidence relating to the provision of education across the United Kingdom (UK) and internationally. The overall aim of the project was to inform the development of an evidence based and research-informed education strategy for Children's Hospices Across Scotland (CHAS).

The objectives of the project were:

1. To review the literature and evidence base pertaining to policy, practice and research in children's palliative care education.
2. To identify the current and future education, learning and continuing professional development requirements of practitioners, volunteers and professionals working across the field of children's palliative care in Scotland.
3. To provide recommendations for and contribute to the development of an evidence-based education strategy for CHAS which can inform the future service agenda and influence the delivery of a national approach to children's palliative care education, learning and continuing professional development.

Methods

Three phases of activity were undertaken to meet the above objectives. Phase 1 consisted of a scoping review of the evidence base to provide a comprehensive overview of relevant research, policy and practice pertaining to children's palliative care education. Using a qualitative exploratory design, Phase 2 was comprised of focus group discussions and an online survey to identify the learning and development needs of hospice staff, volunteers and professionals from health, social care, education and early years services with links to children's palliative care. In Phase 3, findings from the literature review, focus groups and

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

survey were reviewed and synthesised to propose a set of recommendations which would form the basis of an education strategy for CHAS.

Key Findings and Recommendations

A scoping review of 85 papers and 35 items of grey literature was undertaken. Engagement with 79 stakeholders through focus groups (n=61) and completion of an online survey (n=18) was also completed. These stakeholders represented a wide range of services and care providers including the NHS (acute and community), children's hospices, the voluntary sector, social care and education services.

The themes identified during review of the literature were consistent with those originating from engagement with the children's palliative care workforce in Scotland. Education, learning and development are core to developing and maintaining a workforce capable of delivering the best possible care to children with palliative care needs and their families. The findings emanating from this project contribute to the evidence base surrounding the requirement for further development of educational initiatives to enhance capacity and capability of the workforce. Moreover, they provide a strong and focused argument for the development of a comprehensive and inclusive education strategy within CHAS.

The resultant recommendations are as follows:

Recommendation 1: The education strategy should adopt a strong philosophy and culture of learning, enquiry and evidence-based practice. Across the organisation, there should be a clear understanding of how education and research support the delivery of best care to children and families. With a focus on valuing learning and development, individuals can be supported and motivated to become life-long adult learners.

Recommendation 2: Developing and implementing an education strategy will have resource implications and requires a dedicated learning and development team. Within the team, there should be the inclusion of expertise from both paediatric palliative care practice and higher education. There may be merit in expanding the current practice education team to facilitate the development, delivery and evaluation of education to all teams within the hospice and to external palliative care providers.

Recommendation 3: Consider conducting a formal learning and development needs analysis on a regular basis to ensure that education and training is responsive to the changing needs of staff and volunteers. Whilst not an exhaustive list, some of the current priority learning and development needs identified during this project include:

- communication skills, including communicating difficult information to families and providing psychosocial and emotional support;
- end of life and bereavement care across a range of settings (home, hospice, hospital);

- clinical skills and management of the symptoms associated with complex and rare life limiting conditions;
- spirituality and culturally sensitive care;
- complex ethical dilemmas, advanced decision making and managing parental expectations.

Recommendation 4: The education strategy should be cognisant of the relational and emotional context within which staff and volunteers are caring for and supporting children and families. Through evidence based educational approaches, self-care, self-awareness and resilience building should be addressed to support staff and volunteers in managing the emotional dimension of their roles.

Recommendation 5: Consider implementing the educational strategies and approaches identified from the literature review and focus group discussions:

- involve children and families in the education process by learning from their stories and experiences;
- promote experiential learning or ‘learning on the job’ by integrating education into everyday practice;
- encourage those who are more experienced in children’s palliative care to act as role models in supporting their colleagues;
- adopt an interdisciplinary approach to palliative care education and training where relevant and possible;
- embrace technology and establish opportunities for individuals to connect with and learn from others delivering children’s palliative care both nationally and internationally.

Recommendation 6: Consider developing formal relationships with higher education institutions to further the development and accreditation of educational courses. Specific consideration should be given to the development of an inter-professional post-graduate educational pathway in the context of advanced paediatric palliative care practice. This is important for supporting the development of future leaders in children’s palliative care and promoting the creation and dissemination of evidence-based knowledge in paediatric palliative care.

Recommendation 7: Further development and enhancement of clear career pathways for all staff groups within CHAS (newly qualified, qualified, support staff and volunteers) should be prioritised to ensure opportunity for continuing personal and professional development and progression.

Recommendation 8: Three main populations were identified as a priority for implementing educational initiatives in children’s palliative care – the public, those working in generalist roles, and palliative care specialists.

CHAS are ideally placed to lead the development of such initiatives and it is recommended that CHAS consider developing educational initiatives in partnership with key stakeholders and experts across NHS Scotland.

Recommendation 9: Consideration should be given to maximising opportunities for building capacity and capability in the small and specialist field of paediatric palliative care, through sharing of knowledge and expertise. Strategies to achieve this may include:

- the creation of joint posts or rotational secondments between the hospice and the NHS (acute and community services);
- establishing formal links with other children’s hospices in the UK to encourage a collaborative approach to education. This could include opportunities for reciprocal short-term exchanges and learning placements.

Recommendation 10: CHAS should consider linking with higher education institutions to influence the curriculum by sharing innovative and feasible ways of integrating the concepts of children’s palliative care into undergraduate education. Establishing formal links with higher education institutions would provide an opportunity to establish consistency in education. In addition, further promotion of practice learning experiences with CHAS would be beneficial to link theory with palliative care practice.

Next Steps

The overall findings of this project identified many examples of good practice in palliative care education whilst also highlighting gaps in provision. Future work in exploring families’ views surrounding education provision would be beneficial. Addressing the recommendations put forward in this report to develop a robust education strategy would enable CHAS to meet the current and future educational needs of its staff. Working collaboratively with external practice partners across Scotland and beyond would enable CHAS to influence and support further development of children’s palliative care education.

1. Background and Context

Over recent years the provision of palliative care for babies, children and young people in Scotland has emerged as a growing speciality with the publication of leading research by Fraser and colleagues (2015) highlighting the increasing prevalence and need for further education and care provision. The proportion of children requiring palliative care remains small in comparison to the adult palliative care population, however, there is continued recognition of the distinct differences in the care requirements of these two groups of patients. This recognition is evident in Commitment 4 of the *Strategic Framework for Action on Palliative and End of Life Care* (Scottish Government 2015), which highlights the need to promote the development of holistic palliative care for children from 0-25 years of age.

In order to meet this commitment and deliver holistic palliative care, we need a workforce which is competent, capable and equipped with the appropriate knowledge, skills and attitudes to deliver high quality care. The requirement for specific education relating to children's palliative care was highlighted in the *Framework for the Delivery of Palliative Care for Children and Young People in Scotland* (Scottish Children and Young People's Executive (SCYPPEX) 2012). One of the Framework's ten objectives was a need for education and training to be available in every Health Board for staff working in this specialist area of care. The more recently published *Strategic Framework for Action on Palliative and End of Life Care* (Scottish Government 2015), recognised the need for an educated workforce in Scotland, making a commitment to create a national education and training framework for health and social care staff. This framework, *Palliative and End of Life Care: A framework to support the learning and development needs of health and social care workforce in Scotland* (NES/SSSC 2017), uses a developmental approach towards knowledge and skills acquisition for all staff working across health and social care settings who are providing palliative care to people with multiple needs and underlying conditions. This framework is a welcome addition to the area of palliative care as it provides a pathway of educational development for all staff, regardless of individual discipline or qualification. The challenge now is to ensure this is implemented in a consistent and integrated way across services and to ensure it is adapted to meet the needs of children and young people.

Considering the above evidence, a clear need is emerging to ensure developments in the provision of paediatric palliative care education continue to be progressed and enhanced. This scoping exercise was commissioned by CHAS as part of their wider strategic aim to **influence** paediatric palliative care through the development of a research-informed education strategy which will ensure staff and volunteers have access to education programmes which are evidence based and which will prepare them to deliver the highest quality care and support to children and their families.

2. Scoping Project Design and Methods

2.1 Research Question

The key research question posed in this project was:

How can CHAS influence children's palliative care through education?

2.2 Aim and Objectives

The aim of this scoping exercise was to inform the development of an evidence based and research-informed education strategy for CHAS. The education strategy would provide a framework for the ongoing learning and development requirements of CHAS staff and volunteers, aiming to influence the delivery of palliative care for children and their families across Scotland.

The following objectives were set:

1. To review the literature and evidence base pertaining to policy, practice and research in children's palliative care education.
2. To identify the current and future education, learning and continuing professional development requirements of practitioners, volunteers and professionals working across the field of children's palliative care in Scotland.
3. To provide recommendations for and contribute to the development of an evidence-based education strategy for CHAS which can inform the future service agenda and influence the delivery of a national approach to children's palliative care education, learning and continuing professional development.

2.3 Project Steering Group

A Steering Group was convened to guide the project, review the methods and analysis and adopt an advisory role in monitoring progress and performance. The Steering Group played an important role in advising on key contacts and informants to approach as participants for the focus groups and online survey. The Steering Group met at face-to-face meetings on three separate occasions, once at the beginning of the project, once at the middle stage and again towards the end of the project. Additional correspondence by electronic and telephone communication took place throughout the project period. Details of Steering Group membership are provided in Appendix 1.

2.4 Research Ethics

The requirement for ethical approval was explored and following advice from the Scientific Advisor for NHS South East Research Ethics Committee (REC) it was established that NHS ethical approval was not required for this project. The project was submitted to the School of Health and Social Care's Research Integrity Committee within Edinburgh Napier University and received full ethical approval.

The project team adhered to Edinburgh Napier University's ethical protocols, in addition to the individual researcher's own professional body guidelines (Nursing and Midwifery Council). Members of the project team are experienced in facilitating focus group discussions and ensured that participants were supported when sharing their views of education and professional development in the field of children's palliative care. An important ethical consideration in this project was to guarantee the anonymity of all respondents and ensure discussions remained confidential. The research team are aware of the difficulties regarding confidentiality when working in small groups. Throughout this project, every effort was made to protect the anonymity of participants and confidentiality was guaranteed and maintained at all time.

Prior to enrolment in the project, individuals were provided with an information sheet and a full explanation of their potential involvement. It was also ensured that participants had adequate time in which to consider their involvement and the opportunity to discuss it with others if they wished. Individuals participating in the focus group were required to give informed written consent. The online survey contained an information section outlining the purpose of the project, assurance of maintaining confidentiality and permission to use anonymised written quotes. Individuals participating in the online survey were required to accept the informed consent section before going on to complete the survey.

All data collected during the project were anonymised and stored securely in password-protected files on Edinburgh Napier University network drives or in locked filing cabinets in offices in the School of Health and Social Care (Sighthill Campus). In accordance with data management policy, and in line with Research Council UK (RCUK) guidance, all data collected for the purposes of the project will be stored securely for 10 years before being destroyed.

2.5 Scoping Review Methods

Three phases of activity were undertaken to meet the objectives of this scoping project. Phase 1 consisted of a scoping review of the evidence base to provide a comprehensive overview of relevant research, policy and practice pertaining to children's palliative care education. The findings from this review informed the subsequent phases of the project. In Phase 2, a qualitative exploratory design using focus group discussions and an online survey, was implemented to identify the learning and development needs of hospice staff, volunteers and those professionals across health, social care, education and early years

services with links to children’s palliative care. In Phase 3, the results arising from the previous phases were combined to shape key recommendations for the development of an education strategy for CHAS. (Figure 1)

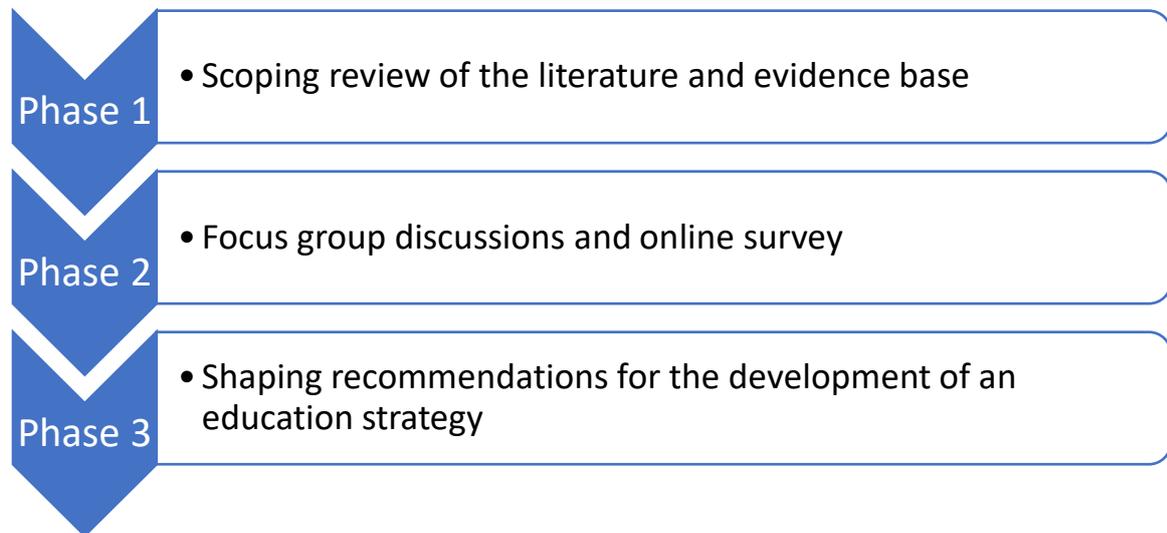


Figure 1: Methodology

3. Phase 1 - Review of the Literature and Evidence Base

A review of published and grey literature was undertaken to provide a comprehensive overview of current research, policy and practice pertaining to multi-professional education in the field of children's palliative care.

3.1 Literature Review Methods

Scoping reviews are *'a form of knowledge synthesis that addresses an exploratory research question aimed at mapping key concepts, types of evidence, and gaps in research related to a defined area or field by systematically searching, selecting and synthesising existing knowledge'* (Colquhoun et al. 2014, p. 1292-94). A protocol for the literature review was developed in line with the principles of scoping review methodology as outlined in Arksey and O'Malley's (2005) framework and further elaborated on by Levac and colleagues (2010). The five stages which comprise the framework are as follows:

1. Identifying the research question
2. Identifying relevant studies
3. Study selection
4. Charting the data
5. Collating, summarising and reporting the findings

This methodology was chosen as it would allow for comprehensive mapping and review of the evidence within the short timeframe available. Moreover, the method does not require quality appraisal of the evidence which permits the inclusion of both empirical studies and the wide range of policy and practice papers that may not be published in peer-reviewed journals but are pertinent to the research questions (Arksey & O'Malley 2005; Levac et al. 2010; Colquhoun et al. 2014).

Identification of the research questions

This scoping review aimed to explore the research, policy and practice surrounding education, learning and continuing development of individuals working in the field of children's palliative care. To ensure that an extensive range of evidence related to the topic was captured within the review process, the following questions were set to guide the search:

1. What is known about building capacity for quality and effective children's palliative care through education, learning and continuing professional development?
2. What are the education needs and requirements of the children's palliative care workforce?

3. What strategies and interventions are being implemented to meet the educational needs and requirements of those working in children's palliative care?

Identification of relevant studies

A comprehensive and systematic approach to the identification of evidence was adopted. Members of the project team [CM, DM] developed the initial search plan. To ensure rigour, the expertise of a senior subject specialist librarian was sought to further develop and refine the search strategy and carry out the electronic database searches.

Ten electronic databases, including MEDLINE, PubMed, PsycINFO, CINAHL, AMED, ASSIA, ERIC, Cochrane Library, Australian Education Index and British Education Index were searched in November 2017. Various combinations of the search terms were used to reflect the core concepts of paediatric palliative care, education, and the workforce involved in delivering palliative care to neonates, infants, children and young people. All papers published in the English language between the dates of January 1995 to November 2017 were considered. There were no restrictions on study design, however, commentaries, editorials and opinion pieces were excluded.

In addition, the reference lists of all papers identified through the database searches were then scanned to identify any further relevant papers. Recent issues (January 2015 to December 2017) of five key journals in the field of palliative care (*Palliative Medicine*, *BMJ Supportive and Palliative Care*, *International Journal of Palliative Nursing*, *European Journal of Palliative Care*, and the *American Journal of Hospice and Palliative Care*) were hand-searched by CM. All references were managed using Endnote.

Grey literature was located by applying the same search strategy principles. Internet searches of Google, Google Scholar, and OpenGrey databases were undertaken. The websites of organisations and networks that are pertinent to palliative and hospice care were also searched.

This approach allowed for a comprehensive review of both empirical studies published by researchers and academics as well as policies, frameworks and strategies being implemented by government, health authorities, educational institutions and organisations involved in paediatric palliative and end of life care.

Study selection

Papers were eligible for inclusion if they reported on educational approaches, interventions, strategies, principles or priorities for those responsible for the care of neonates, infants, children and young people with palliative and end of life care needs. Education was defined broadly as teaching, training, learning and/or continuing professional development.

For empirical papers, there was no restriction on study design. Literature reviews (including narrative reviews) were also included, however, commentaries, editorials and opinion

pieces were excluded. Within all papers, be they empirical or grey literature, education was required to be the primary focus or aim. Those papers where education was mentioned incidentally or as an aside were excluded.

Papers were required to be published between January 1995 and the end of November 2017. This timeframe was chosen for two main reasons. Firstly, paediatric palliative care is a relatively emerging subspecialty and preliminary searches identified few relevant papers prior to 1995. Secondly, it was important to ensure contemporary and current approaches to education were identified.

Papers were excluded from the scoping review if they were not published in English or if the full text version of the paper was not available for review. Two members of the project team independently reviewed the title and abstracts of all identified papers to ensure the inclusion and exclusion criteria were met. Full text papers were then screened by CM to make the final assessment of eligibility for inclusion in the scoping review.

Charting the data

Charting of the data involved ensuring all relevant details were extracted from each paper. This included author(s), year of publication, location of study, study population and design, methodology and a brief summary of the main findings or recommendations. It was not possible to chart some of the grey literature, such as strategic frameworks or policy in this way. Instead, a summary of the grey literature was documented to communicate those data that are consistent with the scoping review purpose and research questions.

Collating, summing and reporting findings

A qualitative analytical approach was undertaken to present an overview of the evidence included in this scoping review. Using the qualitative data analysis software QSR NVivo 10 (QSR International PTY Ltd., Victoria, Australia), content analysis was carried out to identify trends and patterns across the extracted data. Project members (CM, DM) reviewed the data independently and engaged in critical discussions of the emerging topics and themes until a consensus was reached.

A modified PRISMA flowchart is provided in Appendix 2 to communicate the search strategy and paper selection process. A total of 85 papers and 35 grey literature items were determined to be eligible for inclusion in this scoping review. The papers comprised peer-reviewed journal articles; reports by a professional or voluntary organisation; policy, strategies and/or educational frameworks; educational competences; project final reports; and a book chapter. There was representation from a number of countries with the majority of the papers originating from the United Kingdom (n=39) and the USA (n=32). Appendix 3

outlines the papers included in the review and Appendix 4 details the sources of grey literature.

Following coding and analysis of the included papers, it was evident that the extracted data was closely aligned to the three research questions posed in the review and therefore the data will be reported under each research question in turn. Several sub-themes also emerged from the data which will be discussed within the findings section under the relevant research question.

3.2 Literature Review Findings

What is known about building capacity for quality and effective children's palliative care through education, learning and continuing professional development?

A recurring topic within the papers reviewed was the requirement to support the development of an effective and responsive workforce through education to ensure the palliative care needs of children with life limiting conditions and their families are met both now and in the future. Papadatou (1997) published a seminal paper recognising paediatric palliative care emerging as a distinct specialty field and thus acknowledging the need for specialised palliative care education for health care professionals. Since then, this finding has been echoed widely across the literature. In 2003, the Institute of Medicine (IOM) released their report on children's palliative care entitled *When Children Die: Improving Palliative and End of Life Care for Children and their Families*. This report called for improved education amongst professionals working in the field to better address the care and support needs of children and families (Field & Behrman 2003). It is important to be cognisant of the unique palliative care and support requirements at different ages and stages of childhood from neonates to young people when considering education needs of the workforce and ensure these are addressed within evidence based educational approaches (Mancini et al. 2013; Wiener et al. 2015).

Hain and colleagues (2012) stressed that whilst paediatric palliative care is recognised as a specialty area, a 'fortress of knowledge' should not be erected around. Instead efforts should be made to ensure that education and training is available for all who care for children with palliative care needs, including those in generalist as well as specialist roles and those working across a range of agencies, including the NHS, children's hospices, the voluntary sector, social care and education services. Moreover, there are a diverse range of supportive roles in each of these settings, including administrative staff, volunteers, and many others, who 'develop numerous, substantial, direct interactions with dying children and families' yet lack sufficient knowledge or training in palliative care (Swinney et al. 2007, p. 44). It is vital that education and development opportunities are available for those in supportive roles as well.

Several core standards, frameworks, competencies and curriculum for education in paediatric palliative care were identified in the review process and are outlined in Appendix 4. These form a basis for paediatric palliative care education and thus play a valuable role in contributing to the development and maintenance of an appropriately trained and skilled workforce (ACT/CHUK 2009). The literature focuses on a stepped approach to palliative care education. Gamondi and colleagues (2013) suggest a three-tiered approach which has also been adopted and adapted by the European Association for Palliative Care (EAPC) Children’s Palliative Care Education Taskforce’s in their published core competences for education in paediatric palliative care (table 1) (Downing et al. 2013). The different levels (basic, intermediate and specialist) recognise that the knowledge and skill required by an individual will vary depending on their role, the setting in which they are working, their level of responsibility and involvement with children and their families. Such an approach recognises that to ensure quality of care for children and families, all members of the workforce require at least a general level of awareness and education related to palliative care and individuals will then build on their knowledge and skills as they gain more experience and become specialised in the field.

Table 1. Levels of education (Downing et al. 2013, p.19)

Level	Description
Basic training – The palliative care approach	This level of education aims to educate students and professionals with the purpose of integrating palliative care methods and procedures in settings not specialised in either palliative care for adults or children. It is made available to undergraduate students, general practitioners and staff in general hospitals, as well as to nursing services.
Intermediate training – General paediatric palliative care	This level of education is made available to students in health care, as well as to professionals who are involved more frequently in palliative care, such as paediatric oncologists, neurologists and neonatologists but do not provide palliative care as the main focus of their work. Depending on discipline, it may be taught at an undergraduate or postgraduate level or through continuing professional development.
Specialist training – Specialist paediatric palliative care	This level of education is made available to students at post-graduate level and is available to professionals whose main activity is the provision of paediatric palliative care.

The Association for Children's Palliative Care (ACT) (now Together for Short Lives) described the workforce as being the "primary building block for developing reliable, responsive and sustainable services to enable the delivery of care and support that children and families need, delivered where and when they need it" (ACT 2009, p.24). To achieve the delivery of required care and support to children and families, there needs to be interlinking of care pathways, education commissioning and provision and service commissioning and provision (ACT 2009). *Right People, Right Place, Right Time: Planning and developing an effective and responsive workforce for children's and young people's palliative care* (ACT and CHUK 2009) provides an education and training framework directed at workforce development in paediatric palliative care. It describes a Skills Pathway with a four-tiered approach called the "Learning Cone" which facilitates a growth in expertise from novice to expert through different spheres of practice: communication skills, assessment skills, complex care management and role development.

Delivering quality care and services through strong educational foundations must be recognised at governmental level if there is to be commitment to advance any area of health and social care practice. In the UK, several strategies and frameworks in relation to paediatric palliative care were recently published and the identification of education as a means to support workforce development is visible within each of them. *Better Care: Better Lives* (Department of Health 2008), *Ambitions for Palliative and End of Life Care: A National Framework for Local Action 2015-2020* (National Palliative and End of Life Care Partnership 2015), *The Strategic Framework for Action on Palliative and End of Life Care 2016-2021* (Scottish Government 2015) and *A Strategy for Children's Palliative and End of Life Care 2016-2026* (Department of Health 2016), all identify a shared need to develop sustainable and high quality palliative care services for children and young people which enables them to achieve their full potential, regardless of diagnosis or life expectancy. Within each of these strategies and frameworks, the role of education in ensuring every professional is competent and confident to deliver quality palliative and end of life care is emphasised. The priority is to now embed these policy documents in clinical practice to enable improvements in paediatric palliative care to be achieved.

In Scotland, the recent development and subsequent publication of *Palliative and End of Life Care: A framework to support the learning and development needs of the health and social service workforce in Scotland* (NES/SSSC 2017) demonstrates a national commitment to education within the field of palliative care. Scotland aims to ensure that its workforce is adequately prepared to deliver palliative and end of life care and that informal carers, family members and volunteers are able to access support, education and guidance. The framework is all encompassing and directed at "every worker who might come into contact with people who have palliative and end of life care needs" across a range of settings (NES/SSSC 2017, p.4). Five domains are included in the framework: fundamentals of palliative care; communication and conversations; loss, grief and bereavement; care

planning and delivery; and care in the last days of life. Within each domain there are four levels of knowledge and skills: informed; skilled; enhanced; and expert. These increasing levels of education from informed to expert mirror other pedagogical approaches within palliative care (Downing et al. 2013; Gamondi et al. 2013).

Underpinning principles of education in children's palliative care

Downing and colleagues (2013) suggest that the philosophy of palliative care should underpin all education programmes with an emphasis on optimising quality of life for children and families with care being provided from diagnosis through to death and into bereavement as required. Downing and Ling (2012) acknowledge that whilst individual educational programmes for paediatric palliative care will vary, there are key principles which should be present in any education and training and these include: the philosophy of paediatric palliative care; a relational approach to learning; inter-professional and interdisciplinary education; practical experience and expertise; competency-based education; education based on the principles of adult learning; the need for skilled and experienced educators; and the evaluation of the process and outcomes of education.

In their discussion paper on paediatric palliative care education, Ferguson and colleagues (2012) define three core components of the curriculum: knowledge, skills and attitudes. A number of papers included in the review emphasised the complexity of palliative care and stressed that education must be mindful not to focus solely on the acquisition of knowledge and skills but in addition, include an emphasis on the attitudes, beliefs and behaviours required when applying knowledge and skills related to palliative care (Charlton 1996; Papadatou 1997; Sahler et al. 2000; Liben et al. 2008). Liben and colleagues (2008) suggest that educational programmes should offer structured opportunities for reflection and exploration of personal experiences, attitudes and responses to death, dying and bereavement. The development of reflective practice and self-awareness has been identified as a core competency for those working in paediatric palliative care settings (Downing et al. 2013).

Challenges to children's palliative care education

Challenges to developing and further enhancing children's palliative care education were recognised in several papers. Papadatou (1997) identified seven main challenges involved in the training of health professionals: 1) definition of educational objectives 2) selection of teaching methods and content of training 3) definition and teaching of emotional involvement 4) support of training participants 5) promotion of interdisciplinary collaboration 6) evaluation of the training process and its outcomes and 7) background and skills of educators. Whilst this paper was published nearly 20 years ago, these challenges remain prominent on the current education agenda.

Downing and Ling (2012) reported on findings of the European Association for Palliative Care (EAPC) Children's Palliative Care Education Taskforce survey which offers a European

perspective on some of the challenges to providing paediatric palliative care education. These include, but are not limited to, the following: a lack of recognition of paediatric palliative care as a distinct specialty; the limited number of paediatric palliative care specialists available to teach and the large number of people required to be trained; a lack of recognition or accreditation of courses; a need for development of interdisciplinary thinking and collaboration; a need for the transfer of theory learning to practice; lack of funding or resources; reluctance of staff to be involved in educational initiatives; and a small number of people attending courses and thus making them not financially viable (Downing and Ling 2012; Downing et al. 2013).

Jacobs and colleagues (2009) offer additional yet similar challenges to providing paediatric palliative care education from the perspective of paediatric nurses attending the End of Life Nursing Education Consortium for Pediatric Palliative Care (ELNEC-PPC) programme in the USA. This is a 'train-the-trainer' course delivered over two and a half days after which the intention is that learning is disseminated across practice and university settings. The curriculum consists of 10 modules which are specific to the care of children with life limiting conditions and families. From the perspective of nurses undertaking this course, some of the challenges to learning in children's palliative care include: discomfort and fears associated with the death of children; lack of educational materials available; lack of prepared faculty to teach palliative care; lack of time and resources for staff to attend training; staff turnover and shortages; cultural differences regarding palliative care; other competing educational needs; and a small paediatric population requiring palliative care.

The infrequency in which some professionals are exposed to end of life and bereavement can pose a challenge to education. In care settings where paediatric deaths occur relatively infrequently, there is not sufficient opportunity or incentive for all professionals to seek further training and education in palliative care. Sheetz and Bowman (2008) suggest that in such settings, particularly tertiary care, paediatric hospital-based palliative care consultation services have the potential to offer an educational curriculum for professionals and can act as role models to address the needs of children and families.

A final challenge to consider is workforce planning and succession building to make sure there are adequate numbers of professionals with the knowledge, skills and experience needed to provide quality palliative care in the future. A recent survey of children's hospice organisations in the UK revealed an increasing vacancy rate and difficulty filling nursing posts (Together for Short Lives 2017). Similar shortages in NHS-provided community children's nurses (CCNs) were also observed. A range of recommendations were contained in this report including the need to ensure children's palliative care is integrated within undergraduate education and that students have the opportunity to undertake practice placements in children's hospices and other palliative care settings.

What are the education needs and requirements of the workforce?

Evidence surrounding the education needs and requirements of the paediatric palliative care workforce was extensive and included papers reporting the outcomes of educational needs analysis surveys of hospital doctors (Amery & Lapwood 2004; Kolarik et al. 2006; Baker et al. 2007; McCabe et al. 2008; Sheetz & Bowman 2008; Michelson et al. 2009; Lee et al. 2016), nurses (Price & McNeilly 2006; Botwinski 2010; Neilson et al. 2010; Ahern 2013; Peng et al. 2013; Quinn & Hillis 2015; Lee et al. 2016), health professionals (surveyed a range of health professions) (Huijter et al. 2008; Amery et al. 2010; Amery 2012; Crighton 2012; Gallagher et al. 2012), hospice staff (Amery & Lapwood 2004; Billings et al. 2011; Quinn & Hillis 2015; Taylor & Aldridge 2017) and hospital support staff (Swinney et al. 2007).

A key point emanating from these papers was the unmet need and overwhelming demand for paediatric palliative care education across a range of professions and care settings. Priorities for children's palliative care education, from the perspectives of the workforce, included pain control and symptom management (Amery & Lapwood 2004; Amery et al. 2010; Ahern 2013; Peng et al. 2013; Quinn & Hillis 2015; Lee et al. 2016); palliative care emergencies (Amery & Lapwood 2004; Quinn & Hillis 2015); providing bereavement and emotional support to families (Amery et al. 2010; Ahern 2013; Quinn & Hillis 2015); end of life care planning (McCabe et al. 2008; Botwinski 2010; Gallagher et al. 2012; Quinn & Hillis 2015); care of self and personal coping strategies (Amery & Lapwood 2004; Swinney et al. 2007; Amery et al. 2010); communication skills (Amery & Lapwood 2004; Kolarik et al. 2006; Huijter et al. 2008; Amery et al. 2010; Botwinski 2010; Peng et al. 2013; Quinn & Hillis 2015; Lee et al. 2016); ethical decision making (Gallagher et al. 2012; Peng et al. 2013; Lee et al. 2016) and providing culturally sensitive care (Swinney et al. 2007).

In the papers reviewed, the broad area of communication, including but not limited to discussing a poor prognosis or breaking bad news, was the most frequently identified learning need. Whilst not all sections of the paediatric palliative care workforce or care settings were represented in the papers, in those professions and settings that were, there was clear consensus that communication was a priority topic for further education. In a clinical learning needs survey of children's hospice staff conducted by Quinn and Hillis (2015), respondents (namely nurses and health care assistants/nursery nurses) prioritised communication skill development especially related to breaking bad news as a priority learning area. Amery and Lapwood (2004) surveyed the education needs of children's hospice doctors in England and interestingly found that when asked to self-rate their learning needs, hospice doctors rated typically 'clinical' topics such as symptom control as those areas of practice that they would most value support, education and training in. However, when asked to keep a personal educational diary, it was revealed that children's hospice doctors would most value educational input into areas such as communication skills, team-working and personal coping strategies. The authors note the disparity between educational needs of hospice doctors as derived from self-rated competences and from educational diary keeping. They suggest future educational approaches and curricula

acknowledge that inter-personal and intra-personal competences such as communication and personal coping strategies are equally as important as clinical competences such as symptom control (Amery & Lapwood 2004). Communication is a fundamental and inherent aspect of children's palliative care which is reflected in professional competences (RCN 2012; Downing et al. 2013; APPM & RCPC 2015) yet it remains a key learning need for the workforce.

Taylor and Aldridge (2017) explored the perceived rewards and challenges of working in a children's hospice with the aim to identify staff support and development needs. Hospice staff, particularly those who had worked in this setting for a number of years, noted the increase in complexity and care requirements of children. Many children required very complex and individualised care, often over prolonged time periods, thus creating additional education and training needs for hospice care staff. Moreover, because of the rarity of many life limiting conditions, there can be a lapse in time between caring for children with these exceptional needs and thus limited opportunities to embed new learning in practice.

A recent epidemiological study recommended that children under one year of age be recognised as a priority group for input from palliative care services after reporting a significant prevalence of childhood deaths in Scotland occurring in this age bracket (Fraser et al. 2015). The findings from an evaluation of the Diana Children's Nurse (DCN) Service in Scotland revealed that whilst provision of palliative care services within the neonatal specialism is growing, it remains at an earlier stage of development than the larger field of paediatric palliative care and as such those working in neonatal care have general learning needs related to palliative care (Miller & Woodhouse 2017). This further highlights the requirement for educational initiatives to equip the workforce to meet the care and support needs of this population. Three of the reviewed papers focused specifically on the education needs and requirements of neonatal staff. They identified communicating bad news (Botwinski 2010; Ahern 2013; Peng et al. 2013), managing pain in neonates (Ahern 2013; Peng et al. 2013), and providing emotional support to families (Ahern 2013) as the priority areas for education. Ahern (2013) made the observation that neonatal staff identified similar learning needs to other professionals caring for children with palliative care needs which concurs with the findings of the literature review, as discussed above.

Self-care needs of those providing children's palliative care

A sub-theme emerging from the broader theme of education needs and requirements of the paediatric palliative care workforce was the concept of self-care. The papers reviewed reported that working in this field can have a powerful emotional impact on individuals (Amery & Lapwood 2004; Browning & Solomon 2006; Malloy et al. 2007; Swinney et al. 2007; Amery et al. 2010; Taylor & Aldridge 2017). In an exploratory, qualitative study conducted by Taylor and Aldridge (2017), children's hospice staff described their work as being emotionally intensive and multi-faceted. Receiving informal support from colleagues

and participating in group clinical reflection were identified by hospice staff as key resources to reflect on and learn from, in addition to providing them with emotional support. Unfortunately, such opportunities for clinical reflection were limited. The researchers recommend children's hospices provide regular, structured and dedicated clinical reflection to allow their staff to come together for both support and learning (Taylor & Aldridge 2017).

The importance of self-care for professionals working in paediatric palliative care is evident internationally through its presence within numerous core competences, practice frameworks and education programmes (Browning & Solomon 2005; Craig et al. 2007; Schiffman et al. 2008; ACT 2009; RCN 2012; Downing et al. 2013; APPM & RCPCH 2015). In addition to health and social care professionals, the personal and professional lives of those in support staff roles are also adversely affected by this field of practice and they would also benefit from training and support to help them cope with grief and emotional stress (Swinney et al. 2007).

In order to best support staff and volunteers in their capacity to provide quality and compassionate children's 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 support the paediatric palliative care workforce to manage the emotional dimension of their role.

What strategies and interventions are being implemented to meet the educational needs and requirements of those working in children's palliative care?

Several papers included in the review described the implementation and subsequent evaluation of different training approaches and teaching interventions. These educational interventions were predominantly aimed at individual disciplines namely nursing (Malloy et al. 2006; Price & McNeilly 2006; Rogers et al. 2008; Jacobs et al. 2009; Twamley et al. 2013; Zhang & Lane 2013; Murakami et al. 2015) and medicine (namely trainees and medical residents) (Bagatell et al. 2002; Baughcum et al. 2007; Schiffman et al. 2008; Yazdani et al. 2010; Brown et al. 2012; Harris et al. 2015; Barnett et al. 2016; Moody et al. 2017; Singh et al. 2017; Snaman et al. 2017), with a few additional interventions targeted to a range of health professionals and associated disciplines (Mackenzie & MacCallam 2009; Carter & Swan 2012; Mancini et al. 2013; Price et al. 2015; Kain 2017).

Carter and Swan (2012) described a one-day training event attended by 24 participants from various disciplines (doctors n=7; nurses n=8; social workers n=4; child life specialists n=3; chaplains n=2 and bereaved parents n=2). All participants worked at a children's hospital in the USA and the parents attending the training event had experienced the loss of their child at the same hospital. The training event utilised teaching materials from the Initiative for Pediatric Palliative Care (IPPC) curriculum (Solomon et al. 2010) and included topics such as relational communication, cultural humility, pain and symptom management, family-centred care, team problem solving, and strategic planning. The impact of the training event

was measured through participants' completion of a self-report survey which demonstrated a positive impact on new knowledge gained, value in collaborative learning with both health care professionals and families, and the opportunity to work with professionals outside of their area of practice.

A further study conducted in the USA by Baughcum and colleagues (2007), described the development and evaluation of a one-day educational workshop for oncology fellows. The workshops covered palliative care topics such as pain and symptom management, communication, ethics, and bereavement. A before and after evaluation of training, knowledge, behaviour and attitudes regarding paediatric palliative care was undertaken. Oncology fellows reported a general lack of previous training in end of life care and any knowledge and skills they possessed had arose from experience and learning from colleagues. Post-workshop evaluations showed an improvement in palliative care knowledge. Participants gave encouraging feedback on the workshop and believed the training would have a positive impact on their clinical practice. Many participants' comments indicated that the parent speakers were informative and emotionally powerful.

Kain (2017) undertook a study to test and pilot the first of three modules within an evidence-based educational programme for neonatal palliative care clinicians. The study took place in a tertiary level hospital in Australia and included 40 participants. Pilot testing of this first module demonstrated that this educational intervention resulted in positive changes in both knowledge and attitude among participants, thus supporting the premise that evidence-based education for neonatal palliative care has potential to improve clinicians' confidence, through an increase in knowledge and positive attitudes toward neonatal palliative care delivery (Kain 2017).

The above findings were echoed in many other papers (Bagatell et al. 2002; Price & McNeilly 2006; Rogers et al. 2008; Schiffman et al. 2008; Jacobs et al. 2009; Mackenzie & MacCallam 2009; Yazdani et al. 2010; Brown et al. 2012; Mancini et al. 2013; Twamley et al. 2013; Zhang & Lane 2013; Harris et al. 2015; Murakami et al. 2015; Barnett et al. 2016; Moody et al. 2017; Singh et al. 2017; Snaman et al. 2017). The evidence included in this review consisted of predominantly descriptive studies and many of the training approaches and educational initiatives described involved one-off or brief interventions. It is not known whether the benefits following such short-term educational approaches are maintained over a long-term period. Future studies are required, particularly the use of larger scale intervention studies. Despite this, the evidence clearly indicates that even brief educational interventions can have a positive impact on the knowledge, skills and attitudes of professionals and enhance the care and support of children and families.

Similar educational initiatives have been developed for undergraduate education in nursing (Price et al. 2013; Price et al. 2014; O'Shea et al. 2015) and medicine (Kato et al. 2011) highlighting the value of an early introduction to the principles of paediatric palliative care to help enhance the practice of health professionals. Price and colleagues (2013) described

an educational initiative aimed at increasing undergraduate child health nursing students' awareness of palliative care through an educational visit to a children's hospice. Another initiative introduced to undergraduate nursing students involved the integration of paediatric and perinatal palliative care and end of life care principles throughout the undergraduate curriculum. This proved successful in increasing the knowledge base of nursing students.

There is evidence which supports the education needs and requirements of children's hospice staff (Amery & Lapwood 2004; Billings et al. 2011; Quinn & Hillis 2015; Taylor & Aldridge 2017). However, it is important to note the dearth of descriptions or evaluations of teaching initiatives and interventions employed within the children's hospice setting, due partly to under-representation of this section of the paediatric palliative care workforce in the current evidence base. The settings represented in the majority of the papers were tertiary care and specialist hospital units. Thus, there is a requirement for further investigation and evaluation of the educational interventions employed specifically for the children's hospice workforce or collaborative initiatives which are employed across a range of care settings.

In addition to describing the implementation and subsequent evaluation of different training approaches and teaching interventions, four additional sub-themes were identified in the evidence reviewed: i) children and families as educators; ii) interdisciplinary approaches to children's palliative care education; iii) international learning in children's palliative care; and iv) palliative care professionals' preferred methods and approaches to learning.

Children and families as educators

There is evidence to support the involvement of children and families, in the design, delivery and evaluation of learning and continuing professional development in children's hospice and wider palliative care. Children with life-limiting conditions and their families can offer valuable input and help ensure professionals are equipped with the knowledge, skills, and attitudes required to provide appropriate and effective care (Spalding & Yardley 2016). The literature reviewed describe a range of approaches for engaging children and families in the training and education of those working in children's hospice and palliative care (Browning & Solomon 2006; Schiffman et al. 2008; McNeilly et al. 2008; Solomon et al. 2010; Carter & Swan 2012; Adams et al. 2013; Summers 2013; Spalding & Yardley 2016; Widger et al. 2016; Snaman et al. 2017).

In an action research project, Spalding and Yardley (2016) engaged children, parents and children's hospice staff when exploring how medical students might best learn about paediatric palliative care. Drawing on their lived experiences, the participants considered what they believed to be helpful and unhelpful interactions with doctors. The findings from this project were then used to produce educational materials for medical students aiming to

develop their learning about patient-centred care. The participants also came up with a few additional educational activities they believed would be of value to medical students. These included medical students undertaking a children's hospice practice placement to gain authentic experience and filming family stories to allow more students to access and learn from the 'real-life experiences' of children and families (Spalding & Yardley 2016).

The experiences and impact of bereaved parents being involved as educators in paediatric palliative care was explored by Adams and colleagues (2013). Nine bereaved parents and 11 health care professionals were interviewed about their experiences participating in a paediatric palliative care education programme using the Initiative for Pediatric Palliative Care Curriculum (IPPC). During the programme, parents took an active role in facilitated discussions surrounding topics relating to communication, family support, and end of life care and support. One of the benefits of participating, as reported by parents, was the opportunity to make meaning out of their experience by telling their story and having it validated by health care professionals. Parents also acknowledged the challenges in taking part, specifically surrounding emotional management as they discussed intense emotions arising from their experiences. The overall findings from this qualitative research, however, indicate that the participation of bereaved parents in palliative care education offers greater benefits than burdens for both parents and health care professionals (Adams et al. 2013).

McNeilly and colleagues (2008) describe how the Paediatric Palliative Care Programme at Queen's University Belfast, UK, implemented a learning activity aimed at deepening students' understanding of families' experiences of having a child requiring palliative care, and to enable them to reflect on their own role of providing support to these families. The students, who consisted of hospice nurses, social workers and youth workers, were required to read and answer questions on a selection of books which included biographies of parents whose child had died, books of quotations about the death of a child, and a variety of storybooks that could be used to support children and young people. Student feedback was positive, and this learning activity suggests that the use of biographies and stories in children's palliative care education may deepen professionals' understanding of parents' experiences and enable them to provide sensitive and meaningful support (McNeilly et al. 2008).

An innovative initiative within the UK saw the voluntary organisation, Child Bereavement UK, and the RCPCH, join forces to develop a course for paediatric registrars which was aimed at enhancing the quality of care delivered to children and parents around end of life issues through increasing doctors' skills and confidence in supporting families at the end of life and during the bereavement process. The course was underpinned by the contribution of bereaved parents who shared their stories and provided a powerful and effective learning opportunity for doctors. Mancini and colleagues (2013) described how an independent evaluation rated the training and the experience of the participants as extremely high and participants believed the course should be introduced at an earlier stage of their medical training.

Overall, the evidence in this theme demonstrates that involving children and families in palliative care education can yield significant benefits and be of value to both the children and families and professionals. There is a requirement to ensure service user involvement is recognised as an integral component of paediatric palliative care education.

Interdisciplinary approaches to children's palliative care education

One of the most widely used definitions of inter-professional education originates from the Centre for the Advancement of Inter-professional Education (CAIPE): "*Inter-professional education occurs when students or members of two or more professions learn with, from and about each other to improve collaboration and the quality of care*" (Barr & Low 2013, p.4). Within children's hospices and the wider field of paediatric palliative care, there is immense value in engaging in inter-professional education and training as this is reflective of the way that care is delivered to children and families. A wide and diverse range of team members are involved in children's hospice care both internally and externally in the statutory and third sector thus acknowledging the importance of learning and working together to ensure delivery of an integrated and collaborative approach to children's palliative care. Moreover, interdisciplinary education affords professionals the opportunity to gain a better understanding and appreciation of each other's roles and responsibilities and enhances both team-working and communication. Following the development and delivery of an inter-professional postgraduate programme in children's palliative care, Nicholl and colleagues (2016) reported on students' evaluation of their learning. The findings indicated that the programme was effective in clarifying roles amongst the professions and creating an awareness of the significance and importance of collaboration and teamwork in children's palliative care.

Several papers identified in the review focused on implementing inter-professional approaches to paediatric palliative care education (Browning & Solomon 2005; Solomon et al. 2010; Wager et al. 2013; Nicholl et al. 2016). The evidence from the papers reviewed suggest that whilst there will be some aspects of the paediatric palliative care curriculum that are specific to different professions and groups, much of the core knowledge and skills can, and should where possibilities allow, be taught to an inter-professional or interdisciplinary group (Downing et al. 2013). It was also noted in the literature that it is important to maintain a balance. Whilst multi-professional education or shared learning offers benefits, education within disciplines is also important to ensure the distinct needs of each profession is addressed.

International learning in children's palliative care

The delivery of paediatric palliative care education across the world varies depending upon the patient, community and service needs. Additionally, it also depends upon the

accessibility and availability of resources, relying on the creation of educational initiatives using various methods of delivery to enhance learning and develop further understanding.

The International Paediatric Palliative Care Course (IPPCC) is an international and multi-professional course designed to address the difficulties in accessing training and education in children's palliative care due to differences in the availability of such courses across Europe and between countries. Wager and colleagues (2013) reported on the outcomes of the IPPCC course held in Germany in 2012. Health professionals from 35 countries attended the seven-day course and found it very beneficial in not only increasing knowledge of children's palliative care issues but also in terms of opportunities to network and share practice.

The International Children's Palliative Care Network (ICPCN) (2018) offer an e-learning programme encompassing a variety of topics from a basic introduction to children's palliative care through to specifics such as pain assessment, communication and end of life care. The existence of an electronic platform such as this offers flexibility to the workforce and is accessible to staff across the world in both statutory and third sector services, regardless of their professional base. Such an approach may be useful in positively addressing the issue of consistency in educational delivery. However, unlike the IPPCC, the ICPCN's e-learning programme does not offer an opportunity for students to learn together and share practice experiences. The development of an internationally accessible online learning programme in children's palliative care that includes a social learning platform through either discussion boards or video-conferencing may be beneficial.

Price and colleagues (2015) describe how online discussion forums can be implemented and utilised in an international multi-professional course. Students from Northern Ireland, UK and Melbourne, Australia, undertaking a postgraduate palliative care programme participated in a moderated online discussion forum to discuss the current and future challenges within children's palliative care. The student participants included representation from medicine, nursing and social work. The outcomes of this project revealed positive evaluations by the students as reflected in the theme of 'we are not alone' where the opportunity to engage in discussions and gain international perspectives on children's palliative care was found to be of great value.

Methods and approaches to learning – what the evidence tells us

A wide variety of teaching and learning approaches can be found in the palliative care literature, including, but not limited to, role play, supervised clinical practice, clinical simulation, in-depth skill building workshops, interactive lectures, mentorship and clinical supervision, reflection, small group discussions, case-based learning, hospice visits, trigger videos with interactive participant discussions, e-learning and self-directed learning modules (Billings et al. 2011). Whilst the value and utility of these approaches to learning are recognised, many professionals found that those approaches which aim to embed education

into their practice are the most effective. Sahler and colleagues (2000) emphasise the importance of taking advantage of those “teachable moments” which include those spontaneous opportunities that arise in our day to day caring of patients and can teach us such important lessons. The significance of experiential learning was also discussed by Baker and colleagues (2007) in a survey of medical residency programme directors (n=246) and students (n=253) to explore how palliative and end of life care could be implemented into resident training. The study reported palliative care learning was best accomplished ‘at the bedside’ and during medical rounds as experiential learning opportunities. There was consensus in the literature reviewed that experiential learning is a very effective way of students being able to learn and see palliative care in action through exposure to the clinical situation and role modelling. Experiential learning should form an essential part of any training programme.

Review Limitations

It is important to note that the recommendations emanating from the findings of this scoping review will be limited to the evidence available. Whilst a large quantity of papers were located in the review process, the majority of these were descriptive in nature, with only a minimal number of robust intervention studies. A diverse range of professionals, care providers and services are involved in the care of children with palliative care needs yet not all were equally represented in the papers reviewed. The current evidence tends to focus on children’s palliative care education and learning related to nurses, doctors and medical students. There is a need to know more about the education and learning needs of all those involved in caring for children with palliative care needs including support workers and volunteers. Similarly, the current evidence base focused predominantly on education and learning related to those working in tertiary centres and there is a need to further explore education and learning within all settings including community care and children’s hospices.

It is acknowledged that there may be evidence base on education and learning in the field of adult palliative care. However, the adult palliative care literature was not searched or accessed as part of the current scoping review. The rationale for taking this approach centres on the premise that it may not be valid to assume that the education and learning needs of those working in children’s palliative care are similar to those working in adult palliative care. There are distinct differences between the two disciplines and the aim of the current scoping review project was to focus on informing the development of a research-informed education strategy for the delivery of children’s palliative care.

Conclusions

This scoping review provided an extensive overview of the current evidence base surrounding education, training and continuing professional development within the children's palliative care workforce. The review responded to the three research questions posed at the outset and, in addition, identified the following key sub-themes: underpinning principles of education in children's palliative care; challenges to children's palliative care education; self-care needs of those providing children's palliative care; children and families as educators; interdisciplinary approaches to children's palliative care education; international learning in children's palliative care; and methods and approaches to learning: what the evidence tells us.

A considerable body of evidence was available and many sections of the children's palliative care workforce and a range of different settings within which palliative care is provided were represented. That said, a large proportion of the evidence focused on health care professionals, namely doctors and nurses, and centred on tertiary care settings. Greater representation of all parts of the workforce, including those in generalist, specialist and supportive roles and of the network of agencies delivering palliative care services in future education research would be of value.

The evidence included in this review was predominantly descriptive but comprehensive in nature and provided very useful contextual data that can be applied when developing education strategies for the children's palliative care workforce. Through mapping the evidence, it became apparent that there is a clear requirement for further education to enhance care provision and ensure the workforce is prepared to deliver effective care to children with palliative care needs both now and in the future. The greatest unmet learning need, across all disciplines included in the research, was related to psychosocial issues, particularly providing bereavement and emotional support to families and communicating bad news. There is a need for evidence based educational opportunities to be accessible to the workforce and to maximise on these opportunities for learning as they arise in practice. Interdisciplinary approaches to learning should be prioritised as should the involvement of children and families, in the design, delivery and evaluation of learning and continuing professional development. Finally, clinical practice in this field has a powerful emotional impact on the workforce and appropriate support, development and training for their own wellbeing and role in caring for and supporting children and families is essential.

Ultimately, it is through education that developments to practice can be made and palliative care for children and families enhanced. Current policy plays a key role in recognising the importance of education and maintaining a commitment to support workforce development. The priority is to now embed this policy in practice through integrated and coordinated approaches to paediatric palliative care education.

Summary of Key Points from Phase 1 – Review of the Literature and Evidence Base

- The importance of education in preparing the workforce to deliver quality palliative and end of life care to children and families was evident in the papers reviewed. A commitment to lifelong learning and continuous professional development is required to ensure the workforce has the capacity and skills to provide safe, effective and high-quality children’s palliative care.
- The agenda for paediatric palliative care education has largely been informed by the development of national and international core standards and frameworks that guide best practice within palliative care. Programmes of learning should be based on these recognised paediatric palliative care competency frameworks and standards. Moreover, it is acknowledged that the care and support needs of children and families are continually changing. As they change so will the education and training needs of those who are providing their care and support. It is important that education is responsive to these evolving care needs.
- Children’s palliative care is delivered by a network of service providers from health, social care, and education settings within the statutory, voluntary and independent sectors yet not all sections of the workforce were represented in the literature reviewed. The emphasis was on education requirements and initiatives for doctors and nurses working in tertiary care settings with most other disciplines, including those working within children’s hospices, currently under-represented. The growing complexity of children’s palliative care provided in the community underlines the importance of ensuring there is adequate education, training and support for this part of the workforce. Further research to explore the education and learning needs of those delivering community-based care would be of value.
- All individuals who are in contact with children with palliative care needs must have the knowledge, skills, and attitudes to do this effectively and compassionately. Across a range of settings, support staff (including reception staff, porters, ward clerks) serve a vital role in the provision of palliative care and there is a clear need to provide better training and support services for these individuals.
- Education is clearly visible in recent UK policy. Commitment 3 within the *Scottish Government’s Strategic Framework for Action on Palliative and End of Life Care* explicitly highlighted their support in developing a national educational framework to support workforce development in this field. In 2017, the *Palliative and End of Life Care: A framework to support the learning and development needs of the health and social service workforce in Scotland* (NES/SSSC 2017) was published. The framework is all encompassing and directed at “every worker who might come into contact with

people who have palliative and end of life care needs” across a range of settings. There are four increasing levels of knowledge and skills in the framework which mirrors other tiered approaches to education within palliative care. Such approaches acknowledge the requirement for all individuals to receive education on the principles and practices of palliative care, with those individuals whose work is primarily focused on palliative care move to a specialist level of knowledge.

- There was extensive evidence on the unmet learning needs of those delivering palliative and end of life care. Priority content areas included pain control and symptom management, managing palliative care emergencies, providing emotional support and bereavement care to families, end of life care planning, care of self and personal coping strategies and psychosocial skills.
- Communication skills, including discussing uncertainty and poor prognosis, was the most frequently identified learning need in the literature. Whilst not all sections of the paediatric palliative care workforce or care settings were represented in the papers, in those professions and settings that were, there was clear consensus that communication was a priority content area for further education.
- There is evidence to suggest that working in the field of children’s palliative care has a powerful emotional impact on individuals. The literature reviewed emphasises the importance of self-care and personal coping strategies being included as part of a well-rounded curriculum. The emotional investment individuals make in delivering quality palliative care is valued and appropriate support, development and training for their role is warranted.
- The principles of paediatric palliative care should be introduced at an undergraduate level and continue during postgraduate education and through continuing professional development. Where possible, practice placements that provide opportunities for learning in a range of settings where palliative and end of life care is delivered should be promoted.
- Within children’s hospices and the wider field of children’s palliative care, there is immense value in engaging in multi-professional education and training as this is reflective of the way that care is delivered and facilitates effective team-working and communication. However, it was also noted in the literature that it is important to maintain a balance. Whilst multi-professional education or shared learning offers benefits, education within disciplines is also important to ensure the distinct needs of each profession is addressed.

- Involving children and families in the design, delivery and evaluation of education has been shown to be effective in children's hospice and wider palliative care settings and is valued by both professionals and families. The literature offers a range of approaches for engaging children and families in the training and education of those working in children's hospice and palliative care.
- All education and training should be based on effective and evidence-based approaches that reflect the "real world". Effective learning methods described in the literature included experiential or "on the job learning", case-based learning, clinical simulation, reflection and small group discussions. Those approaches which aim to embed education into daily practice are deemed to be the most effective.
- In addition to increasing the knowledge base and developing skills, attitudes form a core component of the palliative care curriculum. Emphasis on how the values, beliefs, attitudes, and ethics of paediatric palliative care can best be taught would be of merit.
- The challenge in accessing learning opportunities in children's palliative care was acknowledged in the evidence base. Many children have complex and rare life limiting conditions which pose an additional challenge for educating the workforce. It is therefore important to maximise those opportunities for learning as they arise in practice. Education in children's palliative care should ideally be facilitated by individuals who are experts in paediatric palliative care and have experience in education and pedagogy.

4. Phase 2 – Education Requirements of the Children’s Palliative Care Workforce

Design

Using a qualitative exploratory design, the views and perceived learning and development requirements of hospice staff, volunteers and professionals working in the field of children’s hospice and palliative care across Scotland were explored through focus group discussions. Whilst focus groups were the main method of data collection, an online survey was also employed to capture the perspectives of those individuals purposively identified during the recruitment process but not available to attend the focus group. This approach aimed to maximise participation from a range of key informants across a range of agencies and services involved in children’s palliative care.

We drew on the findings of the scoping review conducted in Phase 1 to inform the development of a list of discussion areas for the focus groups. The project Steering Group reviewed and commented on the list which was then refined and finalised to the following four broad discussion areas:

- Current education, learning and development opportunities available
- Learning and development needs and requirements
- Preferred learning methods or approaches
- The role of CHAS in children’s palliative care education

An example of the final version of the focus group discussion guides is included in Appendix 5 (CHAS staff) and Appendix 6 (External professionals).

A survey version of the focus group schedule was designed and administered using a web-based application called NOVI Survey. This offered a pragmatic approach for participation of those informants based across a wide geographical area or who were not available to attend the focus group. The survey contained open-ended questions that mirrored those posed in the focus groups.

Recruitment

A purposive sampling strategy ensured representation from across the CHAS service and from other relevant professions and services where children’s palliative care was the main area of practice. This method of sampling acknowledged the importance of an integrated and collaborative approach to children’s palliative care across Scotland. Six distinct focus groups were planned. A focus group would take place in each of CHAS’ children’s hospices (Rachel House and Robin House) and in each region of practice covered by the three Diana Children’s Nurses (DCNs): East (Edinburgh); West (Glasgow); and North (Inverness and Aberdeen). Given the large geographical area of the North, two separate focus groups were arranged for this area, thus yielding a total of six focus group discussions.

Key informant lists for the focus groups were generated and aimed for the inclusion of up to fifteen participants in a session. A lead representative for each children's hospice was responsible for identifying potential participants that would include representation from a selection of the various volunteer and staff groupings. The DCNs work alongside health and social care and other services providing clinical leadership and support in the planning and delivery of children's palliative care. They were thus ideally placed to inform the recruitment process to help ensure representation from relevant stakeholders across Scotland.

An invitation email was circulated to all potential participants. Those who responded but were unable to attend the focus groups were then invited to complete an online survey instead. The surveys were administered via an email containing a direct link to the online survey. The time frame for completion of the survey was two weeks with a reminder email being sent five days after the initial email.

The focus group discussions were facilitated by a member of the project team and a second member recorded field notes. A brief presentation providing an overview of the project and the purpose of the focus groups was provided at the beginning. Ground rules for the session including issues of confidentiality, anonymity and sensitivity were discussed and each participant was required to sign a project consent form prior to the discussions commencing.

Analysis

Focus group and survey transcripts were transcribed and then uploaded into the data management software, QSR NVivo 11 (QSR International Pty Ltd., Victoria, Australia). Qualitative content analysis was undertaken with the data systematically grouped into categories, which were then coded and analysed for patterns or themes (Hsieh & Shannon 2005). Two members of the project team independently conducted the initial analysis to identify emerging themes and topics, which were then validated by the wider team. Further analysis to refine the themes was conducted by CM. All team members reviewed the final themes allowing for consensus to be reached in the thematic mapping of the data, thus enhancing rigour and trustworthiness of the analysis.

Focus Group and Survey Findings

Six focus group discussions were conducted during the months of March and April 2018 with a total of 61 participants. In addition, a further 18 individuals who were not able to attend a focus group (due to work timetables and conflicting appointments) participated through completion of the online survey. There was representation from a wide range of services and care providers including the NHS (acute and community), children's hospices, the voluntary sector, social care and education services. Table 2 outlines the number and category of participants for each of the six focus groups and table 3 outlines the number and

category of participants for the survey completion. The focus groups undertaken at Rachel House and Robin House have been grouped under the broad heading of CHAS whilst the remaining four focus groups are grouped by region. The North region includes two separate focus group discussions (Inverness and Aberdeen). The discussions lasted a minimum of 66 minutes and a maximum of 110 minutes.

Table 2: Focus group participants (n=61)

Focus Group	Location	Participants	Number
1 and 2	CHAS	Care Team	11
		Physiotherapy	2
		Social Work	2
		Pharmacy	1
		Activities Team	2
		Administration	1
		Maintenance/ Housekeeping	2
		Volunteer Services	1
		Management	5
Sub-Total		27	
3 and 4	North Region	Consultant Paediatrician	1
		Diana Children's Nurse	1
		Charity Organisation	1
		Social Work	4
		Community Children's Nursing Team	1
		Hospital Nursing Team	1
Sub-Total		9	
5	East Region	Community Children's Nursing Team	3
		Palliative Care Nursing Team	2
		Neonatal Nursing Team	2
		Charity Organisation	1
		University Lecturer - Medicine	1
		Oncology Nursing Team	1
		Clinical Skills Facilitators	2
		Diana Children's Nurse	2
Sub-Total		14	
6	West Region	Practice Development Nurse	1
		Consultant Paediatrician	2
		Community Children's Nursing Team	2
		Clinical Nurse Specialist	1
		Intensive Care Nursing Team	1
		Charity Organisation	2
		Oncology Nursing Team	1
		Diana Children's Nurse	1
Sub-Total		11	
TOTAL		61	

Table 3: Survey participants (n=18)

Location	Participants	Number
CHAS	Volunteer Services	1
	Care Team	1
	Family Support Team	1
	Chaplain Team	1
Sub-Total		4
North Region	Consultant Paediatrician	1
	General Practitioner	2
Sub-Total		3
East Region	Community Children's Nursing Team	4
	Community Health Support Worker	1
Sub-Total		5
West Region	Advanced Nurse Practitioner	1
	School Nursing Team	1
	Consultant Paediatrician	1
	Paediatric Nursing Team	2
	Clinical Nurse Manager	1
Sub-Total		6
TOTAL		18

Each of the focus groups yielded very productive and engaging discussions. A strong sense of enthusiasm for and commitment to the topic of education, learning and development was evident amongst the participants. Following content analysis of the focus group transcripts (n=6) and the survey responses (n=18), the data was categorised into six principal themes. There was similarity amongst five themes generated in the focus groups attended by CHAS staff and those attended by external professionals with one additional theme emerging from CHAS staff as highlighted in Figure 2. To create a distinction between the perspectives of CHAS staff and the perspectives of those working in other services, the findings are discussed separately and then synthesised in the summary to illustrate commonalities and differences between the groups.

CHAS Staff	Professionals
<ul style="list-style-type: none"> • Current opportunities in education • Learning and support needs of hospice staff and volunteers • Preferred learning approaches • Challenges in children's palliative care education • Building capacity and capability for children's palliative care through education • Promoting a philosophy and culture of lifelong learning 	<ul style="list-style-type: none"> • Current opportunities in education • Learning and support needs of professionals and support staff • Preferred learning approaches • Challenges in children's palliative care education • Building capacity and capability for children's palliative care through education

Figure 2. Principal themes emerging from the focus group discussions.

When reporting the findings and presenting direct quotes from participants, the terms 'CHAS Staff' and 'Professional' will be used to differentiate between those working or volunteering at CHAS and those working in external agencies and services whilst at the same time maintaining anonymity and confidentiality with respect to the participants' responses.

Findings from CHAS Staff

Current opportunities in education

Participants were asked to identify those education, training and development opportunities that are currently available to enable them to undertake their role within the hospice. They indicated that most of the education and training currently available is formalised around specific training (example - ventilator or T34 syringe pump training) or mandatory training and updates (example - health and safety). Participants acknowledged the importance of such training in maintaining a high standard of practice and in ensuring quality and safety in the delivery of patient care. When staff identified external training events or conferences that would benefit their practice, requests to attend were supported by the organisation in a positive manner.

The education and training roles undertaken by the Practice Nurse Educators and the DCNs were acknowledged as an asset to ensuring ongoing professional development within the hospice and especially within the Care Team. Specific examples of educational opportunities which are valued by the Care Team staff include attendance at the 'Grand Rounds' and the key working day training sessions.

Over recent years, there has been an increase in requests from external organisations for members of the CHAS team to deliver training and development sessions. Participants commented on the value of such teaching and identified mutual benefits both to the organisation and staff or students receiving the training and to the members of the CHAS team who are delivering the sessions. It was noted that this training is largely being delivered on an informal or ad-hoc basis and there is scope to further develop these opportunities in future.

Promoting a philosophy and culture of lifelong learning

An interesting discussion thread centred around the importance of fostering a culture of lifelong learning within CHAS and this surfaced in both hospice focus groups. Many participants, particularly those who have worked in the organisation for a number of years, advocated the development and promotion of a culture of lifelong learning. Whilst there is some evidence of a growing culture of learning across the various teams, there is a need to embed this in a more integrated and cohesive manner. Participants spoke of the ubiquitous nature of learning and described how learning takes place in all aspects of hospice work. The following extract provides an example of this:

I think things have changed in the last 10 years. People went off on study days and that was all they did (with respect to learning). I look now and learning is happening every single day. People are learning in different ways now. They are working alongside people, shadowing, visiting different departments, maybe doing ad hoc training sessions alongside the teams...but not all of it needs protected time. Some of it does – absolutely. I think if people are going off on courses it is really important to invest that time cause otherwise there is no point in doing the course because you're not going to get into it. But I think it is also the importance of people recognising that they are learning all of the time and embracing it. Some people don't want to embrace it and some do. Everybody needs to be part of that culture of learning and use everybody's skills so we can all learn from each other. (CHAS Staff)

The arrival of new staff and volunteers within the hospice brings a wealth of experience and new perspectives, thus it is of value to take advantage of this as outlined in the following extract:

I think there are a lot of people that bring a lot of education and knowledge from different areas and I think it's been good...the culture...to be open and honest with each other about our learning and learning from each other...cause we're learning every day. (CHAS Staff)

Participants spoke of the importance of valuing people and acknowledging the contributions they make to children's hospice care, regardless of which part of the organisation they work or volunteer in. Two suggestions were put forward as to how this might be achieved. The first was by adopting a people-centred culture where there is acknowledgement that every individual in the organisation plays a valuable role and they are encouraged to utilise their knowledge, skills and experience to provide the best possible care to children and families. The second suggestion was to consider implementing the 'Learning from Excellence' initiative (<https://learningfromexcellence.com/>) to motivate individuals through celebrating their successes. This initiative was developed at Birmingham Children's Hospital and is cognisant of the potential to miss opportunities to learn from excellent practice if we only follow a learning from errors approach in healthcare. 'Learning from Excellence' aims to 'identify, appreciate, study and learn from episodes of excellence in frontline healthcare' in order to both improve patient care and enhance staff morale. One participant, quoted below, commented on the potential of this approach:

I think that would improve the culture of learning and education and valuing each other's contributions...Learning from Excellence...I think it would be good for the culture. (CHAS Staff)

Learning and support needs of hospice staff and volunteers

When participants were asked to identify what they perceived to be the priority areas for future learning and development, a topic which generated a lot of discussion and consensus amongst the group was providing end of life care and bereavement support to families. Participants spoke about having little formal education in this very important aspect of palliative care and therefore much of their learning was acquired in practice. Whilst learning in practice is valuable, the inclusion of additional formalised education in this area would increase participants' confidence in supporting families and further enhance the quality of care provided:

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. (CHAS Staff)

Moreover, as the service continues to expand, there may be a greater requirement for staff to deliver end of life care in both the hospice and the home setting. Participants commented on the importance of having additional training in this area as articulated by one participant in the extract below:

We're getting to the situation where we're trying to reach more families and if the hospice beds get fuller and the choice, if you like, to families of where you would like to be cared for in their anticipatory care plan and they would prefer to be at home, but if you've got staff who maybe haven't got very much experience of end of life care to actually go and provide it

in the home...you feel more isolated don't you going out to the home to provide it. (CHAS Staff)

There was consensus amongst participants that communication is an important area for learning. Within the broad domain of communication, participants highlighted the need for further education surrounding communicating with children and families when providing psychosocial and emotional support; delivering bad news or discussing uncertainty around a prognosis; having difficult conversations; communication amongst members of the interdisciplinary teams within which they work and learning how to listen. Participants acknowledged the impact that the changing climate within palliative care, and particularly, the rise in high profile media cases, is having on hospice staff and the need to be better prepared to manage such challenging situations. Additionally, participants recognised the complexity of ethical dilemmas and decision making in children's palliative care and would benefit from additional education in this area to further enhance their practice:

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 do. We all need to be more knowledgeable, more proactive, more upskilled. (CHAS Staff)

Participants also reiterated that effective communication is essential to quality palliative care as articulated by one participant in the quote below:

I think there needs to be communication training for all staff. We need to get communication right because that is the crux of what we do. (CHAS Staff)

Communication was referred to in relation to working directly with children and being able to communicate appropriately and effectively with them. It was acknowledged that not all staff may have knowledge and skills specifically related to child growth and development or an understanding of the importance of play activities. As this is a fundamental part of the care provided, and relevant to CHAS' growing workforce, it is of merit to ensure staff and volunteers have a sound understanding of child development, as quoted by one participant:

So, it's the whole 'being a child' training – child growth and development, child play...and that's for volunteers as well, cause again, we have volunteers who want to work with children but who haven't actually had a lot of experience working with a child directly. So, we spend a lot of time just saying 'this is what you do...this is how you communicate with children of different ages and ability.' All that sort of thing. (CHAS Staff)

Additional areas identified by participants as being a priority for future learning and development included symptom management and control, spirituality, and providing culturally sensitive care.

Support staff have specific learning needs too

The learning needs of hospice support staff and volunteers emerged as a clear sub-theme throughout the focus group discussions. Those in support roles, including but not limited to, housekeeping, administrative and maintenance staff, and volunteers, are an integral part of the hospice team responsible for providing quality care and support to children and families. Focus group participants recognised the value of support staff and volunteers' roles and wanted to ensure that their learning needs were recognised in the discussions. There was strong consensus amongst the participants that support staff and volunteers have unique and specific learning and support needs which are not always catered for in the current service. Often, individuals in these roles find themselves in situations where they are either the first point of contact for a family or where families engage in emotionally sensitive or difficult conversations with them. However, not all support staff and volunteers will have the underpinning knowledge and skills to enable them to confidently and competently manage such situations as is illustrated in the following two extracts:

The volunteers' role is really important cause we rely on volunteers so much, especially volunteers that are kind of front line as you put it with our families. Like the drivers who go out and pick up the families and a lot of times that is when families will talk...and it's difficult when you are concentrating on driving and you've got a family talking to you as well and I don't think we really appreciate that. (CHAS Staff)

Participants expressed the need for further development in this area and spoke of the merit of both support staff and volunteers engaging in learning and development around topics such as the philosophy and principles of children's palliative care; grief, loss and bereavement; how to communicate with children and families; and how to care for and look after yourself. The importance of ensuring support staff and volunteers are appropriately prepared to work with the children and families is expressed in the following extract:

...volunteers....they're working in a hospice and who actually told them about grief, who's talked to them about palliative care or how to have a conversation with a family, when do we do that? (CHAS Staff)

Looking after yourself – the importance of self-care

A second sub-theme focused on the requirement of hospice staff and volunteers to care for and look after themselves. The emotional impact of caring for children and families was recognised and participants discussed the range of support currently available to them in terms of self-care. Peer supported clinical supervision was believed to be an effective strategy, but it wasn't available across all teams within the hospice. Volunteers and bank staff were identified as people who miss out on such supervision which caused concern for some participants. Debriefing sessions were also described as beneficial and supportive, however, there were inconsistencies in how often these sessions took place after a traumatic event and who attended. Participants acknowledged the difficulty in managing

this aspect of staff support and self-care due to workload, timing and personalities. Suggestions for development included offering a range of options, both informal and formal so that staff could avail themselves of support which would be useful to them as an individual:

We need a variety of supervision to meet different needs..... developing better support networks would be good. (CHAS Staff)

Participants highlighted the value of emotional wellbeing initiatives, such as Schwartz Rounds, as a supportive mechanism where staff and volunteers could come together to talk about the emotional and social aspects of working in palliative care:

...Schwartz Rounds where it's about what you do, you know, people feedback.....it's about your emotions...and I think those kind of things would have worked beautifully for that [debriefing].....they [Schwartz rounds] are when you look at the emotional wellbeing of people. So three different people or two are present....and they sit and talk about it and people ask questions....it was quite interesting because it actually doesn't just look at the moment, it looks at what's around about that as well....what that brings up for you.....the emotions, it's really good. (CHAS Staff)

Challenges to children's palliative care education

Four main challenges related to the provision of education in children's palliative care were identified during the focus groups and each is discussed in turn.

1. Time and resources

A lack of time was thought to be one of the primary challenges from the perspective of the participants. This included not only the time to undertake any education but importantly the time and resources to apply that learning and embed it in practice. Participants spoke about how they appreciated the organisation's support of individuals to engage in learning and development, yet time was still considered to be an obstacle:

I think time. Time is a massive thing. I think CHAS are really good at investing in training and the budgets are there and they value it but it's the time to do it and then bring it back into practice...or disseminate it...or the time to link it back. (CHAS Staff)

When discussing implementation of the NES/SSSC framework and acknowledging the value of having everyone in the organisation trained to the appropriate level of the framework for their particular role, there was some concern as to how the time and resources would be made available to accommodate this, especially at a time when the service is expanding, as outlined in the extract below:

Even talking about going through the NES/SSSC Framework and going through the different levels of it...and my concern with it is we could...we will need to roll this out to everyone and then it will be all the different levels. Where is the time for that? Where is the staffing? How do you continue the service? So again, I would say...as you were both talking about...time is pretty pivotal. (CHAS Staff)

In terms of resource related to education, participants commented on the fact that there is little education available locally that is specific to children's palliative care. Most study days, conferences and educational programmes available are related to adult palliative care with little relevance to paediatrics. Attending a paediatric based educational event often requires individuals to travel across the UK and this reduces the number of staff who can access the training. Participants emphasised the absence of a nationally accepted postgraduate programme of education in paediatric palliative care within Scotland and highlighted the benefits that having such an educational pathway would have on developing and maintaining expertise within the field. There was acknowledgment of current resources which CHAS has already developed, however this was identified alongside a general feeling of inconsistency in educational provision and a need to review and collate existing good practice, as highlighted in the following quote:

Lots of bits have been done over the years but nothing structured and brought together. (CHAS Staff)

2. Complexity of care

Children's palliative care is a specialist area of practice involving the holistic care and support of children with multiple and often complex needs. Participants emphasised the rarity of many conditions and the very specific care requirements that children have. Moreover, hospice staff work in close partnership with each family to ensure that care delivered is personalised as much as possible to that individual child and family. This requires staff to regularly adapt and change their practice to the specific needs of the family as described in the quote below:

We're trying to get it right for each and every child and their needs can be so different, even if it's two children with exactly the same condition...their needs can be so different. The way their care plan goes is so different and actually that's hard to manage...you need to learn about each child. (CHAS Staff)

Maintaining the fine balance between individualising care and following practice guidelines when caring for children with such complex needs requires, as described by participants, the need to be an 'expert practitioner':

You really need to be an expert practitioner really...to apply that learning that you've got but also be able to adjust it, within safe parameters, you really have to be confident and an expert practitioner. (CHAS Staff)

Participants acknowledged the need for further and ongoing education, training and development to maintain that ability to function as 'expert practitioners' and to continue to provide quality and effective children's palliative care.

3. Extending Reach

There was some discussion regarding CHAS' current strategic aim to reach out to more families across Scotland and the resultant impact on the education needs of staff and volunteers within the organisation. It was suggested that not everyone within the organisation may be aware of and have a clear understanding of what 'reach' means in terms of changing volume of families accessing the service and a changing demographic pattern as is described in the extract below:

Fairly recently with one of your team [Support Staff]...we had a number of deaths and someone came to speak to one of the Charge Nurses one weekend. They were quite upset...there were a few deaths and they hadn't been in the service very long and there were quite a lot of babies and we said this is what it is going to be like. We explained the ChiSP report and the fact that there were a lot of children under one that we hadn't supported before and explained it more because the [Support Staff] hadn't really been aware of that changing focus and what we're doing. (CHAS Staff)

Reaching more families across Scotland, and from different health boards, has resulted in the care staff having to familiarise themselves, often in a short timeframe, with different care plans and protocols and different models of equipment such as ventilators. It was suggested by participants that this is a specific area of training and development that would be beneficial to enhancing their practice.

4. Children's palliative care is a small field

Children's palliative care is a relatively small yet distinct field. Participants acknowledged the limited opportunities for learning and continuing professional development this poses. A number of recommendations were put forward as ways to encourage the bringing individuals working in children's hospice care together to share learning and best practice. These included secondment opportunities in other children's hospices across the UK, shadowing palliative care experts in different practice settings, and utilising technology to encourage learning and develop communities of practice. The requirement to engage in shared learning with other children's hospices is not specific to one team and would benefit all those working for and volunteering with CHAS:

Having links with children's hospices in other areas would be beneficial for sharing experiences, knowledge and practice since we are the only service of our kind in Scotland. Perhaps having staff carry out secondments to these hospices would assist with this. (CHAS Staff)

Preferred learning approaches

Participants identified a range of learning approaches in the focus group discussions with the four most preferred methods being experiential learning (learning on the job), case-based learning, technology enhanced learning and learning within small groups:

We did a learning needs analysis a few years ago and we asked all of the family support team and the nursing team how they liked to learn and what the biggest thing that came back was people liked small groups....people are far more inclined in a smaller group to be vocal and share things and they felt that was a good way to learn. (CHAS Staff)

The merit of interdisciplinary learning was also clearly articulated in both hospice groups. Participants recalled learning and development sessions that they used to attend years ago when the organisation was much smaller. It was possible then to have learning and development sessions that were attended by all teams and disciplines. As the organisation grew in size and the number of staff and volunteers increased, it was difficult to maintain this approach:

At the beginning when we were a smaller team and a smaller organisation, all of our training days were for the house...the whole house...all of our staff had two days training as a whole big team. Now it's pretty much impossible to do that because of the numbers but I think it had its advantages because you felt like you were all a team...you were all equal...whether you were from maintenance or a doctor and I think we shared a lot more information. Now we've got to be split up because of the size so that's missing. (CHAS Staff)

Participants acknowledged this but questioned whether there could be an emphasis on interdisciplinary learning albeit in a different way. The benefits of interdisciplinary learning in terms of facilitating effective team working and communication and increasing awareness and appreciation of each other's roles were highlighted. One participant spoke about a recent project within CHAS where there was opportunity to work with other disciplines and with individuals in different roles as highlighted in the following extract:

I was involved in a project where there were lots of different people from different areas within CHAS who got together, and I got to work alongside a gardener. Now I'm a [Member of Care Team]...when would I ever get to work alongside a gardener? Never. But this was a specific project and I think it's just brilliant. It's having different attitudes that actually you can learn from each other not just within your own discipline. So, I mean I'm used to working with nurses and doctors. It's nice to see it from a different way and having that visibility. (CHAS Staff)

Involving families in education

The sub-theme of involving families in palliative care education generated interesting discussions and identified innovative ways of enhancing the learning and development of staff and volunteers by incorporating families' experiences. Participants described the unique perspective that families can provide and the importance of listening to and learning from their stories:

I wonder if you could use it or look at it a bit differently and use a situation that has maybe happened with a family and then use it in a learning situation...ask them for permission to use it in a learning situation. You can use their story then and use it in a learning situation so you're not actually asking them to do the training or do the teaching but you can use something that happens or an incident and use it as a learning situation to share with staff which I think we do in some clinical incidents and different things but...(CHAS Staff)

Participants also recognised the importance of ensuring the child's voice is heard as well as conveyed in the following quote:

I think we are 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. (CHAS Staff)

Participants also spoke of how in addition to staff and volunteers identifying their learning and development needs, it would be useful to involve children and families in the process:

I do think it would be helpful to ask them what they think our learning is and where the gaps are, because we can sit here and say this is what we need for these families, but they actually might be sitting there thinking 'actually you are missing...' (CHAS Staff)

Throughout this discussion there was also acknowledgment of the need for caution when involving families to ensure there was fair representation of the population rather than always relying on, or asking, the same families to be involved. One participant highlighted the importance of feeding back to the families to let them know how 'their story' impacted on people's learning, thereby reflecting a person-centred care and values-based learning approach.

Building capacity and capability for children's palliative care through learning and development

Participants recognised the important role that education, learning and continuing professional development plays in enhancing children's palliative care. The discussions that took place around this theme were engaging and there was a strong sense of enthusiasm for learning. Participants spoke about the wide range of knowledge, skills and experiences of existing staff and volunteers within CHAS. They suggested that it was important to identify individuals' areas of expertise and determine ways in which this expertise could be

maximised to benefit wider children's palliative care as communicated in the following two extracts:

Because it just feels like all of these things that we're talking about...there's huge expertise in the organisation and lots of people would learn, as opposed to us learning from them, lots of people would learn from us. We should be leading in education. (CHAS Staff)

I think that's where CHAS has a role and an opportunity to be that educator in Scotland and to be part of that education in Scotland...to be providing palliative care education to the community out there. (CHAS Staff)

Participants spoke of how everyone in the organisation has a role to play in terms of education and where possible should be supporting others to learn. This offers potential benefits in terms of succession planning and building future capacity. Learning from each other and from those with expertise in a particular area is essential, reflecting on the importance of interdisciplinary learning. The mutual benefits from teaching others is highlighted by one participant in the extract below:

There are more opportunities for nurses on the team to be involved in teaching as well, so we've all got areas that we're more knowledgeable of that we can then share. I've been involved in the T34 training and in pain management training, so just being able to use what knowledge and skills we've got and the Practice Education Nurses are really good at pulling us in to be part of that so that we're then using that knowledge, and again I would reiterate what [CHAS Staff] said, by teaching it you're then having to think on it a lot more and understand it to a greater depth. (CHAS Staff)

Regardless of which team individuals work in, or the role that they occupy within the organisation, having an opportunity to 'develop yourself' was identified as an additional way to build capacity. Participants spoke of wanting to have the opportunity to develop themselves in terms of leadership and management skills, building confidence and resilience and mentoring others. The need for a defined pathway in terms of career development was also suggested:

For many staff there is not a way for them to progress in their career, for example there is not a senior post they could apply for. To retain staff, I believe it is important to allow them some sort of progression in their learning, but also to consider their development within the context of their career, not just within their current role. (CHAS Staff)

There was some discussion around the need for greater education of the wider health and social care workforce surrounding the philosophy and principles of children's palliative care 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 a hospital will say 'oh they're not at end of life yet so they don't need palliative care' and so just sometimes the terminology and the common understanding of what it means can be a barrier as well. (CHAS Staff)

Participants reflected on the *Palliative and End of Life Care: A framework to support the learning and development needs of the health and social service workforce* (NES/SSSC 2017) and there was general agreement that such a framework may offer a way of increasing the awareness and understanding of children's palliative care. The challenge would be to ensure a consistent and integrated approach to children's palliative care across all services and agencies in Scotland. It was proposed by participants that CHAS are in an ideal position to lead on the implementation of this framework:

I think it's a case of could we be taking that [education using the NES/SSSC framework] out to others? Could people come and learn from us because that is the basic thing around terminology and understanding of 'What is palliative care?' 'What is end of life care?' Cause I still think there are paediatric nurses working out there that don't know the difference (CHAS Staff)

Findings from Professionals

Current opportunities in education

The current opportunities for learning and continuing professional development in health and social care appear to be, for the most part, locally developed initiatives specific to individual services or disciplines. Examples of good practice and innovative developments in education were shared within the focus groups. Whilst some of these initiatives are described in this section, it is not intended to be an exhaustive list and there may be other examples of good practice in children's palliative care education that were not reported in the discussions.

The Diana Children's Nurses (DCN) have been instrumental in assessing learning needs and delivering targeted educational sessions across a wide range of professionals and services. This was mentioned in the East, West, and North region focus groups with participants expressing their appreciation of the input made by the DCNs and highlighting the importance of further educational developments being delivered by this influential team.

The DCN team are responsible for maintaining and editing the NHS Education Scotland's Managed Knowledge Network for Babies, Children and Young People's Palliative Care Community of Practice which provides a host of accessible resources housed in an electronic platform. Not all focus group participants were aware of this Community of Practice and many didn't know how to access the site. This formed the basis for a wider conversation on the need to establish a national directory of children's palliative care resources and to ensure the resources were signposted and easily accessible.

Within one of the Community Children's Nursing teams, an experiential continuing professional development approach has been developed to ensure all staff are competent and confident in meeting the palliative care and end of life needs of children. The approach includes self-directed learning, reflection, group supervision and debriefs, study days and shadowing or buddying with colleagues during active care with children and families. Participants questioned whether there was opportunity to roll out effective approaches such as this, across other services and professional groupings.

An online resource called the 'Life-limiting conditions, palliative care, loss, bereavement and trauma support pack'

(http://www.highland.gov.uk/download/downloads/id/18031/trauma_loss.pdf) was recently developed by a multi-agency palliative care group chaired by a DCN in the North region. It was intended to be a source of guidance for parents, teachers and health professionals dealing with children facing unforeseen traumatic events and bereavement. The pack has been adopted by a range of agencies and recently won the COSLA Silver Award. Participants explained the potential this resource has in educating teachers who previously have been highlighted as having little knowledge or experience of palliative care, yet they continue to be supporting more and more children with complex and palliative care needs in schools.

Participants working in children's hospitals and having a remit for palliative care commented on the current informal approach to palliative care education and training as highlighted in the extract below:

I feel it's probably quite ad hoc training that goes on...[NAME] and I do deliver a lot of training but nothing is embedded into something that's repeating or annual or anything like that...so it's about us going and offering teaching, but it doesn't feel formalised.
(Professional)

Although there is a dearth of educational opportunities in children's palliative care, the specialities of neonatal and perinatal palliative care have seen a recent growth in local and national educational developments. Participants noted the importance of this population group and indicated a need to ensure such developments continued in the future.

Learning and support needs of professionals and support staff

When focus group participants were asked to identify the most important topic areas for future educational initiatives, the majority suggested communication skills as a key priority. Whilst this is a very broad topic, there were specific elements of communication that were highlighted as particularly pertinent. These included the effective communication when providing end of life care, the ability to actively listen, and to discuss uncertainty and prognosis. The quotes below highlight the requirement for additional education surrounding communication skills:

I run a bereaved parents group and the things that are very important to them are communication and care in the last days of life. I would say these are the kind of...are the main things they can remember. I mean, it always shocks me how people remember what you say, like, years later...they'll say 'I remember you said...' and you think my goodness, you know, so communication is so important because you can inadvertently just say the wrong thing. (Professional)

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. (Professional)

So there's specific training that needs to address specific areas as well, so once you start getting up towards the enhanced and skilled, I think there has to be real development of good training around the communication skills, enhanced communication skills, ethics, how to practically manage difficult ethical situations which I think are only going to increase. (Professional)

Participants acknowledged the importance of faith and culture and felt it would be extremely valuable to explore how one's faith and culture, be it from the perspective of the care provider or the care recipient, affect an individual's responses to palliative and end of life care. Participants identified this as an example of an area in which there is little formal education, leaving professionals to rely on experience acquired in practice.

Participants also requested further guidance on managing parents' expectations related to their child's care and treatment and an exploration of how to effectively cope with challenging situations. There was acknowledgement amongst participants that such situations are being experienced more often and professionals require guidance to be able manage parents' needs and expectations in an effective and compassionate manner. The following extract articulates this point from the perspective of one professional:

And I think a lot, we probably all need it, a lot of guidance about parental expectations. So I've seen lots in the paper 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 who are 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, you know, 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 and their expectations. (Professional)

Additional areas of palliative care that participants would value further support, education and training on included Anticipatory Care Plans (ACP) and the Children and Young People Acute Deterioration Management (CYPACD) policy; symptom control; medications used in palliative care; ethical dilemmas and advanced decision making; support for siblings; and providing psychosocial and emotional support to families, particularly surrounding grief and loss.

Participants clearly articulated the requirement to ensure all individuals who come into contact with children and families, regardless of role or position, are engaged in palliative care education:

I think if you look at the context of children being at home and in the community then you've got health visitors, community children's nurses....and then they [children] go to school so they may be in a special needs or mainstream environment supported by teachers. They may have a package of care so there may be voluntary services involved, social work, support workers...so there's a huge range of people who are involved in children's palliative care and need education. (Professional)

In addition to these, there are a number of support staff who have regular and often prolonged contact with children and families with palliative care needs and would also benefit from education in this area. Participants suggested that the NES/SSSC framework (2017) affords an opportunity to develop and implement training for all staff groups to an informed level, including those in support roles, as highlighted in the quote below:

The NES/SSSC framework is directed at porters, housekeeping...it's across the board and it's not just nursing, and AHPs and medics. It should be anybody that comes into contact in a care setting with families with children who have palliative needs. (Professional)

Looking after yourself – the importance of self-care

When participants were asked to consider the role of self-care for those working in the field of children's palliative care, there was consensus amongst the groups that this is an important area of their practice which currently does not receive adequate attention. There was a sense that many professionals don't actively acknowledge the emotional demands of their role and are sometimes hesitant to come forward for support. One participant described a recent change to this pattern with nursing staff acknowledging the need for self-care more frequently than in the past:

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. (Professional)

Many participants suggested that further support strategies should be put in place to build resilience and to guide professionals in how to best engage in self-care activities. Whilst there are opportunities for clinical supervision and debriefs in most settings, this is often done on an ad hoc basis or in some cases is delayed and doesn't take place until too long after the event. Participants acknowledged that facilitating a debrief and/or a clinical supervision session is an advanced skill and there is a need for additional training in this area to ensure all staff have access to effective support:

Learning platforms need to build in proper 'debriefs' after a crisis situation or post-death. Clinical supervision is difficult and emotional and needs to be handled carefully...people need to be comfortable with each other. Outcomes from clinical supervision HAVE to be taken forward – 'the benefit of clinical supervision is in the action'. (Professional – survey)

A lack of staff support has implications for the person, the team, and the overall service. Examples where staff members left the profession as a result of the emotional impact of the role were shared. The additional impact of relying on a small pool of staff members caring for children at the end of life, due to limited members of their team having sufficient experience and expertise in palliative care, is a pressure all too often felt in these services. This suggests that formalised supports must be in place to reduce the risk of staff burnout and ensure there isn't an adverse effect on capacity in the palliative care workforce:

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. (Professional)

Preferred learning approaches

Learning approaches which participants considered to be most effective included case-based learning, simulated practice, experiential learning and shadowing or buddying with experienced colleagues. Experiential learning or learning through exposure to a clinical situation and role modelling, has particular relevance in children's palliative care, enabling staff to link theory to their practice. 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 may have 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. (Professional)

It's about sharing it, it could be writing case reports on cases that folk had in the past, there might be unique cases out there but I'm sure every case is unique, but it's actually putting it on paper...what you did, if there's been any changes in practice...we learn from that and it's a sharing of stories. (Professional)

Participants spoke about the preference for opportunities to practice and apply their knowledge and skills in safe and supported environment. An important distinction was that there was an expert practitioner there to guide individuals through this process. The importance of having an opportunity to practice various skills is described in the following extracts:

I think some of the things we're talking about is really being able to have a safe space to practice how are you going to say that, how are you going to get your message across, what words do you want to use...and I think that's something that I never had during my training, but I've had that in recent years and it's really helpful. (Professional)

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. (Professional)

Participants recognised the challenges in identifying those professionals with palliative care expertise and in knowing where to go and how to access support. The presence of a specialist children's palliative care team within the hospital setting was advocated as way of signposting key contacts and experts in the field. It was felt that this team would have a key role in educating and supporting other staff in providing palliative care.

There was an emphasis on the importance of maintaining a balance between clinical skills and communication skills highlighting the importance of psychosocial support in children's palliative care and all professionals having competence in this area:

The equality is a big thing for me and I think staff should all be trained to the same level in both clinical and the softer skills. (Professional)

Technology was discussed as an effective medium to promote shared learning across different services and disciplines, particularly for those providing care to families in rural and remote areas. Experiences of using *Project ECHO* as a means of connecting with and sharing learning between professionals delivering children's palliative care were shared in one of the focus groups and there was consensus that such initiatives have the potential to be further developed and implemented across Scotland, thus improving accessibility. For some, the use of online teaching was felt to be the least useful form of learning when discussing an emotive subject such as palliative care, however the use of this mode as an 'introduction' to the topic was seen to be helpful:

Practical helpful suggestions to move from uninformed to at least informed..a basic online module about what palliative care ...should mean today.....whether or not you make it mandatory, at least then it's one resource that can be developed . (Professional)

Participants valued the opportunity to 'learn together' with colleagues across disciplines and suggested this is embedded within education whilst maintaining opportunities for discipline specific learning as well.

Involving families in education

Participants placed an emphasis on the value of learning from families' experiences and suggested there are a number of ways in which this could be achieved. 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 they suggested this to be a very powerful and effective approach.

If you get a parent this is the most powerful thing, getting somebody's personal story about what they've been through and their reflection on it. (Professional)

Professional often assume that families don't want to tell their story and share them as an educational tool and this point was captured in the following extract:

I think we tend to gatekeep as well...We think oh we wouldn't want to put a family through that, so we would shy away from doing it, but actually I think the research shows that families really want to do that, they want to have their voice heard. (Professional)

Challenges in children's palliative care education

Three main challenges related to the provision of education in children's palliative care were identified during the focus groups and each is discussed in turn.

1. Resources to support education

Insufficient resources to support palliative care education was identified as a challenge. Participants spoke of a lack of priority for children's palliative care education in health and social care. Unlike other topics areas, such as child protection which is deemed to be mandatory and training is expected across all staff and disciplines, palliative care is not recognised in this way. The recent publication of the NES/SSSC (2017) framework offers the potential to address this and ensure children's palliative care is given the attention it deserves:

It's a bit of a vicious circle because you actually rely on people to opt in [to training]...at this moment in time palliative care is a specialty that you can chose to opt into if you've got a genuine interest, whereas child protection is everybody's business, yet a lot of the literature says children with palliative care needs are everybody's business but that's not embedded into practice. It's not mandatory. (Professional)

Unless it is pertinent to that person at that time, it doesn't get attention. But we all will at some time in our life encounter a palliative care situation and need to have some understanding of the impact that has on a child and their family. (Professional – survey)

Having access to educators with expertise in children's palliative care was highlighted as an additional resource requirement as there is currently difficulty in doing this as described by one participant in the extract below:

I find some of the challenges is keeping it varied as well in terms of who's delivering that training because there aren't very many people who have that skill set in palliative care to be able to teach palliative care to...it's trying to get various speakers rather than one person doing the session all the time. (Professional)

2. Maintaining knowledge and skills in children's palliative care

The relative rarity of children's palliative care was suggested as a challenge. Many professionals, depending on the area they work in, will have limited exposure to children with palliative care needs. This results in these professionals either not seeing the relevance of education because they won't need to apply the learning to their regular practice or in the cases where they do undertake learning and development 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're right, 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? (Professional)

Staff turnover was identified as challenge. Participants commented on a high turnover of nursing staff in the acute hospital setting with experienced staff leaving the profession and new staff appointed being early in their careers and with little experience in caring for children and families with palliative care needs.

Participants reiterated the importance of ensuring professionals across all services and disciplines know how to access specialist support and guidance when they find themselves

in a situation where they need additional support in providing palliative and end of life care to children and their families.

3. *A need for raising awareness and understanding of children's palliative care*

There is evidence to suggest that a limited awareness and understanding of children's palliative care continues to exist for many health, social care and education professionals. The equation of palliative care with end of life care remains prevalent as highlighted in the extract below:

But actually we have children who come into intensive care who have palliative needs but may not be at the end of their life and I think that's throughout the hospital a lot of people think palliative care's end of life and I remember a few years ago being on a ward saying 'you're not allowed to talk to that family they're palliative' but actually there's many children in the hospital that have palliative care needs but are not dying now. (Professional)

A key theme generated from the focus group discussions was a 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 also identified as a challenge and there were suggestions to 'rebrand' palliative care with an alternative term such as 'supportive care' or 'life-shortening conditions':

Partly I think it's a branding thing. I think 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. (Professional)

Understanding the terminology and the differences between how long somebody can be in palliative care before it's end of life. That's huge. (Professional)

The term [palliative care] is awful! People think end of life or end stage. (Professional)

Building capacity and capability for children's palliative care through education

All three of the focus group discussions generated positive and encouraging suggestions for how education could support building capacity and capability in children's palliative care. Participants advised that the introduction to palliative care must start early by including the principles and philosophy of children's palliative care in undergraduate education for all health and social care professions. Moreover, the opportunity to undertake a clinical

placement within a children's hospice as part of undergraduate education should be prioritised where possible. The quote below describes a potential way that children's palliative care could be introduced at undergraduate level from the perspective of one focus group participant:

I just wonder whether CHAS could...if they developed some sort of package and even were able to deliver some sort of workshop. I'm thinking about undergraduate stuff either for nursing or medics. If they could deliver some sort of workshop and actually go to the university and say 'we have this package about...and it takes one afternoon and we will staff it, we will provide it, we have the expertise, we've created the little stories that make it interesting and actually people engage with and we can integrate this with your curriculum, or can we provide it as an add on or an optional thing? I mean, for me, that could then link them with people who are running the paediatric courses...(Professional)

The requirement for a collaborative approach to education within children's palliative care to ensure practice and approaches are consistent across services and disciplines was acknowledged:

The equality of palliative care provision for patients who are cared for in hospital, home or hospice environments throughout Scotland requires standardised, formal education with strict governance. (Professional)

Participants advocated 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. (Professional)

Participants clearly articulated that, currently, there are limited opportunities for the continuing professional development of those with an interest and experience in children's palliative care. They highlighted the absence of postgraduate degrees that are paediatric specific and reiterated the importance of having a clear pathway for postgraduate level study in building capacity and capability in the field. It is important to foster the development of specialists and leaders in children's palliative care who can continue to contribute to the advancement of the evidence base in this field.

In addition to both ensuring children's palliative care is present in health and social care undergraduate education and supporting the development of specialist practitioners in children's palliative care, participants recognised the need to integrate education initiatives for those working in generalist roles, including but not limited to ward clerks, porters, housekeeping, and nursery nurses, who would clearly benefit from broader and more detailed guidance on children's palliative care. Finally, there are still improvements to be made in increasing understanding of children's palliative care amongst the public as recently evidenced by recent high-profile media cases and the resulting discussions in social media platforms.

Summary of Key Points from Phase 2 – Education, learning and continuing professional development requirements of the children's palliative care workforce

The experiences and perspectives described by CHAS staff members and those professionals delivering children's palliative care in different services and regions in Scotland were largely homogenous. There were issues related to education that were specific to each group, however, the overall consistency in the discussions provides a strong rationale for considering a standardised and national approach to education in children's palliative care.

The underlying importance of education in enhancing the quality of care delivered to children with palliative care needs and families was compelling and resonated across the focus group discussions. Educational initiatives should be targeted at all those who have contact with children and families with palliative care needs, including individuals working in support roles and volunteers. The level and scope of education should be dependent on an individual's role and responsibilities.

Areas identified for future learning and continuing professional development were consistent across the focus groups with the domain of communicating with children and families surfacing as one of the main priorities. There were many examples of communication skills that could be enhanced through further education, including communicating difficult information to families and providing psychosocial and emotional support. Participants acknowledged that further education on end of life and bereavement care should also be prioritised. A recurrent theme running through each of discussions was the essential requirement for self-care. The emotional impact of working with in the field of palliative care was acknowledged and an educational framework for self-care where professionals can discuss, reflect and learn from their experiences in practice is required.

Preferred learning approaches were also comparable between CHAS staff and external professionals and included case-based learning, small group learning, simulated practice and experiential learning. Participants emphasised the merit of 'learning on the job' and where possible, children's palliative and end of life care education should be integrated into everyday practice. It is important to share learning and for those who are more experienced in paediatric palliative care to support others in gaining knowledge and skills. Participants

recognise that effective children's palliative care is predicated on inter-professional collaboration and team-working and support an interdisciplinary approach to palliative care education and training.

There were many similarities in the key challenges identified for children's palliative care education. Mutual challenges involved resource implications, namely time, to access training and apply learning to practice and limited opportunities for continuing professional development including an absence of postgraduate programmes that focus on children's palliative care.

Challenges specific to CHAS' workforce were also raised. A recent strategic aim within the organisation to extend their 'reach' and provide care to more babies, children and young people with palliative care needs across Scotland is advocated by its staff and volunteers. However, this expansion in the service has identified specific learning and development needs that can be addressed through a future education strategy to best support staff and volunteers in delivering care.

The focus groups generated both innovative and achievable ways in which capacity and capability for children's palliative care could be fostered through education. The potential for CHAS to lead such educational developments and serve as an expert resource to the broader children's palliative care community resonated within the discussions.

Having a strong organisational philosophy and culture of learning was identified by the participating CHAS staff and volunteers as a means of motivating and encouraging lifelong learning within the hospice. There was a clear enthusiasm amongst participants to create and nurture a culture of evidence-based learning.

In summary, the findings from this phase of the scoping exercise provides further evidence to inform the development and implementation of a comprehensive programme of evidence-based palliative care education which will meet the learning and development needs of CHAS's workforce. Such a programme would additionally be of value if it were extended to professionals working in the wide ranges of settings where children with palliative care needs and their families are cared for and supported.

5. Phase 3 – Recommendations for the Development of an Education Strategy

The recommendations which have been developed from this work are outlined below and whilst not exhaustive of the extensive evidence generated during the scoping project, reflect the key aspects to consider when developing an education strategy. The recommendations are as follows:

Recommendation 1: The education strategy should adopt a strong philosophy and culture of learning, enquiry and evidence-based practice. Across the organisation, there should be a clear understanding of how education and research support the delivery of best care to children and families. With a focus on valuing learning and development, individuals can be supported and motivated to become life-long adult learners.

Recommendation 2: Developing and implementing an education strategy will have resource implications and requires a dedicated learning and development team. Within the team, there should be the inclusion of expertise from both paediatric palliative care practice and higher education. There may be merit in expanding the current practice education team to facilitate the development, delivery and evaluation of education to all teams within the hospice and to external palliative care providers.

Recommendation 3: Consider conducting a formal learning and development needs analysis on a regular basis to ensure that education and training is responsive to the changing needs of staff and volunteers. Whilst not an exhaustive list, some of the current priority learning and development needs identified during this project include:

- communication skills, including communicating difficult information to families and providing psychosocial and emotional support;
- end of life and bereavement care across a range of settings (home, hospice, hospital);
- clinical skills and management of the symptoms associated with complex and rare life limiting conditions;
- spirituality and culturally sensitive care;
- complex ethical dilemmas, advanced decision making and managing parental expectations.

Recommendation 4: The education strategy should be cognisant of the relational and emotional context within which staff and volunteers are caring for and supporting children and families. Through evidence based educational approaches, self-care, self-awareness and resilience building should be addressed to support staff and volunteers in managing the emotional dimension of their roles.

Recommendation 5: Consider implementing the educational strategies and approaches identified from the literature review and focus group discussions:

- involve children and families in the education process by learning from their stories and experiences;
- promote experiential learning or ‘learning on the job’ by integrating education into everyday practice;
- encourage those who are more experienced in children’s palliative care to act as role models in supporting their colleagues;
- adopt an interdisciplinary approach to palliative care education and training where relevant and possible;
- embrace technology and establish opportunities for individuals to connect with and learn from others delivering children’s palliative care both nationally and internationally.

Recommendation 6: Consider developing formal relationships with higher education institutions to further the development and accreditation of educational courses. Specific consideration should be given to the development of an inter-professional post-graduate educational pathway in the context of advanced paediatric palliative care practice. This is important for supporting the development of future leaders in children’s palliative care and promoting the creation and dissemination of evidence-based knowledge in paediatric palliative care.

Recommendation 7: Further development and enhancement of clear career pathways for all staff groups within CHAS (newly qualified, qualified, support staff and volunteers) should be prioritised to ensure opportunity for continuing personal and professional development and progression.

Recommendation 8: Three main populations were identified as a priority for implementing educational initiatives in children’s palliative care – the public, those working in generalist roles, and palliative care specialists.

CHAS are ideally placed to lead the development of such initiatives and it is recommended that CHAS consider developing educational initiatives in partnership with key stakeholders and experts across NHS Scotland.

Recommendation 9: Consideration should be given to maximising opportunities for building capacity and capability in the small and specialist field of paediatric palliative care, through sharing of knowledge and expertise. Strategies to achieve this may include:

- the creation of joint posts or rotational secondments between the hospice and the NHS (acute and community services);
- establishing formal links with other children's hospices in the UK to encourage a collaborative approach to education. This could include opportunities for reciprocal short-term exchanges and learning placements.

Recommendation 10: CHAS should consider linking with higher education institutions to influence the curriculum by sharing innovative and feasible ways of integrating the concepts of children's palliative care into undergraduate education. Establishing formal links with higher education institutions would provide an opportunity to establish consistency in education. In addition, further promotion of practice learning experiences with CHAS would be beneficial to link theory with palliative care practice.

6. Conclusion

Education, learning and continuing professional development are an integral part of the provision of high-quality palliative care. This scoping project has brought together existing evidence from published and grey literature in this specialty area with newly acquired evidence generated from the perspectives of those working and volunteering in children's palliative care across Scotland. It is clear that there is a commitment to and enthusiasm for further enhancing education in the field. Whilst there are examples of innovative and effective learning and development initiatives across Scotland, there is a need to ensure a more cohesive and standardised approach to education. The evidence from this scoping project has been used to shape a set of recommendations which may inform the development of an education strategy for CHAS and influence the delivery of a national approach to education in children's palliative care.

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8. Appendices

Appendix 1 – Members of the Project Steering Group

Appendix 2 - PRISMA flowchart of search strategy and paper selection process

Appendix 3 - Papers included in the scoping review

Appendix 4 - Grey Literature

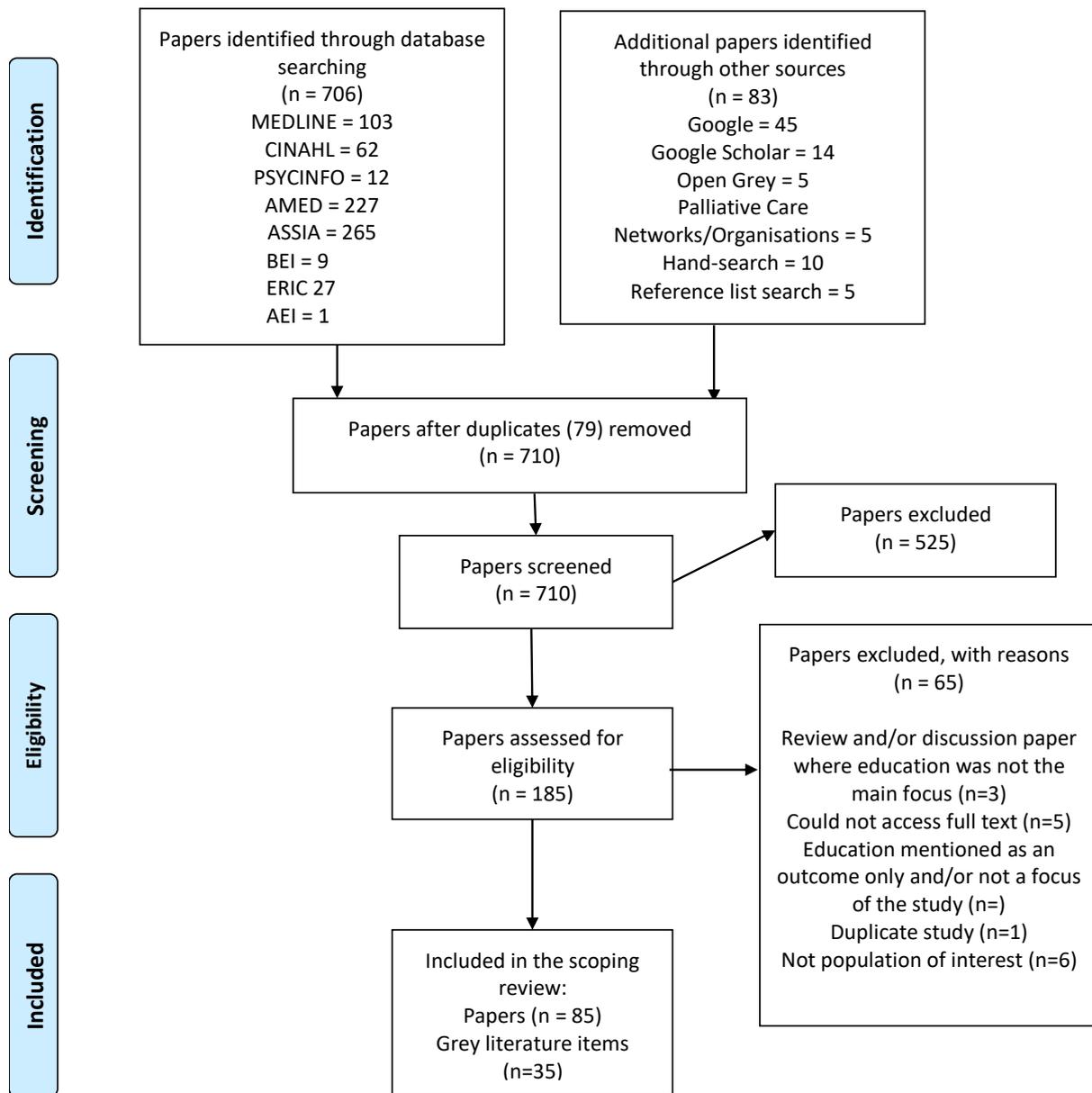
Appendix 5 – Focus Group Discussion Guide (CHAS Staff)

Appendix 6 - Focus Group Discussion Guide (External Professionals)

Appendix 1: Members of the Project Steering Group

Name	Affiliation
Maria McGill	Chief Executive, CHAS
Pat Carragher	Medical Director, CHAS
Sue Hogg	Director of Children and Families, CHAS
Jayne Grant	Clinical Nurse Manager, CHAS
Yvonne Caie	Clinical Nurse Manager, CHAS
Evelyn Rodger	Diana Children's Nurse
Fiona Reid	Diana Children's Nurse
Caroline Porter	Diana Children's Nurse
David Smyth	Paediatric Advanced Nurse Practitioner, Children's Community Team, NHS Fife
Elizabeth Gillespie	Community Children's Nurse, Team Lead, NHS Greater Glasgow and Clyde
Sandra Stewart	Administrator, CHAS

Appendix 2: PRISMA flowchart of search strategy and paper selection process.



Appendix 3: Papers included in the scoping review.

	Author (year of publication)	Origin	Type of Paper
1	ACT (2009)	UK	Report by professional or voluntary organisation
2	ACT & CHUK (2009)	UK	Report by professional or voluntary organisation
3	Adams et al. (2013)	USA	Peer-reviewed journal – descriptive qualitative design
4	Ahern (2013)	Australia	Peer-reviewed journal – Delphi consensus method
5	Amery (2012)	UK	Peer-reviewed journal - descriptive questionnaire survey design
6	Amery et al. (2010)	Uganda	Peer-reviewed journal – mixed qualitative and quantitative survey design
7	Amery & Lapwood (2004)	UK	Peer-reviewed journal article - descriptive questionnaire survey design
8	APPM & RCPC (2015)	UK	Educational resource
9	Bagatell et al. (2002)	USA	Peer-reviewed journal article – pre- and post-test survey design
10	Baker et al. (2007)	USA	Peer-reviewed journal article – review (narrative)
11	Barnett et al. (2016)	USA	Peer-reviewed journal article - pre- and post-test survey design
12	Baughcum et al. (2007)	USA	Peer-reviewed journal article - pre- and post-test survey design
13	Billings et al. (2011)	UK	Peer-reviewed journal article – multi-method scoping project and strategy development
14	Bishop et al. (2009)	South America	Peer-reviewed journal article – review (narrative)
15	Botwinski (2010)	USA	Peer-reviewed journal - descriptive questionnaire survey design
16	Brown et al. (2012)	USA	Peer-reviewed journal article – matched pre- and post-test survey design
17	Browning & Solomon (2005)	USA	Peer-reviewed journal article - descriptive
18	Browning & Solomon (2006)	USA	Peer-reviewed journal article – review (narrative)
19	Carter & Swan (2012)	USA	Peer-reviewed journal article - descriptive

20	Charlton (1996)	UK	Peer-reviewed journal article - review (narrative)
21	Crichton (2012)	UK	Peer-reviewed journal article – review (narrative)
22	Craig et al. (2007)	UK	Peer-reviewed journal articles – practice standards
23	Department of Health (2008)	UK	National framework/guideline
24	Department of Health (2016)	UK	National framework/guideline
25	Downing & Ling (2012)	UK	Peer-reviewed journal articles - discussion paper
26	Downing et al. (2013)	UK	Report by professional or voluntary organisation
27	Ferguson et al. (2012)	UK	Book Chapter
28	Field & Behrman (2003)	USA	Report by professional or voluntary organisation
29	Gallagher et al. (2012)	UK	Peer-reviewed journal article - descriptive questionnaire survey design
30	Gamondi et al. (2013)	Switzerland	Peer-reviewed journal article – white paper on competencies
31	Hain et al. (2012)	UK	Peer-reviewed journal article - review (narrative)
32	Harris et al. (2015)	USA	Peer-reviewed journal article – pre- and post-test survey design
33	Henner & Boss (2017)	USA	Peer-reviewed journal article - review (narrative)
34	Huijjer et al. (2008)	Lebanon	Peer-reviewed journal article - descriptive questionnaire survey design
35	Jacobs et al. (2009)	USA	Peer-reviewed journal article - pre- and post-test survey design
36	Kain (2017)	Australia	Peer-reviewed journal article – pre- and post-test survey design
37	Kato et al. (2011)	Japan	Peer-reviewed journal article – pre- and post-test survey design
38	Kolarik et al. (2006)	USA	Peer-reviewed journal - descriptive questionnaire survey design
39	Lee et al. (2016)	Taiwan	Peer-reviewed journal - descriptive questionnaire survey design

40	Liben et al. (2008)	Canada	Peer-reviewed journal article – review (narrative)
41	Mackenzie & MacCallam (2009)	UK	Peer-reviewed journal article – evaluation research
42	Malloy et al. (2006)	USA	Peer-reviewed journal article – descriptive review of the implementation of an educational programme
43	Malloy et al. (2007)	USA	Peer-reviewed journal article - description of the implementation of an educational programme
44	Mancini et al. (2013)	UK	Peer-reviewed journal article – review (narrative)
45	McCabe et al. (2008)	USA	Peer-reviewed journal - descriptive questionnaire survey design
46	McNeilly et al. (2008)	UK	Peer-reviewed journal article - evaluation research
47	Michelson et al. (2009)	USA	Peer-reviewed journal - descriptive questionnaire survey design
48	Miller & Woodhouse (2017)	UK	Project Final Report
49	Moody et al. (2018)	USA	Peer-reviewed journal article - pre- and post-test survey design
50	Murakami et al. (2015)	Japan	Peer-reviewed journal article – pre- and post-intervention survey design
51	National Palliative and End of Life Care Partnership (2015)	UK	National framework/guideline
52	Neilson et al. (2010)	UK	Peer-reviewed journal article - qualitative design
53	NES/SSSC (2017)	UK	National framework/guideline
54	Nicholl & Price (2012)	UK	Peer-reviewed journal article - review (narrative)
55	Nicholl et al. (2016)	UK	Peer-reviewed journal article - evaluation research
56	O’Shea et al. (2015)	USA	Peer-reviewed journal article – matched pre- and post-test survey design
57	Papadatou (1997)	Greece	Peer-reviewed journal article - review (narrative)
58	Peng et al. (2013)	Taiwan	Peer-reviewed journal article – descriptive questionnaire survey design

59	Pfund (2005)	UK	Peer-reviewed journal article – descriptive
60	Price & McNeilly (2006)	UK	Peer-reviewed journal article - descriptive
61	Price et al. (2013)	UK	Peer-reviewed journal article – evaluation research
62	Price et al. (2014)	USA and UK	Peer-reviewed journal article – evaluation research
63	Price et al. (2015)	UK and Australia	Peer-reviewed journal article – evaluation research
64	Quinn & Hillis (2015)	UK	Peer-reviewed journal article - descriptive questionnaire survey design
65	RCN (2018)	UK	Educational competences
66	Rogers et al. (2008)	USA	Peer-reviewed journal article - quantitative pre-test, intervention, post-test design
67	Sahler et al. (2000)	USA	Peer-reviewed journal article - review (narrative)
68	Schiffman et al. (2008)	USA	Peer-reviewed journal article - pre- and post-test survey design
69	Scottish Government (2012)	UK	National framework/guideline
70	Scottish Government (2015)	UK	National framework/guideline
71	Sheetz & Bowman (2008)	USA	Peer-reviewed journal article - descriptive questionnaire survey design
72	Singh et al. (2017)	USA	Peer-reviewed journal article - descriptive questionnaire survey design
73	Snaman et al. (2017)	USA	Peer-reviewed journal article – pre- and post-test survey design
74	Solomon et al. (2010)	USA	Peer-reviewed journal article – evaluation research
75	Spalding & Yardley (2016)	UK	Peer-reviewed journal article - action research design
76	Summers (2013)	UK	Peer-reviewed journal article - descriptive
77	Swinney et al. (2007)	USA	Peer-reviewed journal article – cross-sectional quantitative and qualitative survey design
78	Taylor & Aldridge (2017)	UK	Peer-reviewed journal article – qualitative design
79	Together for Short Lives (2017)	UK	Report by professional or voluntary organisation

80	Twamley et al. (2013)	UK	Peer-reviewed journal article – pre- and post-test survey design
81	Wager et al. (2013)	Germany	Peer-reviewed journal article - descriptive questionnaire survey design
82	Widger et al. (2016)	Canada	Peer-reviewed journal article - description of study protocol
83	Wiener et al. (2015)	USA	Peer-reviewed journal article - descriptive questionnaire survey design
84	Yazdani et al. (2010)	USA	Peer-reviewed journal article - pre- and post-test survey design
85	Zhang & Lane (2013)	USA	Peer-reviewed journal article – pre- and post-test survey design

**Appendix 4: Grey Literature
COMPETENCES AND CURRICULAE**

Provider and country of origin	Target audience	Overview	Mode of learning and outcome
Royal College of Nursing (RCN) (2018), UK	Healthcare support workers, newly qualified and experienced nurses	Identifies four dimensions of knowledge which are mapped to all levels of the Department of Health Knowledge and Skills Framework (KSF) via individual competences	Ongoing as part of role evidence of continuing professional development (CPD)
European Association for Palliative Care (EAPC) (2013), Italy (Downing <i>et al</i>)	All health professionals in general and specialist services	Specific levels of education (palliative care approach; general and specialist) all of which stipulate separate domains of knowledge appropriate to the level of practice	Ongoing as part of role
Royal College of Paediatrics & Child Health (RCPCH) (2010), UK	Trained paediatricians	Details knowledge skills and behaviours expected of trained paediatricians in UK through two sets of competences: generic competences/generic clinical competences and speciality-specific competences	Ongoing as part of role Paediatric Palliative Medicine (PPM) Paediatrician
RCPCH (2017), UK	Trained paediatricians	Mapped against GMC generic professional capabilities. Contains learning outcomes, key capabilities and assessment tools	Ongoing as part of role Paediatric Palliative Medicine (PPM) Paediatrician

Association of Paediatric Palliative Medicine (APPM) & RCPCH (2015), UK	Trained paediatricians	Knowledge identified in three domains which are sub-divided into specific competences which are system and symptom-specific	Ongoing as part of role Paediatric Palliative Medicine (PPM) Paediatrician
EAPC (2013)	Medical students	Guiding syllabus regarding basic content for undergraduate medical curricula focusing on seven domains of practice	Ongoing as part of undergraduate role
Initiative for Paediatric Palliative Care (IPPC), USA	Interdisciplinary staff working in paediatric palliative care settings	Free of charge online learning programme requiring registration with IPPC. Curriculum consist of five modules offered as a combination of online lectures and seminars, focusing on knowledge, skills and attitudes of practitioners	Part-time. Modules can be accessed as part of the overall programme, or stand-alone.
American Association of Colleges of Nursing (AACN) and End of Life Nursing Education Consortium (ELNEC), USA	Interdisciplinary staff (undergraduate and post-graduate) working in paediatric palliative care settings	Curriculum consists of 10 modules exploring various key topics relating to paediatric palliative care. Modules are available via an independent external online care and behaviour health provider. Requires registration with ELNEC and payment for each individual module.	Part-time. On completion of the 10-module programme, certificate of completion is awarded

EDUCATION FRAMEWORKS AND STRATEGIES

Provider and Country of origin	Programme title	Target audience	Overview	Mode of learning and outcome
NHS Education for Scotland and Scottish Social Services Council (NES/SSSC) (2107), UK	A framework to support the learning and development needs of the health and social service workforce in Scotland	All health and social care staff working in Scotland	Identifies four levels of knowledge which are applied to five specific domains of practice to enable staff to determine existing knowledge and highlight areas for CPD	Ongoing as part of role Evidence of continuing professional development (CPD)
Scottish Government (2015), UK	Strategic Framework for Action on Palliative and End of Life Care 2016-2021	All staff working in Scotland's care services who are providing palliative care	Creation of 10 commitments which take account of the National Health and Wellbeing Outcomes. Reference to paediatric palliative care is made in commitment 4, with a further two commitments being focused on the development of a general education framework and establishment of a Scottish Research Forum	n/a – guidance document
Scottish Government (2012) Scottish Children and Young People's Palliative Care Executive Group (SCYPPEX), UK	A Framework for the delivery of Palliative Care for Children and Young People in Scotland	All staff delivering paediatric services in Scotland	Framework consists of five outcomes with additional key objectives, one of which relates to education and training provision	n/a – guidance document

Department of Health (2016), UK	Providing high quality palliative care for our children. A strategy for children's palliative and end-of-life care 2016-18	All staff delivering palliative care in England and Wales	Eight foundations of good care delivery which including a recommendation that every locality has a framework in place for education, training and CPD.	n/a – guidance document
Department of Health Northern Ireland (2016), UK	A strategy for Children's Palliative and End of Life Care 2016-26		Outcomes based framework via 23 specific objectives, two of which relate to the need for pre and post-registration education for professionals and the additional development of interagency training and education for health, social care and voluntary staff	n/a – guidance document
National Palliative and End of Life Care Partnership (2015), UK	Ambitions for Palliative and End of life care: a national framework for local action		Six specific ambitions for practice, one of which relates to general principles of education and research with some reference to children	

EDUCATION STANDARDS

Provider and country of origin	Programme title	Target audience	Overview	Mode of learning and outcome
European Association for Palliative Care (EAPC) (2007)	IMPACT: Standards for paediatric palliative care in Europe	All staff in across Europe delivering paediatric palliative care	Document which defines and identifies key standards of care to be adopted across all European countries. Focuses on three levels of knowledge with four general recommendations for training and education	n/a – guidance document
National Hospice and Palliative Care Organisation (2009), USA	Standards of Practice for Pediatric Palliative Care and Hospice	All practitioners delivering palliative care to babies, children and young people in a range of settings	Principles relating to specific areas of practice with associated standards and practice-related examples	n/a – guidance document

GENERAL TRAINING AND EDUCATION

Provider and country of origin	Programme title	Target audience	Overview	Mode of learning and outcome
Hospices across UK	Learning and development strategy for all staff	All staff working in the individual hospices	Various clinically-based education and training programmes exist within each hospice to meet the needs of their staffing profile	variable
International children's	ICPCN e-learning programme	All staff across the world with interest in	Selection of short courses available free of charge, online and offered in a variety of languages	Self-directed and part of CPD

palliative care network (ICPCN)		children's palliative care		
International children's palliative care network (ICPCN)	Post-graduate training and courses	International list of participants	Information relating to current post-graduate paediatric palliative care education provision in countries across Europe	n/a – guidance document
University of the West of England, Bristol, UK	Enhancing practice in palliative care for children, young people and families	Professionals working with children with palliative care needs and families in any setting	20 credit, level 3 (England Undergraduate) and Masters level Short course, 8 days plus online learning activity	part-time Stand-alone module or part of BSc/MSc pathway
University of Central Lancashire	Introduction to children's palliative care short course	Anyone working with children with palliative care needs	Introductory 1-day workshop - care and management of children and young people requiring palliative care	Part-time, CPD
Edgehill University, Lancashire, UK	BSc (hons) Clinical and Professional Child and Younger Person Palliative and End of Life Care Practice	Registered professional with NMC/HPC and practising within a palliative and end of life care environment	Complete educational programme using an interdisciplinary approach to equip professionals with ability to develop knowledge and skills in research and advanced practice relating to children's palliative care	Part-time, 2- 5 years BSc (hons) Clinical and Professional Child and Younger Person Palliative and End of Life Care Practice

Edgehill University, Lancashire, UK	Palliative and End of Life Care for Children and Young People	Registered nurses, AHP's/other professionals, working/have specific interest in palliative care for children & young people	Module exploring key issues in children's palliative care	Part-time, stand alone module. Core module for the BSc (Hons) and option module for BSc (Hons) Clinical and Professional Practice programme
Great Ormond Street Hospital for Children, UK	Paediatric palliative care foundation programme	All practitioners with interest in paediatric palliative care	2 separate taught days over 1-2 months exploring basic issues in paediatric palliative care using face-to-face and online teaching methods	Part-time, CPD
University college London & Louis Dundas Centre for Children's Palliative Care, UK	Varying 'ad-hoc' workshops and short programmes	Specialists in paediatric palliative care across all professional, clinical and academic groups	Various workshops and short programmes	Part-time, CPD
American Association of Colleges of Nursing (AACN) and End of Life Nursing Education	National 'Train the Trainer' paediatric palliative care programme	Specialists in paediatric palliative care	Includes perinatal and neonatal content in addition to other relevant issues for children, young people and their families	Part-time

Consortium (ELNEC), USA				
University of Plymouth, UK	Enhancing practice in paediatric palliative care	For all health and social care professionals working in paediatric palliative care	20 credit module offered at degree and Master's level	Part-time, BSc or MSc pathway outcome
Cardiff University, UK	Palliative Medicine for Health Care Professionals (MSc)	Healthcare professionals working with children and young people with incurable conditions	3 year programme – 1 st and 2 nd year consists of taught content relating to core issues in paediatric palliative care. 3 rd year allows students to carry out evidence-based research project relative to their area of practice	Part-time, distance learning 3 outcomes – 1. PG certificate in paediatric palliative care 2. PG Diploma in paediatric palliative medicine 3. MSc in Palliative Medicine
University of South Wales, UK	Paediatric Symptom Management within Palliative Care	Qualified nurses or doctors (in UK or internationally) working with children who have life-limiting conditions	This online module explores critical issues in paediatric palliative care in relation to specific symptom management	Stand-alone module, part of CPD

Kingston University, London, UK	Palliative Care for children, young people and families	Healthcare and other professionals working with children and/or young people who require palliative care	This is an interdisciplinary 10-day module suitable for non-healthcare professionals such as teachers, social workers, play specialists, music therapists and midwives. It is offered at undergraduate and post-graduate level.	Stand-alone and also part of the Healthcare practice DipHE/BSc (Hons)/GradCert
Child Bereavement UK	Various workshops across the UK	Any staff working with children, young people and families who are bereaved	Training is offered on a variety of one-day introductory workshops.	CPD
Together for Short Lives, Bristol, UK	Various workshops across the UK	Any staff working with children, young people and families who are bereaved	Training is offered on a variety of one-day introductory, multidisciplinary workshops	CPD
Coventry University, UK	Introduction to Children and Young People's Palliative and Complex Care	Undergraduate nursing students and any staff working with children and young people with	Online module offered weekly over 11 weeks, introducing the philosophy of paediatric palliative care and exploring key issues in professional care delivery. It is an undergraduate level module.	Stand-alone module, CPD

		palliative/complex care needs		
Dundee University, Scotland, UK	Introduction to Paediatric Palliative Care	Student child health nurses	5-week module offered as part of the 3 rd year undergraduate child health nursing programme	Part of the BN Child Health Nursing award
The Irish Hospice Foundation, Republic of Ireland	Professional Certificate in Children and Loss	All staff working with children who experience loss	Part-time post-graduate certificate course suitable for any practitioners working with children Annual workshops are also offered between January – June each year on a variety of topics and are suitable for nhs and non-nhs staff Staff development workshops are also offered to hospital staff as requested	Stand-alone module, CPD
NUI Galway, Republic of Ireland	Master/Postgraduate Diploma in Health Sciences (Children's Palliative / Complex Care)	Registered Nurses working with children and adolescents with complex or life limiting conditions	2 year full-time course. Students can choose to exit after 1 year with Post-graduate Diploma	Master/Postgraduate Diploma in Health Sciences (Children's Palliative / Complex Care)
NUI Galway, Republic of Ireland	Specialist Practice of Complex Care for Children	Registered nurses	12 weeks part-time course consisting of 4 modules: Complexity in Clinical Care: The Role of Technology in Palliative / Complex Care; Transitioning to home; Managing care delivery in the home:	Stand-alone module CPD

NUI Galway, Republic of Ireland	Quality of Life and Symptom Management in Children's Palliative/Complex Care	Registered nurses and midwives working with children with life limiting illnesses in acute or community settings.	12 Weeks part time course consisting of 5 modules providing an overview of philosophy, principles and practice of children's palliative care	Professional Credit Award Stand-alone module CPD
Northern Ireland Hospice	Introduction to children's palliative care	Any staff working with children in palliative care	Half-day introductory workshop	
Queen's university Belfast	Palliative care for children and their families	Any professional working with children requiring palliative care	Part-time course taught over 2 semesters covering a range of physical, psychosocial and spiritual issues experienced by children and families	Stand alone module Certificate level
Centre of Children's Nurse Education, Crumlin, Ireland	Caring for the Child with a Life-Limiting Condition Level A	Non-registered staff working with children in palliative care setting	4-day education programme over 5 months providing an introduction to the principles and practices of palliative care in the provision of health and social services for children with life-limiting conditions and their families.	Certificate level
Centre of Children's Nurse Education, Crumlin, Ireland	Caring for the Child with a Life-Limiting Condition Level B	Registered nurses and midwives caring for children with life-limiting conditions and their families.	7-Day Programme for Nursing Staff acquire additional knowledge, experiences and values to enable them to provide supportive and palliative care for children with life-limiting conditions and their families	Certificate level

Appendix 5: Focus Group Discussion Guide – CHAS Staff

Scoping Exercise to Inform the Development of an Education Strategy for the Children's Hospices Across Scotland (CHAS)

Focus Group Discussion Guide – CHAS Staff

Thinking about the current education, training and development opportunities available to you here at CHAS...

What have you found helpful or useful in enabling you to undertake your role?

Do you have opportunities to apply what you have learned to your practice? (Probes: can you think of ways in which your learning can be put into your practice? how will it make a difference to the care and support of children and families?)

What is missing in terms of training and development opportunities at the moment?

What suggestions do you have for enhancing the provision of education, learning and development within CHAS?

Thinking about your specific learning and development needs....

In your opinion, what education and training do you need to be able to provide the very best care to children with palliative care needs and their families?

What do you believe to be the priority/most important topics that should be included in future education and training? (Probes: why is this topic so important? what are the gaps in education and training for children's palliative care?)

The ChiSP study (Children in Scotland requiring Palliative Care: identifying numbers and needs) identified a number of psychosocial care and support needs of families. Is this an area where education should be targeted?

Thinking about your preferred learning methods or approaches....

What would be the best way to provide education and training? (Probes: how should it be taught – classroom based, learning on the job, additional professional qualifications/degrees, e-learning; who should teach the courses)

Who should attend training? (Prompts: would you prefer courses attended by many different staff groups and volunteers or single staff groups only? What benefits are there to multi-professional learning? What are the drawbacks?)

Would you like to see families involved in designing and delivering education/training programmes? (Prompts: why or why not? what types of involvement could families have?)

Thinking about CHAS and its role in children's palliative care education across Scotland...

How can CHAS support building capacity and a future workforce in children's palliative care across Scotland? (Probes: how can we share our expertise **and** learn from others)

The NES/SSSC framework 'Palliative and end of life care: a framework to support the learning and development needs of the health and social service workforce in Scotland' sets out the knowledge and skills required by all those who might come into contact with people who need palliative and end of life care, and their families and carers. There are four levels of knowledge and skills – informed, skilled, enhanced and expert. What are your thoughts in how this framework might be implemented in CHAS?

Closing questions...

Of all the things we have discussed today, what is the most important to you?

Is there anything we've missed?

Appendix 6: Focus Group Discussion Guide – External Professionals

Scoping Exercise to Inform the Development of an Education Strategy for the Children's Hospices Across Scotland (CHAS)

Focus Group Discussion Guide – External Professionals

Thinking about the current picture in terms of education, training and development opportunities available to you with respect to children's palliative and end of life care...

What approaches, programmes or educational offerings have worked well in terms of building capacity within children's palliative care and supporting the development of a care workforce with the necessary knowledge, skills and expertise to delivery effective care to children with palliative care needs and their families? What has not worked well?

What are the barriers or challenges in supporting the education needs of those working in children's palliative care in your region/area?

If you already have good capacity, what would make it even better?

Thinking about your learning and development needs....

How can we influence care through education? What education and training would assist in enhancing your capacity, to provide the very best care to children with palliative care needs and their families?

What do you believe to be the priority/most important topics that should be included in future education and training? (Probes: why is this topic so important? what are the gaps in education and training for children's palliative care?)

Thinking about your preferred learning methods or approaches....

What would be the best way to provide education and training? (Probes: how should it be taught – classroom based, learning on the job, additional professional qualifications/degrees, e-learning; who should teach the courses)

Who should attend training? (Prompts: would you prefer courses attended by many different staff groups or single staff groups only? What benefits are there to multi-professional learning? What are the drawbacks?)

Would you like to see families involved in designing and delivering education/training programmes? (Prompts: why or why not? what types of involvement could families have?)

Thinking about CHAS and its role in children's palliative care education across Scotland....

How can CHAS support building capacity and a future workforce in children's palliative care across Scotland through education?

What might an education strategy for CHAS look like?

NHS Education for Scotland (NES) and the Scottish Social Services Council (SSSC) recently developed a national education and development framework to support and foster an integrated and collaborative approach to learning and development in palliative and end of life care. The NES/SSSC framework 'Palliative and end of life care: a framework to support the learning and development needs of the health and social service workforce in Scotland' sets out the knowledge and skills required by all those who might come into contact with people who need palliative and end of life care, and their families and carers. There are four levels of knowledge and skills – informed, skilled, enhanced and expert.

Are you aware of this framework? What are your thoughts in how this framework might be implemented in your area?

Closing questions...

Of all the things we have discussed today, what is the most important to you?

Is there anything we've missed?

Scoping exercise to inform the development of an education strategy for Children's Hospices Across Scotland (CHAS)

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**Publisher: School of Health and Social Care,
Edinburgh Napier University**

Publication date: 03.08.2018

This study was commissioned by Children's Hospices Across Scotland (CHAS).

Children's Hospices Across Scotland is a trading name of Children's Hospice Association Scotland. Scottish Charity number SC 019724