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Assessing Adult Palliative Care Nurses’ Perceived Knowledge, Self-Efficacy, and Clinical Practice Before and After Paediatric Palliative Care Training.

By

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The thesis is submitted to University College Dublin in fulfilment of the requirements for the degree of Master of Science

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ABSTRACT

The global need for paediatric palliative care is increasing, driven by factors such as the advancements in medicine and the broader eligibility criteria to access this care. However, these specialised services are small compared to adult services and are not accessible to all children. As a result, those working in the community sector such as adult specialist palliative care professionals having to fill in this role and provide palliative care to children in the community (Health Service Executive, 2020; Whitla et al., 2020). In light of this, there has been global recognition within bodies such as the World Health Assembly Resolution on Palliative Care (World Health Organisation, 2014), the Children's Palliative Care Education and Training Action Group (Neilson et al., 2021) and Ireland's National Adult Palliative Care Policy (Department of Health, 2024) of the urgent need to standardise paediatric palliative care training for those working in adult palliative care in the community. However, little is known about how adult palliative care nurses currently perceive their knowledge or self-efficacy in paediatric palliative care, and whether additional training can have an impact on their knowledge, self-efficacy and clinical practice.

This study used a quantitative longitudinal pretest-post-test research design in order to assess adult palliative care nurses' perceived knowledge and self-efficacy levels, and the changes to these levels and to their practice after training in paediatric palliative care. Throughout the thesis, the study sample is described as "adult palliative care nurses" but it is important to clarify that this includes adult specialist palliative care nurses and adult palliative care postgraduate nursing students.

The results indicated that adult palliative care nurses perceived they had low levels of knowledge and self-efficacy in paediatric palliative care. The training did improve their perceived knowledge and self-efficacy levels, but these levels decreased overtime and there was minimal impact on their clinical practice, primarily due to their lack of exposure to child patients.

This study contributes to the limited body of research on the perceived gaps in knowledge and self-efficacy among adult palliative care nurses in paediatric palliative care. It identifies specific areas of PPC where these professionals struggle in, as well as the possible rationale for their lack of knowledge or self-efficacy. In addition, this study provides recommendations for education, practice and future research in this topic.

STATEMENT OF ORIGINAL AUTHORSHIP

I hereby certify that the submitted thesis is my own work and was completed while registered as a candidate for the Degree of Master of Science in the College of Health Sciences. I have not obtained a degree elsewhere on the basis of the research presented in this submitted work.

Signed: ______________________________

Date: ____________22/04/2025____________

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GLOSSARY OF TERMS

There are several terms used throughout this thesis that will be abbreviated or shortened for the purposes of parsimony and clarity.

List of abbreviations:

PPC - Paediatric Palliative Care

SPC - Specialist Palliative Care

LLC - Life-limiting condition

PRO - Patient Reported Outcome

LMICs - Low-and middle-income countries

CHAPTER 1: INTRODUCTION

1.1 Introduction

The World Health Organisation defines paediatric palliative care (PPC) as “the active total care of the child’s body, mind and spirit, and also involves giving support to the family” (World Health Organisation, 1998, p. 8). It begins at diagnosis, or earlier, and aims to improve the quality of life of children and their families (Benini et al., 2022).

It is estimated there are 21 million children who need PPC or end-of-life care, and approximately 8 million children requiring specialist palliative care services worldwide (Connor, Downing and Marston, 2017). International standards that set out to classify the conditions requiring PPC, describe these conditions as either life-life-limiting conditions (LLCs), life-threatening conditions or terminal illnesses (Benini et al., 2022). LLCs, or also known as life-shortening conditions, under these standards are those where there is no reasonable hope of cure and from which premature death is expected. These conditions can be progressive in nature for children, leading to increased dependence on parents or caregivers. Life-threatening conditions on the other hand are defined as those for which there is a high probability of premature death due to severe illness, but also a chance of long-term survival to adulthood e.g. cancer. However, terminal illnesses as defined by these standards, are those in which death is inevitable.

LLCs or life-threatening conditions have been further broken down into four disease groups based on their disease trajectory (Association for Children with Life-threatening or Terminal Conditions and their Families and the Royal College of Paediatrics and Child Health, 1997). The four disease groups include LLCs for which treatment could fail, conditions in which premature death is inevitable, progressive non-curative conditions, and irreversible non-progressive conditions that can lead to disability and the possibility of premature death (Together for Short Lives, 2018). Evidence has begun to suggest that the eligibility for PPC needs to expand, including care complexity factors and a perinatal or neonatal fifth group (Together for Short Lives, 2018; Jankovic et al., 2019; Benini et al., 2022; Delamere et al., 2024). For ease of reference, the term “LLCs” will be used to encompass life-limiting conditions, life-threatening conditions and terminal illnesses.

The need for PPC services is increasing globally, mainly due to children living longer thanks to current advancements in medicine but also possibly due to the wider eligibility criteria for

PPC involvement (Benini et al., 2022). PPC is essential for these children as it has the potential to improve symptom control and the quality of life of children and their family (Benini et al., 2022), as well as reduce the number of hospitalisations and offer the option to die in their preferred place of death (Mitchell et al., 2017). Benini et al. (2022) describes how PPC is provided at three different levels of ascending specialisation. Level one is the palliative care approach, which is provided by all healthcare professionals. Level two is generalist PPC, where general palliative care is provided by disease-specific specialists educated on palliative care. Lastly, level three is specialist PPC, where specialist PPC is provided by experts in PPC.

There has been growing recognition in Ireland (Health Service Executive, 2020; Department of Health, 2024), USA (Field and Behrman, 2003), Canada (Lalloo et al., 2021), United Kingdom (NHS England, 2023) and other countries (Chong and Abdullah, 2017) that adult specialist palliative care nurses play a key role in the provision of PPC in the community. Adult palliative care nurses care for adults, predominantly those over 65 years (World Health Organisation, 2018.). However, they are being asked to provide their services to children in the community due to several reasons such as the varying access to specialised PPC resources depending on place of residence and ultimately the lack of standardised PPC training (Friebert and Williams, 2014; Marston, Boucher and Downing, 2018; Brock, 2021). Evidence suggests that adult palliative care nurses do not have adequate knowledge or training to provide PPC (Field and Behrman, 2003; Reid, 2013; Quinn and Bailey, 2011; Chong and Abdullah, 2017; Doherty et al., 2021; Bogetz et al., 2022; Kang et al., 2022). There is a clear difference between the care of a child and an adult. For example, when caring for a child it is important to recognise the central role of play, the rarity and genetic nature of many childhood diagnoses, the typically longer duration of care and the distinct developmental needs children have in terms of communication and understanding their illness (Together for Short Lives, 2018). While similarities between children and adults in the context of palliative care include their approaches to symptom management, and their acknowledgement and inclusion of the family when providing care (Together for Short Lives, 2018). However, adult palliative care nurses continue to feel inadequately prepared and supported to deliver PPC in the community.

1.2 Background

The United Nations Convention on the Rights of the Child emphasises that professionals working with children and young people should receive appropriate training to deliver care tailored to their specific needs (Children’s Rights Alliance, 2010). In the Republic of Ireland, specialist PPC services consists of two hospital-based consultants with a special interest in paediatric palliative medicine, clinical nurse specialists and the services provided by the country's only children's hospice, Lauralynn, all situated in Dublin (Health Service Executive, 2016; Irish Hospice Foundation, 2019). These professionals not only care for families referred to specialist PPC but also provide 24/7 advisory support to healthcare professionals who may be caring for children with a LLC in Ireland such as general practitioners, public health nurses, specialist paediatric teams and primary paediatricians (Health Service Executive, 2016). However, specialist PPC services heavily rely on community supports to extend their reach to children around the country. These services include Children's Outreach Nurses, adult SPC teams, and the Jack and Jill Children's Foundation (Health Service Executive, 2016). However, equitable access to specialist PPC services remains challenging with the concentration of specialist expertise in Dublin and the reliance on other non-specialist community services, especially the adult SPC teams, to cover the community and regional areas around Ireland (Health Service Executive, 2016). This is not anticipated to change as the number of children requiring palliative care is expected to exceed the existing capacity of trained and experienced specialist PPC professionals (Friedrichsdorf, S.J. et al., 2019). Demonstrating the insufficient capacity to meet the increasing demand of specialist PPC in the community in Ireland.

Yet, in Ireland (Ling et al., 2015) and globally (Benini et al., 2022) it has been reported that estimated prevalence rates of children with LLCs is increasing. Half of these children with LLCs will require access to PPC at any given time (Association for Children with Life-Threatening or Terminal Conditions and their Families, 2009). However, it is important to note that the current prevalence numbers are only estimates as there is no universally accepted method in measuring population-level need for PPC (Hain et al., 2013; Noyes et al., 2013; Delamere et al., 2024) due to challenges in defining the population in need of PPC services (World Health Organisation, 2018; Jankovic et al., 2019) and due to the lack of available data such as the number of child deaths caused by a LLC (Fraser, Bluebond-Langner, 2020; Benini et al., 2022). It is essential to identify this population to better understand their needs and ensure sufficient and appropriate resources are allocated effectively within their community (Hayden et al., 2013).

There have been a number of publications in Ireland such as “A Palliative Care Needs Assessment for Children” (Department of Health and Children and Irish Hospice Foundation, 2005) and “Palliative Care for Children with a Life Limiting condition in Ireland: A National Policy” (Department of Health and Children, 2009) that have influenced the development of PPC in the community. However one particular limitation still exists, which is the lack of standardised training in PPC for those working in the community sector (World Health Organisation, 2014; Neilson et al., 2021; Department of Health, 2024). This lack of standardised training combined with the growth of children requiring palliative care (Benini et al., 2022) and the lack of preparedness felt by adult palliative care professionals (Clarke and Quin, 2007; Reid, 2013; Weaver et al., 2021) is a very current and pressing issue.

In light of the evidence provided, a short half-day PPC training workshop was initiated in 2023 for adult palliative care nurses (see workshop agenda in Appendix 10). This workshop used a didactic pedagogical approach (Osbeck, Ingerman, and Claesson, 2018) where experienced clinical and academic professionals presented contemporary topics in complex care. Speakers included a Coordinator for Children with Complex Care Needs, a Professor of Children's Nursing and a Clinical Nurse Coordinator for Children with Life-Limiting Conditions. The aim of the training workshop was to enhance adult palliative care nurses' knowledge and self-efficacy in the care of children living with complex and LLCs, with a focus on community-based PPC.

The specific objectives of the workshop included the following:

1. Understand/Feel confident in identifying the key contemporary issues in the care of children with complex needs.
2. Understand the role of the Complex Care Coordinator and the Clinical Nurse Coordinator for Children with Life-limiting Conditions in supporting children and families in the community.
3. Understand/Feel confident in identifying best practices for the care of children with complex and life-limiting conditions in the community.

This thesis aimed to assess the perceived knowledge and self-efficacy levels before and after the adult palliative care nurses attended this workshop.

1.3 Rationale for the Study

A report made by Craig et al. (2008) set international standards for PPC as far back as 2008 stating that all countries should develop specific training for all professionals involved in PPC. Following this, the Department of Health in Ireland (2024) published a National Adult Palliative Care Policy that recommended that all postgraduate specialist palliative care training incorporates PPC curricula. Unfortunately, a framework that sets out standardising PPC education has not yet been established in Ireland or the United Kingdom. However, a Children's Palliative Care Education and Training Action Group for Ireland and the United Kingdom has been established to take this initiative forward and standardise PPC training (Neilson et al, 2021). Already, there are several PPC training programmes being set up in North America (Lalloo et al., 2021), Oceania (Slater et al., 2018.), Asia, Europe, Sub-Saharan

Africa, the Middle East, and the UK (Downing and Ling, 2012; Slater et al., 2018; Postier et al., 2022; Daniels and Downing, 2018). Educational workshops, whether conducted alone or alongside other interventions, has been shown to enhance healthcare professionals' practice and improve patient health outcomes (Forsetlund et al., 2021). Progress is slowly being made in the right direction, but there is a lot of work to be done to adequately train and support adult palliative care nurses who continue to care for children in the community.

Knowledge (what nurses know) and self-efficacy (what nurses believe they can do) (Fadaei et al., 2024) were measured before and after PPC training in this study in order to assess whether the nurses learned and how confident they felt applying their knowledge in practice. These measurements are important as nurses' knowledge and self-efficacy levels are factors that can affect the quality of care provided to patients (Tomita, 2024; Alsulami et al., 2025). According to Bandura's Self-efficacy Theory, a framework that aims to explain how people learn and behave, self-efficacy or one's belief in their ability to perform a task, is a key determinant of whether knowledge is translated into effective action (Bandura, 1997). Therefore, this study measured both perceived knowledge and self-efficacy, recognising that improvements in knowledge alone are insufficient and nurses must also believe in their ability to apply that knowledge effectively in practice.

The rationale for this study was to address the recommendations for PPC training as reported in the National Adult Palliative Care Policy (Department of Health, 2024) by assessing the levels of perceived knowledge and self-efficacy of adult palliative care nurses before and after PPC training.

1.4 Aim and Objectives of the Study

1.4.1 Aim of the Study

The primary aim of this study was to assess adult palliative care nurses' perceived knowledge and self-efficacy levels in providing PPC to children pre and post a PPC training workshop.

1.4.2 Objectives of the Study

The key objectives of the study were to:

1. Profile the adult palliative care nurses' specific demographic factors.
2. Measure adult palliative care nurses' perceived knowledge levels of PPC at baseline and at two post-workshop time points.
3. Measure adult palliative care nurses' perceived self-efficacy levels providing PPC at baseline and at two post-workshop time points.
4. Assess adult palliative nurses' perceived practice changes or patient level changes at two post-workshop time points.
5. Assess adult palliative care nurses' reflections and acceptability levels after a half-day workshop for PPC.
6. Assess the influence of demographic factors on perceived knowledge and self-efficacy levels at baseline.

1.5 Significance of the Study

It is envisaged that the findings from this study will demonstrate why PPC training is essential for adult palliative care nurses working in the community and how such training can be effectively delivered to support their knowledge and self-efficacy.

Firstly, this study addresses a key gap in the literature by focusing on adult palliative care nurses delivering PPC in the community - an under-researched group identified as requiring additional support and PPC training (Department of Health, 2024).

The findings revealed that adult palliative care nurses had limited baseline knowledge and self-efficacy in delivering PPC. In particular, the lowest scores were reported in non-pain symptom management, ethical decision-making, communication about death or illness, and depression and anxiety in children. Highlighting both the need for PPC training and the specific areas in which adult palliative care nurses require further support in.

This study also reported on the limited change in practice for respondents after the training, primarily due to the limited exposure to child patients. However, potential strategies to address this issue in training is suggested, such as implementing regular training sessions rather than once off workshops. Importantly, the training in general was well-received, and respondents expressed a clear interest in further PPC education, reinforcing the value and relevance of such initiatives.

Lastly, this is one of very few longitudinally designed studies looking at adult palliative care nurses’ perceived knowledge and self-efficacy. It is anticipated that the findings from this study will inform the future development and delivery of PPC training and underscore its importance in community-based adult palliative care practice.

1.6 Layout of the Thesis

This chapter began by providing an overview of the definition, development and importance of PPC. It then highlighted the central role of adult palliative care nurses in the provision of PPC in the community, despite the growing evidence of adult palliative care nurses feeling unprepared and unsupported in this role. The aims and objectives of the study were then described.

Chapter Two presents a review of the literature which examined the current evidence on the care of children provided by adult specialist palliative care professionals in the community. The review had only a limited number of papers, however with the few that were included, it was identified that there was a lack of preparedness in adult specialist palliative care professionals in providing PPC, inadequate PPC training and a lack of high-quality empirical evidence available.

Chapter Three describes the methodologies and methods used to answer the research question and fulfil all the objectives of the study. In addition, the chapter provides information about the study design, respondents, ethical considerations, data collection procedures and the data analyses undertaken to achieve the findings of this thesis.

Chapter Four presents the results of the study and discusses the results to address the study’s aim and objectives.

Lastly, Chapter Five comprehensively discusses the findings considering the current literature and identifies the impact of the study findings on research, policy and practice.

CHAPTER 2: LITERATURE REVIEW

2.1. Introduction

This study aimed to assess adult palliative care nurses' perceived knowledge and self-efficacy in paediatric palliative care (PPC) before and after PPC training. As outlined in the previous chapter, there is a lack of empirical research on this population and it's care of children. Therefore, it was decided that this review would use broad search terms in order to comprehensively map and understand the scope of the available evidence. This chapter presents the scoping review conducted in order to review the evidence on adult specialist palliative care (SPC) professionals providing their services to children in the community.

2.1.1. Aim of the Review

The aim of this scoping review was to evaluate the current literature on the care of children provided by adult SPC professionals in the community, with a focus on identifying knowledge gaps and examining adult SPC professionals' perceived training, preparedness and challenges in delivering PPC.

2.2. Methods

A scoping review was conducted to find and map the available literature as well as to bring to light what future research may be needed (Armstrong et al., 2011; Munn et al., 2018). The Arksey and O'Malley (2005) methodological framework was used while incorporating the updated guidance provided by the Joanna Briggs Institute (Peters et al., 2020a). The Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) standards were adopted to report the relevant findings from the literature search (McGowan et al., 2020).

In addition, a protocol was completed for this scoping review using the PRISMA-P checklist. The draft was revised by an experienced senior academic at University College Dublin [MC] who provided suggestions for review. With the appropriate revisions made and further analysis by the research team, the final protocol was registered to Open Science Framework on the April 18th, 2024 (Appendix 2).

2.2.1. Identifying the Research Question

The research question was to explore and map the existing body of evidence related to adult SPC professionals caring for children in the community. Key stakeholders with expertise and experience in PPC as well as in adult palliative care supported and helped develop the research question.

2.2.2. Identifying the Relevant Studies

The inclusion and exclusion criteria was set to gather the appropriate literature that would answer the review question. The recommended Population, Concept and Context (PCC) framework (Peters et al., 2020a; 2020b) for scoping reviews was used to structure the eligibility criteria as shown in Table 2.1. Eligible studies must include adult SPC professionals (population). There does not seem to be a specific definition for “adult SPC professionals” in Ireland (Department of Health, 2024) or the UK (NHS England, 2021). However, for this review adult SPC professionals were defined as healthcare professionals who provide a SPC service that primarily provides care to adults (18 years or older). SPC can be defined as care provided by healthcare professionals (usually involving an interdisciplinary team e.g. doctors, nurses, dietitians etc.) with the appropriate education, training, and clinical experience in palliative care, and whose main role involves delivering such care (Cherny et al., 2021). Paediatric SPC professionals whose primary patient population are children, were excluded.

The place of work had to be in the community setting (context). Studies focused on a hospice or inpatient/outpatient hospital setting were excluded.

Eligible studies had to mention paediatric patients (concept). For this review, a child is described as anyone under the age of 18 as recognised by the United Nations Convention on the Rights of the Child (United Nations, 1989). Studies that only mentioned adult patients were excluded. Studies were excluded if they were clinical trials, non-empirical research, or studies not relating to humans or not reported in English.

To identify potentially relevant papers, the following databases were used: PubMed, PsycINFO, CINAHL, Scopus, ERIC and Cochrane Library. No limits were applied to the databases. The first search was conducted in November 2023 and rerun in July 2024 and again in April 2025 to check for any new references. The search strategy was drafted by the researcher MMD with support from a key stakeholder in palliative care [MC]. Then further refined by the Specialist Librarian [FL] at the Education & Research Centre of Our Lady’s Hospice & Care Services who peer-reviewed using the Peer Review of Electronic Search Strategies (PRESS) checklist, and a librarian at University College Dublin. Lastly, the search strategy was finalised by senior academics, experienced in the scoping review process. An example of the final search strategy for PubMed can be found in Appendix 1. The final search results from each database were systematically exported to EndNote. They then were transferred to Covidence where duplicates were automatically removed.

EndNote 20™ bibliographic software (Clarivate Analytics LLP, USA) was used to store the papers retrieved from all the searches. Screening of the records was completed using a web-based software platform called Covidence (Veritas Health Innovation, Australia).

Table 2.1: Inclusion and Exclusion Criteria

PCC	Inclusion Criteria	Exclusion Criteria
Population	Adult specialist palliative care professionals (doctors, nurses, physiotherapists etc.)	Paediatric specialist palliative care professionals whose primary patient population are children
Concept	Caring for children (0-18 years)	Caring for only adults (>18 years)
Context	Working in the community setting	Working only in an inpatient / outpatient setting

2.2.3. Study Selection

Once duplicates were removed by Covidence, two reviewers [MMD and MC] independently screened title and abstracts and completed full-text reviews of the eligible papers. Both reviewers agreed to include any papers when there was doubt over its eligibility for further analysis. Disagreements during the independent review process were resolved by discussion and consensus between the two reviewers. A third reviewer was available if consensus was not achieved. The results are reported in the PRISMA flowchart (Page et al., 2021) (PRISMA flowchart shown in Figure 2.1). The reference list of all retrieved full text papers were hand searched to assess their eligibility for inclusion in the review. Nineteen were identified through the hand search but no papers met the PCC criteria during full text review. The two rerun searches did not find any new eligible papers to include in the review.

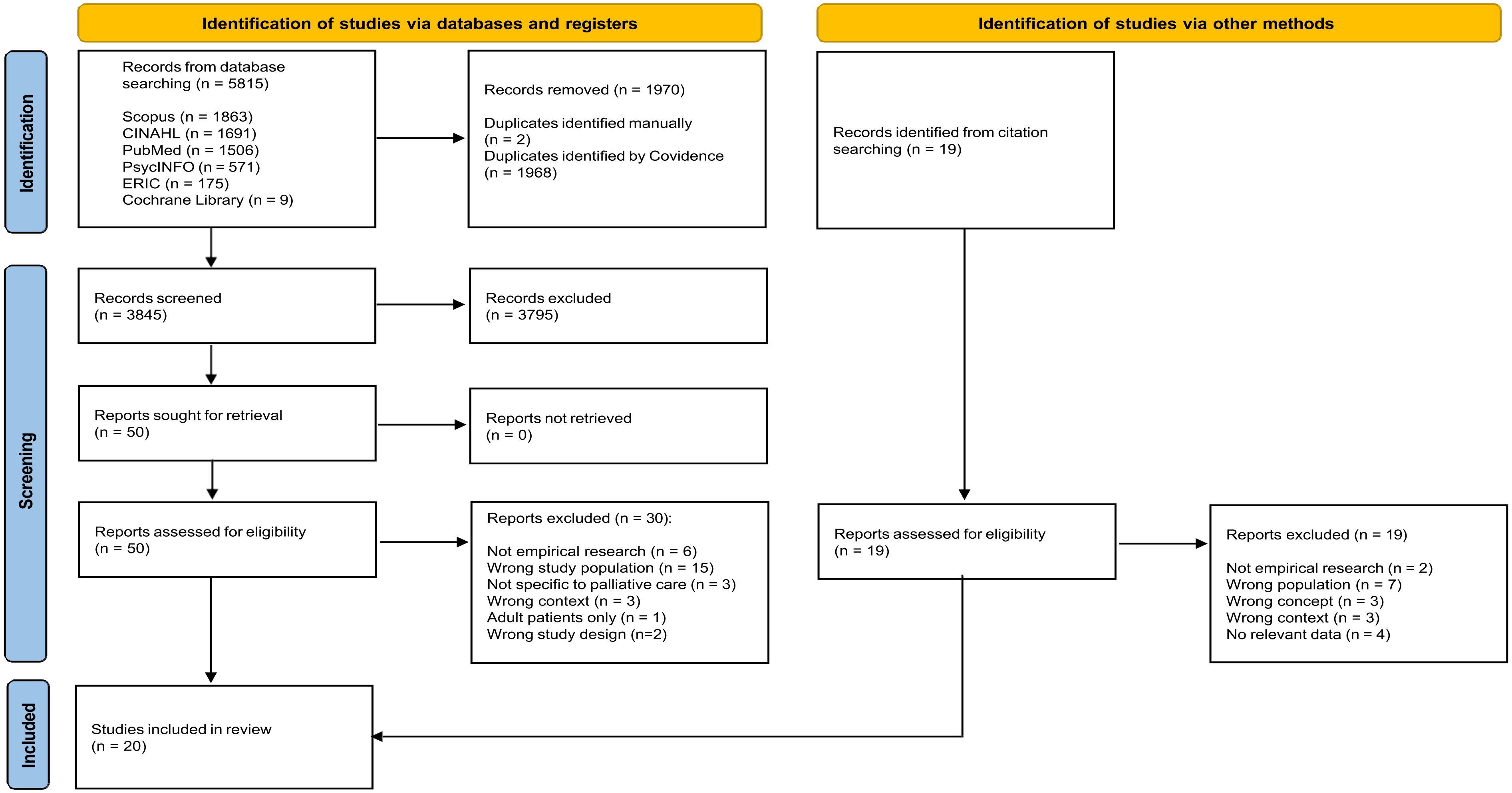

Figure 2.1: PRISMA Flow Diagram

2.2.4. Charting the Data

Once the two reviewers completed full-text review, MMD extracted the relevant information from the final 20 papers using a review-specific template in which MC reviewed iteratively and provided feedback on the data charted. It was then further refined in accordance with the Joanna Briggs Institute guidelines (Peters et al., 2020a).

The data extraction table as shown in Appendix 3 shows the data extracted and analyses. The agreed characteristics of the data extracted included the following headings: author(s), year, country, journal, aim(s), response rate, methodology, and key findings. Key findings included the following headings: PC experience (number of years working in palliative care or those identified as working in palliative care), PPC experience (number of children cared for or time providing PPC), previous PPC training, setting (primary practice setting e.g. community), perceived preparedness in providing PPC, challenges in PPC provision or training, and professional development needs identified.

2.2.5. Collating, Summarising and Reporting the Results

The extracted data underwent two phases of analyses: numerical and then descriptive content analysis that captured the main categories addressing the review question. The diverse nature of the studies meant that they were reviewed individually for emerging themes.

2.3. Results

2.3.1. Selection of Studies

5815 citations were identified from the database search. 1968 citations were automatically removed as duplicates, with a further 2 manually removed during screening. 3847 citations were screened, however there were only 52 included in the full text review (Figure 2.1). The final number of records for data extraction was 20. The main reasons for exclusion were wrong study population, non-empirical research or wrong context.

2.3.2. Description of studies

Overall, this review yielded a small number of 20 papers, yet they all brought a unique perspective into the types of issues that adult SPC professionals can face when caring for children in the community.

The year of publication for the selected papers ranged from 1994 to 2022, but the majority (n=13) were new publications within the last 5 years. This demonstrates how PPC is a relatively recent focus in the literature. The oldest paper published in 1994 (Jeffrey, 1994) is at least a decade older than the rest of the 19 papers which may highlight a period where the topic was overlooked or no longer prioritised in the research community, to then re-emerge notably from the year 2020. This may be due to the relatively new but exponential medical advancements during this time and increase in children living longer with life-limiting conditions (Benini, 2022). Resulting in recognition of the need for more research on the changing PPC environment. It is known that there is limited quality research in PPC due to the lack of dedicated studies and ethical issues involved in conducting these studies (Kumar, 2011).

As shown in the data extraction table (Appendix 3), half of the studies were from the USA, 3 from the UK, 2 from Ireland and finally 1 from each of the following countries Malaysia, India, Australia, South Korea and Canada. It was not surprising that most studies were from the USA or UK as they have notably been involved in the early development of PPC. Few European countries were found in the search even though they account for 3 of the 7 countries who provide the most developed PPC service globally (Clelland et al., 2020). This however could be due to only English language citations being included in this review.

The methodological approach was heterogeneous with 12 focusing on quantitative, 7 qualitative, and 1 mixed method. The preferred methodologies used were surveys or semi-structured interviews with adult SPC professionals. Five studies conducted cross-sectional surveys (Jeffrey, 1994; Kaye et al., 2019; Johnson et al., 2020; Bogetz et al., 2022; Kang et al., 2022) while 7 focused on longitudinal designs (e.g. pretest and post-test) (Kristjanson et al., 2005; Vesel and Beveridge, 2018; Weaver et al., 2020; Doherty et al., 2021; Lalloo et al., 2021; Weaver et al., 2021; Hamre et al., 2022) to collect the relevant data. The cross-sectional surveys largely evaluated the present state of PPC, the learning needs of adult SPC professionals, the challenges of providing effective PPC, as well as adult SPC professionals' comfort levels in providing PPC. While the longitudinal surveys focused on evaluating the impact of PPC training or telemedicine practices on adult SPC professionals.

It was noteworthy that 14 out of the 20 studies selected were published in dedicated palliative care journals. The population sample size of the papers ranged from an approximated 4 to 551 adult SPC professionals. It was challenging to identify the number of adult SPC professionals as many studies did not provide detailed information on the population's demographics such as their training or experience in palliative care or paediatrics, or their primary patient cohort or clinical setting. This may be due to a lack of recognition or definition of the "adult SPC professional". Studies that may not fully meet our population criteria but could reasonably be presumed to do so due to a lack of data were still included in the analysis.

Eleven studies had nurses as the professionals while the rest had a mix of multidisciplinary members including doctors, occupational therapists, medical social workers etc. This was expected as nurses play a key role in the care of children with LLCs in the community (Together for Short Lives, 2018).

Following a detailed analysis of the extracted data, 4 broad categories emerged from the literature. These categories examined the training, preparedness, challenges and future directions in relation to adult SPC professionals caring for children in the community.

2.4. Training

The level of training and development of palliative care services differed between countries. The majority (n=18) of the 20 selected studies within this review are in countries classified at the highest level of palliative care development (USA, Canada, Australia, South Korea, UK and Ireland) (Clarke et al., 2020). While the studies from Malaysia and India in this review are three levels below in the "isolated palliative care provision" category yet still presented findings that were relevant and comparable to the other countries. An example of a related area of interest for different countries would be on the provision of adequate PPC training to resource-limited or rural communities (Weaver et al., 2020; Doherty et al., 2021; Weaver et al., 2021).

The studies differed in the extent to which they reported on the prior PPC training of adult SPC professionals. Many studies focused solely on their previous clinical experience in PPC e.g. number of years' experience or number of children cared for (Johnson et al., 2020; Bogetz et al., 2022; Greenfield et al., 2022), or just their palliative care clinical experience (not specified whether adult or children's) (Kristjanson et al., 2005; Porter et al., 2021), or the number of years in their respective profession (not specifically palliative care) (Doherty et al., 2021; Lalloo et al., 2021). Some studies reported their previous theoretical or academic training in PPC (Hamre et al., 2022) or just palliative care (not specified if training content included PPC) (Jeffrey, 1994). Interestingly, there were only 2 papers that asked about whether they had previous paediatric training in general (Reid, 2013; Vesel and Beveridge, 2018). One study from Malaysia detailed that no formal PPC training is available nationally (Chong and Abdullah, 2017). Three studies did not ask the health professionals about their previous training at all (Clarke and Quinn, 2007; Johnson et al., 2020; Weaver et al., 2020). And only 7 studies considered to report whether these professionals had both theoretical and experience-based training (Quinn and Bailey, 2011; Reid, 2013; Kaye et al., 2019; Kaye et al., 2020a; Kaye et al., 2020b; Weaver et al., 2021; Kang et al., 2022). The inconsistencies in reports of previous

PPC training observed in the review could be attributed to some studies not asking enough questions to fully capture a comprehensive picture of adult SPC professionals' PPC training.

When examining the paediatric clinical experience of adult SPC professionals in more detail, it is evident that adult SPC professionals have little experience working with children in the community. Half of the studies within the review identified this as a particular issue for these providers (Clarke and Quinn, 2007; Reid, 2013; Chong and Abdullah, 2017; Kaye et al., 2019; Kaye et al., 2020b; Johnson et al., 2020; Doherty et al., 2021; Weaver et al., 2021; Bogetz et al., 2022). The studies identified the typical number of paediatric patients these professionals see annually. For example, it was identified that most adult SPC professionals chose the lowest range when it came to selecting the number of children they would or their healthcare organisation would see per year. When given a range of annual paediatric patient numbers, most adult SPC professionals selected less than 5 patients per year (lowest range they could select) (Kaye et al., 2020a; Kaye et al., 2020b; Weaver et al., 2021; Bogetz et al., 2022), or less than 10 patients per year (the lowest range they could select) (Vesel and Beveridge, 2018; Doherty et al., 2021). While others did not give a range but showed that the majority of professionals would annually care for perhaps 1 child (Reid, 2013) or 3 children (Johnson et al., 2020), with some describing their exposure to paediatric patients as every couple of years or less (Kaye et al., 2019; Weaver et al., 2021). The possible reasons provided for the low numbers were that not a lot of children were requiring SPC services in the area (Johnson et al., 2020), or that there was not enough resources or adequately trained staff to take on these patients (Chong and Abdullah, 2017; Bogetz et al., 2022; Kang et al., 2022). No papers explored whether the low number of children requiring SPC services might be attributed to parents or carers assuming the role of SPC providers, or that those working in the subspeciality of PPC were taking on the majority of patients. In addition, 2 studies highlighted that SPC professionals preferred adult patients over children, and that this may deter them from taking on paediatric caseloads (Quinn and Bailey, 2011; Kaye et al., 2020b).

From review of the literature, regardless of the national level of palliative care development, adult SPC professionals are not trained in any systematic way in PPC, they rarely care for children in the community and the reasons for this are multifactorial including systemic issues that go beyond training.

2.5. Preparedness

While adult SPC professionals acknowledged they lacked exposure to paediatric patients in the community, they also admitted they lacked sufficient levels of education (Chong and

Abdullah, 2017; Bogetz et al., 2022; Kang et al., 2022), knowledge (Quinn and Bailey, 2011; Reid, 2013; Doherty et al., 2021; Lalloo et al., 2021), preparedness (Clarke and Quinn, 2007; Reid, 2013), comfort (Chong and Abdullah, 2017; Vesel and Beveridge, 2018; Kaye et al., 2019; Kaye et al., 2020a; Porter et al., 2021; Bogetz et al., 2022; Hamre et al., 2022) and confidence (Reid, 2013; Chong and Abdullah, 2017; Vesel and Beveridge, 2018; Greenfield et al., 2022), in providing PPC.

Many studies asked adult SPC professionals to identify areas within PPC where they felt they required additional support in. The most common topics in PPC that they felt they required additional support in were understanding pain (Quinn and Bailey, 2011; Vesel and Beveridge, 2018; Kaye et al., 2019; Bogetz et al., 2022; Greenfield et al., 2022) or non-pain symptoms (Quinn and Bailey, 2011; Kaye et al., 2019; Lalloo et al., 2021; Bogetz et al., 2022; Vesel and Beveridge, 2018), medication management (Quinn and Bailey, 2011; Chong and Abdullah, 2017; Vesel and Beveridge, 2018; Kaye et al., 2020a; Doherty et al., 2021; Greenfield et al., 2022), with one Canadian paper noting medical marijuana (Lalloo et al., 2021), and communication skills (Quinn and Bailey, 2011; Reid, 2013; Chong and Abdullah, 2017; Vesel and Beveridge, 2018; Kaye et al., 2019; Kaye et al., 2020a; Doherty et al., 2021; Lalloo et al., 2021; Porter et al., 2021; Bogetz et al., 2022; Greenfield et al., 2022; Hamre et al., 2022). Others highlighted were understanding complex childhood diagnoses (Clarke and Quinn, 2007; Chong and Abdullah, 2017; Porter et al., 2021; Kang et al., 2022), and providing psychosocial support (Clarke and Quinn, 2007; Quinn and Bailey, 2011; Kaye et al., 2020a; Doherty et al., 2021; Lalloo et al., 2021; Bogetz et al., 2022;), or grief and bereavement support (Kristjanson et al., 2005; Vesel and Beveridge, 2018; Kaye et al., 2019; Lalloo et al., 2021). Uniquely to the others, there was one paper emphasising a limited understanding of hydration and nutrition and removal of ventilation practices (Vesel and Beveridge, 2018). Only one paper tested adult SPC professionals' knowledge (Vesel and Beveridge, 2018), while the rest asked for their "perceived" lack in knowledge using Likert scales. Additionally, another paper highlighted that adult SPC professionals felt it was important compare PPC to the care they would provide to the adult patient to appreciate the key distinctions between each other (Quinn and Bailey, 2011).

However, studies that reported a relatively good level of understanding often lacked detailed explanations for the underlying reasons. For example, one paper found that the nurses they surveyed had a good understanding of grief and bereavement in PPC but did not identify the possible reasons why such as prior PPC training or PPC experience (Kristjanson et al., 2005). Asking these kinds of questions is important as many of the studies would mention that the lack of exposure to paediatric patients was one of the most impactful variables on providers' confidence or comfort levels (Chong and Abdullah, 2017; Kaye et al., 2019; Kaye et al., 2020b; Greenfield et al., 2022). Highlighting the importance of regular clinical exposure to paediatric patients to help clinicians build confidence. One study supported these findings, suggesting that formal PPC training was the most significant variable with respect to comfort with "management of severe symptoms at the end of life" (Kaye et al., 2020b, p. 1144). Furthermore, another study found that having a previous children's qualification was the most important to improve confidence, not the clinical experience or how young the healthcare professional was (Reid, 2013). However, other studies found that more nursing experience in general was an important factor in confidence levels (Hamre et al., 2022). This highlights the importance of paediatric trained staff being involved in PPC services in the community. Some papers did express interest in having a specialist paediatric-trained nurse in the community to support adult SPC professionals in their role and the overall coordination of care (Quinn and Bailey, 2011; Kaye et al., 2019; Kaye et al., 2020a; Kaye et al., 2020b). This could be important as some papers had identified how adult SPC professionals are sometimes confused about their role in the community due to a lack of communication or coordination with other community health professionals (Quinn and Bailey, 2011; Reid, 2013; Greenfield et al., 2022).

Many of the papers in this review developed training programmes in order to improve the gap in knowledge and address the lack of confidence, comfort or preparedness in adult SPC professionals providing PPC in the community. It is clear that adult SPC professionals have a desire to receive additional training in PPC (Kristjanson et al., 2005; Clarke and Quinn, 2007; Reid, 2013; Chong and Abdullah, 2017; Vesel and Beveridge, 2018; Kaye et al., 2019; Johnson et al., 2020; Kaye et al., 2020a; Lalloo et al., 2021; Porter et al., 2021; Bogetz et al., 2022; Greenfield et al., 2022; Kang et al., 2022). With one paper stating that adult SPC professionals felt "reinvigorated" and "inspired" after a 2-day education programme on paediatric palliative and hospice care (Vesel and Beveridge, 2018, p. 211). It is important to consider how experienced the population in these studies were. The population cohorts in these studies were usually quite inexperienced with less than 5 or 10 years of clinical experience for the sample majority (Kristjanson et al., 2005; Vesel and Beveridge, 2018; Kaye et al., 2020b; Doherty et al., 2021; Bogetz et al., 2022).

With regards to the training, many papers developed their programme using their own needs assessment (Doherty et al., 2021; Lalloo et al., 2021; Weaver et al., 2021), or through Delphi studies and professional expertise (Kristjanson et al., 2005; Hamre et al., 2022). One study developed an education programme using input from a pilot group but did not specify its sample size or composition (Vesel and Beveridge, 2018). The training varied in content, frequency, structure and mode of delivery and trainer. Chosen education content and identified learning needs of adult SPC professionals are broken down in Table 2.2. The most common frequency was a short 1–2-day training (Kristjanson et al., 2005; Vesel and Beveridge, 2018; Weaver et al., 2021; Hamre et al., 2022). While others focussed on a more regular education programme that occurs weekly, biweekly (Doherty et al., 2021) or monthly (Lalloo et al., 2021). The most common mode of delivery was in-person (Kristjanson et al., 2005; Vesel and Beveridge, 2018; Weaver et al., 2021; Hamre et al., 2022), but there was interest from adult SPC professionals to have education sessions delivered online (Weaver et al., 2021). Trainers providing the education were usually paediatric trained staff (Kristjanson et al., 2005; Doherty et al., 2021; Lalloo et al., 2021; Hamre et al., 2022).

Table 2.2: Training Topics and Learning Needs Identified in the Literature

PPC training topics for adult specialist palliative care professionals	**Common learning needs identified by adult specialist palliative care professionals**
Introduction to PPC (e.g. define PPC, PPC history, current PPC services, patient stories) *(Lalloo et al., 2021; Weaver et al., 2021; Hamre et al., 2022)*	Understanding what children's palliative care is *(Kang et al., 2022; Kaye et al., 2020a)*
Symptom and pain assessments and management (e.g. nausea, vomiting, constipation, fatigue, pruritis, dyspnoea, agitation, secretions, delirium, sleep problems etc.) *(Doherty et al., 2021; Lalloo et al., 2021; Weaver et al., 2021; Hamre et al., 2022)*	Understanding of childhood life-limiting conditions *(Clarke and Quinn, 2007; Chong and Abdullah, 2017; Kaye et al., 2020a; Kang et al., 2022)*
Medication management (e.g. palliative sedation, opioid use in children) *(Doherty et al., 2021; Lalloo et al., 2021)*	Assessment skills for child patients (e.g. general health assessments, pain assessments etc.) *(Chong and Abdullah, 2017; Doherty et al., 2021)*
Psychosocial support for children and families (e.g. identifying and managing depression and anxiety in children, spiritual considerations, respite care, supportive therapies such as music therapy, art, aromatherapy) *(Doherty et al., 2021; Lalloo et al., 2021; Weaver et al., 2021; Hamre et al., 2022)*	Symptom and pain assessments and management (e.g. pain, seizures, dyspnoea, secretions, neuro-irritability) *(Quinn and Bailey, 2011; Vesel and Beveridge, 2018; Kaye et al., 2019; Lalloo et al., 2021; Porter et al., 2021; Bogetz et al., 2022)*
Communication skills (e.g. communicating according to child's developmental levels, advance care planning, breaking bad news, talking about death and dying etc.) *(Kristjanson et al., 2005; Doherty et al., 2021; Lalloo et al., 2021; Weaver et al., 2021; Hamre et al., 2022)*	Medication management (e.g. different dosages, different medications, palliative sedation) *(Quinn and Bailey, 2011; Chong and Abdullah, 2017; Vesel and Beveridge, 2018; Doherty et al., 2021; Porter et al., 2021)*
Grief and bereavement (e.g. assessment / management of grief, grief during different stages of development, complex grief) *(Kristjanson et al., 2005; Lalloo et al., 2021; Weaver et al., 2021)*	Psychosocial support for children and families (e.g. managing depression or anxiety in child or family) *(Quinn and Bailey, 2011; Kaye et al., 2020a; Doherty et al., 2021; Lalloo et al., 2021; Bogetz et al., 2022)*
End of life care (e.g. resuscitation, caring for the dying child, medical assistance in dying) *(Lalloo et al., 2021; Weaver et al., 2021)*	Communication skills (e.g. advance care planning, goals of care, communication after child's death, communication on death or dying, coordinating care, prognostication questions)

	(Clarke and Quinn, 2007; Quinn and Bailey, 2011; Chong and Abdullah, 2017; Vesel and Beveridge, 2018; Kaye et al., 2019; Doherty et al., 2021; Lalloo et al., 2021; Porter et al., 2021; Bogetz et al., 2022; Hamre et al., 2022)
Ethical and legal issues regarding PPC *(Lalloo et al., 2021; Weaver et al., 2021)*	Grief and bereavement (adolescents' bereavement or grief, siblings' grief) *(Kristjanson et al., 2005; Vesel and Beveridge, 2018; Kaye et al., 2019; Lalloo et al., 2021)*
Perinatal and neonatal palliative care *(Lalloo et al., 2021; Weaver et al., 2021)*	End of life care (e.g. what to expect and how to manage) *(Jeffrey, 1994; Clarke and Quinn, 2007; Quinn and Bailey, 2011; Kaye et al., 2019)*
Transition from children to adult services *(Lalloo et al., 2021)*	Using medical equipment (e.g. respiratory machines, extubation at home) *(Quinn and Bailey, 2011; Vesel and Beveridge, 2018)*
Growing a PPC skillset in the rural setting *(Weaver et al., 2021)*	Explaining the concept of "allowing a natural death" to the child or family *(Hamre et al., 2022)*
	Hydration and nutrition in PPC *(Vesel and Beveridge, 2018)*
	Medical marijuana *(Lalloo et al., 2021)*

2.6. Challenges

There were several challenges identified by adult SPC professionals including barriers to receiving additional PPC training and barriers preventing them from providing their services to children in the community.

The identified barriers to receiving PPC training were limited time (Jeffrey, 1994; Kristjanson et al., 2005), limited finances (Jeffrey, 1994), or lack of awareness of training opportunities or benefits of the training (Porter et al., 2021).

Several barriers were identified in regards to restricting professionals from providing their services to children in the community including lack of trained staff (Clarke and Quin, 2007; Quinn and Bailey, 2011; Reid, 2013; Chong and Abdullah, 2017; Bogetz et al., 2022; Greenfield et al., 2022), lack of finances (Chong and Abdullah, 2017; Johnson et al., 2020;

Bogetz et al., 2022), lack of resources e.g. access to home infusions or durable medical equipment (Clarke and Quin, 2007; Quinn and Bailey, 2011; Bogetz et al., 2022; Greenfield et al., 2022), lack of perceived benefits or understanding of their role in the community (Quinn and Bailey, 2011; Kang et al., 2022), or how increasingly remote a child's home is (Johnson et al., 2020). One paper noted the lack of children in the community requiring the services as one of the reasons for not providing PPC services (Johnson et al., 2020).

2.7. Future directions

From the review it is clear that adult SPC professionals both perceive that they need and want additional PPC training so they can provide effective care to children in the community. It was evident that papers developing their own education programmes showed variation in delivery. They usually provided either regular virtual training sessions or a once off in-person training workshop. Both were received well by attendees. However, there may have been a preference for a virtual platform with various challenges identified for in-person training such as difficulty working around busy working schedules (Jeffrey, 1994; Kristjanson et al., 2005), or lack of finance to provide accommodation overnight (Weaver et al., 2021). In one paper, adult SPC professionals noted that a once off training does not sufficiently prepare them with one nurse saying, "I mean, I got a whole week and a half of (PPC) training total in hospice, and then I had to wing it on my own" (Porter et al., 2021, p. 6). Future studies should explore whether single-session or recurring training, and whether virtual or in-person delivery, is the most preferred and effective for this cohort.

There were several identified future research directions or gaps in the literature highlighted in this review. Regarding gaps, only 1 paper reported patient-reported outcomes (PROs) from their research (Weaver et al., 2020), while 2 papers noted that there is a need for more PROs or data collected directly from patients or families (Vesel and Beveridge, 2018; Kaye et al., 2019). Recommendations have been made for more longitudinally designed studies in the future to evaluate the nursing impact on patient outcomes related to PPC training (Hamre et al., 2022). Others have advocated for more public awareness around PPC (Quinn and Bailey, 2011; Kang et al., 2022). An increase in collaboration with PPC hospital teams and adult SPC professionals in the community was reported (Kaye et al., 2020a; Kaye et al., 2020b; Johnson et al., 2020; Greenfield et al., 2022). Additionally, a need for a greater focus on rural, regional or low- and middle-income countries (LMICs) were acknowledged (Kristjanson et al., 2005; Reid, 2013; Johnson et al., 2020; Doherty et al., 2021). Studies from Malaysia (Chong and Abdullah, 2017) and Australia (Kristjanson et al., 2005) noted the need for the standardisation of PPC training in undergraduate education for healthcare professionals. One paper noted that adult SPC professionals advocated for more community supports and respite services, rather than the development of more children hospices (Clarke and Quin, 2007). Emphasising the need for community providers to be sufficiently prepared, confident and trained to provide their services to children.

2.8. Conclusion

This scoping review has provided insights into what is anecdotally known about the current landscape of adult SPC professionals' training, preparedness, and challenges providing PPC in the community. Ultimately, adult SPC professionals do not feel adequately prepared to provide PPC in the community. They do not receive standardised PPC training even though there is a clear demand for it. They do not have regular exposure to paediatric patients for a variety of systemic reasons. All of which reinforces the uncertainty surrounding their role in the community. This highlights the need to establish clear and appropriate expectations and training for this cohort of professionals.

Regarding the limitations of this review, most of these studies included small population samples with only 3 studies having a population larger than 100 (Kaye et al., 2019; Kaye et al., 2020a; Kaye et al., 2020b). Papers were also limited to only the English language.

Research gaps such as the lack of consensus on the health conditions suitable for PPC, lack of PROs in PPC research, and fragmented care coordination in the community continues to be an issue even though PPC is already in its fourth decade of research.

CHAPTER THREE: METHODOLOGY

3.1. Introduction

This chapter presents the rationale for the methodological approach and methods used in this study. The aim of this study was to assess how adult palliative care nurses perceive their knowledge and self-efficacy in paediatric palliative care (PPC) before and after their participation in a training workshop.

The previous chapter presented a scoping review evaluating the existing evidence on adult SPC professionals providing their services to children in the community. Specifically, the review focused on whether adult SPC professionals feel sufficiently prepared to deliver their services to children in the community. However, the outcomes from the review demonstrated that there is a scarcity of robust research on this population or topic. In addition, the findings identified that adult SPC professionals perceive that they have a lack of knowledge, self-efficacy, and PPC training or experience, hindering their ability to effectively care for children in the community.

This chapter begins by outlining the research aims, objectives, and research question. Then the research design and ethical considerations that underpin the study are then discussed. The data collection instruments, pretesting, reliability and validity testing, sample population, data collection procedures, and data analysis methods used are also presented.

3.2. Aim, objectives and research question

3.2.1. Aim of the study

The primary aim of this study was to assess adult palliative care nurses' perceived knowledge and self-efficacy levels in providing PPC to children pre and post a PPC training workshop.

3.2.2. Objectives

The key objectives of the study were to:

1. Profile the adult palliative care nurses' specific demographic factors.
2. Measure adult palliative care nurses' perceived knowledge levels of PPC at baseline and at two post-workshop time points.
3. Measure adult palliative care nurses' perceived self-efficacy levels providing PPC at baseline and at two post-workshop time points.

4. Assess adult palliative nurses’ perceived practice changes or patient level changes at two post-workshop time points.
5. Assess adult palliative care nurses’ reflections and acceptability levels after a half-day workshop for PPC.
6. Assess the influence of demographic factors on perceived knowledge and self-efficacy levels at baseline.

3.2.3. Research question

The research question was as follows:

“What are adult palliative care nurses perceived levels of knowledge and self-efficacy in providing palliative care to children, and what was the impact of a training workshop on their perceived knowledge, self-efficacy and clinical practice?”

3.3. Research Design

Research is a systematic inquiry that depends on carefully planned methodologies in order to answer questions and clarify problems (Polit and Beck, 2022). Nursing research on the other hand can be defined as a structured and thorough inquiry aimed at exploring and answering key questions important to nurses and their patients (Polit and Beck, 2022). This pursuit of knowledge ensures that best practices are consistently applied and reviewed, an integral foundation for nursing (Boswell and Cannon, 2022). However, for research to be applied effectively in any setting, a well-structured research design is important (Polit and Beck, 2022).

A research design is an overall plan for answering the research question, including the ways to improve its integrity (Polit and Beck, 2022). Joyner et al. (2018) offers a more simplified description of a research design, likening it to a recipe book for the conduct of research. Within the literature, there are several commonly used approaches including but not limited to quantitative, qualitative and mixed methods (Cresswell and Poth, 2018). Quantitative research involves gathering and analysing statistical data, whereas qualitative research emphasises understanding the meaning behind observed experiences (Curtis and Drennan, 2013). Mixed methods on the other hand is an increasingly popular approach, combining and integrating both quantitative and qualitative measures to collect information and use both methods in the analysis (Curtis and Drennan, 2013). One of the many advantages of a quantitative research design would be that it can study a big population in a timely and sometimes financially sustainable manner (Dillman et al., 2014), for example when using surveys or automated data collection methods. Qualitative approaches excel in providing rich, detailed, and context-specific insights, making them ideal for exploring experiences, generating new theories, and addressing complex or sensitive topics (Morse, 2012; Curtis and Drennan, 2013). Mixed method research is often argued to provide a holistic and comprehensive approach to data collection as it analyses both quantitative and qualitative data (Curtis and Drennan, 2013).

Based on this study's aims, objectives and research question, a quantitative research design was chosen. A quantitative design was preferred to collect data objectively and anonymously in a time-effective and cost-effective manner from a relatively large sample at several time points. In addition, the review of the literature identified that a quantitative design was the most used approach for studies that had a similar research question, target population and objectives to this study (Vesel and Beveridge, 2018; Lalloo et al., 2021; Weaver et al., 2021; Hamre et al., 2022).

However, it is important to understand that all designs have their own limits. For example, the limitations of quantitative and qualitative approaches are in some way interrelated. Quantitative research can be limited by its lack of depth and inflexibility due to predefined frameworks, while qualitative research, although rich in subjective insights, may struggle with maintaining validity and reliability (Polit and Beck, 2022). However, no matter how different these approaches are, they all follow a specific paradigm or philosophical stance.

Powers and Knapp (2006) define a paradigm as an organising framework that includes concepts, theories, assumptions, beliefs, values, and principles shaping how a researcher interprets the subject matter. In essence, a paradigm is a world view that guides the approach to inquiry (Polit and Beck, 2022). The positivist paradigm has been widely embraced since the 19th century and can be described as an approach that is rational and scientific with a fundamental assumption that reality exists and can be studied and understood (Polit and Beck, 2022). The positivist method focuses on the collection and statistical analysis of numerical data in order to explain phenomena (Curtis and Drennan, 2013). In contrast, a constructivist (or naturalistic) paradigm, often adopted by qualitative researchers, emphasises a subjective and multi-dimensional understanding of reality (Polit and Beck, 2022).

The positivist paradigm was chosen for this study for several reasons. Firstly, this paradigm aligns with the objective, measurable nature of the research question. Secondly, this design focuses on outsider knowledge as the researcher is kept separate to the participants who are anonymised. And finally, the design is fixed, and a pre-specified survey design was used to collect the data, which is another key feature of a positivist paradigm (Polit and Beck, 2022). By adopting a positivist approach, it was expected that the results from this study would be potentially generalisable and interpreted as reflecting real changes in participants' competencies.

3.4. Study Design

This study used a quantitative descriptive longitudinal pretest-post-test research design in order to assess adult SPC nurses’ and adult palliative care postgraduate nursing students’ perceived knowledge and self-efficacy levels, and the changes to these levels and to their clinical practice after a half-day PPC training workshop.

This study design was deemed to be the most appropriate way to answer the research question. A quantitative approach was preferred for a variety of reasons. Firstly, the literature review identified a number (n=5) (Kristjanson et al., 2005; Vesel and Beveridge, 2018; Lalloo et al., 2021; Weaver et al., 2021; Hamre et al., 2022) of already developed and tested quantitative measurement tools assessing adult SPC professionals’ perceived knowledge or self-efficacy levels, making this approach easily reproducible. Secondly, the time-efficiency and ability to collect data from a large sample in a short period of time was favourable due to the limited time available. In addition, the opportunity to use statistical analysis techniques was preferred to identify and analyse trends objectively. Finally, the approach provided an opportunity to collect data in a confidential manner as participants were kept anonymous.

A longitudinal design involves the collection of data over multiple time points over an extended period (Polit and Beck, 2022). For this study, it was decided that a longitudinal pretest-post-test design was to be used in order to collect data from study participants before (baseline) and after PPC training at 6 weeks post-training and at 6 months post-training. This was to assess possible cause and effect relationships (effect of PPC training on knowledge, self-efficacy and clinical practice changes) and capture the long-term impact of the PPC training. It was anticipated that attrition would be a challenge as it is common in longitudinal studies (Polit and Beck, 2022), therefore measures were put in place to avoid this such as ensuring survey ease of access and sending reminder emails to participants.

This study design was applied to address the research aims and objectives in a way that was evidence-based, practical and realistic for the time and resources that were available at the time.

3.5. Ethical Considerations

Ethical approval was granted by the University College Dublin (UCD) Human Research Ethics Committee – Sciences (HREC-LS) and the Our Lady's Hospice & Care Services (OLH&CS Education and Research Sub-Committee, Harold's Cross. This study was determined as low risk as it was using non-vulnerable participants for anonymous surveys on non-sensitive issues. Two gatekeepers one each from UCD and OLH&CS who already had the personal contact details of the potential participants distributed the information leaflets and survey links appropriately (information leaflet in Appendix 11 and informed consent form in Appendix 12) to maintain their anonymity using an invitation email provided by the researcher MD (invitation email in Appendix 4). Potential participants would receive this email with the information leaflet and online survey link where they could provide their informed consent by ticking the informed consent box on the first page of the survey. Complete anonymity was provided to the respondents to ensure their responses were kept confidential. The researcher expected that the anonymity would encourage participants to provide honest answers, as they would be confident that their privacy would be safeguarded which is important for fellow students and staff members.

3.6. The Survey

A survey aims to obtain information about a population or phenomenon, often collecting information on the prevalence, distribution and relationships of variables within that population or phenomenon (Polit and Beck, 2022).

Surveys are a popular research method due to their efficiency and practicality, but they also come with some limitations. Advantages of a survey include its cost-effectiveness and ability to reach large and geographically diverse populations with minimal expense, especially through digital platforms. Digital or online surveys offer a quick and efficient way to administer surveys, collect and analyse data (Maymone et al., 2018), while also serving as an environmentally friendly approach to data collection. In addition, surveys can be distributed by mail or face-to-face if digital methods are not suitable. Surveys also ensure consistency by presenting all participants with the same set of questions, reducing variability and increasing reliability. Surveys can also include a wide range of questions, enabling flexible evaluation across multiple research domains. And finally, surveys are excellent for collecting large amounts of data quickly, making them particularly useful for quantitative studies where statistical analysis is required.

However, surveys also have their limitations. They often lack the depth provided by qualitative methods (Jolley, 2020). Poorly designed surveys can introduce bias, and respondents might provide answers they think are socially acceptable rather than truthful (Quick and Hall, 2015). Low response rates are another common issue with surveys, potentially compromising the representativeness of the data (Polit and Beck, 2022). Furthermore, surveys do not allow for clarification of ambiguous questions, which can lead to misinterpretation and unreliable responses (Jolley, 2020). Lastly, once a survey is distributed, it cannot be modified to address any unforeseen issues. These factors highlight the importance of careful planning and thoughtful design when using surveys in research.

3.6.1. Instruments and Measures

The data collection instrument used was a quantitative longitudinal pretest-post-test online survey. The surveys were derived from an existing tool developed by Lalloo et al. (2021). With permission from the author (Appendix 5), the surveys were contextualised to Ireland with minor adjustments. Lalloo et al. (2021) developed this survey to assess multidisciplinary healthcare professionals' perceived changes in knowledge, self-efficacy and clinical practice after PPC training. They created their own tool instead of using other validated tools as they could not find any that incorporated multidisciplinary members. This was important for this study at the beginning of its conception as there were expectations that other multidisciplinary members may participate in the PPC training. This did not happen as only those from the nursing profession attended the training workshop. However, this did not limit the applicability of the survey especially as the nursing profession represented the largest proportion of the sample population in Lalloo et al.'s (2021) own survey results.

However, for this study, further validation testing was conducted. Reviews of the surveys were completed by four experts in the field of quantitative methods, palliative care and paediatrics. The minor amendments to the surveys and rationale for each are displayed in Appendix 6.

The adapted data collection instruments included a 28-item pre-training survey (Appendix 7), 43-item 6 weeks post-training survey (Appendix 8) and a final 32-item 6 months post-training survey (Appendix 9). All three measured self-assessed knowledge and self-efficacy at pre-training, as well as at two time points post-training in addition to training programme acceptability and clinical practice impact. Tables 3.1—3.3 provide a quick description of the chosen surveys.

Table 3.1: Pre-training Survey

Concept	Number of Questions	Question Types
Demographics and Experience	6	5 forced-choice, 1 open-text
Knowledge	12	11 Likert scale (8-point), 1 open-text
Self-Efficacy	10	10 Likert scale (8-point)
Total	**28**	Mixed

Table 3.2: Six Weeks Post-Training Survey

Concept	Number of Questions	Question Types
Reflection on Participation	1	1 multiple-choice
Acceptability and Satisfaction	8	7 Likert scale (7-point), 1 open-text
Comfort Level	3	3 Likert scale (7-point)
Knowledge	14	11 Likert scale (8-point), 1 forced-choice, 2 open-text
Self-Efficacy	10	10 Likert scale (8-point)
Practice and Patient-Level Changes	7	5 Likert scale (8-point), 1 multiple-choice, 1 forced-choice
Total	**43**	Mixed

Table 3.3: Six Months Post-Training Survey

Concept	Number of Questions	Question Types
Reflection on Participation	1	1 multiple-choice
Knowledge	14	11 Likert scale (8-point), 1 forced-choice, 2 open-text
Self-Efficacy	10	10 Likert scale (8-point)
Practice and Patient-Level Changes	7	5 Likert scale (8-point), 1 multiple-choice, 1 forced-choice
Total	**32**	Mixed

The decision to include a third time point, unlike Lalloo et al. (2021), allowed researchers to assess whether the participants retained their perceived knowledge and self-efficacy levels after the training and whether any changes in their clinical practice were sustained.

There were several advantages to using these adapted surveys. Firstly, the surveys were not costly or time intensive for the researcher. There was no researcher influence on participant responses and the anonymity ensured security for students and nurses taking part. The surveys incorporated relevant PPC learning topics identified in the current literature. And lastly, they were easy to complete with Likert scales, and easy to access using an online survey link and a tick box consent process.

The reason for assessing participants' reflection on the training, comfort levels, and acceptability levels post-training were to provide possible rationale to why participants may select low or high levels of perceived knowledge or self-efficacy in PPC. In addition, the rationale for not including the two concepts "acceptability and satisfaction with the training" and "comfort level with the training" again in the 6-month post-training survey was due to them not being relevant for an additional measurement at a later time point, especially as it could be introducing recall bias.

Overall, this survey was selected for various reasons such as its relevance to the research objectives, generalisability to multidisciplinary professionals, its use in a similar pre and post-test context, and finally its comprehensiveness and well-informed selection of PPC topics.

3.6.2. Pre-testing

Pretesting is known as the trial period of a newly developed instrument to identify any possible weaknesses (Polit and Beck, 2022). Instrument weaknesses can include unclear or ambiguous wording, misspelled or missing questions, poorly designed response scales, too many questions, cultural or demographic biases, and digital technical issues (Dillman et al., 2014). Pretesting is invaluable as it can help researchers avoid these weaknesses and ensure high quality data is collected. Pretesting can be conducted through methods such as cognitive interviews, pilot testing or through pilot fieldwork such as focus groups or expert review panels (Curtis and Drennan, 2013).

This survey was reviewed by four experts in palliative care, PPC, and quantitative research designs in order to finalise content and to highlight any problems with understanding. All modifications made to the surveys are outlined in Appendix 6. Modifications were made to enhance the reliability and validity of the surveys. The review process promoted reliability by ensuring standard questions, appropriate terms and clear language was used, and validity by comparing them to similar surveys in the literature review. Standardised questions in research are important as they are reliable in ensuring the collection of data is consistent and comparable across different participants (Polit and Beck, 2022). In addition, the use of appropriate terms is important as it involves avoiding acronyms or abbreviations to prevent participant misinterpretation (Dillman et al., 2014). While clear language and an organised structure of questions is another crucial step to ensure the survey is accessible and understandable to participants resulting in accurate responses (Dillman et al., 2014).

3.6.3. Reliability and Validity

Reliability refers to the consistency of a measurement tool, indicating its ability to produce the same results under consistent conditions each time it is used (Frost et al., 2007). It reflects how much an instrument is free from random errors, ensuring stability and precision in repeated use. Researchers can evaluate reliability by measuring internal consistency reliability (Cronbach’s coefficient alpha) and reproducibility such as test-retest or interviewer reliability (Curtis and Drennan, 2013). Validity refers to the degree to which an instrument measures what it is supposed to measure (Frost et al., 2007). It is a unified concept that relies on integrating various validation processes to assess its effectiveness and accuracy in measuring what it intends to measure (Curtis and Drennan, 2013). For these surveys, it was the first time these questions were collated together and tested on a sample of adult SPC nurses' and adult palliative care postgraduate nursing students from Ireland.

In terms of validity, it can be separated into two broad headings: translational and criterion validity (Curtis and Drennan, 2013). For this section, the following translational validity measures will be discussed: content, face and construct validity. Content validity has been suggested to be one of the most important validity measures as it ensures the survey items are in line with the construct that is being measured (Curtis and Drennan, 2013). Content validity was upheld as four subject experts reviewed and modified the survey to ensure it aligned with the research question. The experts also helped select which questions were important, or which could be removed. Face validity refers to when an item can be completed and understood by participants (Curtis and Drennan, 2013). Face validity was supported when the surveys were reviewed by experts, in addition to one adult SPC nurse (not involved in the main study) who read and provided feedback on the final surveys' legibility. Construct validity refers to the extent to which a test or instrument accurately measures the theoretical construct it is intended to measure (Curtis and Drennan, 2013). For this study, the surveys used were compared to other surveys from similar theoretical constructs such as similar population samples and designs (Kristjanson et al., 2005; Vesel and Beveridge, 2018; Doherty et al., 2021; Weaver et al., 2021; Hamre et al., 2022) to evaluate how they compared to one another.

3.6.4. The Sample

For this study, convenience sampling was used to select the sample population. Convenience sampling is a non-probability sampling technique where participants are selected based on their availability and willingness to participate (Polit and Beck, 2022). The chosen population were those attending the PPC training workshop (held in-person and online via Zoom) which was targeted at adult SPC professionals working in the community, including adult palliative care postgraduate nursing students, all from the island of Ireland. The data was collected from students completing a Graduate Diploma in Palliative Care or adult SPC nurses at three time points: Prior to completing PPC training, and at 6 weeks and 6 months post completion of the PPC training workshop. The reason that workshop administrators were targeting this sample was due to the newly published National Adult Palliative Care Policy (Department of Health, 2024). This policy recommends community adult SPC teams to be trained in PPC. There is no specified definition for "adult SPC professionals" in Ireland (Department of Health, 2024) or the UK (NHS England, 2021). However, adult SPC professionals can be broadly defined as healthcare professionals who provide a SPC service that primarily provides care to adults (18 years or older). SPC services can be defined as a multidisciplinary team (medical, nursing, physiotherapy, occupational therapy, social work and spiritual support (Borgstrom et al., 2024)) with palliative care as their core specialty, under the direction of a consultant physician in palliative medicine (Department of Health, 2024). Inclusion criteria were that they had to be attendees to the training workshop, all those who did not attend were not sent an email with the survey link.

3.6.5. Sample Size

The sample size was dictated by the interest in and attendance of the half day PPC training workshop. The full attendance (in person and online) was 45 attendees. For this study, the aim was to assess the perceived knowledge and self-efficacy levels of adult SPC nurses and nursing students completing a Graduate Diploma in Palliative Care before and after attending a PPC training workshop.

For this study, the necessary sample size and the number of participants who would be receiving surveys were carefully considered. Quantitative research typically employs either probability or nonprobability sampling methods (Kalton, 2023).

According to Polit and Beck (2022), probability sampling involves selecting participants randomly from the population, ensuring that everyone has an equal chance of being included. While nonprobability sampling involves selecting participants through non-random methods, meaning not every individual has a chance to be selected. The main strategies under nonprobability sampling include convenience, quota, and purposive sampling. On the other hand, probability sampling methods include simple random sampling and stratified random sampling.

In this study, a nonprobability convenience sampling method was chosen as it was a selection of the most readily available participants for the study. This was the most convenient sampling method to include as many participants in the sample size as possible as it was time-effective and cost-effective in a resource and time-limited research environment. It is important to note, that there is no database currently that holds the number of adult SPC nurses in Ireland. Limiting the ability to determine how representative the study sample is of the total population.

3.6.6. Sampling Procedure

A sampling procedure refers to the method used to select a sample from a larger population for research purposes (Polit and Beck, 2022). It outlines the steps involved in how participants are chosen, which ensures that the sample represents the population adequately and aligns with the study's aims. It is important that the chosen sampling procedure is thought through carefully as it can affect the validity, generalisability, and reliability of the results (Polit and Beck, 2022).

For this study, the sampling selection process and the distribution of the surveys were facilitated by the gatekeepers from UCD and OLH&CS. They had the contact details of the attendees and could distribute the email that was drafted by the researcher MD with the information leaflet and survey link. They also emailed notifications one week and two weeks (after 6 months only) after sending the survey to remind attendees to complete the survey. There was an effort to emphasise the importance of their contribution in the surveys by mentioning that it was a part of a Master's Degree.

3.6.7. Data Collection Procedure

The method of data collection should be carefully chosen by the researcher. This is essential because the validity of study conclusions is easily challenged if inappropriate data collection methods are used (Polit and Beck, 2022). Data collection can either involve using pre-existing data, such as information from national databases or medical records, or it can involve new data obtained through direct observation or self-reporting methods, such as surveys (Polit and Beck, 2022). This study collected new data through self-reported or self-administered surveys. Data was collected anonymously through the three longitudinal online surveys sent via email before the training (sent 14 November 2023), approximately 6 weeks after (3rd January 2024), and then 6 months after (22nd May 2024). Reminders were sent via email.

This data collection procedure was chosen because it was cost-effective, convenient for participants, and time-efficient for researchers. It was convenient as it ensured the same participants could be reached at each time point. Additionally, the method maintained participant anonymity and was environmentally friendly, as it eliminated the production of paper waste. Limitations to this data collection procedure included that it was not a random sample but a sample of relevant nurses in the specialty area, there were no preventative measures to stop multiple participation of participants, response rates relied on participant willingness to open and complete surveys, and technological issues could prevent participants opening the online link.

3.6.8. Data Analysis.

For collected data to answer the research question, the data needed to be systematically analysed for trends and patterns (Polit and Beck, 2022). A quantitative measure can be categorised according to the levels of measurement (Polit and Beck, 2022). The levels of measurement are an important system as quantitative analysis can be applied, depending on the type of measurement level used. For example, the four levels of measurement in quantitative data analysis are nominal, ordinal, interval, and ratio (Polit and Beck, 2022). For this study, the surveys used nominal measurements which involves categorisation without any order ("What is your primary profession?"), ordinal measurements which can be ranked, but the intervals between ranks are not consistent ("please indicate how many years have you worked in specialist palliative care (adult)?"), and interval measurements which has ordered categories with equal intervals, for example 7 or 8-point Likert scales (ranging from strongly agree - strongly disagree).

There are several ways to analyse quantitative data including descriptive and inferential statistics (Polit and Beck, 2022). Descriptive statistics are used to describe and organise data, for example using averages and percentages (Jolley, 2020). While inferential statistics, takes the data from a sample and can make broader conclusions or generalisations about a larger population (Polit and Beck, 2022). In essence, descriptive statistics is about describing what is in the data, while inferential statistics is about drawing conclusions or making predictions about the data.

Descriptive statistical analysis was conducted using Statistical Package for the Social Sciences (IBM SPSS version 29.0). This type of statistics was chosen to analyse the collected data for a variety of reasons. Firstly, to assess the sample population's demographics as well as measures of central tendency (mean, median, mode) and variability (range) for self-efficacy, knowledge levels and clinical practice changes at each of the corresponding time points. In addition, training acceptability and satisfaction was assessed using a threshold of a mean score of ≥ 5 on the 7-point Likert scale (Lalloo et al., 2021). Data was presented in tables and graphs to visualise identified trends from the findings. In addition, analysis of response rates was conducted, and an assessment of the response bias and the generalisability of the findings were conducted. To assess potential attrition and response bias, the demographic characteristics of respondents were analysed to ensure that no demographic group was disproportionately represented or underrepresented within the sample.

3.7 Conclusion

This chapter outlined the methodology and rationale used to address the research question, beginning with a presentation of the research aims, objectives, and guiding question. The research design, ethical considerations, data collection instruments, and sample population were discussed, followed by a description of the data analysis methods used. The next chapter will present the next step of the research process, describing the results of this study.

CHAPTER 4: RESULTS

4.1. Introduction

This chapter presents the questionnaire results gathered from respondents over three time points: pre-training, 6 weeks post-training and 6 months post-training. This was conducted in order to answer the research question “What are adult palliative care nurses perceived levels of knowledge and self-efficacy in providing palliative care to children, and what was the impact of a training workshop on their perceived knowledge, self-efficacy and clinical practice?”

The data analysis was conducted using Statistical Package for the Social Sciences (IBM SPSS version 29.0). A codebook was developed to enable data analyses. Graphs were also generated using Microsoft Excel to visualise the data collected and highlight key trends. The results included data on respondent demographics, with knowledge and self-efficacy levels collected both before and after the training workshop. In addition, changes in their practice, their reflections and acceptability levels of the training were also captured post-training.

4.2. Sample

The sample included 45 nurses who attended the paediatric palliative care (PPC) training workshop on November 2024. The useable response rates were 60% (n=27) for the pre-training, 29% (n=13) for the 6 weeks post-training, and 31% (n=14) for the 6 months post-training questionnaire.

4.3. Demographics

The demographics were collected from the pre-training questionnaire only. Most respondents were either Clinical Nurse Specialists (CNSs) in palliative care (n=15, 56%) or Registered General Nurses (RGNs) (n=11, 41%). There was one (4%) Public Health Nurse.

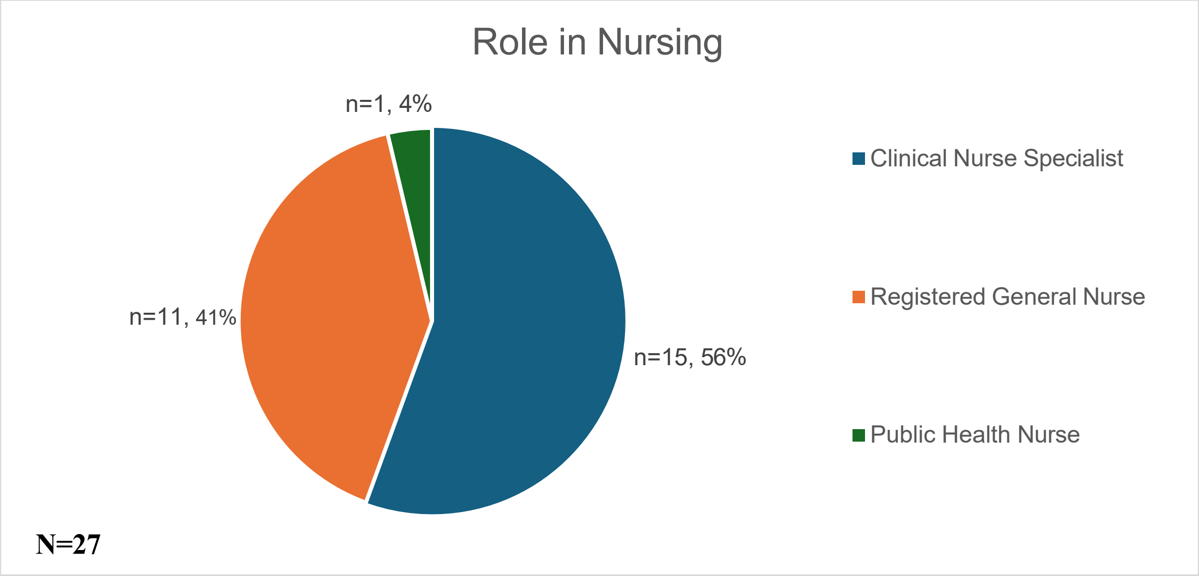

Figure 4.1: Role in Nursing

Within the CNS group, there were eleven working as part of a Community Palliative Care Team and four working in an adult hospice. Of the eleven RGNs, eight were working in an adult hospice, one was working in the Community Palliative Care Team and two worked as RGNs (not in palliative care) in a public hospital.

Nearly half of the respondents were working greater than 10 years in specialist palliative care (SPC) (41%, n=11) (Figure 4.2). Most respondents worked in a suburban/urban environment (74%, n=20), six (22%) worked in rural localities and one (4%) worked in both rural and suburban/urban. None of the respondents worked in a remote working environment.

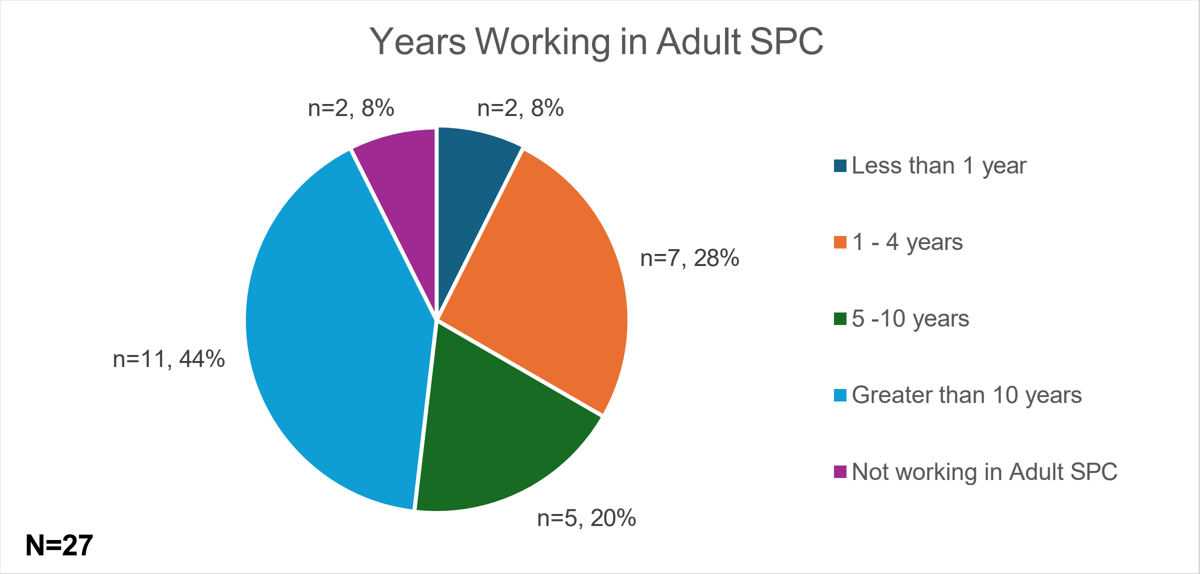

Figure 4.2: Years Working in Adult Specialist Palliative Care

4.4. Level of Perceived Knowledge

At each time-point, knowledge levels were assessed using eleven 8-point Likert scale questions and one open-text question. The open-text question asked respondents: “Please tell us about any other specific topics related to paediatric palliative care that would be useful for your scope of practice”. After the training, two additional questions on knowledge change were posed using forced-choice and open-text to encourage respondents to elaborate on their perceived knowledge changes.

4.4.1. Level of Perceived Knowledge at Pre-training

Overall, the results suggest that the respondents had a low level of knowledge at baseline (Table 4.1). In particular, the items “Neuro-irritability in children” (M= 1.89, SD=1.34), “Talking to children about death” (M=2.07, SD=1.66) and “Depression and anxiety in children” (M=2.37, SD=1.57) scored the lowest in knowledge levels. The items that had the highest knowledge mean scores were “The importance of respite for families” (M=4.04, SD=2.16), and “Preparing for death and the time that follows” (M=3.70, SD=2.29). The total knowledge score result (M=30.41, SD=17.63) suggests that overall, the respondents were consistently reporting low levels of perceived knowledge in core topics of PPC.

Table 4.1: Pre-training Knowledge Mean Scores, Total Score and Percentage* Agreement or Disagreement

No	Pre-training Knowledge Items	n	Minimum***	Maximum****	Mean (SD)	Percentage Agreement	Percentage Disagreement
1	Introducing paediatric palliative care to families	27	1	8	3.00 (2.04)	29.6%	55.55%
2	Neuro irritability in children	27	1	8	1.89 (1.34)	3.7%	85%
3	Preparing for death and the time that follows	27	1	8	3.70 (2.29)	48.1%	48.1%
4	Forgoing artificial nutrition and hydration at end of life	27	1	8	3.00 (2.04)	33.3%	55.5%
5	Talking to children about death	27	1	8	2.07 (1.66)	14.8%	81.5%
6	Nausea & vomiting in children	27	1	8	2.52 (1.81)	18.5%	70.4%
7	Dyspnoea in children	27	1	8	2.63 (1.084)	22.2%	70.4%
8	Pain at end of life in children	27	1	8	2.67 (2.00)	22.2%	70.4%
9	The importance of respite for families	27	1	8	4.04 (2.16)	55.6%	44.4%
10	Legacy creation / Memory making	27	1	8	2.74 (1.83)	25.9%	63%
11	Depression & anxiety in children	27	1	8	2.37 (1.57)	11.1%	77.8%
Total knowledge score**		**27**	**11**	**88**	**30.41 (17.63)**		

1=Strongly Disagree, 2=Disagree, 3=Somewhat Disagree, 4=Neutral, 5=Somewhat Agree, 6=Agree, 7=Strongly Agree, 8=Unsure

*Overall percentage for “somewhat agree” to “strongly agree” on an eight-point Likert scale and overall percentage for “somewhat disagree” to “strongly disagree” on an eight-point Likert scale.

**This is the total summated score for the 11 items on the Knowledge Scale

***Low scores indicate a perceived low degree of knowledge for that topic

****High scores indicate a perceived high degree of knowledge for that topic

For further analysis, percentage agreement and disagreement were used to summarise individual item responses. The responses “somewhat agree” to “strongly agree” were combined into a single category as were “somewhat disagree” to “strongly disagree” (Table 4.1). The items yielding the highest, second and third highest percentage agreement were as follows “The importance of respite for families”, “Preparing for death and the time that follows” and “Forgoing artificial nutrition and hydration at end of life”. However, it is important to note that only one of them reached a percentage agreement over 50% (“The importance of respite for families”). The three highest percentage disagreement items were as follows “Neuro-irritability in children”, “Talking to children about death” and “Depression and anxiety in children”. These results consistently demonstrate the low perceived knowledge levels across all items, with notably limited knowledge levels regarding neuro-irritability, depression and anxiety in children and talking to children about death.

4.4.2. Level of Perceived Knowledge Post 6 Weeks and Post 6 Months

Overall knowledge scores from the 11 Likert scale items increased initially at 6 weeks before slightly declining at 6 months (Table 4.2): baseline (M=30.41, SD=17.63), post 6 weeks (M=49.54, SD=19.16) and post 6 months (M=40.29, SD=16.02).

At six weeks post-training, the three lowest-scoring items remained the same, but all showed consistent improvement in comparison to pre-training levels (Table 4.2). While the highest knowledge levels at 6 weeks were “Introducing paediatric palliative care to families” (M=5.08, SD=1.89) and “The importance of respite for families” (M=5.08, SD=1.94).

At 6 months post-training, the respondents’ lowest knowledge scores were “Neuro-irritability in children” (M=2.86, SD=1.61), “Forgoing artificial nutrition and hydration at end of life” (M=3.36, SD=1.39), and “Depression and anxiety in children” (M=3.36, SD=1.74). While the highest knowledge scores were “Introducing paediatric palliative care to families” (M=4.57, SD=2.03) and “Preparing for death and the time that follows” (M=4.36, SD=1.65). There are notable trends throughout the time points, respondents seem to consistently perceive they have a poor level of knowledge relating to neuro-irritability, and depression and anxiety in children. There was a difference in the highest scoring items, with “Introducing paediatric palliative care to families” becoming more understood by respondents after the training.

Table 4.2: Post 6 Week and 6 Month Training Knowledge Mean Scores and Total Scores

No	Knowledge Items	6W n	6M n	Minimum**	Maximum***	Post 6 Week Mean (SD)	Post 6 Month Mean (SD)	Difference Between Means
1	Introducing paediatric palliative care to families	13	14	1	8	5.08 (1.89)	4.57 (2.03)	0.51
2	Neuro-irritability in children	13	14	1	8	3.69 (1.80)	2.86 (1.61)	0.83
3	Preparing for death and the time that follows	13	14	1	8	4.92 (2.02)	4.36 (1.65)	0.56
4	Forgoing artificial nutrition and hydration at end of life	13	14	1	8	4.69 (1.93)	3.36 (1.39)	1.33
5	Talking to children about death	13	14	1	8	3.85 (1.99)	3.43 (1.65)	0.42
6	Nausea & vomiting in children	13	14	1	8	4.46 (2.02)	3.43 (1.45)	1.03
7	Dyspnoea in children	13	14	1	8	4.31 (2.02)	3.43 (1.45)	0.88
8	Pain at end of life in children	13	14	1	8	4.31 (2.89)	3.50 (1.45)	0.81
9	The importance of respite for families	13	14	1	8	5.08 (1.94)	4.14 (1.83)	0.94
10	Legacy creation / Memory making	13	14	1	8	4.92 (2.02)	3.86 (1.61)	1.06
11	Depression & anxiety in children	13	14	1	8	4.23 (1.83)	3.36 (1.74)	0.87
Total knowledge score*		**13**	**14**	**11**	**88**	**49.54 (19.16)**	**40.29 (16.02)**	**9.25**

*This is the total summated score for the 11 items on the Knowledge Scale
**Low scores indicate a perceived low degree of perceived knowledge for that topic
***High scores indicate a perceived high degree of perceived knowledge for that topic
6W: 6 weeks post-training
6M: 6-month post-training

By 6 months post-training, certain items were not well retained by respondent. The three items that reported the biggest declines between 6 weeks and 6 months were in “Forgoing artificial nutrition and hydration at end of life” (difference between means -1.33), “Legacy creation/memory making” (difference between means -1.06), and “Nausea and vomiting in children” (difference between means -1.03), indicating that knowledge in these areas was not well retained over time. While training initially boosted knowledge across all topics, certain areas particularly related to end-of-life nutrition and hydration, symptom management and memory making, experienced the most decline over an extended period.

Six weeks after the workshop, respondents were asked to describe if there were any changes in their perceived knowledge in relation to the management of PPC patients (Figure 4.3). Most respondents (n= 7, 54%) perceived some kind of change in knowledge levels, and the remaining either perceived their knowledge as “almost the same” (n=3, 23%) or that there was “no change” in knowledge (3, 23%). In regard to any change to their current practice as a result of knowledge change, only 1 respondent (8%) perceived any practice change while the rest (n=12, 92%) perceived that the knowledge had “not made any real difference in my practice” to “no change” at all.

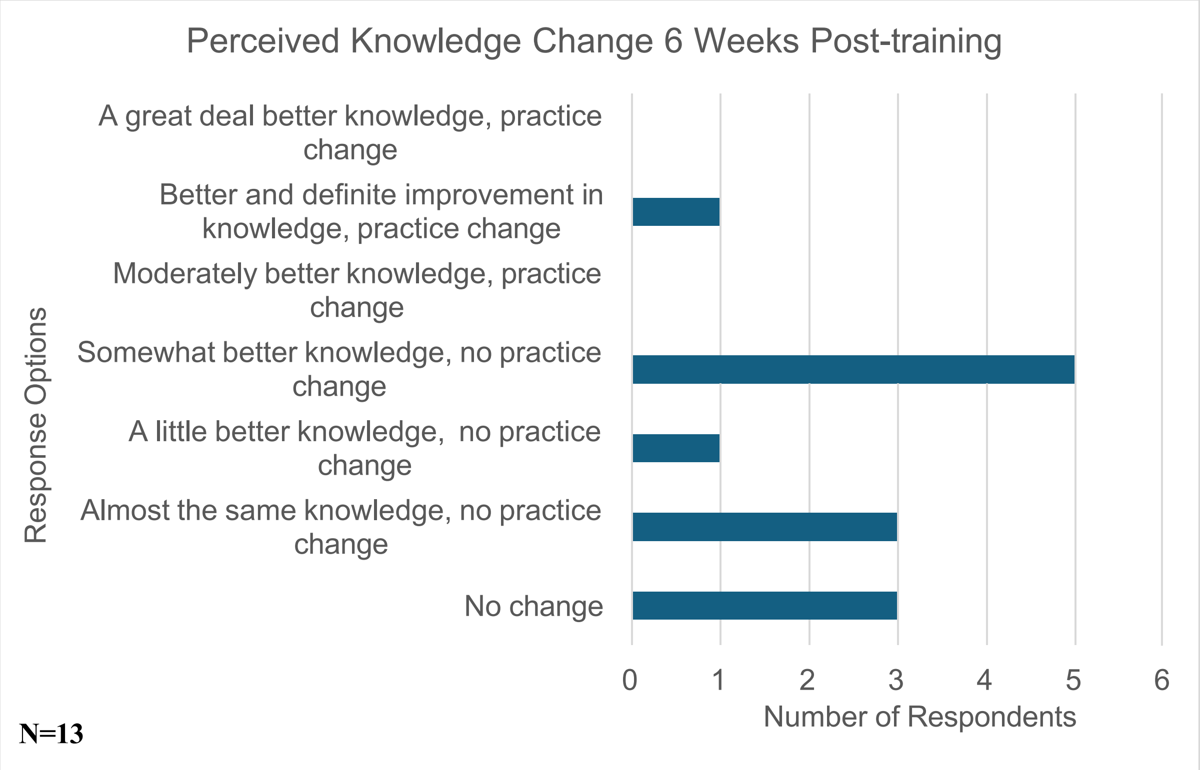

Figure 4.3: Perceived Knowledge Change 6 Weeks Post-training Related to Management of PPC Patients

The same question on perceived knowledge and practice change was asked again at 6 months post-training (Figure 4.4). At this time point, nearly all respondents (n=13, 93%) reported that whether there was change or no change in knowledge, they perceived that the training did not significantly change their practice. This highlights that at both 6 weeks and 6 months, most respondents perceived no significant change in their practice. The reasons for the no change in practice were reported in the open-text box for both the 6 week and 6-month post-training questionnaires. The most common reasons provided were that the respondents worked exclusively with adults and were not actively engaged in PPC. Highlighting how without ongoing exposure, initial knowledge gains may not result in long-term practice impact. One respondent after 6 months reported in the open-text box the need for further education to solidify their understanding, indicating that a single session may not be sufficient.

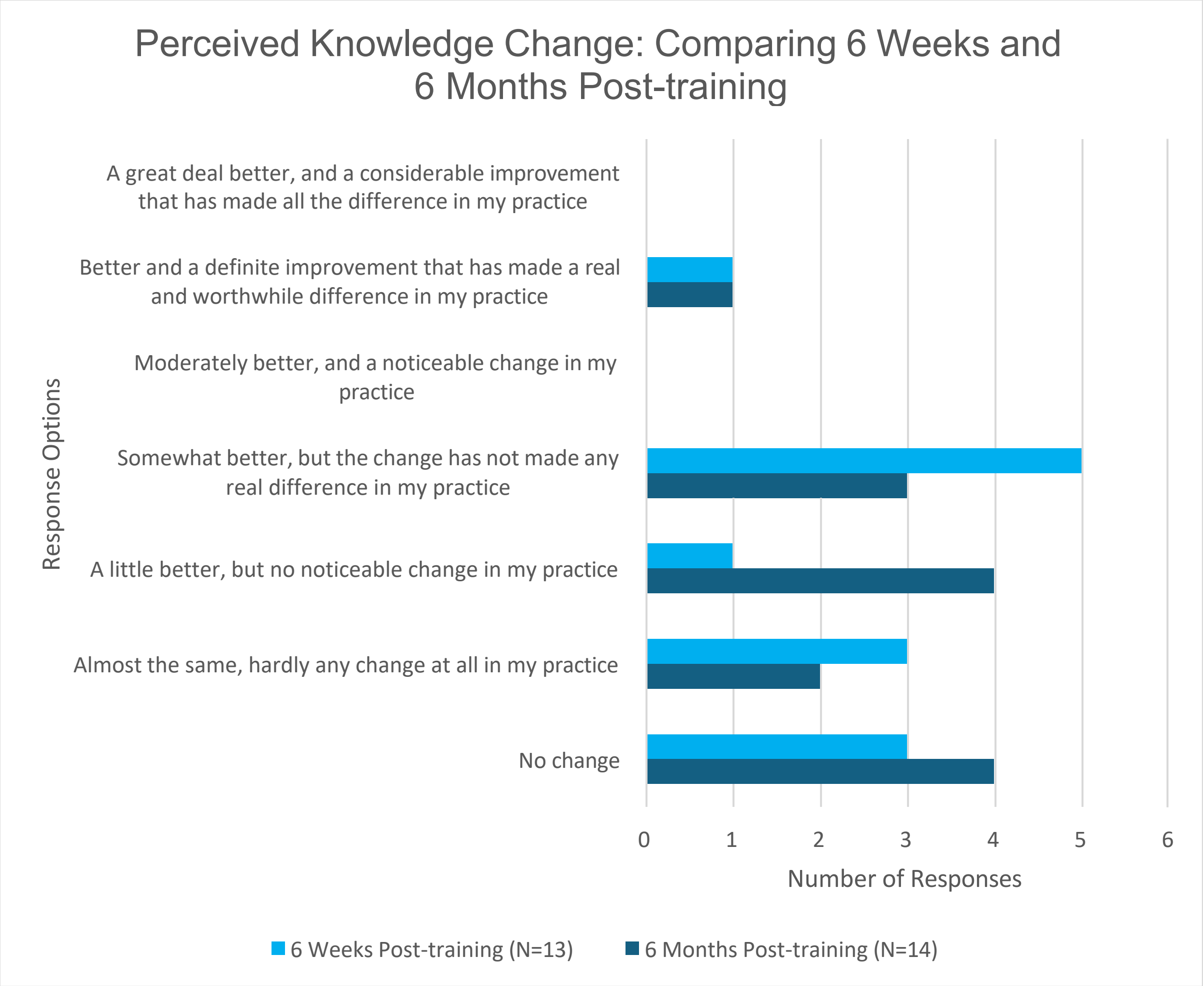

Figure 4.4: Perceived Knowledge Change Related to Management of PPC Patients: Comparing 6 Weeks and 6 Months Post-training

4.5. Level of Perceived Self-efficacy

The perceived level of self-efficacy or confidence of respondents was assessed using ten 8-point Likert scale questions at each time point.

4.5.1. Level of Perceived Self-efficacy at Pre-training

The pre-training perceived self-efficacy or confidence levels varied across different topics in PPC, with some areas showing higher confidence while others indicated a need for improvement (Table 4.3).

The three items scoring the highest in confidence levels at pre-training were “Identify and define who may benefit from palliative care involvement” (M=5.26, SD=2.07), “Recognise multisystem care needs and work within a collaborative team” (M=4.78, SD=2.42), and “Introduce and discuss palliative care with families and other healthcare providers” (M=4.93, SD=2.34). In contrast, the three items that respondents scored the lowest in perceived confidence were “Talk to children at various ages and developmental levels about serious illness and death” (M=2.56, SD=1.70), “Serve as a source of information in the community for paediatric palliative care-related questions and issues” (M=2.93, SD=2.15), and “Manage non-pain symptoms in children with serious illness, including at the end of life” (M=3.04, SD=1.97).

Table 4.3: Pre-training Self-efficacy Mean Scores, Total Score and Percentage* Agreement or Disagreement

No	Self-efficacy Items	n	Minimum***	Maximum****	Mean (SD)	Percentage Agreement	Percentage Disagreement
1	Identify and define who may benefit from palliative care involvement	27	1	8	5.26 (2.07)	77.8%	18.5%
2	Introduce and discuss palliative care with families and other healthcare providers	27	1	8	4.93 (2.34)	74%	25.9%
3	Support children with serious illness, as well as their families	27	1	8	3.56 (2.29)	44.4%	48.1%
4	Manage pain in children with serious illness, including at end of life	27	1	8	3.11 (2.06)	29.6%	55.6%
5	Manage non-pain symptoms in children with serious illness, including at end of life	27	1	8	3.04 (1.97)	29.6%	55.6%
6	Talk to children at various ages and developmental levels about serious illness and death	27	1	8	2.56 (1.70)	14.8%	66.7%
7	Understand the importance of communication and advance care planning in children with serious illness	27	1	8	4.33 (2.20)	51.9%	40.7%
8	Serve as a source of information in my community for paediatric palliative care-related questions and issues	27	1	8	2.93 (2.15)	22.2%	59.3%
9	Provide support to bereaved families	27	1	8	4.04 (2.16)	51.9%	37%
10	Recognise multisystem care needs and work within a collaborative team	27	1	8	4.78 (2.42)	59.3%	22.2%
Total self-efficacy score**		**27**	**11**	**88**	**38.56 (17.66)**		

1=Strongly Disagree, 2=Disagree, 3=Somewhat Disagree, 4=Neutral, 5=Somewhat Agree, 6=Agree, 7=Strongly Agree, 8=Unsure

*Overall percentage for “somewhat agree” to “strongly agree” on an eight-point Likert scale and overall percentage for “somewhat disagree” to “strongly disagree” on an eight point Likert scale.

**This is the total summated score for the 10 items on the Self-efficacy Scale

***Low scores indicate a perceived low degree of self-efficacy or confidence in that topic

****High scores indicate a perceived high degree of self-efficacy or confidence in that topic

To clearly highlight the areas respondents felt most or least confident in, responses were summarised into percentage agreement and disagreement (Table 4.3). “Somewhat agree” to “strongly agree” were grouped, as were “somewhat disagree” to “strongly disagree”. The three items of highest percentage agreement and disagreement repeat the same results as the mean scores discussed above. However, interestingly the respondents expressed greater percentage confidence in their abilities than in their knowledge levels. In the self-efficacy questionnaire, the majority agreed they had sufficient confidence in 5 out of 10 items, whereas in the knowledge questionnaire, only 1 out of 11 items had majority agreement.

4.5.2. Level of Perceived Self-efficacy Post 6 Weeks and 6 Months

Like knowledge levels, respondent self-efficacy scores showed an overall improvement from pre-training to 6 weeks post-training, followed by a slight decline at 6 months (Table 4.4). This is highlighted in the overall mean scores at pre-training (M=38.56, SD=17.66), 6 weeks post-training (M=51.08, SD=14.13), and 6 months post-training (M=42.86, SD=14.50). Additionally, the individual item scores at 6 months do generally remain higher than pre-training levels.

At 6 weeks post-training, the three highest-rated self-efficacy items were very similar to the pre-training items. However, except for one item that replaced “Recognise multisystem care needs and work within a collaborative team” with “Understand the importance of communication and advance care planning in children with serious illness”. While the lowest-rated self-efficacy, items remained the same as those identified pre-training but showed an increase in confidence (Table 4.4).

By contrast, at 6 months, the three items that scored the highest in self-efficacy were similar to the pre-training and 6 weeks post-training items except for the third highest being “Provide support to bereaved families” (M=4.86, SD=1.80) instead of “Recognise multisystem care needs and work within a collaborative team” or “Understand the importance of communication and advance care planning in children with serious illness”. The items that scored the lowest in self-efficacy at 6 months were again the same items as at pre-training and at 6 weeks post-training. This indicates a consistent trend of perceived low confidence in managing non-pain symptoms in children, acting as a PPC resource for the community, and communicating with children.

Table 4.4: Post 6 Week and 6 Month Training Self-Efficacy Mean Scores and Total Scores

No	Self-efficacy items	6W n	6M n	Minimm **	Maximum ***	Post 6W Mean (SD)	Post 6M Mean (SD)	Difference Between Means
1	Identify and define who may benefit from palliative care involvement	13	14	1	8	6.00 (1.00)	5.21 (1.25)	0.79
2	Introduce and discuss palliative care with families and other healthcare providers	13	14	1	8	5.92 (1.26)	5.07 (1.54)	0.85
3	Support children with serious illness, as well as their families	13	14	1	8	4.92 (1.55)	3.93 (1.69)	0.99
4	Manage pain in children with serious illness, including at end of life	13	14	1	8	4.92 (1.85)	3.79 (1.72)	1.13
5	Manage non-pain symptoms in children with serious illness, including at end of life	13	14	1	8	4.77 (1.83)	3.71 (1.82)	1.06
6	Talk to children at various ages and developmental levels about serious illness and death	13	14	1	8	3.85 (1.77)	3.36 (1.87)	0.49
7	Understand the importance of communication and advance care planning in children with serious illness	13	14	1	8	5.54 (1.45)	4.71 (1.73)	0.83
8	Serve as a source of information in my community for paediatric palliative care-related questions and issues	13	14	1	8	4.62 (1.61)	3.50 (1.91)	1.12
9	Provide support to bereaved families	13	14	1	8	5.08 (1.94)	4.86 (1.80)	0.22
10	Recognise multisystem care needs and work within a collaborative team	13	14	1	8	5.46 (1.81)	4.71 (1.82)	0.75
Total self-efficacy score*		**13**	**14**	**11**	**88**	**51.08 (14.13)**	**42.86 (14.50)**	**8.22**

*This is the total summated score for the 10 items on the Self-efficacy Scale

**Low scores indicate a perceived low degree of perceived self-efficacy for that topic

***High scores indicate a perceived high degree of perceived self-efficacy for that topic

6W: 6 weeks post-training

6M: 6-month post-training

Certain items respondents struggled to retain confidence in over the 6 months. The three biggest declines from 6 weeks to 6 months post-training were in “Manage pain in children with serious illness, including at end of life” (difference between means -1.13), “Introduce and discuss palliative care with families and other healthcare providers” (difference between means -0.85), and “Serve as a source of information in my community for paediatric palliative care-related questions and issues” (difference between means -1.12). While training was effective at initially boosting confidence, some areas especially pain management, introducing PPC to families or providers, and community engagement had notable declines over time.

4.6. Practice and Patient Level Changes

Practice and patient level changes were assessed at 6 weeks and 6 months post-training. This section consisted of five 8-point Likert scale questions, 1 multiple-choice question, and finally 1 forced-choice question at both time points.

The five Likert scale questions reported on what kind of impact the training had on the respondents. Responses at 6 weeks were largely positive as no response went lower than neutral (Figure 4.5). The most frequent response for each of the 5 statements was neutral. At 6 months, findings were very similar with the most common response once again being neutral for each item except for the overall mean score trending down from 6 weeks (M=26.92, SD=6.66) to 6 months (M=22.93, SD=6.03).

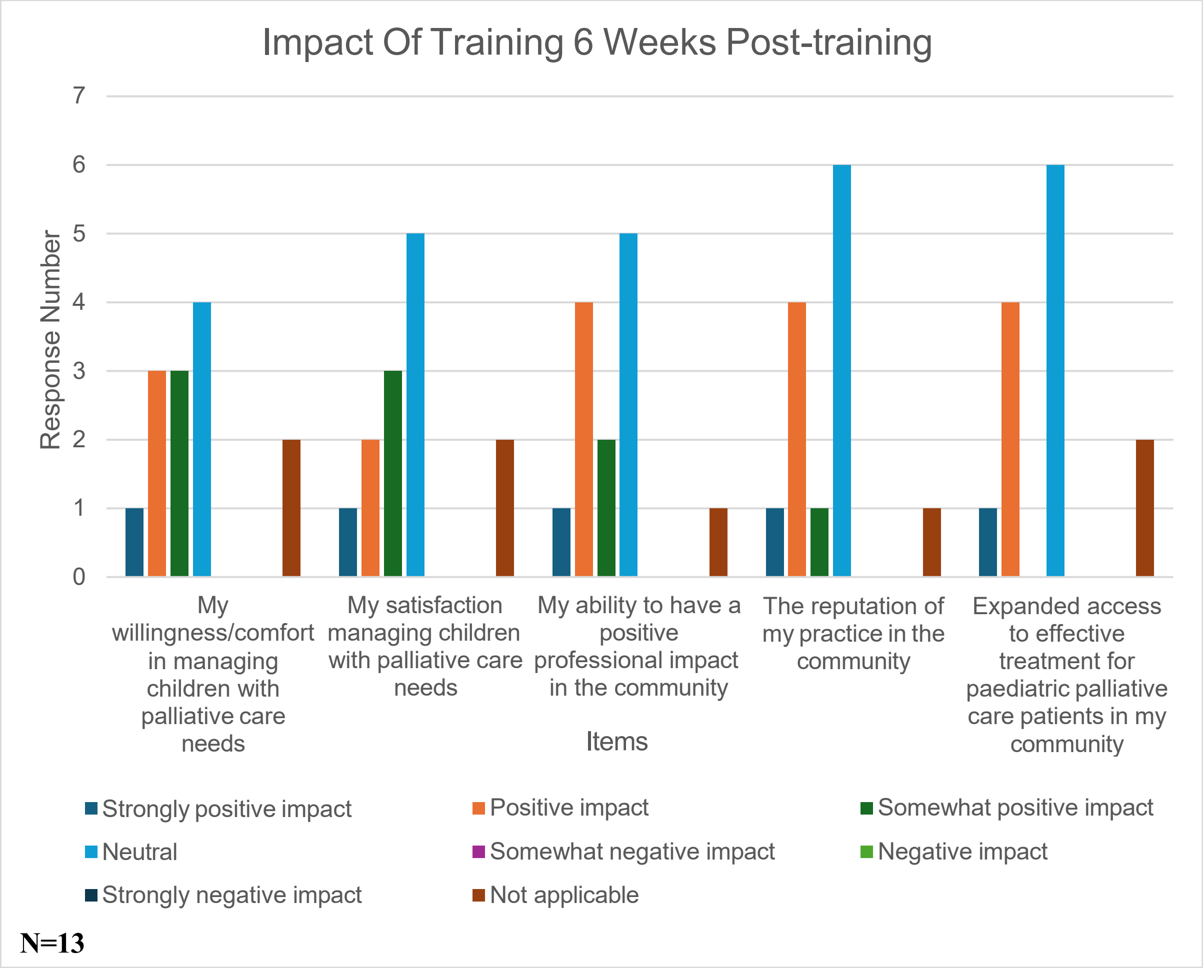

Figure 4.5: Impact of Training at 6 Weeks Post-training

The multiple-choice question asked respondents about the skills they may have improved on because of the PPC training. At 6 weeks and 6 months, “identifying patient needs” was the most frequent response regarding skill improvement (6 weeks n=10, 77%) (6 months n=8, 57%). However, unlike the responses at 6 weeks, at 6 months a select few (n=2, 14%) felt they did not improve any skills because of the training.

There were mixed results from respondents when asked whether they perceived a change in the management of patients at 6 weeks and 6 months post-training (Figure 4.6). At 6 weeks, most respondents selected “not applicable” (n=6, 46%). While at 6 months, there was an increase in more definitive yes (n=5, 36%) or no (n=5, 36%) responses.

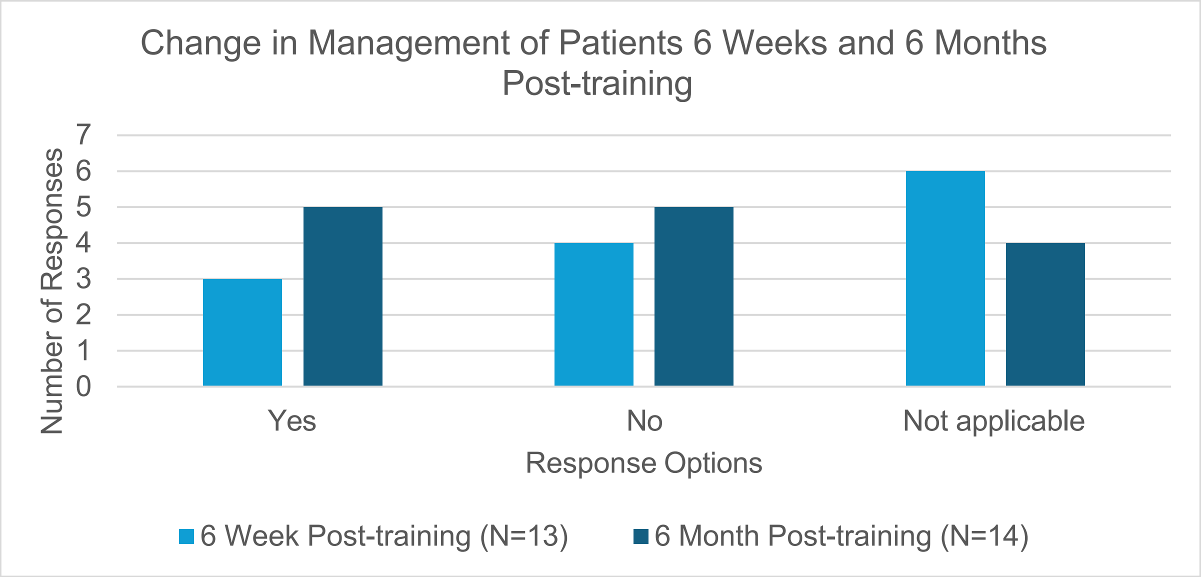

Figure 4.6: Change in Management of Patients 6 Weeks and 6 Months Post-Training

4.7. Reflections on and Acceptability of Training

4.7.1. Reflections on the Training

After the PPC training workshop, respondents were asked to reflect on the training and indicate if any of the (listed) goals had been met for them in one multiple-choice question. Responses at 6 weeks and 6 months post-training are shown in Figure 4.7.

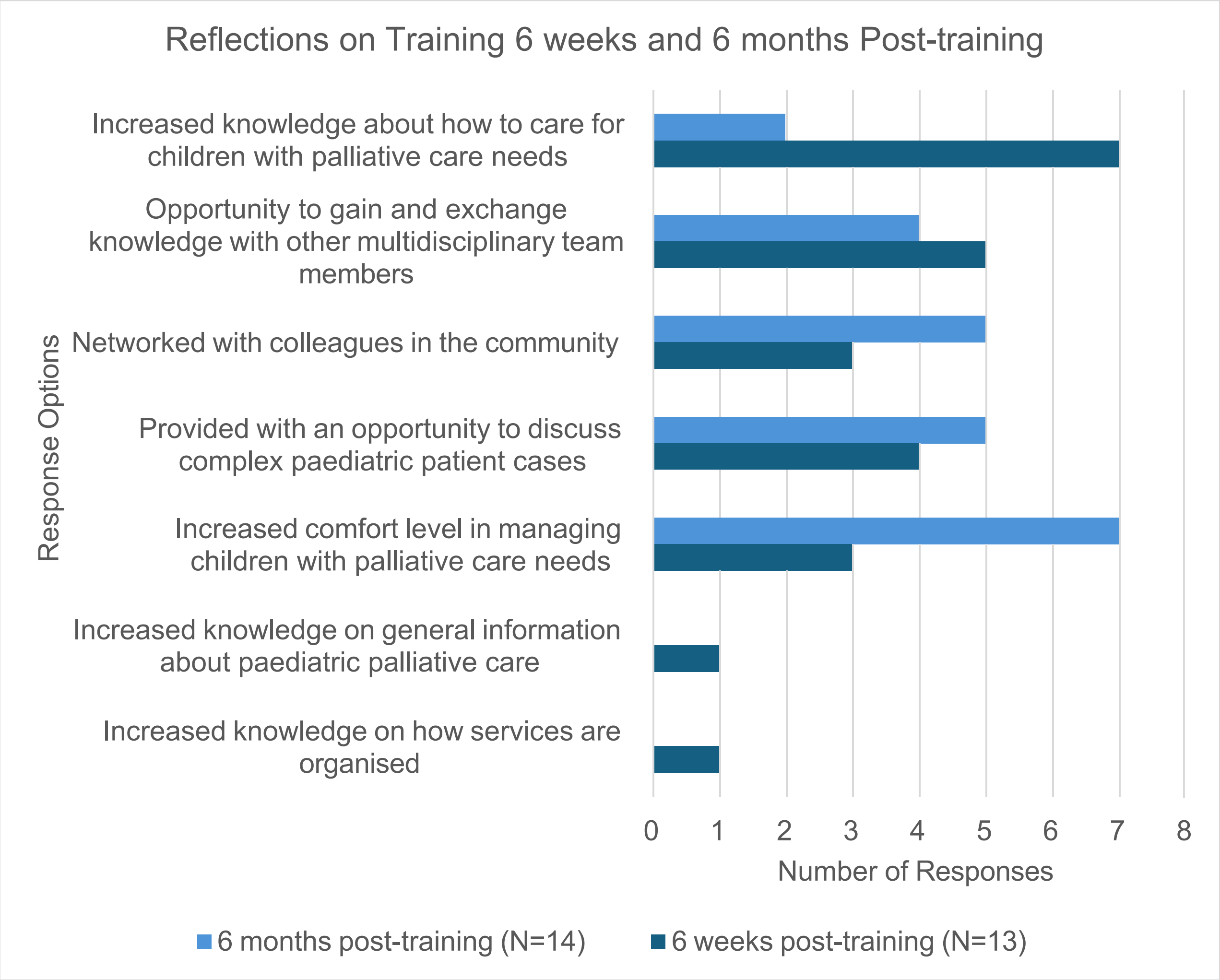

Figure 4.7: Reflections on Training 6 weeks and 6 months Post-training

At 6 weeks post-training, the most common goals that were met were: “Increased knowledge about how to care for children with palliative care needs” (n=7, 54%), “Opportunity to gain and exchange knowledge with other multidisciplinary team members” (n=5, 38.5%) and “Provided with an opportunity to discuss complex paediatric patient cases” (n=4, 31%).

At 6 months post-training, the most common goals that were met were: “Opportunity to gain and exchange knowledge with other multidisciplinary team members” (n=7, 50%), “Networked with colleagues in the community” (n=5, 36%), and “Increased knowledge about how to care for children with palliative care needs” (n=5, 36%).

4.7.2. Acceptability and Comfort Level with Training

At 6 weeks post-training acceptability, satisfaction and comfort levels with training were assessed. Acceptability and satisfaction were assessed using seven 7-point Likert scale questions and one open-text question (Table 4.5). Comfort levels were assessed using three 7-point Likert scale questions (Table 4.6).

Respondents were mostly satisfied with the following aspects of the training: “The training was a worthwhile experience for me” (M=5.62, SD=1.50), “I would recommend this training to my colleagues” (M= 5.62, SD=1.62), “The training created a supportive community of practice” (M= 5.69, SD=1.11), and “I have benefitted from the knowledge of the facilitators involved in the training” (M=5.62, SD=1.39). All statements ranging on average from somewhat agree to agree. The questions that received the lowest mean scores for acceptability and satisfaction were: “I have learned best practice care through the training” (M=4.77, SD=1.64) and “The training was an effective way for me to learn” (M= 5.31, SD=1.65). Ranging from neutral to somewhat agree. Training acceptability was assessed using the same threshold of a mean score of ≥ 5 on the 7-point Likert scale as applied by the authors of the original instrument (Lalloo et al., 2021). All answers to the questions were above the accepted threshold, except for the item “I have learned best practice care through the training” (M=4.77, SD=1.64).

Table 4.5 Six Week Post-Training Acceptability and Satisfaction Item Scores and Percentages*

No	Acceptability & Satisfaction Items	n	Mean (SD)	Percentage Agreement
1	The training was a worthwhile experience for me	13	5.62 (1.50)	76.9%
2	I would recommend this training to my colleagues	13	5.62 (1.50)	76.9%
3	The training created a supportive community of practice	13	5.69 (1.11)	76.9%
4	The training was an effective way for me to learn	13	5.31 (1.65)	76.9%
5	I have learned new information through the training	13	5.46 (1.71)	84.6%
6	I have learned best practice care through the training	13	4.77 (1.64)	53.8%
7	I have benefitted from the knowledge of the facilitators involved in the training	13	5.62 (1.39)	84.6%

1=Strongly Disagree, 2=Disagree, 3=Somewhat Disagree, 4=Neutral, 5=Somewhat Agree, 6=Agree, 7=Strongly Agree
*Overall percentage for “somewhat agree” to “strongly agree” on a seven-point Likert scale

Within the acceptability open-text question, respondents were asked to “indicate other ways in which you feel you have benefitted from participating in the training”. Nearly half reported that they “gained more knowledge on the topic of paediatric palliative care” (n=6, 43%), however some did feel that the training either did not meet expectations (n=2, 14%) or additional training in PPC was still needed (n=1, 7%).

Comfort levels with the training were mostly positive according to respondents with mean scores ranging from somewhat agree (M=5.69, SD=0.75) to agree (M=6.15, SD=0.69), with no respondents selecting below neutral (Table 4.6).

Table 4.6: Six Week Post-Training Comfort Item Scores

No	Comfort Items	n	Mean	SD
1	I felt comfortable speaking, asking questions, and sharing my opinion with other participants	13	5.69	0.75
2	I felt the facilitators were supportive and approachable	13	6.15	0.69
3	I felt the facilitators made an effort to include and engage me in the discussion	13	5.85	0.90

4.8. Comparisons within the Sample Profile

To gain a more comprehensive understanding of the sample profile, comparisons were made between groups within the pre-training sample and the knowledge and self-efficacy levels data collected. The following groups were used for comparisons: Nursing profession, years in adult SPC, and practice setting.

4.8.1. Nursing profession

As shown in Table 4.7, CNSs perceived themselves as having the highest knowledge (M=39.93, SD=16.52), followed by the PHN (M=28), then the RGNs (M=17.64, SD=10.46) according to their total mean scores. In terms of the items that scored highest in perceived knowledge, 15 CNSs in palliative care scored the highest in “The importance of respite for families” (M=5.0, SD=1.69), “Preparing for death and the time that follows” (M=4.80, SD=1.78) and “Introducing paediatric palliative care to families” (M=4.20, SD=1.90). The 11 Registered General Nurses (RGNs) scored highest in “The importance of respite for families” (M=2.64, SD=2.11), “Depression and anxiety in children” (M=1.91, SD=1.81) and “Legacy creation / Memory making” (M=1.82, SD=1.66). While the one PHN scored highest in “The importance of respite for families” (M=5.0) and “Legacy creation / Memory making” (M=5.0).

The lowest scored items in knowledge for both the CNSs and RGNs were “Neuro-irritability in children” and “Talking to children about death”. While the CNSs felt “Depression and anxiety in children” (M= 2.73, SD=1.39) to be an additional topic not well understood while RGNs perceived that “Pain at end of life in children” (M=1.36, SD=0.81) was their third least understood topic. The PHN’s lowest levels were low in all items (M=2.0) except for the two highest scored items as mentioned above.

As shown in Table 4.7, again CNSs self-efficacy levels were the highest (M=48.13, SD=12.52), the PHN after (M=31) and then the RGNs (M=26.18, SD=16.74) according to their total mean scores. The CNSs scored the highest in perceived self-efficacy for the items "Identify and define who may benefit from palliative care involvement", "Introduce and discuss palliative care with families and other healthcare providers" and "Recognise multisystem care needs and work within a collaborative team". RGNs scored the highest in the same two items except for the third being "Recognise multisystem care needs and work within a collaborative team". While the PHN scored the highest in "Introduce and discuss palliative care with families and other healthcare providers" and "Support children with serious illness, as well as their families". All professions felt they lacked confidence in particular items such as "Talk to children at various ages and developmental levels about serious illness and death", "Manage non-pain symptoms in children with serious illness, including at end of life" and "Manage pain in children with serious illness, including at end of life".

Table 4.7: Comparing Sample Profile with Knowledge and Self-efficacy Total Scores

Groups		**Knowledge Levels**		**Self-efficacy Levels**	
	n	Total Mean Score	SD	Total Mean Score	SD
Nursing Profession					
CNSs	15	39.93	16.52	48.13	12.52
RGNs	11	17.64	10.46	26.18	16.74
PHNs	1	28	N/A	31	N/A
Years in Adult SPC					
< 1 year	2	20	14.20	25.50	7.78
1 - 4 years	7	23.86	14.20	34.57	16.63
5 -10 years	5	39.60	13.40	50.80	12.38
> 10 years	11	35.36	20.53	39.55	20.95
Practice Setting					
Adult Hospice	12	25.50	19.53	31.67	20.94
Community Palliative Care Team	12	38.33	14.29	47.58	11.71
Public Hospital	2	13.50	3.54	29.50	3.54
Local Health Centre	1	28	N/A	31	N/A
Environment					
Suburban/Urban	20	27.70	18.62	35.15	18.73
Rural	6	36.50	12.76	48	10.51
Both Suburban and Rural	1	48	N/A	50	N/A

4.8.2. Years in Adult SPC

As shown in Table 4.8, those with over 4 years of SPC experience tended to report the highest knowledge and self-efficacy levels. While less years of SPC experience (<1 year or 1-4 years) showed significantly lower knowledge and self-efficacy scores.

Table 4.8: Comparing years in SPC with Knowledge and Self-efficacy Total Scores

Indicate number of years working in specialist palliative care (adult)?	Total Knowledge Items			Total Self-efficacy Items	
	n	Mean	SD	Mean	SD
<1 year	2	20.00	11.314	25.50	7.778
1-4 years	7	23.86	14.206	34.57	16.632
5-10 years	5	39.60	13.502	50.80	12.377
>10 years	11	35.36	20.529	39.55	20.954

4.8.3. Practice Setting

According to the primary practice setting, the 12 who worked in the Community Palliative Care Team had the highest scores in knowledge and self-efficacy (Table 4.7). Those working in the Local Health Centre scored higher in knowledge (M=28) in comparison to the 12 respondents from the adult hospice (M=25.50, SD=19.53), however, there was only one PHN representing the Local Health Centre. The 2 RGNs working in the public hospital scored the lowest in both knowledge (M=13.50, SD=3.54) and self-efficacy (M=29.50, SD=3.54).

Working in rural areas or both suburban and rural scored the highest in both knowledge and self-efficacy (Table 4.7). However, this may be due to all respondents in the rural setting having extensive experience (5 or more years in SPC) or because they all work in either an adult hospice or within a Community Palliative Care Team. While those working in the suburban/urban setting included a mix of less experienced professionals (with less than 5 years SPC experience) and those working in non-SPC settings.

4.9. Conclusion

The findings of this study highlight a significant gap in perceived knowledge and self-efficacy among respondents regarding PPC, particularly in symptom management, ethical decision-making, and communication with children and families. Baseline results indicated that most respondents felt inadequately prepared in most PPC topics, with notable deficiencies in areas such as managing neuro-irritability, discussing death with children, depression and anxiety, and ethical considerations like forgoing artificial nutrition and hydration. The variation in knowledge levels across different professional groups and settings suggests disparities in prior training and SPC years of experience.

The training programme led to an initial increase in perceived knowledge and self-efficacy at the six-week follow-up, particularly in previously weak areas. However, knowledge retention declined slightly by six months, with most respondents reporting no significant impact on their practice, especially those working primarily with adult patients.

Despite these challenges, respondents acknowledged benefits from the training, particularly in fostering collaboration, networking, and interdisciplinary learning.

CHAPTER 5: DISCUSSION

5.1. Introduction

The purpose of this thesis was to assess the perceived knowledge and self-efficacy of adult palliative care nurses in delivering paediatric palliative care (PPC) before and after a targeted training workshop.

Currently an estimated 21 million children around the world require some form of PPC, including 8 million who need specialist services (Connor, Downing and Marston, 2017). With the advances in healthcare and broader eligibility criteria for PPC involvement, more children with life-limiting conditions (LLCs) are living longer and receiving care at home (Law, McCann and O'May, 2011; Ling, et al., 2015; Benini et al., 2022). This shift has increased reliance on community-based healthcare professionals to deliver PPC, including adult palliative care nurses. In the Republic of Ireland, adult palliative care professionals are recognised as key workers in the care of children with LLCs in the community (Health Service Executive, 2020; Department of Health, 2024). However, within the literature adult palliative care nurses consistently report that they lack adequate levels of education (Chong and Abdullah, 2017; Bogetz et al., 2022; Kang et al., 2022), knowledge (Quinn and Bailey, 2011; Reid, 2013; Doherty et al., 2021; Lalloo et al., 2021), preparedness (Clarke and Quinn, 2007; Reid, 2013), comfort (Chong and Abdullah, 2017; Vesel and Beveridge, 2018; Kaye et al., 2019; Kaye et al., 2020a; Porter et al., 2021; Bogetz et al., 2022; Hamre et al., 2022) and confidence (Reid, 2013; Chong and Abdullah, 2017; Vesel and Beveridge, 2018; Greenfield et al., 2022) in providing their services to children in the community.

In response, there has been growing emphasis in Ireland (Clarke and Quin, 2007; Quinn and Bailey, 2011; Reid, 2013) and internationally (Vesel Beveridge, 2018; Kaye, 2020a; Porter et al., 2021) on providing PPC education to adult palliative care nurses. Despite this, evidence remains limited on whether such training effectively improves their knowledge or self-efficacy, particularly over time. This study addresses this gap by using a longitudinal design to measure changes of knowledge and self-efficacy levels before and after PPC education.

This chapter presents the discussion that will explore how the findings from Chapter 4 of this study compares to current research. The chapter then concludes by addressing the study limitations, recommendations and final thesis conclusion.

5.2. The Study Sample

The data for this study was collected using a convenience sampling method. Twenty-seven respondents completed the pre-training questionnaire, 13 completed the 6 weeks post-training questionnaire and 14 completed the 6 months post-training questionnaire. All 45 attendees of the workshop received an email and had access to the survey before and at 6 weeks and 6 months after training. The study sample consisted of adult specialist palliative care (SPC) nurses and nursing students completing a Graduate Diploma in Palliative Care in the Republic of Ireland. The administration staff for the PPC training were able to verify the accuracy and credibility of the total sample population. The sample of adult palliative care nurses at baseline included a diverse range of nursing roles, years of experience in SPC, primary practice settings, and urban or rural work environments. The trends within the study sample were like other studies within the literature review presented in Chapter 2. Most respondents in this study were either Clinical Nurse Specialists (n=15, 56%) or Registered General Nurses working in palliative care (n=9, 33%). Compared to other studies, Quinn and Bailey (2011) present a sample profile made up of Clinical Nurse Specialists in palliative care only. Reid (2013) included Registered General Nurses and Clinical Nurse Specialists in palliative care. Clarke and Quin (2007) had 79% (n=60) of the study sample made up of Clinical Nurse Specialists or Clinical Nurse Managers.

In contrast with the literature, the sample in this study had more years of SPC experience with 11 respondents (41%) working for greater than 10 years in SPC. Kaye et al. (2019) reported 54% (n=296) nurses had less than 5 years SPC experience. Porter et al. (2021) found that 73% (n=30) of nurses had less than 10 years SPC experience. Vesel and Beveridge (2018) reported that 58% (n=42) had 5 or less years of experience. While Kristjanson et al. (2005) presented an average of 2.8 years (n=59) in SPC experience from respondents.

Most respondents worked in suburban/urban environments (n=20, 74%), while the rest worked in rural localities (n=6, 22%) and one (4%) worked in both rural and suburban/urban. One strength of this study was that it targeted adult palliative care nurses in rural settings as they often lack supportive resources compared to urban environments (Reid, 2013; Chong and Abdullah, 2017; Weaver et al., 2020; Weaver et al., 2021). This study found that those working in rural or both rural and urban environments had the highest levels in perceived knowledge and self-efficacy compared to just urban/suburban. This is discussed in further detail later in the discussion.

The useable response rates for each time-point were 60% (n=27) for pre-training, 29% (n=13) for 6 weeks post-training, and 31% (n=14) for 6 months post-training. Unfortunately, there is no available data on the number of practicing palliative care nurses in Ireland. Therefore, it was not possible to contextualise the representativeness of the study sample.

Low response rates have been frequently reported in studies with similar study samples, as shown in the data extraction table (Appendix 3). Hamre et al. (2022) had a response rate of 30% (n=31) out of a total population of 103. Porter et al. (2021) reported a response rate of 18% (n=41) drawn from an accessible population of 226. The decline in response rates for longitudinal questionnaires is also common. Vesel and Beveridge (2018) present response rates ranging from 77% at pre-training, 67% post-training, and 28% 6 months post-training. Weaver et al. (2021) recorded 100% response rates for their pre-training and post-training (straight after training) questionnaire, however at 6 months post-training questionnaire the response rate decreased to 55%.

In summary, the study sample included adult SPC nurses and nursing students completing a Graduate Diploma in Palliative Care. The response rates were low and decreased with time during the longitudinal study, however this has been frequently reported in similar studies. The sample was diverse in nature, with nursing roles like those reported in the literature. However, it differed from other studies in that respondents had more years of SPC experience and rural nurses reported higher perceived knowledge and self-efficacy levels in PPC. This study is unique as it is one of the few longitudinal assessments of adult palliative care nurses' knowledge and self-efficacy before and after PPC training.

5.3. Lack of Baseline Knowledge and Self-efficacy in Paediatric Palliative Care

Adult palliative care nurses in this study consistently reported low perceived knowledge and self-efficacy levels across the PPC items. Similar results are reported in other studies in which low baseline knowledge (Quinn and Bailey, 2011; Reid, 2013; Doherty et al., 2021; Lalloo et al., 2021), and low baseline self-efficacy or confidence levels (Quinn and Bailey, 2011; Reid, 2013; Vesel and Beveridge, 2018; Lalloo et al., 2021) is a common finding in adult palliative care nurses. Several studies have presented their rationale for the lack in knowledge and self-efficacy in PPC. One reason being the limited exposure to child patients that adult palliative care nurses have in the community (Clarke and Quinn, 2007; Reid, 2013; Chong and Abdullah, 2017; Kaye et al., 2019; Kaye et al., 2020b; Johnson et al., 2020; Doherty et al., 2021; Weaver et al., 2021; Bogetz et al., 2022). Respondents in this study reported the lack of child patients in the open-text fields. Another reason could be the lack of standardised training in the community (World Health Organisation, 2014; Neilson et al., 2021; Department of Health, 2024). Standardised PPC training has been described as imperative by the Children's Palliative Care Education and Training Action Group as it can improve the knowledge and skills in providing safe and effective PPC in the community (Neilson et al., 2021). Studies have also reported that having a children's qualification is the most important factor in improving confidence in PPC (Reid, 2013), while others would argue that more nursing experience in general was important for confidence (Hamre et al., 2022). In previous studies, there was no information gathered on whether years of experience in adult SPC was an indicator for better knowledge. This study showed that the respondents with more than 4 years of adult SPC experience had better knowledge and self-efficacy scores than those with less years. There is no definitive reason that has been proposed for the lack of knowledge or self-efficacy in PPC, likely due to the varied nature of the role of the community adult palliative care nurse.

The lack of knowledge and self-efficacy highlights the need for tailored PPC training that supports adult palliative care nurses, even if they care for a limited number of children during their profession. Future research should consider exploring if the number of years as a nurse, or years in adult SPC, or previous paediatric-specific training supports adult palliative care nurses in delivering their services to children.

5.4. Particular Challenges in Paediatric Palliative Care

There were recurring items that scored the lowest in knowledge and self-efficacy by adult palliative care nurses. Items that respondents reported poor perceived knowledge in were "Neuro-irritability in children", "Talking to children about death", "Depression and anxiety in children" and "Forgoing artificial nutrition and hydration at end of life".

Neuro-irritability, and depression and anxiety have been identified by international standards as one of the most common symptoms in PPC (Benini et al., 2022). Evidence suggests that neuro-irritability is a topic in PPC that adult palliative care professionals lack knowledge in (Lalloo et al., 2021). Neuro-irritability can be described as persistent episodes of behaviours that are suggestive of pain in a child with severe neurological impairment once other sources of pain are ruled out (e.g. gastroesophageal reflux, constipation or reflux) (Hauer and Houtrow, 2017). A group of PPC experts taking part in a Delphi study conducted by Avagnina et al. (2023) found that there is limited research on the management of neuro-irritability. The gap in knowledge in neuro-irritability for adult palliative care nurses as well as a notable lack in information on its management highlight the need for this topic to be addressed in PPC training. If not managed properly, neuro-irritability can have a significant effect on the quality of life of both the child and their family, potentially effecting the relationship with the family and the clinical team (Avagnina et al., 2023).

Communication in PPC whether that is about end-of-life care, breaking bad news or goals of care is consistently reported as a knowledge gap for adult palliative care professionals (Kaye et al., 2020; Doherty et al., 2021; Lalloo et al., 2021; Bogetz et al., 2022). Additionally, lack of knowledge in psychological or psychosocial aspects of PPC such as managing depression and anxiety in children are also prominent issues reported in the literature (Chong and Abdullah, 2017; Vesel and Beveridge, 2018; Kaye et al., 2019; Kaye et al., 2020a; Doherty et al., 2021; Lalloo et al., 2021; Bogetz et al., 2022; Hamre et al., 2022). Effective skills in communication and the provision of psychosocial care is paramount in palliative care as they form part of its very definition, as outlined in the National Adult Palliative Care Policy in Ireland (Department of Health, 2024). However, in children these skills are different to adults and pose their own challenges for adult palliative care nurses. Children are continuously developing even when facing a serious illness, meaning clinicians must adapt their communication to each child’s developmental stage and understanding of their illness (World Health Organisation, 2018). While the psychosocial aspects of care can present differently in children compared to adults, and can require different approaches to its management such as the use of play therapy (Benini et al., 2022).

Topics on hydration and nutrition were only found in one other study as an identified learning need (Vesel and Beveridge, 2018), like this study. Five studies were broader in their description and mentioned the need for more training in end-of-life care practices (Jeffrey, 1994; Clarke and Quinn, 2007; Quinn and Bailey, 2011; Kaye et al., 2019; Greenfield et al., 2022). End-of-life topics such as hydration and nutrition can be ethically, emotionally and clinically complex in their management (Schwartz et al., 2021). Therefore, it is imperative to not only ensure to provide training on the typical challenges in PPC but also include the more complex ethical issues that may surface in PPC. There have been only three studies, including this one, that assessed adult palliative care professionals’ knowledge on ethical issues in PPC (Lalloo et al., 2021; Weaver et al., 2021).

While the items that respondents in this study scored particularly low in perceived self-efficacy were “Talk to children at various ages and developmental levels about serious illness and death”, “Serve as a source of information in the community for paediatric palliative care-related questions and issues”, and “Manage non-pain symptoms in children with serious illness, including at the end of life”. These items scored the lowest at each time point during the entirety of this study. There seems to be a clear trend in which knowledge and self-efficacy is low in both communication and non-pain symptom management. This gap is not surprising as communication and non-pain symptoms in PPC have been identified as key learning needs for adult palliative care professionals in the literature (Clarke and Quinn, 2007; Quinn and Bailey, 2011; Chong and Abdullah, 2017; Vesel and Beveridge, 2018; Kaye et al., 2019; Doherty et al., 2021; Lalloo et al., 2021; Porter et al., 2021; Bogetz et al., 2022; Hamre et al., 2022). While respondents not feeling confident in acting as a source of information for their community could be a symptom of their overall low knowledge levels in PPC, as already discussed.

Research has indicated that PPC training is the most effective when it avoids a one-size fits all approach and is tailored to the particularly challenging aspects of PPC that learners are facing (Slater et al., 2018; Widger et al., 2018). Aspects such as neuro-irritability or non-pain symptom management, communicating with children about illness or death, depression and anxiety in children, and ethical issues such as hydration and nutrition at end-of-life are topics that should be addressed during PPC training of adult palliative care nurses.

5.5. Difference Between Urban and Rural Nurses

Respondents in this study worked in suburban/urban environments (n=20, 74%), rural (n=6, 22%) or both (4%). Respondents working in rural or both rural and urban/suburban environments were reported to have the highest levels in perceived knowledge and self-efficacy compared to just urban/suburban. Similar findings have been identified within the literature regarding rural adult palliative care nurses with high confidence levels in PPC (Weaver et al., 2021). However, Weaver et al. (2021) do not detail the possible reasons for the high levels reported. When exploring the reasons for this difference between urban and rural nurses, there are several possible factors. One such factor could be that nurses working in rural settings may develop a broader skillset and increased confidence or knowledge in palliative care due to the necessity of managing diverse responsibilities in resource-limited environments. Kaasalainen et al. (2011) supports this in their study that found rural community-based nurses having more confidence in providing palliative care compared to urban. However, there is another possible reason as most of the rural respondents in this study had five or more years of experience in SPC, while those in the urban/suburban setting included respondents with less years in SPC and those with no SPC experience at all. However, with such a small study sample it is hard to definitively conclude whether the work environment or years in adult SPC caused the increase in knowledge and self-efficacy.

Although rural adult palliative care nurses in this study reported higher perceived knowledge and self-efficacy, this may reflect both the demands of practising in resource-limited settings or possibly the more years of experience in SPC. However, given the small sample size, it is not possible to determine which of these are the most likely to cause increased knowledge and self-efficacy or whether both play a role.

5.6. More Confidence, Less Knowledge

This study found that respondents perceived they were more confident in their ability to provide PPC than in their perceived knowledge of PPC. Respondents disagreed that they had an adequate level of knowledge in 10 out of the 11 items on PPC. While respondents disagreed that they had an adequate level of self-efficacy in 5 out of 10 items. This is comparable to findings from another study that also assessed both perceived self-efficacy and knowledge levels (Lalloo et al., 2021). There may be some explanation for this, such as Bandura's Self-Efficacy Theory (Bandura and Adams, 1977) where self-efficacy is described to be often influenced by previous experiences and the perceived difficulty of a task. For example, if someone's knowledge is limited, they might still feel confident in their ability to perform tasks based on their successful experiences in their adult palliative care practice or perhaps even their previous care to a child. Other possible rationale could be that the self-efficacy PPC items were not as age specific as the knowledge items (such as "The importance of respite for families" and "Preparing for death and the time that follows"). This was identified during the analysis of the results, that many of the self-efficacy items could be applied to the adult context, possibly resulting in respondents perceiving a high confidence in. While there is no evidence that has been found in the literature that examines similar findings and the possible rationale in the palliative care context. There have been similar findings observed in other studies regarding nurses, such as a study by Seidel-Fischer et al. (2024) that found that nursing students were often overconfident in hand hygiene practices, which stemmed from a lack of awareness of their knowledge gaps and prior experiences. It could be plausible that adult palliative care nurses may have felt overconfident in their abilities to provide PPC, due to their limited knowledge of PPC best practices.

While self-efficacy is essential for healthcare professionals to perform their roles effectively, it is equally if not more important that this confidence is underpinned by adequate knowledge to ensure the delivery of high quality, and evidence-based care. Although the findings related to self-efficacy were promising, the significant gaps in knowledge highlight a clear need to provide PPC training.

5.7. Retention and Impact of Learning

There was a trend in both knowledge and self-efficacy with levels low at pre-training, to then increase at 6 weeks post-training, and then slightly decline at 6 months. This poor retention of knowledge and self-efficacy differed to other studies that had linear trajectories in increasing knowledge or self-efficacy levels at three time points, from pre-training to post-training (Kristjanson et al., 2005; Vesel and Beveridge, 2018; Weaver et al., 2021).

A possible explanation for the decline in overall knowledge and self-efficacy levels at 6 months was the lack of exposure to children as patients, as reported by respondents, and possibly due to the once-off delivery of the training session. While similar studies would also have reported the lack of regular exposure to paediatric patients as a particular issue (Reid, 2013; Chong and Abdullah, 2017; Kaye et al., 2019; Johnson et al., 2020; Kaye et al., 2020a; Kaye et al., 2020b; Doherty et al., 2021; Weaver et al., 2021; Bogetz et al., 2022).

In addition, it is important to highlight that one study by Vesel and Beveridge (2018), objectively assessed knowledge levels by classifying responses as either correct or incorrect. This objective form of assessment has many advantages, however there is a possibility of recall bias influencing their ability to answer correctly the same questionnaire six months later. Recall bias has been shown to influence longitudinal knowledge assessments (Schwarz, Revilla and Weber, 2020). This study relied on self-assessed or perceived knowledge measures which captured respondents’ subjective evaluation of their own understanding of the PPC items. This form of assessment was the most common within the literature review (Kristjanson et al., 2005; Kaye et al., 2019; Weaver et al., 2020; Lalloo et al., 2021; Weaver et al., 2021; Bogetz et al., 2022; Hamre et al., 2022) and has been identified as the most common form for measuring nurses' knowledge, skills and attitudes in a systemic review (Leung, Trevena and Waters, 2014). Both forms of objective and subjective assessments have their own advantages and disadvantages. Self-assessments can be straightforward to implement and can provide valuable insights about the respondents. While objective assessments can provide very reliable and accurate results on respondents’ understanding of certain topics. However, both have their own possible limitations especially when objective measurements are designed longitudinally.

In regard to the impact of training, there were largely positive responses provided, yet there was little to no practice change after training. When asked whether there was any patient level or practice change, most respondents selected “Not applicable” (n=6, 46%) at 6 weeks, while at 6 months post-training respondents were more definitive with yes (n=5, 36%) or no answers (n=5, 36%). Reasons for the lack in clinical impact could be found in the open text provided where respondents expressed how their practice did not change due to them not caring for children. Again, a repeated issue for adult palliative care nurses as already mentioned in this Discussion Chapter and within the literature (Reid, 2013; Chong and Abdullah, 2017; Kaye et al., 2019; Johnson et al., 2020; Kaye et al., 2020a; Kaye et al., 2020b; Doherty et al., 2021; Weaver et al., 2021; Bogetz et al., 2022). However, the lack of impact of the training on clinical practice in this study contrasts with findings from other studies. For example, Lalloo et al. (2021) reported that there were patient level changes after training. However, this may be because they conducted regular training sessions rather than once off sessions. Regular online or face-to-face PPC education has become more prominent within the literature compared to the once-off sessions (Daniels and Downing, 2018; Marston, Boucher and Downing, 2018; Kennedy et al., 2022). How the PPC education sessions are delivered has shown to be vital. In an evaluation of the impact of PPC education, Slater et al. (2018) emphasises the need for interactive approaches to PPC training such as incorporating storytelling, parent experiences and case studies to enable participants to implement best practice care.

This study's findings and the existing literature emphasises that adult palliative care nurses require regular, interactive training to compensate for the limited exposure to child patients and to support meaningful changes in practice.

5.6. Study Limitations

This quantitative longitudinal pretest-post-test research design examined adult SPC nurses' and adult palliative care postgraduate nursing students' perceived knowledge and self-efficacy levels, and the changes to these levels and to their clinical practice after a PPC training workshop. As with all research, conducting a study within a defined timeframe and scope inherently involves certain limitations that must be acknowledged. A thorough examination of these limitations is outlined below regarding the design, sampling methods and instrument used.

5.6.1. Design

The longitudinal design allowed for the same data to be collected over time to assess changes in perceived knowledge and self-efficacy. This was important as this design was in keeping with the study's aim. However, since the surveys were conducted anonymously to encourage honest responses, it was not possible to follow individual responses over the multiple time points. This prevented more detailed data analysis such as comparing specific demographic characteristics to knowledge and self-efficacy scores over time.

5.6.2. Sampling

A non-probability convenience sample was used, consisting of adult SPC nurses and student nurses enrolled in a Graduate Diploma in Palliative Care. The study sample worked in various settings such as an adult hospice, public hospital, community and Community Healthcare Centre in the urban and rural areas of Ireland. Strategies to enhance response rates were implemented such as sending two email reminders to all attendees at each time point (email invitation in Appendix 4).

Despite this the response rate did steadily decline with a useable response rate of 60% (n=27) at the pre-training questionnaire, to a response rate of 29% (n=13) at 6 weeks post-training, and 31% (n=14) at 6 months post-training. Furthermore, since this study used a non-probability sample from a small population sample of attendees to a training workshop, it is acknowledged that responses may not align with the views or experiences of other adult palliative care nurses in Ireland. The potential for sampling bias and sampling error is recognised as the views of those who did not respond may differ from those who did. Nonetheless, these findings cannot be compared to the population as currently there is no available data on the number of practicing palliative care nurses in Ireland.

5.6.3. Instrument

There were several limitations in relation to the instrument developed by Lalloo et al. (2021) and adapted to the Irish context (details of adaptations in Appendix 6) for this study.

Firstly, certain changes to the demographic questions would have been helpful as follows:

- Adding “community” as one of the possible primary practice settings listed would have been beneficial for respondents and the researcher as respondents had to write in the open-text box to clarify their setting. This then required further analyses to be conducted by the researcher in order to categorise the open-text responses.
- Collecting data on previous PPC training and PPC experience would have provided better insight into the rationale for reported high or low knowledge or self-efficacy levels. Questions such as the ones presented below, informed by the survey conducted by Vesel and Beveridge (2018):
  <u>Question</u>. Have you ever provided paediatric palliative care to a child?
  (Forced-choice responses: Yes, No).

Follow up Question. If so, how often would you have provided paediatric palliative care to a child per year
(Forced-choice responses: 1-4, 4-10, 10 or more).

Question. Do you have any formal paediatric-specific training such as a dual qualification or a post-graduate diploma
(Forced-choice responses: Yes, No, Other with text-box).

- Demographic questions are invaluable, having them asked at each time point may have helped to assess individual trends pre- and post-training while still being anonymous.

Additional limitations:

- Findings were limited by the reliance on self-assessed knowledge and self-efficacy levels, which may not accurately reflect concrete changes in respondents. Within the literature, it is understood that self-assessments are subjective and therefore an over- or underestimation of one's own abilities can occur (Garland, 1996; Cowan, Wilson-Barnett and Norman, 2007; Cowan et al., 2008). Changes in knowledge could be more accurately measured using objective validated tools specifically designed to evaluate PPC knowledge. However, in longitudinal studies, care must be taken in the development of such tools to minimise recall bias.
- It would have been helpful to include assessments on attitude to PPC, as international standards for PPC education and training set by Benini et al. (2022) underline the need to assess attitude in addition to their knowledge, skills, and practice. A number of papers did assess attitude and found respondents' attitudes did improve after training (Kristjanson et al., 2005; Vesel and Beveridge, 2018).
- While this study measured participants' self-efficacy, there are many possible factors that affect self-efficacy levels but were not measured at each time point in the surveys. Self-efficacy can be influenced by multiple contextual factors such as work environment, level of qualification, personal culture (Berhanu, R.D. et al., 2021; Hoegen et al., 2022). Therefore changes in self-efficacy scores should be interpreted cautiously, and not attributed solely to the workshop content.

5.7. Recommendations

The findings from this study highlights an important gap within the literature and emphasises the lack of knowledge, self-efficacy and adequate training that adult palliative care nurses receive in PPC. Recommendations from the findings of this study presented here need to be addressed at education, practice and research levels.

5.7.1. Education

Aligning with the recommendations made by the National Adult Palliative Care Policy (Department of Health, 2024), it is recommended that PPC training is incorporated into all postgraduate specialist palliative care training in Ireland. This is an exciting time as adult SPC professionals have expressed a desire to receive additional training in PPC for a long time (Kristjanson et al, 2005; Clarke and Quinn, 2007; Reid, 2013; Chong and Abdullah, 2017; Vesel and Beveridge, 2018; Kaye et al., 2019; Johnson et al., 2020; Kaye et al., 2020a; Lalloo et al., 2021; Porter et al., 2021; Bogetz et al., 2022; Greenfield et al., 2022; Kang et al., 2022).

PPC training should be delivered in an evidence-based fashion. According to the literature, there is no established educational framework for PPC in Ireland or the UK (Neilson et al., 2021). The majority of PPC training sessions developed within the literature were short (1-2 days long) (Kristjanson et al, 2005; Vesel and Beveridge, 2018; Weaver et al., 2021; Hamre et al., 2022), in-person (Kristjanson et al, 2005; Vesel and Beveridge, 2018; Weaver et al., 2021; Hamre et al., 2022) and provided by paediatric trained staff (Kristjanson et al., 2005; Doherty et al., 2021; Lalloo et al., 2021; Hamre et al.,2022). Aspects of training that seemed to stand out to participants were ones that were hands-on in their approach, such as incorporating complex case study discussions, role plays, comparisons with the similarities or differences in PPC and adult palliative care, and personal accounts from bereaved parents (Vesel and Beveridge, 2018; Hamre et al., 2022). From the findings, there was considerable issues found with retention of knowledge and self-efficacy in PPC for respondents over time. To address these issues, there should be consideration to incorporate regular follow up education sessions in-person and/or online (Lalloo et al., 2021; Kennedy et al., 2022).

In addition, training should have a particular focus on the areas of PPC that have been found to be challenging for adult palliative care nurses in this study. PPC topics such as neuro-irritability or non-pain symptom management, communicating with children about illness or death, depression and anxiety in children, and ethical issues such as nutrition and hydration at end-of-life. These were the PPC topics that adult palliative care nurses felt they had the lowest knowledge or self-efficacy in throughout the study.

5.7.2. Clinical Practice

It is evident from the findings of this study that adult palliative care nurses require more support in their clinical practice for them to feel confident and competent in their role providing PPC in the community. It is therefore recommended that adult palliative care nurses are encouraged by their managers and heads of department to access additional PPC training to support them in their role in the community.

5.7.3. Further Research

The results from this study uncovered several areas which require further investigation in order to gain a deeper understanding of the knowledge and self-efficacy levels of adult palliative care nurses in PPC, as well as the impact of training on these levels.

- Objective knowledge level tools for PPC that can be completed at multiple time points should be developed and tested for reliability and validity.
- Researchers should ensure to include details on how they achieved their response rates in their data collection. This is especially important as the data extraction table from Chapter 2 (Appendix 3) highlighted that there is a lack of consistency of the reporting of response rates within the literature. Palliative care as a research speciality does report on the challenges of participant recruitment (Grant et al., 2024), therefore these findings would be helpful for the research community.
- Findings found some evidence of rural adult palliative care nurses having better knowledge and self-efficacy levels compared to urban working nurses. However, it was not clear whether that was due to their setting or due to the urban nurses having less SPC years of experience. Researchers should enquire further on the differences in knowledge and self-efficacy levels between urban and rural working adult palliative care nurses.
- Researchers should focus on acquiring a bigger, more representative, sample size of adult palliative care nurses to assess their knowledge and self-efficacy. This is especially important as it is in the lead up to the addition of PPC training to the postgraduate specialist training in Ireland.
- There should be national data on the number of nurses actively working in palliative care in Ireland.

5.8. Conclusion

PPC is the “active total care of the child’s mind, body and spirit, and involves providing support to the family” (World Health Organisation, 1998, p. 8). With more children living longer with life-limiting conditions, the demand for high-quality PPC is set to increase (Benini et al., 2022). Evidence shows that access to PPC delivered by professionals with specialised training can significantly improve the quality of life for these children with life-limiting conditions (Marston, Boucher and Downing, 2018.). However, despite this growing need, there is no standardised educational framework for PPC training in Ireland or the UK (Neilson et al., 2021).

The increasing importance of PPC training for adult palliative care nurses has been recognised in the literature (Downing et al., 2013; Quinn et al.; 2017; Benini et al., 2022). In response, a

National Palliative Care Policy (Department of Health, 2024) was published in Ireland that set out recommendations to establish PPC training within all postgraduate specialist palliative care training. Considering this, this study aimed to assess the perceived knowledge and self-efficacy levels of adult palliative care nurses in their delivery of PPC before and after a training workshop.

The literature review highlighted the limited evidence on PPC and key insights into the current state of adult SPC professionals' training, preparedness and challenges in providing PPC in the community. It revealed that adult SPC professionals feel unprepared as they lack standardised PPC training despite a clear demand for it and the limited number of children they cared for annually. These factors contributed to uncertainty regarding their role in the community and underscored the need for clearer role expectations and education for these professionals. In addition, the review identified significant research gaps including the lack of consensus on conditions who require PPC, lack of patient-reported outcomes in PPC research and the fragmented coordination of care in the community.

This study employed a quantitative longitudinal pretest-post-test design. This is one of very few studies that have used a longitudinal design, over three time points, to assess knowledge and self-efficacy in adult palliative care nurses. As such, this contributes significantly to the existing body of work in this area. The instrument used was adapted for the Irish context and every effort was made to ensure validity and reliability. There were several small limitations noted about the instrument to improve its future use.

The study results revealed a significant gap in perceived knowledge and self-efficacy regarding PPC, particularly in areas such as non-pain symptom management or managing neuro-irritability, discussing death with children, depression and anxiety in children and addressing ethical issues like forgoing artificial hydration and nutrition. The variation in knowledge levels across professional groups and settings is evidence of the disparities in prior training and experience in SPC. While the training programme resulted in initial improvement in knowledge and self-efficacy, particularly in previously weak areas, retention declined slightly by 6 months. Additionally, most respondents reported no significant impact on their clinical practice, however the rationale given by respondents was that it was due to them not being exposed to child patients. The training however was valued with many interested to engage in any kind of PPC learning, and respondents were grateful for the opportunity to network with other nurses and engage in new learning.

Recommendations were made for education, practice and research. As recommended heavily within the literature and national policy, PPC training should be integrated into all postgraduate specialist palliative care education programmes. There should be an emphasis on evidence-based, hands-on approaches to PPC education such as the use of case studies, role plays, and parent or carer personal accounts. Regular follow up education sessions with PPC specialists should be considered to improve knowledge retention and support clinical practice. At the practice level, managers and department heads should encourage adult palliative care nurses to pursue PPC training to enhance their self-efficacy and knowledge in delivering PPC in the community. Finally, for future research, it is recommended to develop objective knowledge assessments for PPC that are designed longitudinally, address inconsistencies in the report of response rate data, compare knowledge and self-efficacy in adult palliative care nurses working in rural and urban settings, and to report the number of palliative care nurses working in Ireland to inform resource allocation and future training initiatives.

In conclusion, this thesis is a body of work within an under-researched topic. It delivers evidence of the need for regular PPC training to be accessible for adult palliative care nurses working in the community in Ireland. It identifies how we can tailor PPC training to the needs and preferences of these nurses to impact and possibly improve patient care. And lastly, it underscores the need for ongoing research to ensure this topic remains a priority within palliative care in order for these gaps to be addressed.

REFERENCES

Alsulami, A. et al. (2025) ‘Exploring the relationship between knowledge, attitudes, self-efficacy, and infection control practices among Saudi Arabian Nurses: a multi-center study’, *Healthcare (Basel)*, 13(3), pp. 238.

Arksey, H. and O'Malley, L. (2005) ‘Scoping studies: towards a methodological framework. International journal of social research methodology’, 8(1), pp. 19-32.

Armstrong, R. et al. (2011) 'Scoping the scope' of a cochrane review’, *Journal of public health*, 33(1), pp. 147-50.

Association for Children with Life-threatening or Terminal Conditions and their Families and The Royal College of Paediatrics and Child Health (1997) *A guide to the development of children's palliative care services*. UK: Association for Children with Life-threatening or Terminal Conditions and their Families.

Association for Children with Life-Threatening or Terminal Conditions and their Families (2009) *A Guide to the Development of Children’s Palliative Care Services*. Bristol, UK: Palliative Care Statistics for Children and Young Adults.

Avagnina, I. et al. (2023) ‘International project on troublesome symptoms in paediatric palliative care will focus on neuro-irritability, dystonia and sleep disorders’, *Acta Paediatrica*, 112(3), pp. 569-570.

Bandura, A. and Adams, N.E. (1977) ‘Analysis of self-efficacy theory of behavioral change’, *Cognitive therapy and research*, 1(4), pp. 287-310.

Bandura, A. (1997) *Self-efficacy: The exercise of control.* New York: W.H. Freeman.

Benini, F. et al. (2022) ‘International Standards for Pediatric Palliative Care: From IMPaCCT to GO-PPaCS’, *Journal of Pain and Symptom Management*, 63(5), pp. 529-43.

Berhanu, R.D. et al. (2021) ‘Perceived transcultural self-efficacy and its associated factors among nurses in Ethiopia: A cross-sectional study’, *PLoS One*, 16(7), pp. e0254643.

Bogetz, J.F. et al. (2022) ‘Pediatric Hospice and Palliative Care Services and Needs Across the Northwest United States’, *Journal of Pain and Symptom Management,* 64(1), pp. 7-14.

Borgstrom, E. et al. (2024) ‘Multidisciplinary team meetings in palliative care: an ethnographic study’, *BMJ Supportive & Palliative Care*, 14, pp. 448-451.

Boswell, C. and Cannon, S. (2022) *Introduction to Nursing Research: Incorporating Evidence-Based Practice with Navigate Advantage Access*. Available at: http://ebookcentral.proquest.com/lib/ucd/detail.action?docID=6921346 (Downloaded: 3 November 2024).

Brock, K.E. (2021) ‘Urgent Appeal From Hospice Nurses for Pediatric Palliative Care Training and Community’, *JAMA Network Open*, 4(10), pp. 2127958.

Cherny, N.I. et al. (2021) *Oxford Textbook of Palliative Medicine*. Oxford, UK: Oxford University Press.

Children’s Rights Alliance (2010) *The United Nations Convention on the Rights of the Child*. Dublin: Children’s Rights Alliance.

Chong, L. and Abdullah, A. (2017) ‘Community Palliative Care Nurses' Challenges and Coping Strategies on Delivering Home-Based Pediatric Palliative Care’, American Journal of Hospice and Palliative Medicine, 34(2), pp. 125-31.

Clarke, J. and Quin, S. (2007) ‘Professional carers' experiences of providing a pediatric palliative care service in Ireland’, *Qualitative Health Research*, 17(9), pp. 1219-31.

Clark, D. et al. (2020) ‘Mapping Levels of Palliative Care Development in 198 Countries: The Situation in 2017’, *Journal of pain and symptom management*, 59(4), pp. 794-807.e4.

Clelland, D. et al. (2020) ‘Global development of children’s palliative care: the picture in 2017’, *Wellcome Open Resource*, 5, pp. 99.

Connor, S.R.P., Downing J.P. and Marston J.R.N.M.A. (2017) ‘Estimating the global need for palliative care for children: A cross-sectional analysis’, *Journal of pain and symptom management*, 53(2), pp. 171-7.

Cowan, D.T., Wilson-Barnett, J. and Norman, I.J. (2007) ‘A European survey of general nurses' self assessment of competence’, Nurse Education Today, 27(5), pp. 452–458.

Cowan, D.T. et al. (2008) ‘Measuring nursing competence: development of a self-assessment tool for general nurses across Europe’, *International Journal of Nursing Studies*, 45(6), pp. 902–913.

Craig, F. et al. (2008) ‘IMPaCCT: Standards of paediatric palliative care’, *Der Schmerz* 22, pp. 401-8.

Creswell, J. W. and Poth, C. N. (2018) *Qualitative inquiry & research design: choosing among five approaches*. London: SAGE Publications.

Curtis, E. and Drennan, J. (2013) *Quantitative Health Research: Issues and Methods*. Available at: http://ebookcentral.proquest.com/lib/ucd/detail.action?docID=1336598 (Downloaded: 3 November 2024).

Daniels, A. and Downing, J. (2018) ‘Increasing access to children’s palliative care education through e-learning: a review of the ICPCN experience’, *International Journal of Palliative Nursing*, 24 (7), pp. 351-358.

Delamere, T. et al. (2024) ‘Defining and quantifying population-level need for children's palliative care: findings from a rapid scoping review’, *BMC palliative care*, 23(1), pp. 212-38.

Department of Health and Children and Irish Hospice Foundation (2005) *A Palliative Care Needs Assessment for Children*. Ireland: Stationary Office.

Department of Health and Children (2009) *Palliative Care for Children with Life Limiting Conditions in Ireland – A National Policy*. Dublin: The Stationary Office.

Department of Health (2024) *National Adult Palliative Care Policy*. Dublin: Stationary Office.

Dillman, Don A. et al. (2014) *Internet, Phone, Mail, and Mixed-Mode Surveys : The Tailored Design Method*. Available at: https://ebookcentral.proquest.com/lib/ucd/detail.action?docID=1762797 (Downloaded: 3

November 2024).

Downing, J. and Ling J. (2012) ‘Education in children's palliative care across Europe and internationally’, *International journal of palliative nursing*, 18(3), pp. 115-20.

Downing, J. et al. (2013) ‘Core competencies for education in paediatric palliative care’, *European Association for Palliative Care*, pp. 1-35.

Doherty, M. et al. (2021) ‘Using virtual learning to build pediatric palliative care capacity in South Asia: Experiences of implementing a teleteaching and mentorship program (Project ECHO)’, JCO Global Oncology, 7, pp. 210-22.

Fadaei, S. et al. (2024) ‘Palliative care knowledge and self-efficacy: a comparative study between intensive care units and general units nurses’, *BMC palliative care*, 23(1), pp. 246.

Field, M.J. and Behrman, R.E. (2003) *When children die: improving palliative and end-of-life care for children and their families*. Washington, D.C: National Academies Press.

Forsetlund, L. et al. (2021) ‘Continuing education meetings and workshops: Effects on professional practice and health care outcomes’, Cochrane Database Systemative Review, 9, pp. 1-463.

Fraser, L.K., Bluebond-Langner, M. and Ling, J. (2020) ‘Advances and Challenges in European Paediatric Palliative Care’, Medical sciences, 8(2), pp. 20.

Friebert, S.E. and Williams, C. (2014) *NHPCO facts and figures: Pediatric palliative & hospice care in America*. Alexandria, VA: National Hospice and Palliative Care Organization.

Friedrichsdorf, S.J. et al. (2019) ‘Development of a pediatric palliative care curriculum and dissemination model: education in palliative and end-of-life care (EPEC) pediatrics’, *Journal of Pain and Symptom Management*, 58 (4), pp. 707–720.

Frost, M.H. et al. (2007) ‘What is sufficient evidence for the reliability and validity of patient-reported outcome measures?’, *Value in Health*, 10(2), pp. 94–105.

Garland GA. (1996) ‘Self report of competence—a tool for the staff development specialist’, *Journal of Nursing Staff Development*, 12(4), pp 191–197.

Grant, M., et al. (2024) ‘Palliative care interventional research in general practice: a narrative review of factors affecting research conduct’, *Annals of Palliative Medicine*, 13(4), pp.86979-86879.

Greenfield, D.K. et al. (2022) ‘Healthcare Professionals' Experiences of the Barriers and Facilitators to Pediatric Pain Management in the Community at End-of-Life: A Qualitative Interview Study’, *Journal of Pain & Symptom Management*, 63(1), pp. 98-105.

Hain, R. et al. (2013) ‘Paediatric palliative care: development and pilot study of a 'Directory' of life-limiting conditions’, *BMC palliative care*, 12(1):43.

Hamre, T.J. et al. (2022) ‘Impact of an Evidence-Based Pediatric Palliative Care Program on Nurses' Self-Efficacy’, *Journal of Continuing Education in Nursing*, 53(6), pp. 264-72.

Hauer, J. and Houtrow, A.J. (2017) ‘Section on Hospice and Palliative Medicine, Council on Children with Disabilities. Pain assessment and treatment in children with significant impairment of the central nervous system’, *Pediatrics*, 139(6), pp. e20171002.

Hayden, J. et al. (2023) ‘Palliative care services for children with life-limiting conditions’, *Irish Journal of Medical Science (1971-)*, 192(3), pp. 1285-1290.

Health Service Executive (2016) *A National Model of Care for Paediatric Healthcare Services in Ireland Chapter 39: Paediatric Palliative Care*. Dublin: Health Service Executive.

Health Service Executive (2020) *Clinical governance and operational arrangements for supporting a model of care for children with life-limiting conditions towards the end of life in the community in Ireland*. Dublin: Health Service Executive.

Hoegen, P. et al. (2022) ‘Nurse Leadership and Work Environment Association with Outcome Expectancy and Self-Efficacy in Evidence-Based Practice among Hospital Nurses in The Netherlands: A Cross-Sectional Study’, *International journal of environmental research and public health*, 19(21), pp. 14422.

Irish Hospice Foundation (2019) *Hand in Hand with Temple Street*. Available at: https://hospicefoundation.ie/policy-advocacy/hand-in-hand-with-temple-street/ (Accessed 24 July 2025).

Jankovic, M. et al. (2019) ‘A consensus conference report on defining the eligibility criteria for pediatric palliative care in Italy’, *Italian journal of pediatrics*,45(1), pp. 89-89.

Jeffrey D. (1994) ‘Education in palliative care: a qualitative evaluation of the present state and the needs of general practitioners and community nurses’, *European Journal of Cancer Care*’, 3(2), pp. 67-74.

Johnson, K. et al. (2020) ‘Strengths, Gaps, and Opportunities: Results of a Statewide Community Needs Assessment of Pediatric Palliative Care and Hospice Resources’, *Journal of Pain & Symptom Management*, 60(3), pp. 512-512.

Jolley, J. 2020, *Introducing research and evidence-based practice for nursing and healthcare professionals.* 3rd edn. Oxfordshire, England: Routledge.

Joyner, R. L., et al. (2018) *Writing the Winning Thesis or Dissertation : A Step-By-Step Guide*. Available at: http://ebookcentral.proquest.com/lib/ucd/detail.action?docID=6261527 (Downloaded: 4 November 2024).

Kaasalainen, S. et al. (2011) ‘Palliative care nursing in rural and urban community settings: a comparative analysis’, *International Journal of Palliative Nursing*, 17(7), pp. 344-352.

Kalton, G. (2023) ‘Probability vs. Nonprobability Sampling: From the Birth of Survey Sampling to the Present Day’, *Statistics in Transition,* 24(3), pp.1-22.

Kang, K.A. et al. (2022) ‘Nurses' Perceived Needs and Barriers Regarding Pediatric Palliative Care: A Mixed-Methods Study’, Journal of Hospice and Palliative Care, 25(2), pp. 85-97.

Kaye, E.C. et al. (2019) ‘Provision of Palliative and Hospice Care to Children in the Community: A Population Study of Hospice Nurses’, *Journal of Pain and Symptom Management*, 57(2), pp. 241-50.

Kaye, E.C. et al. (2020a) Hospice nurses request paediatric-specific educational resources and training programs to improve care for children and families in the community: Qualitative data analysis from a population-level survey. Palliative Medicine. 2020;34(3):403-12.

Kaye, E.C. et al. (2020b).‘Investigation of Modifiable Variables to Increase Hospice Nurse Comfort With Care Provision to Children and Families in the Community: A Population-Level Study Across Tennessee, Mississippi, and Arkansas’, *Journal of Pain and Symptom*, 60(6):1144-53.

Kennedy, M. et al. (2022) ‘Reimagining a children's palliative care educational programme for registered nurses in response to the COVID-19 pandemic’, *Nurse Education Today*, 119, pp.105569.

Kristjanson, L. et al. (2005). ‘Evaluation of a nurse education workshop on children's grief’, *Contemporary Nurse*, 20(2), pp. 193-200.

Kumar, S.P. (2011) ‘Reporting of pediatric palliative care: a systematic review and quantitative analysis of research publications in palliative care journals’, *Indian journal of palliative care*, 17(3), pp. 202-209.

Lalloo, C. et al. (2021) ‘Pediatric Project ECHO®: A virtual community of practice to improve palliative care knowledge and self-efficacy among interprofessional health care providers’, *Journal of Palliative Medicine*, 24(7), pp. 1036-44.

Law, J., McCann, D. and O’ May, F. (2011) ‘Managing change in the care of children with complex needs: healthcare providers perspectives’, *Journal of Advanced Nursing*, 67(12), pp. 2551–2560.

Leung, K., Trevena, L. and Waters, D. (2014) ‘Systematic review of instruments for measuring nurses' knowledge, skills and attitudes for evidence-based practice’, *Journal of advanced nursing*, 70(10), pp. 2181-2195.

Ling, J. et al. (2015) Children with life-limiting conditions: establishing accurate prevalence figures, *Irish Medical Journal*, 108(3), p. 93.

Marston, J., Boucher, S. and Downing, J. (2018) ‘International Children's Palliative Care Network: A Global Action Network for Children With Life-Limiting Conditions’, *Journal of pain and symptom management*, 55(2), pp. 104-11.

Maymone, M.B.C. at al. (2018) ‘Research Techniques Made Simple: Web-Based Survey Research in Dermatology: Conduct and Applications’, *Journal of Investigative Dermatology*, 138(7), pp. 1456-1462.

McGowan, J. et al. (2020) ‘Reporting scoping reviews—PRISMA ScR extension’, Journal of Clinical Epidemiology, 123, pp. 177-9.

Mitchell, S. et al. (2017) ‘Specialist paediatric palliative care services: what are the benefits?’, *Archives of Disease in Childhood*, 102(10), pp. 923-9.

Morse, J.M. (2012) *Qualitative health research: creating a new discipline*. 1st edn. California: Left Coast Press.

Munn, Z. et al. (2018) ‘Systematic review or scoping review? Guidance for authors when choosing between a systematic or scoping review approach’, *BMC medical research methodology,* 18(1), pp. 143-143.

Neilson, S. et al. (2021) ‘Children’s palliative care education and training: developing an education standard framework and audit’, *BMC Medical Education,* 21, pp. 539.

NHS England (2021) *Ambitions for Palliative and End of Life Care: a national framework for local action 2021–2026. National Palliative and End of Life Care Partnership*. England: NHS England.

NHS England (2023) *Specialist palliative and end of life care services: Adult service specification*. London: NHS England.

Noyes, J. et al. (2013) ‘Evidence-based planning and costing palliative care services for children: novel multi-method epidemiological and economic exemplar’, *BMC palliative care*, 12(1), pp. 18-18(1).

Osbeck, C., Ingerman, Å. and Claesson, S. (2018) *An introduction to didactic classroom studies*. Available at: http://www.jstor.org/stable/j.ctv1vmnk8c.3 (Accessed 27 July 2025).

Page, M.J. et al. (2021) ‘Updating guidance for reporting systematic reviews: development of the PRISMA 2020 statement’, Journal of Clinical Epidemiology, 134, pp. 103-12.

Peters, M.D. et al. (2020a) ‘*Scoping reviews’, JBI manual for evidence synthesis*. Available at: https://jbi-global-wiki.refined.site/space/MANUAL/355862497/10.+Scoping+reviews (Accessed 20 March 2025).

Peters, M.D. et al. (2020b) ‘Updated methodological guidance for the conduct of scoping reviews’, *JBI evidence synthesis*, 18(10), pp. 2119-26.

Polit, D.F. and Beck, C.T. (2022) *Essentials of nursing research: appraising evidence for nursing practice*. Tenth edn. Philadelphia: Wolters Kluwer.

Porter, A.S. et al. (2021) ‘Community Hospice Nurses' Perspectives on Needs, Preferences, and Challenges Related to Caring for Children With Serious Illness’, *JAMA Network Open*, 4(10), pp. e2127457.

Postier, A.C. et al. (2022) ‘Education in palliative and end-of-life care-pediatrics: Curriculum use and dissemination’, *Journal of Pain and Symptom Management*, 63(3), pp. 349-58

Powers, B. and Knapp, P. (2006) *Dictionary of Nursing Theory and Research*. 3rd edn. New York: Springer.

Quick, J. and Hall, S. (2015) ‘Part Three: The Quantitative Approach’, *Journal of perioperative practice,* 25(10), pp. 192-196.

Quinn, C. and Bailey, M.E. (2011) ‘Caring for children and families in the community: experiences of Irish palliative care clinical nurse specialists’, *International Journal of Palliative Nursing*, 17(11), pp. 561-7.

Quinn, C. et al. (2017) ‘Prioritisation of future research topics in paediatric palliative care in Ireland: a Delphi study’, *International journal of palliative nursing*, 23(2), pp. 88-97.

Reid, F.C. (2013) ‘Lived experiences of adult community nurses delivering palliative care to children and young people in rural areas’, *International Journal of Palliative Nursing*, 19(11), pp. 541-7.

Schwarz, H., Revilla, M. and Weber, W. (2020) ‘Memory Effects in Repeated Survey Questions Reviving the Empirical Investigation of the Independent Measurements Assumption’, *Survey research methods*, 14(3), pp. 325-344.

Schwartz, D.B. et al. (2021) ‘Ethical aspects of artificially administered nutrition and hydration: an ASPEN position paper’, *Nutrition in clinical practice*, 36(2), pp.254-267.

Seidel-Fischer, J. et al. (2024) ‘Interaction between overconfidence effects and training formats in nurses’ education in hand hygiene’, *BMC nursing*, 23(1), pp. 451.

Slater, P.J. et al. (2018) ‘Evaluating the impact of national education in pediatric palliative care: the Quality of Care Collaborative Australia’, *Advances in medical education and practice*, 9, pp. 927-41.

Tavakol, M. and Dennick, R. (2011) ‘Making sense of Cronbach's alpha’, *International journal of medical education*, 2, pp. 52.

Temel, J.S. et al. (2010) ‘Early Palliative Care for Patients with Metastatic Non-Small Cell Lung Cancer’, *NEJM*, 363, pp. 733–42.

Together for Short Lives (2018) *A guide to children’s palliative care*. Bristol: Together for Short Lives.

Tomita, R. (2024) ‘The relationship between general self-efficacy and nursing practice competence for second-year nurses: Empirical quantitative research’, *Nursing Open*, 11(7), p.e2233.

United Nations (1989) *Conventions of the Rights of the Child*. Geneva: United Nations.

Vesel, T. and Beveridge, C. (2018) ‘From Fear to Confidence: Changing Providers' Attitudes About Pediatric Palliative and Hospice Care’, *Journal of Pain and Symptom Management*, 56(2), pp. 205-12.e3.

Weaver, M.S. et al. (2020) ‘Telehealth acceptability for children, family, and adult hospice nurses when integrating the pediatric palliative inpatient provider during sequential rural home hospice visits’, *Journal of Palliative Medicine*, 23(5), pp. 641-649.

Weaver, M.S. et al. (2021) ‘Sowing Across a State: Development and Delivery of a Grassroots Pediatric Palliative Care Nursing Curriculum’, *Journal of Palliative Care*, 36(1), pp. 22-8.

Widger, K. et al. (2018) ‘National impact of the EPEC-pediatrics enhanced train-the-trainer model for delivering education on pediatric palliative care’, *Journal of Palliative Medicine*, 21 (9), pp. 1249–1256.

Whitla, L. et al. (2020) ‘Children’s palliative care: the identified learning needs of paediatricians’, *Irish Medical Journal*, 113 (6), pp. 95.

World Health Organisation (1998) *Cancer pain relief and palliative care in children*. Geneva: World Health Organisation. Available at: https://iris.who.int/bitstream/handle/10665/42001/9241545127.pdf (Accessed 15 March 2025).

World Health Organisation (2014) ‘Strengthening of palliative care as a component of integrated treatment throughout the life course’, *Journal of Pain & Palliative Care*

Pharmacotherapy, 28(2), pp. 130–4.

World Health Organisation (2018) ‘Integrating palliative care and symptom relief into paediatrics: A WHO guide for health care planners, implementers and managers’, Geneva: World Health Organisation;

Appendix 1: Search Strategy

Search strategy used for PubMed database

Database searches

1. "special palliative care"[Title/Abstract] OR "palliat*"[Title/Abstract] OR "end of life care"[Title/Abstract] OR "end of life care"[Title/Abstract] OR "terminal*"[Title/Abstract] OR "hospice care"[Title/Abstract] OR "supportive care"[Title/Abstract] OR "complex care"[Title/Abstract] OR "life-limiting"[Title/Abstract]

2. "Hospice and Palliative Care Nursing"[MeSH Terms] OR "Palliative Care"[MeSH Terms] OR "Palliative Medicine"[MeSH Terms]

3. "special palliative care"[Title/Abstract] OR "palliat*"[Title/Abstract] OR "end of life care"[Title/Abstract] OR "end of life care"[Title/Abstract] OR "terminal*"[Title/Abstract] OR "hospice care"[Title/Abstract] OR "supportive care"[Title/Abstract] OR "complex care"[Title/Abstract] OR "life-limiting"[Title/Abstract] OR "Hospice and Palliative Care Nursing"[MeSH Terms] OR "Palliative Care"[MeSH Terms] OR "Palliative Medicine"[MeSH Terms]

4. "practitioner*"[Title/Abstract] OR "health personnel"[Title/Abstract] OR "health provider*"[Title/Abstract] OR "health professional*"[Title/Abstract] OR "health assistant*"[Title/Abstract] OR "health practitioner*"[Title/Abstract] OR "health worker*"[Title/Abstract] OR "health staff"[Title/Abstract] OR "healthcare personnel"[Title/Abstract] OR "healthcare provider*"[Title/Abstract] OR "healthcare professional*"[Title/Abstract] OR "healthcare assistant*"[Title/Abstract] OR "healthcare practitioner*"[Title/Abstract] OR "healthcare worker*"[Title/Abstract] OR "healthcare staff"[Title/Abstract] OR "healthcare support worker*"[Title/Abstract] OR "home health aide*"[Title/Abstract] OR "allied health professional*"[Title/Abstract] OR "allied health personnel"[Title/Abstract] OR "clinician*"[Title/Abstract] OR "multi disciplinary team*"[Title/Abstract] OR "interdisciplinary team*"[Title/Abstract] OR "nurse*"[Title/Abstract] OR "doctor*"[Title/Abstract] OR "consultant*"[Title/Abstract] OR "physician*"[Title/Abstract] OR "non consultant hospital doctor*"[Title/Abstract] OR "nchd*"[Title/Abstract] OR "dietitian*"[Title/Abstract] OR "dietetic*"[Title/Abstract] OR "occupational therapist*"[Title/Abstract] OR "social worker*"[Title/Abstract] OR "physiotherapist*"[Title/Abstract] OR "physical therapist*"[Title/Abstract] OR "speech and language therapist*"[Title/Abstract] OR "speech language therapist*"[Title/Abstract] OR "psychologist*"[Title/Abstract]

5. "Health Personnel"[MeSH Terms] OR "Allied Health Personnel"[MeSH Terms]

6. "practitioner*"[Title/Abstract] OR "Health Personnel"[Title/Abstract] OR "health provider*"[Title/Abstract] OR "health professional*"[Title/Abstract] OR "health assistant*"[Title/Abstract] OR "health practitioner*"[Title/Abstract] OR "health worker*"[Title/Abstract] OR "health staff"[Title/Abstract] OR "healthcare personnel"[Title/Abstract] OR "healthcare provider*"[Title/Abstract] OR "healthcare professional*"[Title/Abstract] OR "healthcare assistant*"[Title/Abstract] OR "healthcare practitioner*"[Title/Abstract] OR "healthcare worker*"[Title/Abstract] OR "healthcare staff"[Title/Abstract] OR "healthcare support worker*"[Title/Abstract] OR "home health aide*"[Title/Abstract] OR "allied health professional*"[Title/Abstract] OR "Allied Health Personnel"[Title/Abstract] OR "clinician*"[Title/Abstract] OR "multi disciplinary team*"[Title/Abstract] OR "interdisciplinary team*"[Title/Abstract] OR "nurse*"[Title/Abstract] OR "doctor*"[Title/Abstract] OR "consultant*"[Title/Abstract] OR "physician*"[Title/Abstract] OR "non consultant hospital doctor*"[Title/Abstract] OR "nchd*"[Title/Abstract] OR "dietitian*"[Title/Abstract] OR "dietetic*"[Title/Abstract] OR "occupational therapist*"[Title/Abstract] OR "social worker*"[Title/Abstract] OR "physiotherapist*"[Title/Abstract] OR "physical therapist*"[Title/Abstract] OR "speech and language therapist*"[Title/Abstract] OR "speech language therapist*"[Title/Abstract] OR "psychologist*"[Title/Abstract] OR "Health Personnel"[MeSH Terms] OR "Allied Health Personnel"[MeSH Terms]

7. "special palliative care"[Title/Abstract] OR "palliat*"[Title/Abstract] OR "end of life care"[Title/Abstract] OR "end of life care"[Title/Abstract] OR "terminal*"[Title/Abstract] OR "hospice care"[Title/Abstract] OR "supportive care"[Title/Abstract] OR "complex care"[Title/Abstract] OR "life-limiting"[Title/Abstract] OR ("Hospice and Palliative Care Nursing"[MeSH Terms] OR "Palliative Care"[MeSH Terms] OR "Palliative Medicine"[MeSH Terms])) AND ("practitioner*"[Title/Abstract] OR "Health Personnel"[Title/Abstract] OR "health provider*"[Title/Abstract] OR "health professional*"[Title/Abstract] OR "health assistant*"[Title/Abstract] OR "health practitioner*"[Title/Abstract] OR "health worker*"[Title/Abstract] OR "health staff"[Title/Abstract] OR "healthcare personnel"[Title/Abstract] OR "healthcare provider*"[Title/Abstract] OR "healthcare professional*"[Title/Abstract] OR "healthcare assistant*"[Title/Abstract] OR "healthcare practitioner*"[Title/Abstract] OR "healthcare worker*"[Title/Abstract] OR "healthcare staff"[Title/Abstract] OR "healthcare support worker*"[Title/Abstract] OR "home health aide*"[Title/Abstract] OR "allied health professional*"[Title/Abstract] OR "Allied Health Personnel"[Title/Abstract] OR "clinician*"[Title/Abstract] OR "multi disciplinary team*"[Title/Abstract] OR "interdisciplinary team*"[Title/Abstract] OR "nurse*"[Title/Abstract] OR "doctor*"[Title/Abstract] OR "consultant*"[Title/Abstract] OR "physician*"[Title/Abstract] OR "non consultant hospital doctor*"[Title/Abstract] OR "nchd*"[Title/Abstract] OR "dietitian*"[Title/Abstract] OR "dietetic*"[Title/Abstract] OR "occupational therapist*"[Title/Abstract] OR "social worker*"[Title/Abstract] OR "physiotherapist*"[Title/Abstract] OR "physical therapist*"[Title/Abstract] OR "speech and language therapist*"[Title/Abstract] OR "speech language therapist*"[Title/Abstract] OR "psychologist*"[Title/Abstract] OR ("Health Personnel"[MeSH Terms] OR "Allied Health Personnel"[MeSH Terms]

8. "paediatric*"[Title/Abstract] OR "pediatric*"[Title/Abstract] OR "neonat*"[Title/Abstract] OR "newborn*"[Title/Abstract] OR "Infant"[Title/Abstract] OR "Infants"[Title/Abstract] OR "Infancy"[Title/Abstract] OR "Baby"[Title/Abstract] OR "Babies"[Title/Abstract] OR "toddler*"[Title/Abstract] OR "preschooler*"[Title/Abstract] OR "kindergartener*"[Title/Abstract] OR "School-aged"[Title/Abstract] OR "School-aged"[Title/Abstract] OR "Kid"[Title/Abstract] OR "Kids"[Title/Abstract] OR "preteen*"[Title/Abstract] OR "adolescen*"[Title/Abstract] OR "prepubescen*"[Title/Abstract] OR "pubescen*"[Title/Abstract] OR "teen*"[Title/Abstract] OR "Minor"[Title/Abstract] OR "Minors"[Title/Abstract] OR "juvenil*"[Title/Abstract] OR "Youth"[Title/Abstract] OR "Youths"[Title/Abstract] OR "junior*"[Title/Abstract] OR "pre adolescent*"[Title/Abstract] OR "child*"[Title/Abstract] OR "under age"[Title/Abstract] OR "Young people"[Title/Abstract] OR "young person*"[Title/Abstract] OR "boy"[Title/Abstract] OR "boys"[Title/Abstract] OR "boyhood"[Title/Abstract] OR "girl*"[Title/Abstract] OR "girlhood"[Title/Abstract]

9. "Infant"[MeSH Terms] OR "Pediatrics"[MeSH Terms] OR "Child"[MeSH Terms] OR "Adolescent"[MeSH Terms]

10. "paediatric*"[Title/Abstract] OR "pediatric*"[Title/Abstract] OR "neonat*"[Title/Abstract] OR "newborn*"[Title/Abstract] OR "Infant"[Title/Abstract] OR "Infants"[Title/Abstract] OR "Infancy"[Title/Abstract] OR "Baby"[Title/Abstract] OR "Babies"[Title/Abstract] OR "toddler*"[Title/Abstract] OR "preschooler*"[Title/Abstract] OR "kindergartener*"[Title/Abstract] OR "School-aged"[Title/Abstract] OR "School-aged"[Title/Abstract] OR "Kid"[Title/Abstract] OR "Kids"[Title/Abstract] OR "preteen*"[Title/Abstract] OR "adolescen*"[Title/Abstract] OR "prepubescen*"[Title/Abstract] OR "pubescen*"[Title/Abstract] OR "teen*"[Title/Abstract] OR "Minor"[Title/Abstract] OR "Minors"[Title/Abstract] OR "juvenil*"[Title/Abstract] OR "Youth"[Title/Abstract] OR "Youths"[Title/Abstract] OR "junior*"[Title/Abstract] OR "pre adolescent*"[Title/Abstract] OR "child*"[Title/Abstract] OR "under age"[Title/Abstract] OR "Young people"[Title/Abstract] OR "young person*"[Title/Abstract] OR "boy"[Title/Abstract] OR "boys"[Title/Abstract] OR "boyhood"[Title/Abstract] OR "girl*"[Title/Abstract] OR "girlhood"[Title/Abstract] OR "Infant"[MeSH Terms] OR "Pediatrics"[MeSH Terms] OR "Child"[MeSH Terms] OR "Adolescent"[MeSH Terms]

11. "Community"[Title/Abstract] OR "community-based"[Title/Abstract] OR "community-dwelling"[Title/Abstract] OR "home"[Title/Abstract] OR "home-based"[Title/Abstract] OR "home-care"[Title/Abstract] OR "outreach"[Title/Abstract] OR "homecare"[Title/Abstract] OR "home-dwelling"[Title/Abstract] OR "primary care"[Title/Abstract] OR "hospice at home"[Title/Abstract] OR "Domiciliary"[Title/Abstract]

12. "Community Health Services"[MeSH Terms]

13. "Community"[Title/Abstract] OR "community-based"[Title/Abstract] OR "community-dwelling"[Title/Abstract] OR "home"[Title/Abstract] OR "home-based"[Title/Abstract] OR "home-care"[Title/Abstract] OR "outreach"[Title/Abstract] OR "homecare"[Title/Abstract] OR "home-dwelling"[Title/Abstract] OR "primary care"[Title/Abstract] OR "hospice at home"[Title/Abstract] OR "Domiciliary"[Title/Abstract] OR "Community Health Services"[MeSH Terms]

14. "special palliative care"[Title/Abstract] OR "palliat*"[Title/Abstract] OR "end of life care"[Title/Abstract] OR "end of life care"[Title/Abstract] OR "terminal*"[Title/Abstract] OR "hospice care"[Title/Abstract] OR "supportive care"[Title/Abstract] OR "complex care"[Title/Abstract] OR "life-limiting"[Title/Abstract] OR ("Hospice and Palliative Care Nursing"[MeSH Terms] OR "Palliative Care"[MeSH Terms] OR "Palliative Medicine"[MeSH Terms])) AND ("practitioner*"[Title/Abstract] OR "Health Personnel"[Title/Abstract] OR "health provider*"[Title/Abstract] OR "health professional*"[Title/Abstract] OR "health assistant*"[Title/Abstract] OR "health practitioner*"[Title/Abstract] OR "health worker*"[Title/Abstract] OR "health staff"[Title/Abstract] OR "healthcare personnel"[Title/Abstract] OR "healthcare provider*"[Title/Abstract] OR "healthcare professional*"[Title/Abstract] OR "healthcare assistant*"[Title/Abstract] OR "healthcare practitioner*"[Title/Abstract] OR "healthcare worker*"[Title/Abstract] OR "healthcare staff"[Title/Abstract] OR "healthcare support worker*"[Title/Abstract] OR "home health aide*"[Title/Abstract] OR "allied health professional*"[Title/Abstract] OR "Allied Health Personnel"[Title/Abstract] OR "clinician*"[Title/Abstract] OR "multi disciplinary team*"[Title/Abstract] OR "interdisciplinary team*"[Title/Abstract] OR "nurse*"[Title/Abstract] OR "doctor*"[Title/Abstract] OR "consultant*"[Title/Abstract] OR "physician*"[Title/Abstract] OR "non consultant hospital doctor*"[Title/Abstract] OR "nchd*"[Title/Abstract] OR "dietitian*"[Title/Abstract] OR "dietetic*"[Title/Abstract] OR "occupational therapist*"[Title/Abstract] OR "social worker*"[Title/Abstract] OR "physiotherapist*"[Title/Abstract] OR "physical therapist*"[Title/Abstract] OR "speech and language therapist*"[Title/Abstract] OR "speech language therapist*"[Title/Abstract] OR "psychologist*"[Title/Abstract] OR ("Health Personnel"[MeSH Terms] OR "Allied Health Personnel"[MeSH Terms])) AND ("paediatric*"[Title/Abstract] OR "pediatric*"[Title/Abstract]

OR "neonat*"[Title/Abstract] OR "newborn*"[Title/Abstract] OR "Infant"[Title/Abstract] OR "Infants"[Title/Abstract] OR "Infancy"[Title/Abstract] OR "Baby"[Title/Abstract] OR "Babies"[Title/Abstract] OR "toddler*"[Title/Abstract] OR "preschooler*"[Title/Abstract] OR "kindergartener*"[Title/Abstract] OR "School-aged"[Title/Abstract] OR "School-aged"[Title/Abstract] OR "Kid"[Title/Abstract] OR "Kids"[Title/Abstract] OR "preteen*"[Title/Abstract] OR "adolescen*"[Title/Abstract] OR "prepubescen*"[Title/Abstract] OR "pubescen*"[Title/Abstract] OR "teen*"[Title/Abstract] OR "Minor"[Title/Abstract] OR "Minors"[Title/Abstract] OR "juvenil*"[Title/Abstract] OR "Youth"[Title/Abstract] OR "Youths"[Title/Abstract] OR "junior*"[Title/Abstract] OR "pre adolescent*"[Title/Abstract] OR "child*"[Title/Abstract] OR "under age"[Title/Abstract] OR "Young people"[Title/Abstract] OR "young person*"[Title/Abstract] OR "boy"[Title/Abstract] OR "boys"[Title/Abstract] OR "boyhood"[Title/Abstract] OR "girl*"[Title/Abstract] OR "girlhood"[Title/Abstract] OR ("Infant"[MeSH Terms] OR "Pediatrics"[MeSH Terms] OR "Child"[MeSH Terms] OR "Adolescent"[MeSH Terms])) AND ("Community"[Title/Abstract] OR "community-based"[Title/Abstract] OR "community-dwelling"[Title/Abstract] OR "Home"[Title/Abstract] OR "home-based"[Title/Abstract] OR "home-care"[Title/Abstract] OR "outreach"[Title/Abstract] OR "homecare"[Title/Abstract] OR "home-dwelling"[Title/Abstract] OR "primary care"[Title/Abstract] OR "hospice at home"[Title/Abstract] OR "Domiciliary"[Title/Abstract] OR "Community Health Services"[MeSH Terms]

Appendix 2: Scoping Review Protocol

Adult Specialist Palliative Care Providers Caring for Children in the Community: Protocol for a Scoping Review

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Background

Paediatric palliative care (PPC) is an emerging subspecialty in paediatrics that has slowly evolved and expanded globally over the years. The World Health Organization (WHO, 1998) defines PPC as the active total care of the child's body, mind and spirit, and the provision of support to the family. It focuses on improving the quality of life of children and young people (CYP) while also offering support to their families. This involves addressing distressing symptoms, offering respite care, and providing support throughout the end-of-life process and bereavement (Together for Short Lives, 2022). It is an integral aspect of medical care for CYP with life threatening or life-limiting conditions (LLCs) or those requiring end-of-life care (Fraser *et al.,* 2012). The UK were at the forefront in the development of PPC services, opening the world's first children's hospice, Helen House, in 1982 (Farrow, 1981; Burne, Dominica and Baum, 1984) and later influencing the establishment of others globally (Worswick, 2000; Arias-Casais, 2019; Martston, 2022). However, the development and approach of PPC varies widely within countries and internationally (Arias-Casais, 2019; Fraser, Bluebond-Langner and Ling, 2020; Sisk, Feudtner and Bluebond-Langner, 2020). In particular, there has been discussion within the literature about a gap in access to specialist PPC services within the community (Friebert and Williams, 2014; Chong and Abdullah, 2017; Kennedy *et al.*, 2022). Specialist PPC services are defined in Europe and the UK as those supported by a physician (a consultant) with specialty training in paediatric palliative medicine (European Association for Palliative Care, 2008; Hain, Heckford and McCulloch, 2012; Health Service Executive and Royal College of Physicians in Ireland, 2017). Currently, many CYP requiring PPC in the community are being cared for by predominantly adult-trained specialist palliative care professionals due to many factors such as the lack of specialist PPC education and varying access to PPC resources within the communities (Friebert and Williams, 2014; Marston, Boucher and Downing, 2018; Health Service Executive, 2020; Brock, 2021). This is a significant issue as PPC differs greatly to adult palliative care as reinforced by the United Nations Convention on the Rights of the Child, stating that child specific training is required for those working with children (Children's Rights Alliance, 2010). In line with these concerns, we hope that this review will shed light on what kind of evidence is available in the existing literature regarding adult specialist palliative care professionals providing their services to children in the community.

Aims / Objectives

- To evaluate the existing evidence that describes the landscape of adult specialist palliative care professionals providing their services to children in the community, with a focus on their perceived knowledge, self-efficacy levels, and preparedness.
- To identify the gaps in the literature on educational and learning needs of adult SPC professionals in the community.
- To identify priorities for future areas of research.

Review question

Do adult specialist palliative care professionals feel sufficiently trained and prepared to deliver their services to children in the community?

Type of review

A scoping review will be conducted in order to map the available evidence and to identify what future research may be required (Armstrong *et al*., 2011; Munn *et al.,* 2018).

The PCC framework (Population, Concept, Context) is used to help answer the review question and conduct the search strategy.

Criteria for inclusion and exclusion of studies:

Types of studies

Due to the lack of evidence-based research in PPC or a ‘research culture’ within the speciality as noted by Ireland’s Department of Health and Children (2009). I will include as many types of studies that are relevant to the review question identified from the search. However, this excludes clinical trials, or studies not relating to humans or studies not reported in English.

Type of population

The population will be adult specialist palliative care professionals. They are defined as being part of a multidisciplinary team that have received specific education and experience in palliative care, and who provide a service that has palliative care at its core (Payne *et al.,* 2022). We will exclude studies if no specialist palliative care is reported.

Type of concept

The concept will be providing care to children. For this review, a child is described as anyone under the age of 18 as recognised by the Child Care Act 1991 (Ireland. *Child Care Act 1991*) , the Children Act 2001 (Ireland. *Children Act 2001*) and the United Nations Convention on the Rights of the Child (Switzerland. *Conventions of the Rights of the Child 1989)*.

Type of setting/context

The context or setting will only be in the community. Any hospital inpatient/outpatient or hospice settings are excluded.

Search strategy for identification of studies

Databases and Searching Methods:

1. PubMed

2. Cochrane Library

3. CINAHL

4. PsycINFO

5. Scopus

6. ERIC

7. Grey literature (library books, Lenus the Irish Health Repository, Google

Scholar, Irish policies/models of care/frameworks)

8. Citation searching

9. Hand searching

Limits : No limits applied during search.

Framework (PCC) for Search Strategy:

Population – adult specialist palliative care [title/abstract OR Mesh terms] AND Healthcare professionals (MDT terms) [title/abstract OR Mesh terms]

AND

Concept – children [title/abstract OR Mesh terms]

AND

Context - community setting [title/abstract OR Mesh terms]

Example of Search Strategy – Available in Appendix 1.

Detailed Search Strategy - Available in Appendix 1.

Selection of studies

Two authors will independently screen all titles and abstracts identified in our electronic searches. Duplicates will be removed by the online software Covidence. If, after reading the abstract, doubt persists regarding the eligibility of the study, we will include it in the full-text review which is assessed again by the two authors independently. Before initiating the screening process, two reviewers will perform an exercise to ensure consistency in accurately identifying eligible studies. This involves independently screening a random sample of included citations. In the event of disagreement between the reviewers during the exercise, adjustments will be made to the eligibility criteria. Disagreements during the actual independent review process will be resolved by discussion and consensus. A third reviewer will be consulted if consensus is not achieved between reviewers.

Assessment of methodological quality

Assessing the quality of evidence and risk of bias is generally not performed or advised in scoping reviews (Khalil *et al.,* 2016; Peters *et al.,* 2015; Peters *et al.,* 2020). For this reason no assessment of quality of evidence was conducted.

Data extraction

All identified studies from the electronic searches will be collated and uploaded into EndNote (Clarivate Analytics), and then imported onto the online software Covidence where duplicates will be removed and the screening will begin. We will use a standardised form developed from the Joanna Briggs Institute (JBI) data extraction tool (Peters *et al.,* 2020). The reports will include details about the population, concept, context, study methods and key findings. If required, we will contact the authors of selected papers if there is missing or additional data. Since this is a scoping review, data will not be synthesized as this is more appropriate for systematic reviewing (Peters *et al.,* 2020), rather we will descriptively map the data out as described and generate discussion from it, not assess certainty.

Data synthesis

We plan to report our literature search and study screening using the standardised PRISMA-ScR (Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews) checklist (Tricco *et al.,* 2018). We anticipate to have qualitative, quantitative or mixed method study designs for synthesis. Key concepts will be summarised using descriptive content analysis. Results will be presented in tabular or graphic formats according to key findings and knowledge gaps.

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None.

Conflicts of interest

Authors declare that there are no conflicts of interest.

References

Arias-Casais, N. *et al.* (2019) *EAPC atlas of palliative care in Europe.* Vilvoorde: EAPC Press.

Armstrong, R. *et al.* (2011) ‘Cochrane update. “Scoping the scope” of a Cochrane review’, *Journal of Public Health,* 33(1), pp. 147-50.

Brock, K.E. (2021) ‘Urgent appeal from hospice nurses for pediatric palliative care training and community’, *JAMA Network Open*, 4(10), pp. e2127958-e2127958.

Burne, S.R., Dominica, F. and Baum, J.D. (1984) ‘Helen House--a hospice for children: analysis of the first year’, *British Medical Journal*, 289(6459), pp. 1665-1668.

Children’s Rights Alliance (2010) *The United Nations Convention on the Rights of the Child*. Dublin: Children’s Rights Alliance.

Chong, L. and Abdullah, A. (2017) ‘Community Palliative Care Nurses’ Challenges and Coping Strategies on Delivering Home-Based Pediatric Palliative Care: A Qualitative Study’, *American Journal of Hospice and Palliative Medicine,* 34(2), pp. 125-131.

Department of Health and Children (2009) *Palliative care for children with life-limiting conditions in Ireland: A National Policy.* Dublin: Department of Health and Children. Available at: https://acrobat.adobe.com/id/urn:aaid:sc:eu:2ad03737-6820-4a79-b0dc-a11e7a2db976 (Accessed 26 December 2023).

European Association for Palliative Care (2008) ‘IMPaCCT: standards for paediatric palliative care in Europe’, *European Journal of Palliative Care*, 22, pp. 401-408.

Farrow, G. (1981) ‘Helen House: our first hospice for children’, *Nursing Times*, 77(33), pp.1433–1434.

Fraser, L. *et al.* (2012) ‘Rising National Prevalence of Life-Limiting Conditions in Children in England’, *Pediatrics*, 129(4), pp. 923-929.

Fraser, L.K., Bluebond-Langner, M. and Ling, J. (2020) ‘Advances and challenges in European paediatric palliative care’, *Medical Sciences*, 8(2), pp. 20.

Friebert, S.E. and Williams, C. (2014) *NHPCO facts and figures: Pediatric palliative & hospice care in America*. Alexandria, VA: National Hospice and Palliative Care Organization.

Government of Ireland. *Child Care Act (*1991) Dublin: Stationary Office.

Government of Ireland. *Children Act* (2001) Dublin: Stationary Office.

Hain, R., Heckford, E. and McCulloch, R. (2012) ‘Paediatric palliative medicine in the UK: past, present, future’, *Archives of disease in childhood*, 97(4), pp. 381-384.

Health Service Executive and Royal College of Physicians in Ireland (2017) *A national model of care for paediatric healthcare services in Ireland. Chapter 39: paediatric palliative care.* National Clinical Programme for Paediatrics and Neonatology: Dublin Available at: https://www.hse.ie/eng/services/publications/clinical-strategy-and-programmes/paediatric-palliative-care.pdf (Accessed 28 December 2023).

Health Service Executive (2020) *Clinical governance and operational arrangements for supporting a model of care for children with life limiting conditions towards the end of life in the community in Ireland, final report and recommendations*. Health Service Executive: Dublin. Available at: https://www.hse.ie/eng/services/publications/children/operational-and-governance-framework-for-children-with-life-limiting-conditions.pdf (Accessed 30 December 2023).

Kennedy, M. *et al.* (2022) 'Reimagining a children's palliative care educational programme for registered nurses in response to the COVID-19 pandemic', *Nurse education today*, 119, pp. 105569-105569.

Khalil, H. *et al.* (2016) 'An evidence-based approach to scoping reviews', *Worldviews Evidence Based Nursing*, 13(2), pp.118-23.

Marston, J., Boucher, S. and Downing, J. (2018) 'International children's palliative care network: a global action network for children with life-limiting conditions', *Journal of pain and symptom management*, 55(2), pp. 104-111.

Martston, J. A. (2022) *Global history of children's hospice and palliative care. International Children's Palliative Care Network*. Available at: https://www.icpcn.org/a-global-history-of-childrens-palliative-care/ (Accessed 20 March 2024).

Munn, Z. *et al.* (2018) 'Systematic review or scoping review? Guidance for authors when choosing between a systematic or scoping review approach', *BMC Medical Research Methodology*, 18(1), pp. 143.

Payne, S. *et al.* (2022) 'Revised recommendations on standards and norms for palliative care in Europe from the European Association for Palliative Care (EAPC): A Delphi study', *Palliative Medicine*, 36(4), pp. 680-697.

Peters, M.D.J. *et al.* (2015) 'Guidance for conducting systematic scoping reviews', *International Journal of Evidence-Based Healthcare*, 13(3), pp. 141-46.

Peters, M.D.J. *et al.* (2020) *Chapter 11: Scoping Reviews (2020 version)*. Joanna Briggs Institute (JBI) *Manual for Evidence Synthesis.* Australia: JBI. Available at: https://synthesismanual.jbi.global (Accessed 28 December 2023).

Sisk, B., Feudtner, C. and Bluebond-Langner, M. (2020) 'Response to suffering of the seriously ill child: a history of palliative care for children', *Pediatrics,* pp. 145(1), pp. 1–9.

Together for Short Lives (2022) *Categories of life-limiting and life-threatening conditions*. Available at: http://www.togetherforshortlives.org.uk/assets/0000/4089/CPC_definitions.pdf (Accessed 25 March 2024).

Tricco A.C. *et al* (2018) 'PRISMA Extension for Scoping Reviews (PRISMA-ScR): Checklist and Explanation', *Annals of Internal Medicine,* 169(7), pp. 467–73.

United Nations (1989) *Conventions of the Rights of the Child*. Geneva: United Nations.

World Health Organization (WHO) (1998) *Cancer pain relief and palliative care in children*. Geneva: World Health Organization Press.

Worswick, J. (2000) *A house called Helen: the development of hospice care for children*. 2nd

Edition. Oxford: Oxford University Press.

Appendix 3: Data Extraction Table

Supplemental File Number 2: Data Extraction Table

Author(s), Year	**Country**	**Journal**	**Aim(s)**	**Response rate** **n= (%)** **Population** **N=** **Sampling method** **Sample Profile**	**Methodology**	**Key Findings**
Bogetz, J.F. et al. (2022)	USA	Journal of Pain and Symptom Management	To assess the services, training, and learning needs of palliative and hospice care professionals caring for children	Response rate: n=64. Population from which sample was drawn not stated. Sampling method: not stated. Sample profile (discrepancies in	Quantitative descriptive cross-sectional online survey. 84-item survey developed from expert advice and previous regional needs assessments.	▪ PC experience: Unreported. ▪ CPC experience: 21 (40%) participants cared for <5 children / year. ▪ Previous CPC training: Unreported. ▪ Setting: 17 (22%) home-based PC, hospital/hospice/other (n=61, 78%). ▪ Perceived preparedness: lowest comfort levels reported in management of pain (16%) and non-pain symptoms (11%).

				totals): physicians (n=17, 25%), nurses (n=15, 22%), advance practice providers (n=7, 10%), allied health professionals (n=16, 23%) and non-clinical or other (n=12, 16%).		▪ Challenges in CPC provision: reported lack of trained staff (84%), lack of finance (59%), limited access to home infusions (48%), lack of durable medical equipment (32%), and lack of respiratory technology (32%). ▪ Professional development needs: Identified training needs were parent/caregiver psychosocial support (n=19, 40%), goals of care communication (n=21, 44%), and symptom management (n=21, 45%).

Chong, L. and Abdullah, A. (2017)	Malaysia	American Journal Of Hospice & Palliative Care	To explore the challenges and coping strategies palliative care nurses experience when caring for children with life-limiting illnesses at home	Response rate: n=16 (94%). Population: N=17. Sampling method: not stated. Sample profile: Community adult specialist palliative care nurses.	Qualitative semi-structured interviews 25-item interview guide developed from expert advice and literature review.	▪ PC experience: mean of 4 years (range 1-18 years). ▪ CPC experience: 1 nurse had experience, unreported number of child patients. ▪ Previous CPC training: No formal CPC training in Malaysia. Nurses learned from experience working with adult patients and from guidance of colleagues. ▪ Setting: Community. ▪ Perceived preparedness: sense of discomfort from PC nurses when providing CPC due to the lack of child patients, lack of training and lack of resources or finance. ▪ Challenges in CPC provision: lack of trained staff in paediatrics and lack of resources in rural settings. ▪ Professional development needs: formal CPC training and communication skills training for undergraduate programmes. Standardising high quality CPC in Malaysia.

Clarke, J. and Quin, S. (2007)	Ireland	Qualitative Health Research	To explore the experiences of healthcare professionals providing CPC to children with life-limiting conditions	Response rate of focus group interviews: n=15. Response rate of open-ended questions: n=76 (44%), Population of open-ended questions: N=174 completed full questionnaire. Sampling method: Purposeful sampling. Sample profile: Paediatricians (n=9, 12%), clinical nurse managers/specialists (n=60, 79%), social workers (n=4, 5%), PC teams (n=3, 4%). Not all present in each focus group.	Qualitative focus group interviews and responses to 88 open-ended questions from a larger national survey. Focus group guide developed from their questionnaire results and literature review.	▪ PC experience: n=3 (4%) open-ended questions completed by members of “PC teams/groups”. ▪ CPC experience: n=167 (96.5%) currently providing CPC. ▪ Previous CPC training: focus group member - "(We) have not had much training or education and have very different ideas of what palliative care for children means." ▪ Setting: Community and/or hospital. ▪ Perceived preparedness: Uncertainty of the meaning of CPC, childhood non-cancer diagnoses and the unpredictability of child illness-death trajectory. ▪ Challenges in CPC provision: PC discussions with families, ensuring child’s best interest/inclusive decision-making, providing respite, initiating EoL care and ending their relationships with families. ▪ Professional development needs: More community support and training, including debriefing after a child's death.

Doherty, M. et al. (2021)	India	JCO Global Oncology	To ascertain how to create an accessible online learning platform called “Project ECHO” for resource-limited communities focusing on CPC training	Response rate of pre-training survey: Unreported. Only reports the identified learning needs, no response rate or analysis of results. Response rate of post-training survey: n=18. Population from which sample was drawn not stated. Sampling method: not stated. Sample profile: Medical officers (n=10, 56%), consultant physicians (n=4, 22%), pharmacists (n=2, 11%), nurse (n=1, 5.5%), project	Quantitative descriptive longitudinal pre and post training online survey (two time points). 22-item survey developed by authors.	▪ PC experience: n=14 (78%) working within the PC discipline. ▪ CPC experience: n=9 (50%) care for <11 children per month ▪ Previous CPC training: Unreported. ▪ Perceived preparedness: Unreported. ▪ Challenges in CPC training: Unreported. ▪ Professional development needs (identified in pre-test survey): training in pain assessment, pain management, opioid use, identifying and managing depression and anxiety in children, palliative sedation, communication with children, and breaking bad news to parents and children. Preference for training were CPC expert led and a culturally sensitive curriculum, and access to learning resources e.g. recorded sessions.

				coordinator (n=1, 5.5%).		

Greenfield, D.K. et al. (2022)	UK	Journal of Pain and Symptom Management	To explore healthcare professionals' perceived barriers and facilitators to child pain management at the end of life in the community	Response rate: n=29. Population from which sample was drawn not stated. Sampling method: Purposive sampling. Sample Profile: Nurses (n=12, 42%), general practitioners (n=5, 17%), consultants/registrar doctors (n=5, 17%), pharmacists (n=2, 7%), support therapists (n=5, 17%).	Qualitative semi-structured interviews (3 interviews via online due to COVID-19, 26 interviews via in-person). Developed own interview guide.	▪ PC experience: all professionals were involved in community EoL care. ▪ CPC experience: mean number is 11 years (range 2 months-25 years). ▪ Previous CPC training: Unreported. ▪ Setting: Community. ▪ Perceived preparedness: perceived they lacked education or support to manage symptoms. Lacked confidence in medication management due to limited exposure to children. ▪ Challenges in CPC training: general practitioners may avoid CPC training as they may perceive it as intimidating. ▪ Professional development needs: healthcare professionals in the community need to be linked in with specialist teams for child pain management. Confidence enhanced by staff mentoring, support from experienced multi-professional teams and education on the biopsychosocial model of pain management.

Hamre, T.J. et al. (2022)	USA	Journal of Continuing Education in Nursing	To assess whether a one-day, evidence-based CPC training program would impact the self-efficacy of nurses and Advanced Practice Registered Nurses (APRNs) working in inpatient or community-based settings	Response Rate: n=31 (30%) completed both pre/post training surveys. Population: N=103. Sampling method: Convenience sampling. Sample profile: Registered nurses and advanced practice registered nurses working in inpatient or community settings, interested to learn about CPC.	Quantitative inferential longitudinal pre and post training online survey (two time points) using SPSS V26. 42-item survey - Pediatric Palliative Care Questionnaire (PPCQ).	▪ PC experience: Unreported. ▪ CPC experience: Unreported. ▪ Previous CPC training: n=7 (23%) received CPC training in their initial nursing education programme. While n=10 (32%) participated in CPC education before this study. ▪ Setting: Inpatient or community (not measured). ▪ Perceived preparedness: Pre-training survey identified neutral scores for self-efficacy in specific CPC topics ("neither comfortable nor uncomfortable"). Least comfortable with topics “explaining the concept of allow a natural death” and “communicating with families after the death of a child”. ▪ Challenges in CPC provision/training: Unreported. ▪ Professional development needs: A once off 7½-hour educational programme reported to be statistically significant in increasing nurse perceived self-efficacy (Z = 3.53, p < .001).

Jeffrey, D. (1994)	UK	European Journal of Cancer Care	To assess the current status of palliative care education and the learning needs of general practitioners, community hospital nurses, and community nurses	Response rate: n=285 (72.5%). Population: N=393. Sampling method: not stated. Sample profile (discrepancies in totals): general practitioners (n=92, 32%), community hospital staff (n=102, 36%), and community nurses (n=91, 32%).	Quantitative descriptive cross-sectional survey. Developed own survey.	▪ PC experience: n=189 (66%) have post-basic specialist training or qualifications in PC. ▪ CPC experience: Unreported ▪ Previous CPC training: Unreported. ▪ Setting: Community. ▪ Perceived preparedness: "care of the dying child" - n=66 (75%) of community nurses expressed a high interest in learning. ▪ Challenges in CPC training: Doctors reported a lack of dedicated time, while nurses reported both a lack of time and funding as barriers. ▪ Professional development needs: Training was identified as best delivered within a multi-disciplinary setting and during lunch breaks or evenings.
Johnson, K. et al. (2020)	USA	Journal of Pain and Symptom Management	To evaluate the current status and gaps in CPC and hospice services using a community	Response rate: n=57 (41%) responded to the survey (who were representing 37 Georgia Hospice and Palliative Care	Quantitative descriptive cross-sectional online survey, as part of mixed-method design.	▪ PC experience: n=32 (94%) organisations care for adults only. ▪ CPC experience: n=15 (45.5%) do not provide CPC. Median number of n=3 children cared for, out of 18 organisations in 1 year. Most

			needs assessment	Organizations). Population: N=138. Sampling method of survey: not stated. Sample profile: Hospice and palliative care teams in the state of Georgia.	Analysed using SAS Enterprise Guide 7.1 (SAS institute, Cary, NC). 25-item survey developed by authors.	organisations provided CPC to patients with cancer (n=17, 94.4%). ▪ Previous CPC training: Unreported. ▪ Setting: Community. ▪ Perceived preparedness: Unreported. ▪ Challenges in CPC provision: Funding, unequal access to CPC, lack of CPC trained staff, little demand for CPC in community. ▪ Professional development needs: More community CPC experts and better links between community – hospital.

Kang, K. et al. (2022)	South Korea	Journal of Hospice and Palliative Care	To evaluate nurses' perceived needs and barriers to CPC who participated in the End-of-Life Nursing Education Consortium-Pediatric Palliative Care (ELNEC-PPC) training programme	Response rate: n=63 (74.5%) responded and in final analysis. Population from which sample was drawn not stated. Sampling method: Convenience sampling. Sample profile: Registered nurses, charge nurses, nurse specialists, professors.	Mixed method study with an embedded design. 1. Quantitative cross-sectional online survey. 62-item survey. Developed from literature review and validated using 3 rounds of Delphi surveys. 2. Qualitative data from the survey were collected through 6 open-ended questions.	▪ PC experience: n=31 (49%) have a PC career. ▪ CPC experience: n=15 (24%) nurses were described to “have no CPC career”. ▪ Previous CPC training: Unreported. ▪ Setting: n=40 (64%) hospice/other wards, n=16 (25%) university, n=7 (11%) “other”. ▪ Perceived preparedness: unreported. ▪ Challenges in CPC provision: lack of trained staff and education in CPC; lack of CPC services; lack of hospital-community communication; limited staff psychological support; negative perception of CPC by medical staff (synonymous to giving up); lack of CPC awareness in South Korea (most hospices don’t provide CPC); lack of advisory systems e.g. ethics committees. ▪ Professional development needs: Need for more multidisciplinary team approaches, systematic CPC training for doctors/nurses, recruitment of paediatric nurses in the community.

Kaye, E.C. et al. (2019)	USA	Journal of Pain and Symptom Management	To ascertain the levels of experience and perceived comfort levels of hospice nurses caring for children in the community	Response rate: n=551 (40%). Population: N=1366. Sampling method: Not stated. Sample profile: Nurses from 71 community-based hospice organisations.	Quantitative descriptive cross-sectional survey. 36-item survey developed using CPC experts and literature review. Validation by key stakeholder revision panel's iterative review, 3 rounds of serial testing then pilot tested with 7 paediatric hospice nurses.	▪ PC experience: n=296 nurses (54%) had < 5 years' experience as a hospice nurse. ▪ CPC experience: n=279 nurses (51%) had prior experience providing CPC, but n=171 (61%) would describe the exposure as every "couple of years" or "never". Most hospices provided CPC to 0-4 children/year (n=406, 74%). ▪ Previous CPC training: most nurses had no prior CPC training (n=495, 90%). ▪ Setting: Community. ▪ Perceived preparedness: n=256 (46.5%) nurses reported feeling somewhat or very uncomfortable providing CPC, or care during the active dying process (n=257, 47%). Nurses felt somewhat or very uncomfortable taking care of children with severe pain (n=266, 48%), dyspnea (n=263, 48%), seizures (n=281, 51%), asking children how they define their quality of life (n=208, 38%), asking children about their hopes and goals of care (n=167, 30%), talking with children about death and/or dying (n=260, 47%), or family

						bereavement support in the first 12 months (n=167, 30%). ▪ Challenges in CPC provision/training: Lack of CPC training for community hospice nurses. ▪ Professional development needs: additional education for these community professionals providing CPC with little training and supports to limit staff burnout.
Kaye, E.C. et al. (2020)	USA	Palliative Medicine	To explore the types of children's training received and educational content preferred by hospice nurses	Response rate: n=278 (50.5%) completed open-ended questions. Population: N=551 completed survey. Sampling method: Not stated. Sample profile: Nurses from 71 community-based hospice organisations.	Qualitative sub analysis of a population-level cross-sectional survey's open-ended questions. 3 items out of the 36-item survey involved open-ended questions on CPC training.	▪ PC experience: 138 nurses (50%) with <5 years hospice experience. ▪ CPC experience: most nurses have prior experience providing CPC (n=169, 61%). Most hospices (n=197, 71%) provided CPC to 0-4 children/year. ▪ Previous CPC training: Most nurses have no prior CPC training (n=224, 81%). ▪ Setting: Community. ▪ Perceived preparedness: Community hospice nurses identified as often receiving little to no CPC training.

						- Challenges in CPC provision/training: Unreported. - Professional development needs: Most nurses were interested in getting additional or “any” CPC training (n=208, 75%).

Kaye, E.C. et al. (2020)	USA	Journal of Pain and Symptom Management	To assess the association between modifiable variables such as clinical experience, training and patient frequency with hospice nurses' comfort providing CPC in the community	Response rate: n=551 (40%). Population: N=1366. Sampling method: Not stated. Sample profile: Nurses from 71 community-based hospice organisations.	Quantitative inferential sub analysis of a population-level cross-sectional survey using SAS 9.4 software (SAS Institute, Cary, NC). Used a 36-item survey developed using CPC experts and literature review. Validation by key stakeholder revision panel's iterative review, 3 rounds of serial testing then pilot tested with 7 paediatric hospice nurses.	▪ PC experience: 296 nurses (54%) had < 5 years' experience as a hospice nurse. ▪ CPC experience: 279 nurses (51%) had prior experience providing CPC, but 171 (61%) would describe the exposure as every "couple of years" or "never". Most hospices provided CPC to 0-4 children/year (n=406, 74%). ▪ Previous CPC training: most nurses had no prior CPC training (n=495, 90%). ▪ Setting: Community. ▪ Perceived preparedness: CPC clinical experience (frequency of paediatric exposure) was the most impactful variable with respect to comfort with overall and EoL CPC provision. While formal CPC training was the most impactful variable with respect to comfort with management of severe symptoms at EoL. Several times a month or year was statistically relevant to show higher comfort levels. ▪ Challenges in CPC provision/training: Unreported.

						▪ Professional development needs: Need stronger links between hospital and paediatric centres, and community. Introduce shadowing experiences for community hospice nurses with paediatric experts.

Kristjanson, L. et al. (2005)	Australia	Contemporary Nurse	To assess the impact of a community-based bereavement program on nurses' knowledge of children's grief and their attitudes toward death and bereavement	Response rate: n=59 attended and completed the surveys. Population from which sample was drawn not stated. Sampling method: Not stated. Sample profile: Community or inpatient hospice nurses, and community or inpatient paediatric nurses.	Quantitative descriptive longitudinal pre and post-training survey (three time points). Using validated 15-item Bereavement Knowledge Questionnaire and 12-item Understanding the Dying Person and Family Questionnaire.	▪ PC experience: Ranged from 0-16 years and mean of 2.8 years. ▪ CPC experience: 23 (39%) had experience in counselling bereaved families. 18 (30.5%) had counselled from 1-10 families. ▪ Previous CPC training: Unreported. ▪ Setting: Hospice, Community and inpatient (unreported breakdown of percentages). ▪ Perceived preparedness: Pre-training had 61% correct knowledge answers, then post-training 72% were correct and 3 months post-training 74% were correct. ▪ Challenges in CPC training: for shift workers, most preferable to split into 2 half day evenings or 1 full day training workshop. ▪ Professional development needs: Nurses are eager to learn more about paediatric and family grief. Topics highlighted by nurses: adolescents' bereavement and grief concerns, sibling grief, information for other health professionals, and counselling strategies. Bereavement training workshop showed improvement in nurses'

						attitudes and understanding of the dying child/family needs.

Lalloo, C. et al. (2021)	Canada	Journal of Palliative Medicine	To evaluate the attendance of virtual 90-minute CPC education sessions (called TeleECHO), as well as healthcare professionals' session acceptability and perceived changes in knowledge, self-efficacy and practice	Response rate of pre-training: n=108 (43%). Population pre-training: N=252. Response rate of post 6 months training: n=43 (57%) (only included participants who attended ≥1 sessions). Population post 6 months training: N=76. Sampling method: Not stated. Nurses (n=17, 53%), physicians (n=7, 22%), child life specialist (n=1, 3%), allied healthcare professionals and other. All those who provided or were interested in CPC.	Quantitative descriptive and inferential longitudinal pre and post-training online survey (two time points) as part of a mixed-method design. Survey developed by authors. Using 12-item perceived CPC knowledge section, 10-item perceived CPC self-efficacy section, 27-item CPC topic interests section, 8-item training acceptability and satisfaction section, 5-item perceived training comfort levels section, 5-item practice and patient level changes section and open-text/multiple choice sections.	▪ PC experience: Unreported. ▪ CPC experience: Unreported. ▪ Previous CPC training: Unreported. ▪ Setting: Community (n=27, 35.5%), hospital (n=27, 35.5%), community health centre/family health team (n=13, 17%), private practice (n=6, 8%), university (n=2, 3%). ▪ Perceived preparedness: Pre-training perceived knowledge levels were low in neuro-irritability in children (n=44, 58%), talking to children about death (n=33, 44%), medical marijuana in children (n=57, 76%), dyspnea in children (n=30, 40%), and depression and anxiety in children (n=37, 49%). • Perceived self-efficacy levels were low in serving as a CPC community expert; communication with children at various developmental levels about serious illness/death; provide support to bereaved families; Manage pain in serious illness or EoL; Manage non-pain symptoms in serious illness or EoL. ▪ Challenges in CPC provision/training: Unreported.

						▪ Professional development needs: Project ECHO is shown to be a feasible and impactful (improving knowledge, self-efficacy and practice) virtual 90 minute monthly programme for CPC training.

Porter, A.S. et al. (2021)	USA	JAMA Network Open	To explore the paediatric-specific training and support needs of hospice nurses caring for children in the community	Response rate: n=41 (18%) were selected from the n=226 willing to participate in interviews. Population: N=551. Sampling method: purposive sampling. Sample profile: Nurses from 71 community-based hospice organisations.	Qualitative study using semi-structured interviews. 12-item interview guide developed by CPC clinicians and researchers, then iteratively reviewed for validity by CPC doctors/nurses.	▪ PC experience: 30 nurses (73%) have <10 years' PC experience. ▪ CPC experience: Unreported. ▪ Previous CPC training: Unreported. ▪ Setting: Community. ▪ Perceived preparedness: Majority expressed discomfort with caring for children with serious illnesses. In particular with communication with child/siblings/parents, symptom management, understanding child illness trajectory, witnessing child death. ▪ Challenges in CPC training: lack of time, finance, awareness of opportunities, perceived value by hospice and staff burnout. ▪ Professional development needs: highlighted an urgent need for specialised paediatric training and a paediatric expert support network.

Quinn, C. and Bailey, M.E. (2011)	Ireland	International Journal of Palliative Nursing	To understand the views and experiences of adult palliative care Clinical Nurse Specialists working in the community with children and families with palliative care needs	Response rate: n=7 (58%). Population: N=12. Sampling method: purposive sampling. Sample profile: Community adult palliative care clinical nurse specialists.	Qualitative study using semi-structured focus group. Developed own 8-item interview guide, pilot tested using PC nurses.	▪ PC experience: All were specialists in PC, minimum of 2-5 years' experience in PC. ▪ CPC experience: All eligible participants must have cared for a child with CPC needs in the past 2 years. ▪ Previous CPC training: None participated in a CPC training before. Many felt they were just "learning by experience". ▪ Perceived preparedness: Identified areas that caused uncertainty - ability (perceived lack of knowledge/experience), feelings (perceived lack of confidence and emotional preparedness when they go into a home) and organisational challenges (limited guidance on advance care planning for children. All participants were more comfortable caring for adults. ▪ Challenges in CPC provision: lack of knowledge or experience relating to specific equipment, procedures and pharmacology. Lack of nurse recruitment in Ireland. Lack of clarity of their role in CPC in the community, and with each other (n=4 (57%) nurses perceived their

						primary duty was hands-on clinical care, while remaining n=3 (43%) preferred a more supportive role). ▪ Professional development needs: A paediatric trained CNS within the community PC team for guidance/advice. Teaching at the site and short CPC-focused workshops were identified as useful.

Reid, F.C. (2013)	UK	International Journal of Palliative Nursing	To explore the perceived challenges faced by rural adult community nurses when delivering palliative care to children and young people and their families	Response rate: n=10. Population from which sample was drawn not stated. Sampling method: stated as non-probabilistic sampling. Sample profile: 6 district nurses and 4 adult community PC Clinical Nurse Specialists	Qualitative study using individual semi-structured interviews. Description of interview guide items or validity testing not stated.	▪ PC experience: 4 had PC qualifications. ▪ CPC experience: All participants either had 1 (n=7) or 2 (n=3) experiences with CPC. ▪ Previous CPC training: n=2 (20%) nurses had children's qualifications. ▪ Setting: Community. ▪ Perceived preparedness: Nurses felt unprepared and lacked confidence in providing CPC, particularly if they had no children's qualification. ▪ Challenges in CPC provision: emotional preparedness for child's death, discharge planning, building family rapport during peak illness, communication with interdisciplinary teams, maintaining professional boundaries with family, lack of 24 hour resources. ▪ Professional development needs: More psychological support/reflective practices; CPC introduced to adult PC training; paediatric nurses' role in community providing practical/educational support to adult colleagues;

						exploring telemedicine options for rural areas.

Vesel T. and Beveridge, C. (2018)	USA	Journal of Pain and Symptom Management	To evaluate the levels of knowledge, skills and confidence of adult hospice professionals attending a two-day educational workshop in CPC	Response rate pre-training n=72 (77%). Population pre-training: N=93. Response rate post-training: n=62 (67%). Population post-training: N=93. Response rate 6 month post-training: n=26 (28%). Population post-training: N=93. Sampling method: Not stated. Sample profile taken from pre-training survey: adult hospice nurses (n=37, 51%), social workers (n=10, 14%), physicians (n=9, 13%), child life	Quantitative descriptive and inferential longitudinal pre and post-training online survey (three time points) as part of an evaluation study. Using 39-item survey developed by the research team and pilot tested with sample of learners. Qualitative data was collected post-training only for programme feedback.	▪ PC experience: most participants (n=42, 58%) had 5 or less years of experience in the hospice. ▪ CPC experience: 18 (25%) cared for 0 children requiring CPC, majority (n=36, 51%) cared from 1-10 children. ▪ Previous CPC training: Unreported. ▪ Setting: Community. ▪ Perceived preparedness: Those with >10 years hospice experience were more confident than those with less hospice experience (not specific to children). Confidence and comfort levels were particularly low in caring for a child who would be extubated at home; discussing child's prognostication; child advance care planning. ▪ Challenges in CPC provision/training: Unreported. ▪ Professional development needs: Short 2 day 13 module training workshop for adult community hospice providers can improve preparedness levels in children's EoL care as well as attitudes, skills

				specialist (n=2, 3%), health aide (n=1, 1%) and non-clinical/others (n=11, 15%), bank answer (n=2, 3%).		and knowledge levels in CPC for nurses.
Weaver, M.S. et al. (2020)	USA	Journal of Palliative Medicine	To assess whether a telehealth service during the first two home-based hospice visits was acceptable to children, families, and adult-trained home hospice	Response rate: n=15. Population from which sample was drawn not stated. Sampling method: Not stated. Sample profile: Adult-trained hospice	Quantitative inferential longitudinal online survey (two time points) with open-text responses for thematic analyses as part of a case series. Using 15-item modified Technology Acceptance Model 2 (TAM2) surveys.	▪ PC experience: Unreported. All PC nurses. ▪ CPC experience: n=13 (87%) nurses reported that it was their first child patient in 24 months. ▪ Previous CPC training: Unreported. ▪ Setting: Community. ▪ Perceived preparedness: Adult-trained community hospice nurses report feeling uncomfortable with providing EoL services to children. Nurses are not as accepting of

			nurses in the rural setting	nurses working in the rural community.		telemedicine practices compared to caregivers. ▪ Challenges in CPC provision/training: Providing high quality communication about advance care planning in CPC is challenging for nurses. ▪ Professional development needs: More telehealth initiatives to better accommodate and improve communication with CPC patients living in rural communities.

Weaver, M.S. et al. (2021)	USA	Journal of Palliative Care	To evaluate a CPC curriculum for inpatient nurses and community adult-trained hospice nurses caring for children in the rural setting	Response rate pre-training: n=31 (100%). Response rate post-training: n=31 (100%). Response rate 4 months post-training: n=17 (55%). Population: N=31. Sampling method: Not stated. Sample profile: Hospice nurses (n=24, 77%), hospice social worker (n=4, 13%), and administrators (n=3, 10%).	Quantitative descriptive longitudinal pre and post-training online survey (three time points). Developed own 20-item multiple-choice survey piloted by paediatric nurses.	▪ PC experience: n=20 participants (64.5%) had <1-4 years' PC experience. ▪ CPC experience: n=19 participants (61%) had prior CPC experience. Majority provided CPC every couple of years or never (n=20, 64.5%). Most hospices had 0-4 children/year (n=27, 87%) ▪ Previous CPC training: n=27 (87%) participants had no formal CPC training. ▪ Setting: Community. ▪ Perceived preparedness: This cohort had a notable high confidence in CPC. Least confident areas were the intention to provide CPC in the community and feeling supported in their provision of CPC. ▪ Challenges in CPC provision/training: Unreported. ▪ Professional development needs: Family needs, goals of care, and symptom management were ranked as key learning topics. Education delivery preferences included web based (75%), lectures in person (55%), case reviews (55%), small group discussions (50%), and

						written materials such as textbooks or pediatric-specific symptom manuals (45%), bedside mentoring (40%), and telehealth (30%).

Acronyms:

CPC – children's palliative care
PC – palliative care
LLC – life-limiting condition
RR – response rate
EoL – end of life
KI – key informant (e.g. KI interview)
CNS – clinical nurse specialist

Appendix 4: Recruitment Email Invitation

Initial Email Invitation to Participate in Online Surveys:

Dear colleagues,

I hope this email finds you well.

We would like to kindly invite you to take part in an **anonymous pre and post training online survey** (three online surveys in total) as you are currently enrolled in the Palliative Care Workshop provided in partnership by University College Dublin (UCD) School of Nursing, Midwifery and Health Systems and Our Lady's Hospice & Care Services.

We are asking participants to complete our anonymous online survey **before the workshop (before November 22nd), as well as 6 weeks and 6 months after the workshop**. These online surveys will be part of a research study conducted by principal researcher Muireann McDonnell under the supervision of Dr Michael Connolly in part fulfilment of a Masters in Research (MSc) at UCD School of Nursing, Midwifery and Health Sciences.

The aim of this research is to evaluate the levels of knowledge and self-efficacy among adult palliative care providers in the field of paediatric palliative care, both before and after specialist paediatric palliative care training.

Child specific training in palliative care for those who may care for children in their clinical practice has been proposed as a recommendation in the National Model of Care for Paediatric Healthcare Services, the National Strategy for the Future of Children's Nursing and the soon to be published Adult Palliative Care Policy in Ireland. In line with these recommendations, we hope that this study will shed light on the educational needs of adult palliative care providers as well as the impact of specialist paediatric palliative care training on their knowledge, self-efficacy and clinical practice.

A participant information letter has been attached to this email to ensure you are fully informed about this study. Once you have read the information letter and you are happy to participate, we kindly ask you to click on the secure link below. This link will bring you to the online consent page and pre-training survey for you to complete in your own time before November 22nd. This should not take more than 10 minutes to complete.

We appreciate that your time is valuable with your busy schedules so we would like to express our sincere gratitude in advance for your consideration.

For any inquiries regarding this study, you can contact the principal researcher: Muireann McDonnell at muireann.mcdonnell@ucdconnect.ie

6 Weeks and 6 Months Post-Training Email:

(Subject Heading: Children's Palliative Care Workshop: Post-Training Survey)

Dear Colleagues,

We would like to share with you the post-training (anonymous) online survey (6 weeks/6 months after the Children's Palliative Care Workshop). Even if you did not complete the last survey, please complete this one. Your responses in this 5–10-minute survey play a key role in shaping Muireann's thesis in her Research Master's degree, so any contribution is much appreciated.

Online Survey:* *https://forms.gle/52zixFzRogoxX4M77

Many thanks for your continued support and consideration.

6 Weeks and 6 Months Post-Training Reminder Email the Week After:

(Subject Heading: REMINDER: Post-Training Survey)

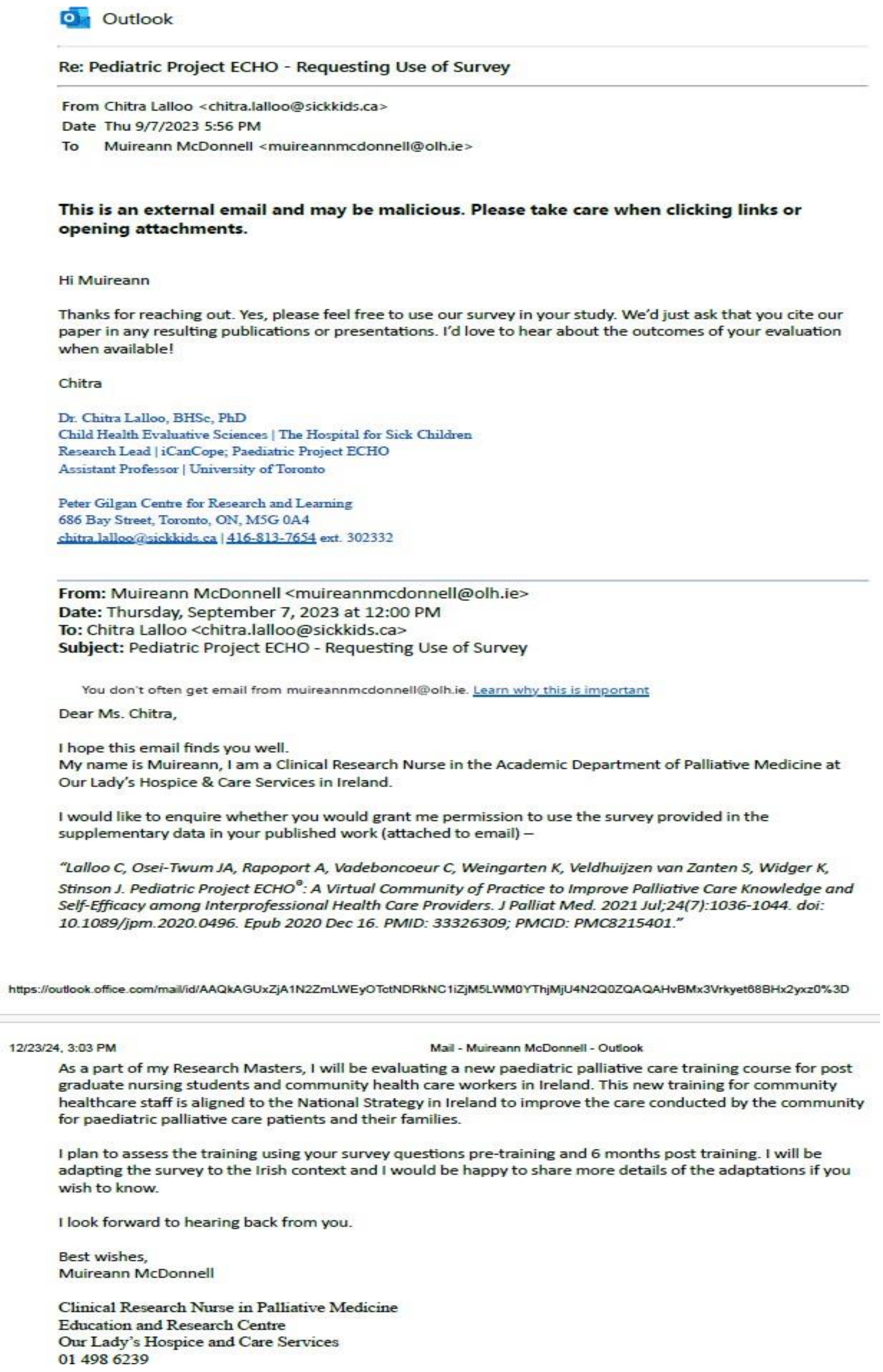
Dear Colleagues,

We would like to remind those who haven't already completed the post-training (anonymous) online survey to please do so at their own convenience. The link will be open for the month to give people time to complete. Your responses in this 5–10-minute survey play a key role in shaping Muireann's thesis in her Research Master's degree, so any contribution is much appreciated.

Online Survey:* *https://forms.gle/52zixFzRogoxX4M77

Many thanks for your continued support and consideration.

Appendix 5: Correspondence with Original Questionnaire Author



Outlook

Re: Pediatric Project ECHO - Requesting Use of Survey

From Chitra Lalloo <chitra.lalloo@sickkids.ca>
Date Thu 9/7/2023 5:56 PM
To Muireann McDonnell <muireannmcdonnell@olh.ie>

This is an external email and may be malicious. Please take care when clicking links or opening attachments.

Hi Muireann

Thanks for reaching out. Yes, please feel free to use our survey in your study. We'd just ask that you cite our paper in any resulting publications or presentations. I'd love to hear about the outcomes of your evaluation when available!

Chitra

Dr. Chitra Lalloo, BHSc, PhD
Child Health Evaluative Sciences | The Hospital for Sick Children
Research Lead | iCanCope; Paediatric Project ECHO
Assistant Professor | University of Toronto

Peter Gilgan Centre for Research and Learning
686 Bay Street, Toronto, ON, M5G 0A4
chitra.lalloo@sickkids.ca | 416-813-7654 ext. 302332

From: Muireann McDonnell <muireannmcdonnell@olh.ie>
Date: Thursday, September 7, 2023 at 12:00 PM
To: Chitra Lalloo <chitra.lalloo@sickkids.ca>
Subject: Pediatric Project ECHO - Requesting Use of Survey

You don't often get email from muireannmcdonnell@olh.ie. Learn why this is important

Dear Ms. Chitra,

I hope this email finds you well.
My name is Muireann, I am a Clinical Research Nurse in the Academic Department of Palliative Medicine at Our Lady's Hospice & Care Services in Ireland.

I would like to enquire whether you would grant me permission to use the survey provided in the supplementary data in your published work (attached to email) –

"Lalloo C, Osei-Twum JA, Rapoport A, Vadeboncoeur C, Weingarten K, Veldhuijzen van Zanten S, Widger K, Stinson J. Pediatric Project ECHO®: A Virtual Community of Practice to Improve Palliative Care Knowledge and Self-Efficacy among Interprofessional Health Care Providers. J Palliat Med. 2021 Jul;24(7):1036-1044. doi: 10.1089/jpm.2020.0496. Epub 2020 Dec 16. PMID: 33326309; PMCID: PMC8215401."

https://outlook.office.com/mail/id/AAQkAGUxZjA1N2ZmLWEyOTctNDRkNC1iZjM5LWM0YThjMjU4N2Q0ZQAQAHvBMx3Vrkyet68BHx2yxz0%3D

12/23/24, 3:03 PM Mail - Muireann McDonnell - Outlook

As a part of my Research Masters, I will be evaluating a new paediatric palliative care training course for post graduate nursing students and community health care workers in Ireland. This new training for community healthcare staff is aligned to the National Strategy in Ireland to improve the care conducted by the community for paediatric palliative care patients and their families.

I plan to assess the training using your survey questions pre-training and 6 months post training. I will be adapting the survey to the Irish context and I would be happy to share more details of the adaptations if you wish to know.

I look forward to hearing back from you.

Best wishes,
Muireann McDonnell

Clinical Research Nurse in Palliative Medicine
Education and Research Centre
Our Lady's Hospice and Care Services
01 498 6239

Appendix 6: Questionnaire Amendments

Questionnaire Amendments

Amendment	Rationale
Changed participant demographic questions to reflect current Irish healthcare professions and practice settings.	To ensure relevance and accuracy for the Irish context.
Removed the needs assessment survey.	A national CPC needs assessment has already been conducted in Ireland (A Palliative Care Needs Assessment for Children, 2005).
Removed mention of ECHO sessions or Canadian palliative care organizations.	Not relevant to this research.
Removed knowledge question on ‘medical marijuana in children.’	Medical marijuana is currently not a legal practice in Ireland.
Changed children with ‘medical complexity’ to ‘palliative care needs.’	This terminology is more widely recognised in the Irish context as per local experts.
Changed ‘interdisciplinary specialist teams’ to ‘other multidisciplinary teams.’	This terminology is more widely recognised in the Irish context as per local experts.
Changed ‘complex patients’ to ‘children with palliative care needs.’	This terminology is more widely recognised in the Irish context as per local experts.
Added ‘memory making’ alongside ‘legacy creation.’	This terminology is more widely recognised in the Irish context as per local experts.
Changed ‘Identify and define who may benefit from palliative care involvement’ to ‘Identify and define which patients may benefit from palliative care involvement.’	To clarify the intent of the question as per guidance from the survey author, Dr. Chitra Lalloo.
Changed ‘not applicable’ Likert scale point to ‘unsure.’	Decision made after discussion with subject experts to improve clarity.
Removed the option to change pre-training levels of self-efficacy.	Anonymity would have to be waived.

Appendix 7: Pre-training Questionnaire

PRE-TRAINING QUESTIONNAIRE

Demographics and Experience

What is your primary profession?

☐ Physician (GP)

☐ Physician

Please indicate specialist area: ______________________

☐ Advanced Nurse Practitioner

Please indicate specialist area: ______________________

☐ Clinical Nurse Specialist

Please indicate specialist area: ______________________

☐ Public Health Nurse

☐ Registered General Nurse

☐ Registered Children's Nurse

☐ Social Worker

☐ Occupational Therapist

☐ Physiotherapist

☐ Dietitian

☐ Other (Please state in comment box below)

Do you currently work in specialist palliative care (adult)?

☐ Yes

☐ No

If you answered yes to the previous question, please indicate how many years have you worked in specialist palliative care (adult) ?

☐ Less than 1 year

☐ 1-4 years

☐ 5-10 years

☐ Greater than 10 years

☐ Not applicable

Please indicate your primary practice setting

☐ Public Hospital

☐ Private Hospital

☐ Local Health Centre

☐ General Practice

☐ Hospice (Adult)

☐ Hospice (Children)

☐ Other (please specify below)

☐ Not applicable

What type of environment do you practice in? (Please check all that apply. If more than one, please elaborate under "Other")

☐ Remote (defined as areas without year-round road access, or which rely on a third party such as an airplane or ferry for transportation to a larger centre)

☐ Rural (defined as areas with a population of less than 30,000 that are more than 30 minutes away from a community with a population of more than 30,000)

☐ Suburban/Urban (defined as areas with populations over 30,000)

☐ Other (please specify below)

Part 1: Knowledge Questions

For the following statements, please use the scale below to select the answer that best describes your **CURRENT LEVEL OF KNOWLEDGE**.

Response Options:

Strongly disagree	Disagree	Somewhat disagree	Neutral	Somewhat agree	Agree	Strongly agree	Unsure
1	2	3	4	5	6	7	8

For my scope of practice, I currently have an appropriate level of knowledge about/to…

1. *Introducing paediatric palliative care to families*

☐ *1 – Strongly disagree*
☐ *2 – Disagree*
☐ *3 – Somewhat disagree*
☐ *4 – Neutral*
☐ *5 – Somewhat agree*
☐ *6 – Agree*
☐ *7 – Strongly agree*
☐ *8 – Unsure*

2. *Neuro-irritability in children*

☐ *1 – Strongly disagree*
☐ *2 – Disagree*
☐ *3 – Somewhat disagree*
☐ *4 – Neutral*
☐ *5 – Somewhat agree*
☐ *6 – Agree*
☐ *7 – Strongly agree*
☐ *8 – Unsure*

3. *Preparing for death and the time that follows*

☐ *1 – Strongly disagree*
☐ *2 – Disagree*
☐ *3 – Somewhat disagree*
☐ *4 – Neutral*
☐ *5 – Somewhat agree*
☐ *6 – Agree*
☐ *7 – Strongly agree*
☐ *8 – Unsure*

4. *Forgoing (“go without”) artificial nutrition and hydration at end of life in children*

☐ *1 – Strongly disagree*
☐ *2 – Disagree*
☐ *3 – Somewhat disagree*
☐ *4 – Neutral*
☐ *5 – Somewhat agree*

☐ *6 – Agree*
☐ *7 – Strongly agree*
☐ *8 – Unsure*

5. Talking to children about death

☐ *1 – Strongly disagree*
☐ *2 – Disagree*
☐ *3 – Somewhat disagree*
☐ *4 – Neutral*
☐ *5 – Somewhat agree*
☐ *6 – Agree*
☐ *7 – Strongly agree*
☐ *8 – Unsure*

6. Nausea & vomiting in children

☐ *1 – Strongly disagree*
☐ *2 – Disagree*
☐ *3 – Somewhat disagree*
☐ *4 – Neutral*
☐ *5 – Somewhat agree*
☐ *6 – Agree*
☐ *7 – Strongly agree*
☐ *8 – Unsure*

7. Dyspnea in children

☐ *1 – Strongly disagree*
☐ *2 – Disagree*
☐ *3 – Somewhat disagree*
☐ *4 – Neutral*
☐ *5 – Somewhat agree*
☐ *6 – Agree*
☐ *7 – Strongly agree*
☐ *8 – Unsure*

8. Pain at end of life in children

☐ *1 – Strongly disagree*
☐ *2 – Disagree*
☐ *3 – Somewhat disagree*
☐ *4 – Neutral*
☐ *5 – Somewhat agree*
☐ *6 – Agree*
☐ *7 – Strongly agree*
☐ *8 – Unsure*

9. The importance of respite for families

☐ *1 – Strongly disagree*
☐ *2 – Disagree*
☐ *3 – Somewhat disagree*
☐ *4 – Neutral*
☐ *5 – Somewhat agree*

☐ *6 – Agree*
☐ *7 – Strongly agree*
☐ *8 – Unsure*

10. Legacy creation/Memory making
☐ *1 – Strongly disagree*
☐ *2 – Disagree*
☐ *3 – Somewhat disagree*
☐ *4 – Neutral*
☐ *5 – Somewhat agree*
☐ *6 – Agree*
☐ *7 – Strongly agree*
☐ *8 – Unsure*

11. Depression & anxiety in children
☐ *1 – Strongly disagree*
☐ *2 – Disagree*
☐ *3 – Somewhat disagree*
☐ *4 – Neutral*
☐ *5 – Somewhat agree*
☐ *6 – Agree*
☐ *7 – Strongly agree*
☐ *8 – Unsure*

Please tell us about any other specific topics related to paediatric palliative care that would be useful for your scope of practice:

Part 2: Self-Efficacy (Confidence)

For the following statements, please use the scale below to select the answer that best describes your LEVEL OF SELF-EFFICACY (confidence):

Response Options:

Strongly disagree	Disagree	Somewhat disagree	Neutral	Somewhat agree	Agree	Strongly agree	Not Applicable
1	2	3	4	5	6	7	8

Within my scope of practice, I feel confident in my ability to...

1. *Identify and define who may benefit from palliative care involvement*

☐ *1 – Strongly disagree*
☐ *2 – Disagree*
☐ *3 – Somewhat disagree*
☐ *4 – Neutral*
☐ *5 – Somewhat agree*
☐ *6 – Agree*
☐ *7 – Strongly agree*
☐ *8 – n/a*

2. *Introduce and discuss palliative care with families and other healthcare providers*

☐ *1 – Strongly disagree*
☐ *2 – Disagree*
☐ *3 – Somewhat disagree*
☐ *4 – Neutral*
☐ *5 – Somewhat agree*
☐ *6 – Agree*
☐ *7 – Strongly agree*
☐ *8 – n/a*

3. *Support children with serious illness, as well as their families*

☐ *1 – Strongly disagree*
☐ *2 – Disagree*
☐ *3 – Somewhat disagree*
☐ *4 – Neutral*
☐ *5 – Somewhat agree*
☐ *6 – Agree*
☐ *7 – Strongly agree*
☐ *8 – n/a*

4. *Manage pain in children with serious illness, including at end of life*

☐ *1 – Strongly disagree*
☐ *2 – Disagree*
☐ *3 – Somewhat disagree*
☐ *4 – Neutral*

☐ *5 – Somewhat agree*
☐ *6 – Agree*
☐ *7 – Strongly agree*
☐ *8 – n/a*

5. *Manage non-pain symptoms in children with serious illness, including at end of life*

☐ *1 – Strongly disagree*
☐ *2 – Disagree*
☐ *3 – Somewhat disagree*
☐ *4 – Neutral*
☐ *5 – Somewhat agree*
☐ *6 – Agree*
☐ *7 – Strongly agree*
☐ *8 – n/a*

6. *Talk to children at various ages and developmental levels about serious illness and death*

☐ *1 – Strongly disagree*
☐ *2 – Disagree*
☐ *3 – Somewhat disagree*
☐ *4 – Neutral*
☐ *5 – Somewhat agree*
☐ *6 – Agree*
☐ *7 – Strongly agree*
☐ *8 – n/a*

7. *Understand the importance of communication and advance care planning in children with serious illness*

☐ *1 – Strongly disagree*
☐ *2 – Disagree*
☐ *3 – Somewhat disagree*
☐ *4 – Neutral*
☐ *5 – Somewhat agree*
☐ *6 – Agree*
☐ *7 – Strongly agree*
☐ *8 – n/a*

8. *Serve as a source of information in my community for paediatric palliative care-related questions and issues*

☐ *1 – Strongly disagree*
☐ *2 – Disagree*
☐ *3 – Somewhat disagree*
☐ *4 – Neutral*
☐ *5 – Somewhat agree*
☐ *6 – Agree*
☐ *7 – Strongly agree*
☐ *8 – n/a*

9. *Provide support to bereaved families*

☐ *1 – Strongly disagree*
☐ *2 – Disagree*
☐ *3 – Somewhat disagree*
☐ *4 – Neutral*
☐ *5 – Somewhat agree*
☐ *6 – Agree*
☐ *7 – Strongly agree*
☐ *8 – n/a*

10. Recognise multisystem care needs and work within a collaborative team
☐ *1 – Strongly disagree*
☐ *2 – Disagree*
☐ *3 – Somewhat disagree*
☐ *4 – Neutral*
☐ *5 – Somewhat agree*
☐ *6 – Agree*
☐ *7 – Strongly agree*
☐ *8 – n/a*

Appendix 8: Six-week post-training questionnaire

POST TRAINING QUESTIONNAIRE – after 6 weeks

Part 1: Reflection on your participation in the Palliative Care workshop (after 6 weeks).

Listed below are some of the common goals that people might describe when first joining the workshop:
Now that you have actively participated in the workshop, please indicate which of the following goals have been met for you.
(select all that apply)

☐ Increased knowledge about how to care for children with palliative care needs
☐ Opportunity to gain and exchange knowledge with other multidisciplinary team members
☐ Networked with colleagues in the community
☐ Provided with an opportunity to discuss complex paediatric patient cases
☐ Increased comfort level in managing children with palliative care needs
☐ Other: *(please specify)*

Part 2: Acceptability and Satisfaction with the training (after 6 weeks)

Please rate your acceptability and satisfaction with the workshop based on the following questions:

	1 – Strongly disagree	**2 – Disagree**	**3 – Somewhat disagree**	**4 – Neutral**	**5 – Somewhat agree**	**6 – Agree**	**7 – Strongly agree**
1. The training was a worthwhile experience for me.							
2. I would recommend this training to my colleagues.							
3. The training created a supportive community of practice.							
4. The training was an effective way for me to learn.							
5. I have learned new information through the training							

6. I have learned best practice care through the training.							
7. I have benefitted from the knowledge of the facilitators involved in the training.							

Please comment on any other ways in which you feel you have benefitted from participating in the training:

Part 3: Comfort Level with the training (after 6 weeks)

Please rate your comfort level with the workshop based on the following questions:

	1 – Strongly disagree	**2 – Disagree**	**3 – Somewhat disagree**	**4 – Neutral**	**5 – Somewhat agree**	**6 – Agree**	**7 – Strongly agree**
1. I felt comfortable speaking, asking questions, and sharing my opinion with other participants.							
2. I felt the facilitators were supportive and approachable.							
3. I felt the facilitators made an effort to include and engage me in the discussion.							

Part 4: Knowledge (after 6 weeks)

Question 1

a) Since completing the workshop, how would you describe the change (if any) in your knowledge related to <u>management of paediatric palliative care patients within your scope of practice</u>?

☐ No change
☐ Almost the same, hardly any change at all in my practice
☐ A little better, but no noticeable change in my practice
☐ Somewhat better, but the change has not made any real difference in my practice
☐ Moderately better, and a noticeable change in my practice
☐ Better and a definite improvement that has made a real and worthwhile difference in my practice
☐ A great deal better, and a considerable improvement that has made all the difference in my practice

b) Please tell us more about why you chose this rating:

Question 2

For the following statements, please use the scale below to select the answer that best describes your CURRENT LEVEL OF KNOWLEDGE:

Response Options:

Strongly disagree	Disagree	Somewhat disagree	Neutral	Somewhat agree	Agree	Strongly agree	Unsure
1	2	3	4	5	6	7	8

For my scope of practice, I currently have an appropriate level of knowledge about/to…

1. Introducing paediatric palliative care to families

☐ *1 – Strongly disagree*
☐ *2 – Disagree*
☐ *3 – Somewhat disagree*
☐ *4 – Neutral*
☐ *5 – Somewhat agree*
☐ *6 – Agree*
☐ *7 – Strongly agree*
☐ *8 – Unsure*

2. Neuro-irritability in children

☐ *1 – Strongly disagree*
☐ *2 – Disagree*
☐ *3 – Somewhat disagree*
☐ *4 – Neutral*
☐ *5 – Somewhat agree*
☐ *6 – Agree*
☐ *7 – Strongly agree*
☐ *8 – Unsure*

3. Preparing for death and the time that follows

☐ *1 – Strongly disagree*
☐ *2 – Disagree*
☐ *3 – Somewhat disagree*
☐ *4 – Neutral*
☐ *5 – Somewhat agree*
☐ *6 – Agree*
☐ *7 – Strongly agree*
☐ *8 – Unsure*

4. Forgoing ("go without") artificial nutrition and hydration at end of life in children

☐ *1 – Strongly disagree*
☐ *2 – Disagree*
☐ *3 – Somewhat disagree*
☐ *4 – Neutral*
☐ *5 – Somewhat agree*
☐ *6 – Agree*
☐ *7 – Strongly agree*
☐ *8 – Unsure*

5. Talking to children about death

☐ *1 – Strongly disagree*
☐ *2 – Disagree*
☐ *3 – Somewhat disagree*
☐ *4 – Neutral*
☐ *5 – Somewhat agree*
☐ *6 – Agree*
☐ *7 – Strongly agree*
☐ *8 – Unsure*

6. Nausea & vomiting in children

☐ *1 – Strongly disagree*
☐ *2 – Disagree*
☐ *3 – Somewhat disagree*
☐ *4 – Neutral*
☐ *5 – Somewhat agree*
☐ *6 – Agree*
☐ *7 – Strongly agree*
☐ *8 – Unsure*

7. Dyspnea in children

☐ *1 – Strongly disagree*
☐ *2 – Disagree*
☐ *3 – Somewhat disagree*
☐ *4 – Neutral*
☐ *5 – Somewhat agree*
☐ *6 – Agree*
☐ *7 – Strongly agree*
☐ *8 – Unsure*

8. Pain at end of life in children

☐ *1 – Strongly disagree*
☐ *2 – Disagree*
☐ *3 – Somewhat disagree*
☐ *4 – Neutral*
☐ *5 – Somewhat agree*
☐ *6 – Agree*
☐ *7 – Strongly agree*
☐ *8 – Unsure*

9. The importance of respite for families

☐ *1 – Strongly disagree*
☐ *2 – Disagree*
☐ *3 – Somewhat disagree*
☐ *4 – Neutral*
☐ *5 – Somewhat agree*
☐ *6 – Agree*
☐ *7 – Strongly agree*
☐ *8 – Unsure*

10. Legacy creation/Memory making

☐ *1 – Strongly disagree*
☐ *2 – Disagree*
☐ *3 – Somewhat disagree*
☐ *4 – Neutral*
☐ *5 – Somewhat agree*
☐ *6 – Agree*
☐ *7 – Strongly agree*
☐ *8 – Unsure*

11. Depression & anxiety in children

☐ *1 – Strongly disagree*
☐ *2 – Disagree*
☐ *3 – Somewhat disagree*
☐ *4 – Neutral*
☐ *5 – Somewhat agree*
☐ *6 – Agree*
☐ *7 – Strongly agree*
☐ *8 – Unsure*

Please tell us about any other specific topics related to paediatric palliative care that would be useful for your scope of practice:

Part 5: Self-Efficacy (Confidence) (after 6 weeks)

Now, we would like you to think about your levels of self-efficacy (confidence) SINCE the workshop.

For the following statements, please use the scale below to select the answer that best describes your CURRENT LEVEL OF SELF-EFFICACY (confidence):

Response Options:

Strongly disagree	Disagree	Somewhat disagree	Neutral	Somewhat agree	Agree	Strongly agree	Not Applicable
1	2	3	4	5	6	7	8

Within my scope of practice, I feel confident in my ability to...

1. *Identify and define who may benefit from palliative care involvement*

☐ *1 – Strongly disagree*
☐ *2 – Disagree*
☐ *3 – Somewhat disagree*
☐ *4 – Neutral*
☐ *5 – Somewhat agree*
☐ *6 – Agree*
☐ *7 – Strongly agree*
☐ *8 – n/a*

2. *Introduce and discuss palliative care with families and other healthcare providers*

☐ *1 – Strongly disagree*
☐ *2 – Disagree*
☐ *3 – Somewhat disagree*
☐ *4 – Neutral*
☐ *5 – Somewhat agree*
☐ *6 – Agree*
☐ *7 – Strongly agree*
☐ *8 – n/a*

3. *Support children with serious illness, as well as their families*

☐ *1 – Strongly disagree*
☐ *2 – Disagree*
☐ *3 – Somewhat disagree*
☐ *4 – Neutral*
☐ *5 – Somewhat agree*
☐ *6 – Agree*
☐ *7 – Strongly agree*
☐ *8 – n/a*

4. *Manage pain in children with serious illness, including at end of life*

☐ *1 – Strongly disagree*
☐ *2 – Disagree*
☐ *3 – Somewhat disagree*
☐ *4 – Neutral*

☐ *5 – Somewhat agree*
☐ *6 – Agree*
☐ *7 – Strongly agree*
☐ *8 – n/a*

5. *Manage non-pain symptoms in children with serious illness, including at end of life*

☐ *1 – Strongly disagree*
☐ *2 – Disagree*
☐ *3 – Somewhat disagree*
☐ *4 – Neutral*
☐ *5 – Somewhat agree*
☐ *6 – Agree*
☐ *7 – Strongly agree*
☐ *8 – n/a*

6. *Talk to children at various ages and developmental levels about serious illness and death*

☐ *1 – Strongly disagree*
☐ *2 – Disagree*
☐ *3 – Somewhat disagree*
☐ *4 – Neutral*
☐ *5 – Somewhat agree*
☐ *6 – Agree*
☐ *7 – Strongly agree*
☐ *8 – n/a*

7. *Understand the importance of communication and advance care planning in children with serious illness*

☐ *1 – Strongly disagree*
☐ *2 – Disagree*
☐ *3 – Somewhat disagree*
☐ *4 – Neutral*
☐ *5 – Somewhat agree*
☐ *6 – Agree*
☐ *7 – Strongly agree*
☐ *8 – n/a*

8. *Serve as a source of information in my community for paediatric palliative care-related questions and issues*

☐ *1 – Strongly disagree*
☐ *2 – Disagree*
☐ *3 – Somewhat disagree*
☐ *4 – Neutral*
☐ *5 – Somewhat agree*
☐ *6 – Agree*
☐ *7 – Strongly agree*
☐ *8 – n/a*

9. *Provide support to bereaved families*

☐ *1 – Strongly disagree*
☐ *2 – Disagree*
☐ *3 – Somewhat disagree*
☐ *4 – Neutral*
☐ *5 – Somewhat agree*
☐ *6 – Agree*
☐ *7 – Strongly agree*
☐ *8 – n/a*

10. Recognise multisystem care needs and work within a collaborative team
☐ *1 – Strongly disagree*
☐ *2 – Disagree*
☐ *3 – Somewhat disagree*
☐ *4 – Neutral*
☐ *5 – Somewhat agree*
☐ *6 – Agree*
☐ *7 – Strongly agree*
☐ *8 – n/a*

Part 6: Practice and Patient Level Changes (after 6 weeks)

What type of impact has the training had on the following areas of your practice?
(*If the question is not applicable, please select 'N/A'*)

	1 – Strongly negative impact	**2 – Negative impact**	**3 – Somewhat negative impact**	**4 – Neutral**	**5 – Somewhat positive impact**	**6 – Positive impact**	**7 – Strongly positive impact**
1. My willingness/comfort in managing children with palliative care needs.							
2. My satisfaction managing children with palliative care needs.							
3. My ability to have a positive professional impact in the community.							
4. The reputation of my practice in the community.							
5. Expanded access to effective treatment for paediatric palliative care patients in my community.							

What types of skills have you improved as a result of participating in the workshop? (Please select all that apply)

☐ Applying best practices
☐ New tools or techniques
☐ Identifying patient needs
☐ Other *(please specify in box below)*

Did discussion in the workshop change your management plan for any of your patients?
* must provide value

☐ No
☐ Yes
☐ Not applicable

Appendix 9: Six months post-training questionnaire

POST TRAINING QUESTIONNAIRE – after 6 months

Part 1: Reflection on your participation in the Palliative Care workshop (after 6 months).

Listed below are some of the common goals that people might describe when first joining the workshop:
Now that you have actively participated in the workshop, please indicate which of the following goals have been met for you.
(select all that apply)
☐ Increased knowledge about how to care for children with palliative care needs
☐ Opportunity to gain and exchange knowledge with other multidisciplinary team members
☐ Networked with colleagues in the community
☐ Provided with an opportunity to discuss complex paediatric patient cases
☐ Increased comfort level in managing children with palliative care needs
☐ Other: *(please specify)*

Part 2: Knowledge (after 6 months)

Question 1

Since completing the workshop, how would you describe the change (if any) in your knowledge related to <u>management of paediatric palliative care patients within your scope of practice</u>?

☐ No change
☐ Almost the same, hardly any change at all in my practice
☐ A little better, but no noticeable change in my practice
☐ Somewhat better, but the change has not made any real difference in my practice
☐ Moderately better, and a noticeable change in my practice
☐ Better and a definite improvement that has made a real and worthwhile difference in my practice
☐ A great deal better, and a considerable improvement that has made all the difference in my practice

Please tell us more about why you chose this rating:

Question 2
For the following statements, please use the scale below to select the answer that best describes your CURRENT LEVEL OF KNOWLEDGE:

Response Options:

Strongly disagree	Disagree	Somewhat disagree	Neutral	Somewhat agree	Agree	Strongly agree	Unsure
1	2	3	4	5	6	7	8

For my scope of practice, I currently have an appropriate level of knowledge about/to…

1. *Introducing paediatric palliative care to families*

☐ *1 – Strongly disagree*
☐ *2 – Disagree*

☐ *3 – Somewhat disagree*
☐ *4 – Neutral*
☐ *5 – Somewhat agree*
☐ *6 – Agree*
☐ *7 – Strongly agree*
☐ *8 – Unsure*

2. Neuro-irritability in children
☐ *1 – Strongly disagree*
☐ *2 – Disagree*
☐ *3 – Somewhat disagree*
☐ *4 – Neutral*
☐ *5 – Somewhat agree*
☐ *6 – Agree*
☐ *7 – Strongly agree*
☐ *8 – Unsure*
3. Preparing for death and the time that follows
☐ *1 – Strongly disagree*
☐ *2 – Disagree*
☐ *3 – Somewhat disagree*
☐ *4 – Neutral*
☐ *5 – Somewhat agree*
☐ *6 – Agree*
☐ *7 – Strongly agree*
☐ *8 – Unsure*

4. Forgoing ("go without") artificial nutrition and hydration at end of life in children
☐ *1 – Strongly disagree*
☐ *2 – Disagree*
☐ *3 – Somewhat disagree*
☐ *4 – Neutral*
☐ *5 – Somewhat agree*
☐ *6 – Agree*
☐ *7 – Strongly agree*
☐ *8 – Unsure*

5. Talking to children about death
☐ *1 – Strongly disagree*
☐ *2 – Disagree*
☐ *3 – Somewhat disagree*
☐ *4 – Neutral*
☐ *5 – Somewhat agree*
☐ *6 – Agree*
☐ *7 – Strongly agree*
☐ *8 – Unsure*

6. Nausea & vomiting in children
☐ *1 – Strongly disagree*
☐ *2 – Disagree*
☐ *3 – Somewhat disagree*

☐ *4 – Neutral*
☐ *5 – Somewhat agree*
☐ *6 – Agree*
☐ *7 – Strongly agree*
☐ *8 – Unsure*

7. Dyspnea in children
☐ *1 – Strongly disagree*
☐ *2 – Disagree*
☐ *3 – Somewhat disagree*
☐ *4 – Neutral*
☐ *5 – Somewhat agree*
☐ *6 – Agree*
☐ *7 – Strongly agree*
☐ *8 – Unsure*

8. Pain at end of life in children
☐ *1 – Strongly disagree*
☐ *2 – Disagree*
☐ *3 – Somewhat disagree*
☐ *4 – Neutral*
☐ *5 – Somewhat agree*
☐ *6 – Agree*
☐ *7 – Strongly agree*
☐ *8 – Unsure*

9. The importance of respite for families
☐ *1 – Strongly disagree*
☐ *2 – Disagree*
☐ *3 – Somewhat disagree*
☐ *4 – Neutral*
☐ *5 – Somewhat agree*
☐ *6 – Agree*
☐ *7 – Strongly agree*
☐ *8 – Unsure*

10. Legacy creation/Memory making
☐ *1 – Strongly disagree*
☐ *2 – Disagree*
☐ *3 – Somewhat disagree*
☐ *4 – Neutral*
☐ *5 – Somewhat agree*
☐ *6 – Agree*
☐ *7 – Strongly agree*
☐ *8 – Unsure*

11. Depression & anxiety in children
☐ *1 – Strongly disagree*
☐ *2 – Disagree*
☐ *3 – Somewhat disagree*

☐ *4 – Neutral*
☐ *5 – Somewhat agree*
☐ *6 – Agree*
☐ *7 – Strongly agree*
☐ *8 – Unsure*

Please tell us about any other specific topics related to paediatric palliative care that would be useful for your scope of practice:

Part 3: Self-Efficacy (Confidence) (after 6 months)
Now, we would like you to think about your levels of self-efficacy (confidence) SINCE the workshop.

For the following statements, please use the scale below to select the answer that best describes your CURRENT LEVEL OF SELF-EFFICACY (confidence):

Response Options:

Strongly disagree	Disagree	Somewhat disagree	Neutral	Somewhat agree	Agree	Strongly agree	Not Applicable
1	2	3	4	5	6	7	8

Within my scope of practice, I feel confident in my ability to...

1. *Identify and define who may benefit from palliative care involvement*

☐ *1 – Strongly disagree*
☐ *2 – Disagree*
☐ *3 – Somewhat disagree*
☐ *4 – Neutral*
☐ *5 – Somewhat agree*
☐ *6 – Agree*
☐ *7 – Strongly agree*
☐ *8 – n/a*

2. *Introduce and discuss palliative care with families and other healthcare providers*

☐ *1 – Strongly disagree*
☐ *2 – Disagree*
☐ *3 – Somewhat disagree*
☐ *4 – Neutral*
☐ *5 – Somewhat agree*
☐ *6 – Agree*
☐ *7 – Strongly agree*
☐ *8 – n/a*

3. *Support children with serious illness, as well as their families*

☐ *1 – Strongly disagree*
☐ *2 – Disagree*
☐ *3 – Somewhat disagree*
☐ *4 – Neutral*
☐ *5 – Somewhat agree*

☐ *6 – Agree*
☐ *7 – Strongly agree*
☐ *8 – n/a*

4. Manage pain in children with serious illness, including at end of life

☐ *1 – Strongly disagree*
☐ *2 – Disagree*
☐ *3 – Somewhat disagree*
☐ *4 – Neutral*
☐ *5 – Somewhat agree*
☐ *6 – Agree*
☐ *7 – Strongly agree*
☐ *8 – n/a*

5. Manage non-pain symptoms in children with serious illness, including at end of life

☐ *1 – Strongly disagree*
☐ *2 – Disagree*
☐ *3 – Somewhat disagree*
☐ *4 – Neutral*
☐ *5 – Somewhat agree*
☐ *6 – Agree*
☐ *7 – Strongly agree*
☐ *8 – n/a*

6. Talk to children at various ages and developmental levels about serious illness and death

☐ *1 – Strongly disagree*
☐ *2 – Disagree*
☐ *3 – Somewhat disagree*
☐ *4 – Neutral*
☐ *5 – Somewhat agree*
☐ *6 – Agree*
☐ *7 – Strongly agree*
☐ *8 – n/a*

7. Understand the importance of communication and advance care planning in children with serious illness

☐ *1 – Strongly disagree*
☐ *2 – Disagree*
☐ *3 – Somewhat disagree*
☐ *4 – Neutral*
☐ *5 – Somewhat agree*
☐ *6 – Agree*
☐ *7 – Strongly agree*
☐ *8 – n/a*

8. Serve as a source of information in my community for paediatric palliative care-related questions and issues

☐ *1 – Strongly disagree*

☐ *2 – Disagree*
☐ *3 – Somewhat disagree*
☐ *4 – Neutral*
☐ *5 – Somewhat agree*
☐ *6 – Agree*
☐ *7 – Strongly agree*
☐ *8 – n/a*

9. Provide support to bereaved families

☐ *1 – Strongly disagree*
☐ *2 – Disagree*
☐ *3 – Somewhat disagree*
☐ *4 – Neutral*
☐ *5 – Somewhat agree*
☐ *6 – Agree*
☐ *7 – Strongly agree*
☐ *8 – n/a*

10. Recognise multisystem care needs and work within a collaborative team

☐ *1 – Strongly disagree*
☐ *2 – Disagree*
☐ *3 – Somewhat disagree*
☐ *4 – Neutral*
☐ *5 – Somewhat agree*
☐ *6 – Agree*
☐ *7 – Strongly agree*
☐ *8 – n/a*

Part 4: Practice and Patient Level Changes (after 6 months)

What type of impact has the training had on the following areas of your practice? (*If the question is not applicable, please select 'N/A'*)

	1 – Strongly negative impact	**2 – Negative impact**	**3 – Somewhat negative impact**	**4 – Neutral**	**5 – Somewhat positive impact**	**6 – Positive impact**	**7 – Strongly positive impact**
My willingness/comfort in managing children with palliative care needs.							
My satisfaction managing children with palliative care needs.							
My ability to have a positive professional impact in the community.							
The reputation of my practice in the community.							
Expanded access to effective treatment for paediatric palliative care patients in my community.							

What types of skills have you improved as a result of participating in the workshop? (Please select all that apply)

☐ Applying best practices
☐ New tools or techniques
☐ Identifying patient needs
☐ Other *(please specify in box below)*

Did discussion in the workshop change your management plan for any of your patients?
* must provide value

☐ No
☐ Yes
☐ Not applicable

Appendix 10: Children’s Complex Care Workshop Timetable

Date: Wednesday 22nd November 2023 **Time: 09:00-13:00** **Location: Online via Zoom**	
Time	**Topic**
09.00 – 09.50	Introduction and overview of contemporary issues in complex care
10.00-11.00	The role of the complex care coordinator in the community
Comfort Break 11.00-11.15	
11.15-12.00	Care of children with complex care needs in the community
12.00-13.00	Clinical Nurse Coordinator for Children with a life limiting condition

Appendix 11: Participant information leaflet

UCD School of Nursing, Midwifery and Health Systems

UCD Health Sciences Centre,
University College Dublin, Belfield,
Dublin 4, Ireland www.ucd.ie/nmhs

T +353 1 716 6488/6491
F +353 1 716 6450

Scoil na hAltrachta, an Chnáimhseachais agus na gCóras Sláinte UCD

Ionad Eolaíocht Sláinte UCD
An Coláiste Ollscoile, Baile Átha Cliath,
Belfield, Baile Átha Cliath 4, Eire

Nursing.midwifery@ucd.ie www.ucd.ie/nmhs

Participant Information Sheet

Study Title: Evaluation of knowledge and self-efficacy in children's palliative care amongst adult palliative care providers

Approval Number: LS-C-23-232-McDonnell-Connolly

Name of Principal Investigator: Ms Muireann McDonnell

You are being invited to participate in a research study.
Thank you for taking time to read this.

What is the purpose of this study?

This research is being conducted by Muireann McDonnell as part of a Master of Science by Research being undertaken at UCD School of Nursing, Midwifery & Health Systems, under the supervision of Dr Michael Connolly.

As part of the proposed new Adult Palliative Care Policy in Ireland, education on children's palliative care needs should be provided as part of graduate study programmes in palliative care and on an ongoing basis to clinicians working in adult palliative care services. The aim of this study is to understand adult palliative care providers' knowledge and self-efficacy regarding children's palliative care, before and after an education workshop.

Why have I been chosen to participate?

You have been chosen to participate in this study because you are currently completing the Graduate Diploma in Palliative Care or you currently work in a Community Palliative Care Team.

What will I be asked to do?

You will be asked to complete an online survey in advance of completing the education workshop and at other two points; 6 weeks and 6 months after you complete the workshop.

Are there any risks involved in participating in this study?

There are no risks associated with this study.

Are there any benefits from my participation?

You will not benefit directly from taking part in this study. We hope the information we gain from you and other participants of the study will contribute to a greater understanding of knowledge and self-efficacy of adult palliative care providers who care for children and their families.

What happens if I do not agree to participate?

You do not have to take part in this study. It is entirely voluntary. If you decide not to take part, you do not have to give us a reason. The research team will not divulge the information you provide, or the fact of your participation, to any person**.**

What happens if I change my mind?

Participation in this study is completely voluntary. Even if you agree to participate, you are free to withdraw from further participation without giving a reason and with no negative consequences. Your decision to take part, or to take part and later withdraw, will not affect your relationship with the research team.

How will you keep my information private and confidential?

By consenting to participate, you are granting the research team permission to collect and use data for the purpose of the study. All questionnaires will be anonymous so the researcher will not be able to trace you back to your answers.

Once the study is completed, the data collected from you will be stored securely as per university policy for research data management. All data collected will be kept on a password protected computer for five years as required by ethical approval of the university. Only the researchers will have access to this information during the project. After the five years all data will be destroyed in accordance with university guidelines and procedures.

Will I be able to find out more about the results of this project?

The results of this research are intended to be made available through publications in a journal article. The confidentiality of participants will be protected at all times.

Who is funding this research?

No funding has been obtained to complete this study.

Will I be paid for taking part in this study?

There will be no payment for taking part in this study.

What if I have a concern or a complaint?

A declaration of low-risk research has been approved by the Chair of the Human Research Ethics Committee at University College Dublin reference number LS-C-23-232-McDonnell-Connolly. If you have a concern or complaint regarding the ethical conduct of this research project and would like to speak to an independent person, please contact the University College Dublin's Ethics Officer at research.ethics@ucd.ie. Any complaint or concern will be treated in confidence and fully investigated. You will be informed of the outcome.

Who do I contact if I have a question about this study?

If you have any questions about this project, please feel free to contact the Principal Investigator:

Muireann McDonnell,

Email: muireann.mcdonnell@ucdconnect.ie

Appendix 12: Informed consent form

UCD School of Nursing, Midwifery and Health Systems

UCD Health Sciences Centre,
University College Dublin,
Belfield, Dublin 4, Ireland
www.ucd.ie/nmhs

T +353 1 716 6488/6491
F +353 1 716 6450

Scoil na hAltrachta, an Chnáimhseachais agus na gCóras Sláinte UCD

Ionad Eolaíocht Sláinte UCD
An Coláiste Ollscoile, Baile Átha Cliath,
Belfield, Baile Átha Cliath 4, Eire

Nursing.midwifery@ucd.ie www.ucd.ie/nmhs

Consent for participants for an Online Survey

For ethical reasons it is extremely important that you give your fully informed consent to participate in this study.

If you would like to participate, please complete this section.

DECLARATION

I have read the information sheet (previous page) and have had time to consider whether to

take part in this study. I understand that my participation is voluntary (it is my choice) and that I am free to withdraw from the research at any time without disadvantage or penalty. I confirm that I am over the age of 18. I agree to take part in this research.

I agree that the data arising from this research can be published and that I will not be identified in any way.

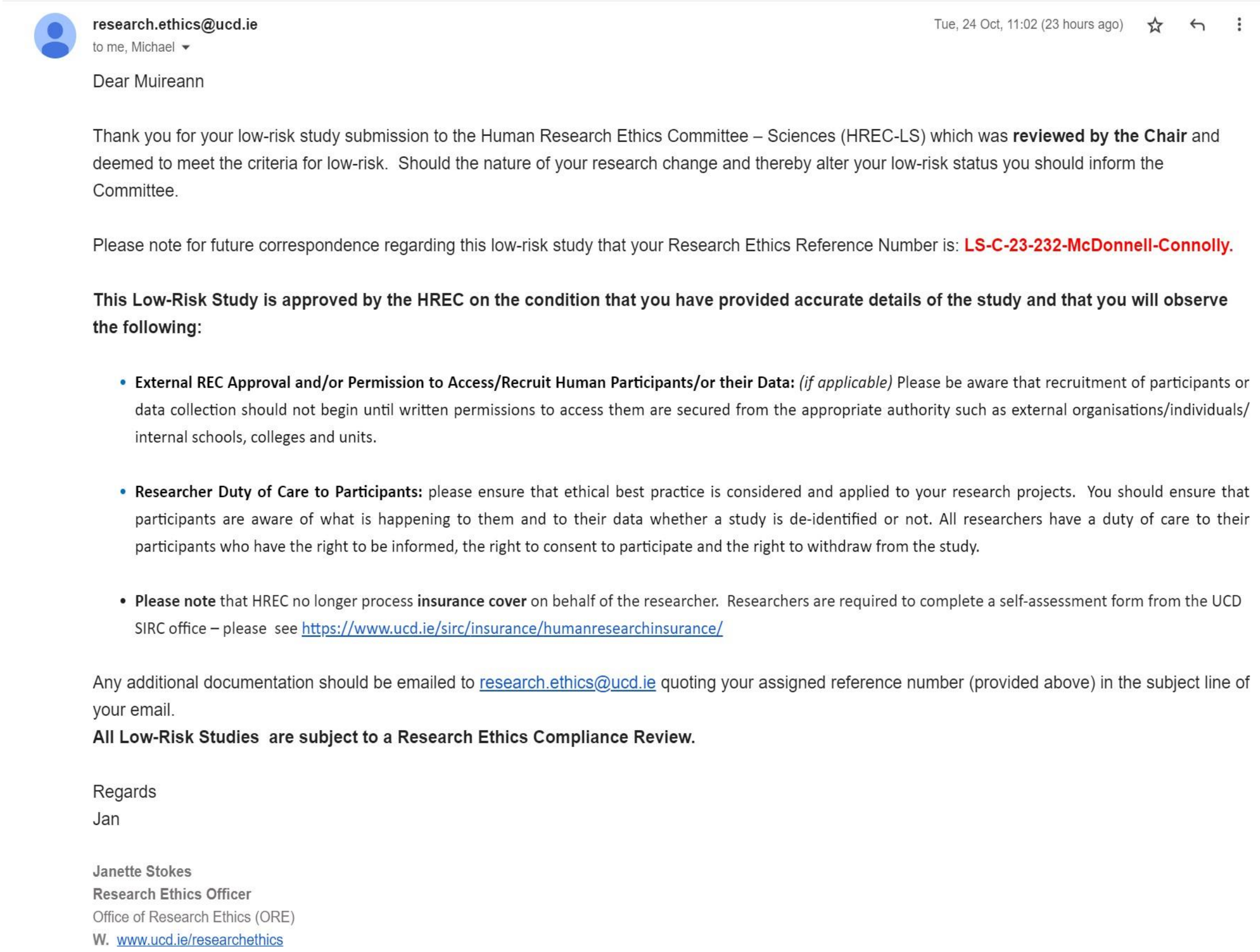
If you have any questions about this research, please contact the Principal Researcher at: muireann.mcdonnell@ucdconnect.ie

I consent and would like to continue with the survey

Yes (please continue to the next section and complete the survey)

No (your information will NOT be kept or analysed. Please close this window)

Appendix 13: UCD Low Risk Ethics Approval



research.ethics@ucd.ie
to me, Michael
Tue, 24 Oct, 11:02 (23 hours ago)

Dear Muireann

Thank you for your low-risk study submission to the Human Research Ethics Committee – Sciences (HREC-LS) which was **reviewed by the Chair** and deemed to meet the criteria for low-risk. Should the nature of your research change and thereby alter your low-risk status you should inform the Committee.

Please note for future correspondence regarding this low-risk study that your Research Ethics Reference Number is: **LS-C-23-232-McDonnell-Connolly.**

This Low-Risk Study is approved by the HREC on the condition that you have provided accurate details of the study and that you will observe the following:

- **External REC Approval and/or Permission to Access/Recruit Human Participants/or their Data:** *(if applicable)* Please be aware that recruitment of participants or data collection should not begin until written permissions to access them are secured from the appropriate authority such as external organisations/individuals/ internal schools, colleges and units.

- **Researcher Duty of Care to Participants:** please ensure that ethical best practice is considered and applied to your research projects. You should ensure that participants are aware of what is happening to them and to their data whether a study is de-identified or not. All researchers have a duty of care to their participants who have the right to be informed, the right to consent to participate and the right to withdraw from the study.

- **Please note** that HREC no longer process **insurance cover** on behalf of the researcher. Researchers are required to complete a self-assessment form from the UCD SIRC office – please see https://www.ucd.ie/sirc/insurance/humanresearchinsurance/

Any additional documentation should be emailed to research.ethics@ucd.ie quoting your assigned reference number (provided above) in the subject line of your email.
All Low-Risk Studies are subject to a Research Ethics Compliance Review.

Regards
Jan

Janette Stokes
Research Ethics Officer
Office of Research Ethics (ORE)
W. www.ucd.ie/researchethics

Appendix 14: Our Lady's Hospice & Care Services Research Approval Form

Our Lady's Hospice & Care Services
Harold's Cross
Blackrock
Wicklow
Respite Rehabilitation Reassurance

14/11/2023

Dear Muireann McDonnell,

Re: "Evaluation of knowledge and self-efficacy in children's palliative care amongst adult palliative care providers".

On behalf of the Education and Research Committee, I would like to thank you for submitting the above proposal. I can confirm that the Committee is satisfied with your submission and has given approval for your proposal.

A copy of your completed project should be submitted to the E&R Committee and the Library at Our Lady's Hospice & Care Services on completion. You will also need to complete yearly and end-of-study Report's.

We wish you the very best of luck with your research.

Yours sincerely,

Mary Flanagan

Mary Flanagan, Interim CEO,
OLHC&CS

Professor Andrew Davies,
Professor of Palliative Medicine,
OLHC&CS

Our Lady's Hospice
& Care Services
Harold's Cross,
D6W RY72

www.olh.ie/education-research

Respite
Rehabilitation
Reassurance

Founded in 1879 by Religious Sisters of Charity
For list of Company Directors please refer to our website: www.olh.ie (About Us/Governance)
Our Lady's Hospice Ltd operating as Our Lady's Hospice & Care Services. Company Registration No. 352404. Charity Registration No. CHY1144

(This paper is not to be used for prescription purposes.)