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PRIMARY CAREGIVERS’ KNOWLEDGE, ATTITUDES AND BELIEFS TOWARD PALLIATIVE CARE FOR CHILDREN WITH CANCER

by
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ABSTRACT
OF THE DISSERTATION OF

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Parents' knowledge, attitudes and beliefs (KAB) toward Pediatric Palliative Care (PPC) in children with cancer remain underexplored, especially in Low and Middle Income Countries (LMICs) where the care relies heavily on family involvement. This two-phase multicenter study examined primary caregivers' KAB toward PPC for children with cancer in order to uncover areas for improvement. The first and second phases share a common specific aim to culturally validate instruments measuring the concepts of interest. The specific aims of the second phase included describing the current primary caregivers' KAB toward PPC for children with cancer, determining the factors associated with primary caregivers' KAB and identifying the primary caregivers' tasks in PPC for children with cancer.

In the first study phase, cultural adaptation, content validation and pilot testing of the questionnaire were conducted. The items were newly developed or taken from previously validated tools such as the Memorial Symptom Assessment Scale and the Palliative Care Knowledge Scale. After two independent forward translations and one back-translation, ten experts in pediatric oncology and palliative care evaluated the questionnaire for content validity and cultural appropriateness. The questionnaire was then piloted through structured interviews via Whatsapp with twenty primary caregivers of children with cancer. The main study used a quantitative cross-sectional descriptive design. A sample of 105 participants from three major pediatric oncology centers in Lebanon completed the study. Data were collected through structured interviews via Whatsapp using the questionnaire validated in the pilot phase.

The experts' reviews revealed excellent Content Validity Index (*CVI*) for the items (*CVI*=0.8-1) and the overall survey (*CVI*=0.99). The sample in the pilot study evaluated the survey's ease, length, clarity, wording and language. Preliminary data was obtained. In the main study, the psychometric analysis of different survey sections yielded satisfactory results for the PPC attitudes scale (Exploratory Factor Analysis revealed a three-factor structure with satisfactory *Cronbach's alpha* coefficient). Results of the main study results suggested that, few primary caregivers have heard about PPC (*n*=18, 17.1%) and only 2% had accurate information about it. When given a brief description of PPC, more than 90% demonstrated positive attitudes (*Mean* attitude above 4) toward the care and recommended its integration at the start of cancer treatment. “Religious and spiritual commitment” was the most common strong facilitator and “Overwhelming negative emotions” was the most common strong barrier to integrating PPC at the individual level. Participants, on average, engaged in 22.1 activities within PPC, even without recognizing the medical term. The bivariate and regression analysis suggested significant associations of knowledge, attitudes and beliefs with several demographic and clinical factors.

Examining parents’ KAB toward PPC in LMICs, such as Lebanon, enhances knowledge and potentially informs practice in these regions. This study promoted PPC understanding, highlighted factors influencing KAB toward PPC, and provided evidence on psychometric properties of novel instruments used among parents of children with cancer.

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ABBREVIATIONS

AAP: American Academy of Pediatric

AUBMC: American University of Beirut Medical Center

CCI: Children's Cancer Institute

CMCC: Care of My Child with Cancer

CVI: Content Validity Index

EOL: End-of-Life

HCP: Healthcare Professionals

HIC: High Income Countries

ICPCN: International Children's Palliative Care Network

IOM: Institute of Medicine

KAB: Knowledge, Attitudes and Beliefs

LHG-UMC: Lebanese Hospital Geitaoui-University Medical Center

LMICs: Low and Middle-Income Countries

MeSH: Medical Subject Headings

PPC: Pediatric Palliative Care

PCPEM: Palliative Care Parental Self-Efficacy Measure

PCQN: Palliative Care Quiz for Nursing

PPCI: Perceptions of Palliative Care Instrument

PCAS: Palliative Care Attitude Scale

PaCKS: Palliative Care Knowledge Scale

SGHUMC: Saint George Hospital University Medical Center

TPB: Theory of Planned Behavior

WHO: World Health Organization

CHAPTER I

INTRODUCTION

Every year, more than 400,000 children below 19 years of age are diagnosed with cancer worldwide, with more than 80% living in Low and Middle-Income Countries (LMICs) (Johnston et al., 2021; Lam et al., 2019; Magrath et al., 2013; Steliarova-Foucher et al., 2017). In High Income Countries (HIC), the overall survival rate bypasses 80% (Gupta et al., 2015; Rodriguez-Galindo et al., 2015; Siegel et al, 2021), yet cancers remain the leading cause of childhood illness-related deaths (Center for Disease Control and Prevention, 2018; Statistics Canada, 2020; Roth et al., 2018). In contrast, the overall survival rates in LMICs are dramatically lower (Gupta et al., 2015; Rodriguez-Galindo et al., 2015), and mortality is often due to infectious diseases, malnutrition, and nutritional deficiencies (Roth et al., 2018). Lebanon, a Middle Eastern middle-income country, witnessed an increase of 54% in pediatric cancer incidence between 2010 and 2015 (National Cancer Registry, 2015). The demands for pediatric oncology services in Lebanon remarkably escalated with the influx of refugees due to political instability in the region (Saab et al., 2018).

A. Children with Cancer and Pediatric Palliative Care

Children with cancer often suffer from a range of physical and psychological symptoms during therapy (Hook & Linder, 2019; Linder & Hook, 2019). Reports from different settings and at different stages of the disease trajectory commonly describe suffering associated with pain, nausea, fatigue, sleep disturbances, sadness, and others symptoms (Abu-Saad Huijer et al., 2013a; Abu-Saad Huijer et al., 2013b, Levine et al., 2017, Saad et al., 2011; Salins et al., 2022; Wolfe et al., 2000). Such experiences affect the quality of life of children with cancer and their families (Litzelman et al., 2011; Junkins et al., 2020; Rosenberg et al., 2016; Yu et al., 2017). Therefore, Pediatric Palliative Care (PPC) is required for children with cancer to alleviate their suffering and enhance their quality of life (Widdas et al., 2013). Globally, a recent study reported that 98% of children with serious health-related suffering (due to cancer and other diseases) reside in LMICs, which accentuates the need for PPC in these regions (Knaul et al., 2018). Particularly, the Eastern Mediterranean region, where Lebanon is located, ranks third in the highest rates of children in need of palliative care (12%) after Africa (51.8%) and South East Asia (19.5%) (Connor et al., 2020).

B. Pediatric Palliative Care (PPC)

Over the last two decades, PPC has been a growing field within the pediatric oncology specialty (Rosenberg & Wolfe, 2017). According to the World Health Organization (WHO, 1998), PPC aims to improve the quality of life of the child and family since it is the “active total care of the child's body, mind and spirit, and also involves giving support to the family . . . Effective palliative care requires a broad multidisciplinary approach that includes the family . . . PPC can be provided in tertiary care facilities, in community health centers and even in children's homes” (WHO, 1998, WHO Definition of Palliative Care for Children section). In 2014, the World Health Assembly issued a global resolution for palliative care as part of universal health coverage to promote accessibility to palliative care as a “human right”. The resolution particularly highlighted the need to train healthcare professionals and family members in order to reduce patient suffering (World Health Organization, 2014). In HICs, several pediatric oncology professional organizations have adopted the WHO definition to establish principles and standards for PPC provision (American Academy of Pediatrics, 2000; Ferrell et al., 2017; Weaver et al., 2015).

1. PPC Provision

The levels of palliative integration within the healthcare systems varies by country. According to Clark and colleagues (2019), the development level of palliative in 123 of 198 examined countries ranges from “no known activities” to “isolated provision” where PPC delivery is sporadic and limited to small number of services (Clark et al., 2020). Advanced stages of palliative care integration existed in only 30 countries, the majority of which are HICs (Clark et al., 2020).

In pediatric oncology, PPC is generally provided by the multidisciplinary oncology team who, at the same time, provides the curative therapy (primary palliative care), in addition to specialized palliative care needed for complex cases (Snaman et al., 2020). These specialized PPC services are often available in HICs where palliative care is well established (Clark et al., 2020). Many reports have described the benefits of specialized PPC teams in terms of patient, family and system outcomes. Timely integration of specialized PPC services in the treatment of pediatric patients with cancer yielded better symptom management, quality of life, communication with the children and their families, and reduced care cost (Chong et al., 2018; Friedrichsdorf et al., 2015; Kassam et al., 2015; Kaye et al., 2016; Kaye et al., 2021; Salins et al., 2022; Schmidt et al., 2013; Vollenbroich et al., 2012).

In LMICs, many barriers - such as lack of human and material resources, training and policies - challenge the development and provision of PPC services

(Downing et al., 2018; Salins et al., 2022). Despite the limited resources, several PPC programs in hospitals or hospices are available primarily in urban hospitals (Caruso-Brown et al., 2014). Home-based services are commonly adopted to enhance accessibility while promoting continuity of care and symptom management through coordination between healthcare providers and the family (Downing et al., 2016; Caruso-Brown, et al., 2014). In addition, palliative care at home may fit the cultural context better than hospital settings. Particularly in Lebanon, a recent policy brief stipulates the provision of palliative care at patients' residence as a "viable option" valuing the family ties (Soueidan et al., 2018). The scarcity of resources and cultural features in LMICs seem to intensify the family role, particularly in PPC delivery.

The family approach within PPC commonly entails addressing the needs of the family (DeCourcey et al., 2019; Law et al., 2014; Virdun et al., 2015). Another facet of this approach is involving parents in caregiving tasks such as managing symptoms and devices at home, decision-making, and ensuring continuity of care between hospital and home (Classen, 2012; Lazzarin et al., 2018; Verberne et al., 2017; Verberne et al., 2018). As caregivers in PPC, the parents, especially the primary caregivers, play a pivotal role in achieving PPC outcomes based on their views, training and skills in PPC, especially in LMICs where the needs are high and parents' involvement is prominent.

2. Views on PPC

The literature regarding caregivers' perspectives on palliative care mostly described the knowledge, attitudes, beliefs (KAB) toward and practices in palliative care of professional providers, where a lack of knowledge was commonly cited (Abu-Saad Huijer et al., 2008; Balkin et al., 2016; Spruit et al., 2018; Thompson et al., 2009).

Consequently, the lack of knowledge and negative attitudes among healthcare providers constituted a barrier to the early integration of PPC in cancer treatment (Davies et al., 2008; De Clercq et al., 2019; Haines et al., 2018; Verberne et al., 2018). Interventions to educate healthcare providers' on PPC improved their knowledge, skills and attitudes (Ghoshal et al., 2018; Kato et al., 2011; Korzeniewska-Eksterowicz et al., 2013; Petersen et al., 2017). In parallel, these educational interventions were found to improve quality of care (Petursdottir et al., 2018), timely referral to PPC services, advanced care planning (Widger et al., 2018) and spiritual care including assessment and coordination of spiritual rituals such as praying (Petersen et al., 2017). While evidence exists regarding professional caregivers' perspectives and their influence on patient outcomes, few studies describe KAB toward palliative care of non-professional caregivers, such as the primary caregivers of children with cancer, namely the parents of children with cancer.

The majority of the research addressing parents' views towards PPC predominantly relies on healthcare professionals' reports (Davies, 2008; Dalberg et al., 2013; Kaye et al., 2015; Thompson et al., 2009). Health care professionals reported that parents carry misconceptions regarding PPC as conflicting with cure; therefore, parents associate PPC with "giving-up" (Dalberg et al., 2013; Kaye et al., 2015; Thompson et al., 2009). Consequently, healthcare professionals commonly cite parents' perspectives as barriers to integrating PPC in the treatment of children with cancer (Haines et al., 2018). However, few recent studies conducted in HICs challenged these findings by reporting positive attitudes toward PPC among parents of children with cancer (Dalberg et al., 2018; Lafond et al., 2015; Levine et al., 2017). The patients' and parents' perspectives on PPC are poorly described (Rosenberg et al., 2019). More research is needed to strengthen the evidence on KAB towards PPC among patients and primary caregivers, by directly soliciting information from them as a primary source.

C. Significance, Study Purpose and Aims

In addition to the paucity of literature in HICs, to our knowledge, no studies have addressed primary caregivers' KAB towards PPC for children with cancer in LMICs, such as Lebanon, where the need for PPC is rising. Filling this gap in the literature may inform effective strategies to support the integration of PPC in areas of highest need. Recently, 177 PPC experts across the United States identified prioirities to strategize advancement in the PPC field (Feudtner et al., 2021a). Exploring "what parents value regarding PPC" was ranked among the top five important actions to improve access to PPC (Feudtner et al., 2021, p.595). It is important to uncover the current primary caregivers' KAB towards PPC in order to judiciously tailor interventions that may improve the care in limited resource settings. In this research, the primary caregiver is defined as the child's parent who is the first line of support and who is deeply involved in the child's healthcare. The purpose of this study is to examine the knowledge, attitudes and beliefs towards PPC of primary caregivers of children with cancer in order to uncover potential areas for improvement. The specific aims of the study are to:

1- Describe the current knowledge, attitudes and beliefs toward PPC among primary caregivers of children with cancer.
2- Determine demographic and clinical factors associated with primary caregivers' knowledge, attitudes and beliefs to PPC services for children with cancer.
3- Identify the primary caregivers' tasks in PPC for their children with cancer.

4- Test the psychometric properties of instruments measuring KAB toward PPC.

D. Research Questions

The following research questions are addressed:

1- What is the level of knowledge about PPC among primary caregivers of children with cancer?

2- What are the attitudes of primary caregivers toward PPC for children with cancer?

3- What are the barriers and facilitators to PPC reported by primary caregivers?

4- What are the associations between demographic variables and child's clinical characteristics, and the primary caregiver's KAB towards PPC in children with cancer?

5- What are the associations between the primary caregivers' attitudes and beliefs, and their PPC intentions and behaviors?

CHAPTER II

LITERATURE REVIEW

An initial review of the literature presents the activities that parents perform for children with cancer, as such, delineating their role within PPC provision. For the purpose of this study, a systematic search of the literature was conducted to describe the existing knowledge on KAB toward PPC among healthcare professionals and non-healthcare professionals (or informal caregivers). The review helped identifying the literature gaps that this study intended to fill. In addition, the chapter briefly presents several studies addressing the perspectives of adult patients' caregivers on palliative care. A section is also added to describe research on the general public views regarding palliative care. Findings from adult caregivers and the general public may be extrapolated to primary caregivers' of pediatric oncology patients since they represent non-professional and informal caregivers' views on palliative care.

A. Primary Caregivers' Role in PPC for Children with Cancer

The literature describing the role of parents in PPC identifies them as care recipients, while at the same time recognizing them as unique caregiving agencies (Classen, 2012; van der Geest et al., 2014). Qualitative and quantitative reports have revealed a myriad of caregiving tasks performed by parents across the disease trajectory. The parental PPC tasks when caring for children with cancer vary in nature and intensity according to the child's condition (Dionne-Odom et al., 2019). The tasks encompass providing direct care and emotional support, managing symptoms, monitoring the patient’s status, and making treatment decisions (Dionne-Odom et al., 2019; Lazzarin et al., 2018; Levy et al., 2020; Verberne et al., 2017).

During the course of childhood cancer, parental caregiving entails an expanded parental role to cover medical, technical and emotional aspects related to the child’s condition (Koch & Jones, 2018). Verberne and colleagues (2017) explored parental caregiving tasks in PPC across the trajectory of various life-limiting illnesses, including cancer. The individual open interviews conducted with parents revealed that participants performed four clusters of tasks motivated by “being a good parent” (p. 347). The first cluster included providing basic and complex direct care that ranges from assisting with activities of daily living to manipulating sophisticated medical equipment. The second cluster pertains to organizing care and treatment in coordination with the healthcare team. A third cluster describes decision-making regarding minor and major issues related to their child’s health. The decisions range from simple judgments regarding day-to-day interventions such as infection precautions, to complex decisions related to treatment choice and goals of care towards the end-of-life. As for the last cluster, the authors reported the considerable parents’ efforts for organizing good family balance through planning and managing care activities, while striving to preserve the family’s routine (Verberne et al., 2017). The authors solicited primary caregivers’ tasks in most of PPC aspects except for the spiritual component. Such omission may be attributed to the scope of the study focusing on the overt behaviors readily performed by parents when caring for their child, and the stand of the cultural group studied on the religious component of PPC.

Additional tasks were noted in a recent qualitative study that used photovoice and social media approach to explore the experience of pediatric palliative caregiving among nine mothers of children with cancer enrolled in a PPC program (Levy et al., 2020). The authors reported the following activities across the emerging themes: dealing with the challenges of getting necessary equipment and medications (under the theme of challenges), sharing own experience with similar caregivers, and praying with the child (under the theme of coping). Although intermittently performed, spiritual and religious activities helped the caregiver and child detach from their struggle and find peace (Levy et al., 2020)

In complex cases, caregiving activities are intensified with more advanced tasks. A study conducted in northern Italy investigated home-based palliative care for young children, including the time spent by parents to meet their child's needs (Lazzarin et al., 2018). The researchers recruited 33 parents of children enrolled in PPC who needed medical support in respiration, feeding, pain and seizures management. Almost three quarters of the children needed tube feeding, making the feeding task the most time consuming (174 minutes/day). Nearly half (55%) had mechanical respirators and 72% needed continuous oxygen monitoring device. Caregivers reported spending an average of approximately one hour a day (63 minutes) managing pain and seizures crises as they occurred. The cumulative average time spent on daily healthcare activities was approximately nine hours a day. This time was significantly influenced by the number of medical devices needed (Lazzarin et al., 2018). Besides delivering these complex caregiving tasks, parents must spend a considerable amount of time learning the skills before actual implementation. As such, training about PPC activities performed by primary caregivers by itself is not to be underestimated.

While decision-making occurs across all the phases of the illness trajectory, parents consider it a major task in the terminal phases of the disease. Parents of terminal patients ranked informed decision-making among the highest attributes and highest priorities for being a “good parent” (Feudtner et al., 2015; Hinds et al., 2009). In a survey of 89 bereaved parents of children with cancer, participants reported on their involvement in the child’s care by responding to four items pertaining to decision-making at the end of life (van der Geest et al., 2014). These items were generated based on the literature, clinical experience and pilot testing. Participants rated their level of agreement with each item on a five-point Likert scale. The mean score for participants’ agreement with these items ranged from M=4.4 *(SD*=1.0*)* and M=4.8 *(SD*= 0.7*)* implying a high level of involvement in decision-making (van der Geest et al., 2014). This emphasizes decision-making as a considerable parental caregiving task in the end-stage of the disease.

Other tasks listed in caregiving for adult cancer patients may be applicable in the pediatric population, especially school age children and adolescents. These include participating in truth-telling, being a communication bridge between physicians and the patient, and reminding patients about precaution measures (Chen et al., 2007).

1. *Measures of PPC Tasks*

In an attempt to measure parental caregiving demands, Wells and colleagues (2002) developed the “Care of My Child with Cancer” (CMCC). This self-administered tool asks parents to rate the amount of time needed and level of difficulty to perform each of 28 tasks for their child in the previous one month. The items pertain to providing physical care; meeting the emotional needs of the child, self, and family members; maintaining daily activities; taking on additional financial responsibilities; and managing information and communication. Initial factor analysis conducted with

158 primary caregivers in nine US institutions revealed physical and emotional caregiving subscales (Wells et al., 2002). This measure demonstrated strong psychometric properties for internal consistency, test-retest reliability and construct validity (Wells et al., 2002; Klassen et al., 2010). However, the list of tasks overlooks some parental caregiving activities in children with cancer as it is restricted to physical and emotional aspects. In particular, the CMCC does not include tasks related to the spiritual/religious dimension of PPC, such as praying with the child, nor to the caregivers' mental process in care, namely decision-making. Two reasons might have led to these deficiencies. First, item generation relied on expert opinion and literature review rather than including parental input. Second, the exclusion of caregivers of terminally ill patients might have contributed to focusing on overt behaviors and omitting covert activities related to spirituality and decision-making that are more present in terminal phases. As such, using this tool within the PPC context would require additional items reflecting all aspects of parental caregiving, regardless of the disease phase.

The "Palliative Care Parental Self-Efficacy Measure" (PCPEM) is another instrument that includes caregiving PPC tasks performed by parents of children with life-threatening illnesses (Bingen et al., 2011). The tool contains 58 items covering six PPC domains: medical discussions and decision-making, symptom management and medication, daily routine or activities, feelings and concerns, spirituality, and end-of-life decisions. A multidisciplinary palliative care team generated the initial items that were subsequently validated with 25 parents including bereaved ones. Despite the comprehensive list of items, the developers placed a considerable focus on end-of-life care, whereby 17 items were directly related to death. Moreover, parents of children with cancer were underrepresented as the majority of the conditions included (76%) were neurologic diseases and congenital malformations (Bingen et al., 2011). Additional reliability and validity testing are needed for evidence of PCPEM's psychometric properties, especially in the pediatric oncology population.

The literature emphasizes the crucial role of primary caregivers of children with cancer in delivering PPC. Various parental PPC tasks were identified among caregivers of children with cancer. Caregiving tasks were found to vary in nature and intensity depending on child's disease stage. Primary caregivers apply these tasks based on their views, skills and training in PPC to ensure successful performance and ultimately contribute to enhancing PPC outcomes.

B. Knowledge, Attitudes and Beliefs toward PPC

A systematic search of the literature was carried out to identify studies addressing KAB toward PPC. Specifically, the objectives of the review were to:

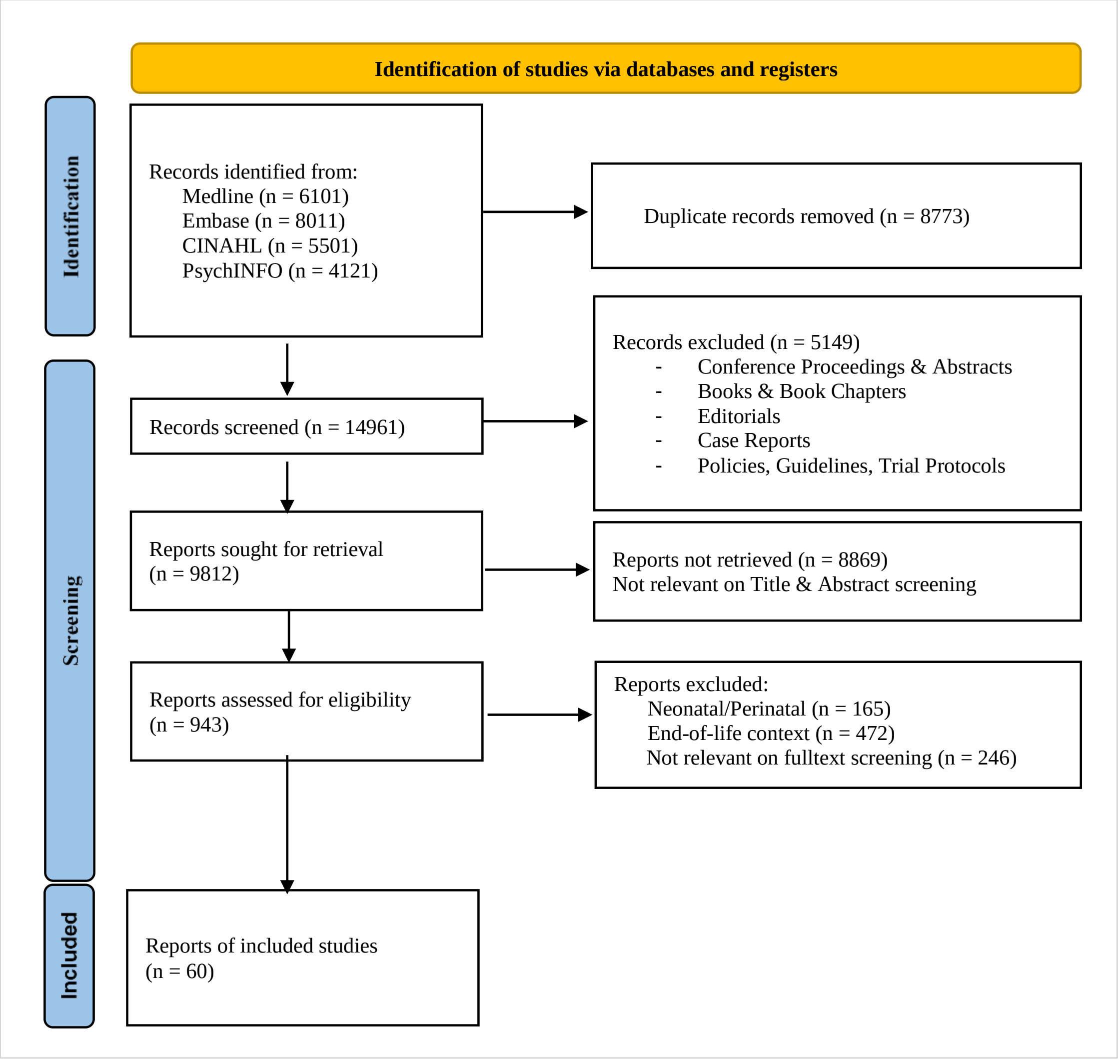
- Identify the current knowledge (awareness, perceived level of knowledge and existing information) regarding PPC among professionals and non-professionals
- Describe the current attitudes and beliefs on barriers and facilitators toward PPC
- Determine the potential factors that influence knowledge, attitudes and beliefs toward PPC.

Four databases were searched: Medline, EMBASE, PsychINFO, and Cumulative Index to Nursing and Allied Health Literature (CINAHL) Complete, hosted by EBSCO platform. The researcher combined Medical Subject Headings (MeSH) terms such as: "palliative care", "child", "awareness" "Attitude to Health", and key words such as: "comfort care", "minor", and "knowledge". The controlled vocabulary and keywords were combined using Boolean operators to identify references related to each concept separately, then to the concepts assembled together. The initial search was conducted on August 27, 2020 and a rerun was performed on September 30, 2021. Included articles encompass qualitative and quantitative studies including observational studies (cohort studies, case-control studies, controlled and uncontrolled pre-/post-studies); retrospective and cross-sectional studies. For a comprehensive search, study conditions incorporated the four disease categories of life-limiting and life-threatening conditions requiring PPC (Together for Short Lives, 2018). These categories include: life-threatening conditions where curative treatment exist but may fail (eg: cancer); conditions entailing intensive and at times prolonged treatment but where death is inevitable (eg:cystic fibrosis), progressive conditions where exclusively palliative care is offered (eg. Baten's disease) and non-progressive disease with severe and irreversible disabilities (e.g. cerebral palsy) (Together for Short Lives, 2018). Likewise, no limit was set on the date of publication.

The exclusion criteria were non-English references, animal studies, conference abstracts or proceedings, case studies, correspondence/letters, books and book sections or chapters. Studies specifically addressing perinatal/neonatal palliative care or palliative care in neonatal intensive care were excluded due specific considerations in this context (Boyden et al., 2018). Moreover, studies restricted to specific aspects to end-of-life period (such as advanced care planning, bereavement, end-of-life care) were excluded. The WHO definition of PPC (WHO, 1998) covers the entire disease trajectory, not only end-of-life. However, the two terms are used interchangeably. Excluding end-of-life studies is intended to uncover the researchers' and participants' broader understanding of PPC rather than narrowing it to end-of-life care.

Two independent reviewers (the researcher and a PhD candidate) screened the articles for title and abstract then for full text screening. After data extraction, the articles were narrowed down from 23734 to 60 articles. Figure 1 illustrates the PRISMA chart of the review process.

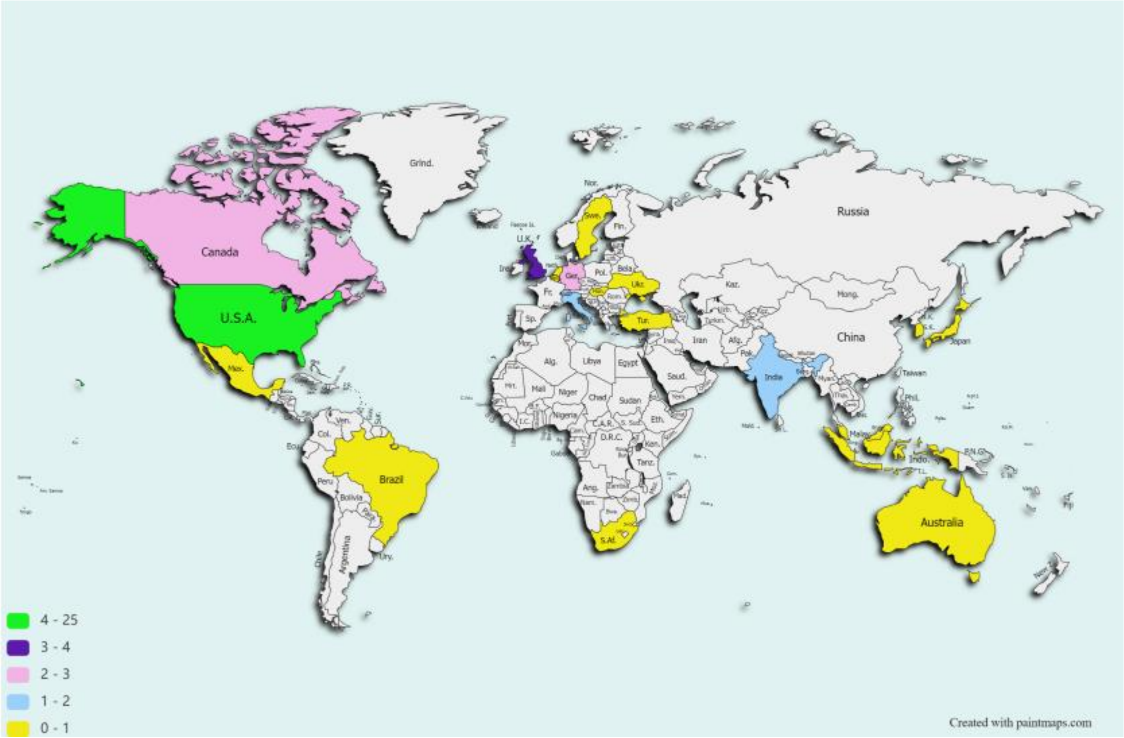
Figure 1 PRISMA Flow Diagram



The majority of the articles (n=49, 81%) were derived from HIC with almost half of them from USA. The references from LMICs were scattered across continents.

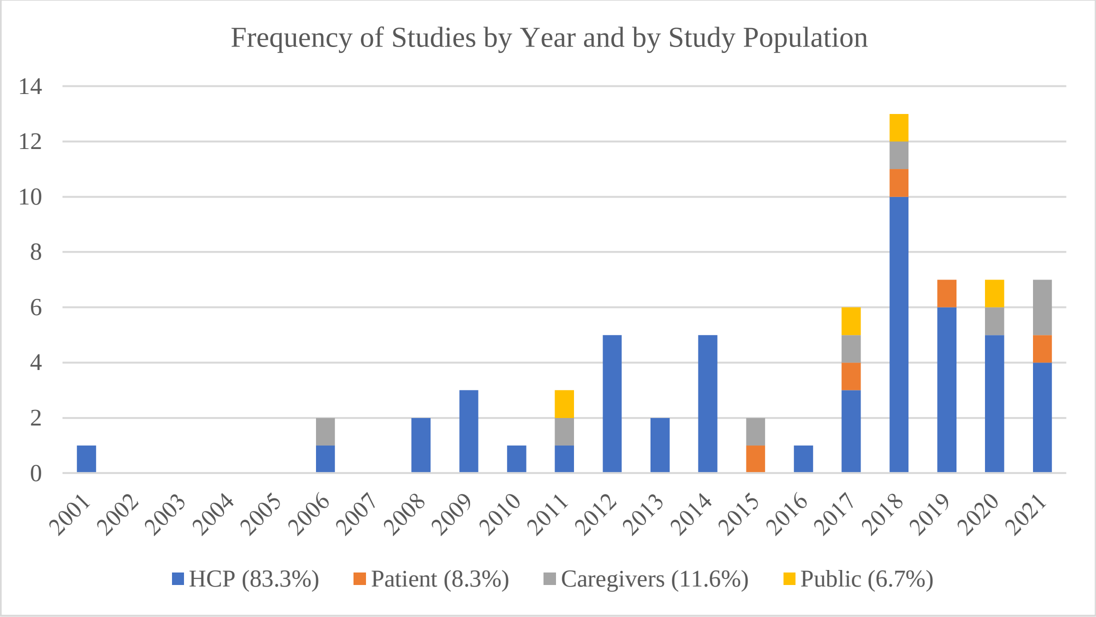
One study was conducted globally (Balkin et al., 2016) and another one regionally (Ehrlich et al., 2020). Figure 2 presents the frequency of studies by country.

Figure 2 Frequency of Studies by Country



Over the years, the perspectives of healthcare professionals (HCP) were much more extensively explored compared to non-healthcare professionals. Among non-professionals, several studies combined parents’ and patients’ views (Dellon et al., 2018; Lafond et al., 2015; Levine et al., 2017; Mitchell et al., 2021). The last four years witnessed a surge in the frequency of studies addressing KAB toward PPC. Figure 3 illustrates the frequency over the year and by study population.

Figure 3 Frequency of Studies by Year and by Study Population



The literature of KAB toward PPC among pediatric healthcare providers represents various hospital and home settings (Abu-Saad Huijer et al., 2008, Balkin et al. 2017; De Clercq et al., 2019; Jünger et al., 2010; Kremeike et al., 2012; Spruit et al, 2018; Saad, et al., 2020). Twenty two studies (36.6%) were conducted in the pediatric oncology context. A handful of articles addressed PPC in the general population (Benini et al., 2011; Johnston et al., 2020; Visagie & Lace, 2017; Westerlund et al., 2018). Appendix A summarizes the studies retrieved on KAB toward PPC.

1. Knowledge, Attitudes and Beliefs toward PPC among Healthcare Providers

Studies from developed countries revealed that despite the adequate knowledge of PPC principles among pediatric providers, there is a confusion of PPC with hospice care or end-of-life care (Spencer & Battye, 2001; Nyirő et al., 2018; Thompson et al., 2009; Thumfart et al., 2019; Twamley et al., 2014). Moreover, the level of PPC knowledge and attitudes are inconsistent among different PPC aspects. Feudtner and colleagues (2007) found that pediatric nurses reported being most competent in pain management and least competent in talking to patients and families about death. In addition, they reported a moderate agreement with being comfortable working with terminally ill patients. The number of hours of palliative care education correlated with higher total palliative care competency scores and higher comfort levels with care provision in healthcare pprofessionals (Feudtner et al., 2007). These results suggest a potential benefit of PPC education in improving nurses' knowledge and attitudes toward PPC.

Adequate PPC knowledge may be present even when PPC services are less developed; however, PPC training remains a crucial need to promote a positive attitude toward and practice of PPC. For example, a study conducted in Lebanon examined the knowledge, attitudes and practices in PPC among 96 pediatric nurses and 27 pediatricians across 15 hospitals (Abu-Saad Huijer, et al., 2008). While only 20.2% of the pediatric nurses and 3.7% of the pediatricians reported having received continuing education in palliative care, both groups demonstrated high knowledge scores. Yet, both groups had only average scores on attitude and practices. Pediatric nurses were significantly more likely than pediatricians to consider the parents' involvement in treatment choices (p=0.003). Only 6.3% of pediatric nurses and 23.5% of pediatricians reported having disclosed the diagnosis to pediatric patients and 30% of each group relied on the family wishes to do so. As noted by the authors, the findings on attitudes and practices among pediatric professionals call for more training to ensure better PPC practice (Abu-Saad Huijer et al., 2008).

When comparing pediatric specialties, discrepancies in the primary reason for incorporating palliative care are revealed. In a large study conducted in 18 institutions across the United States, physicians in pediatric critical care were more likely to integrate palliative care for psychosocial support, while pediatric oncologists integrated it for symptom management (Atwood et al., 2014). Regardless of specialty, female providers and those who received palliative care education were more likely to incorporate palliative care, did so earlier and for reasons other than end-of-life planning compared to their counterparts (Atwood et al., 2014). These results suggest that providers' attitudes after receiving PPC training are more consistent with the definition and recommendations of PPC that are broader than end-of-life care. Another multicenter survey described attitudes toward PPC consultations among 183 pediatric cardiologists (Balkin et al., 2017). The majority of the sample (85%) agreed that PPC involvement was helpful and 61% reported that it occurred "too late". However, the most commonly cited barrier to PPC consultations was the providers' concern of the parents' view of PPC as giving-up on their child (Balkin et al., 2017). These dichotomous views not only call for enhancing providers' knowledge regarding PPC, but also for investigating whether parents would report similar concerns.

Specifically, among pediatric oncology providers, recent publications also emphasize the need to improve KAB towards PPC (De Clercq et al., 2019; Spruit et al., 2018; Saad et al., 2020). A study conducted among 156 nurses and physicians in eight teaching hospitals highlighted the need for PPC training for both groups, with nurses having received fewer formal educational offerings than physicians (Spruit et al., 2018). Despite the lack of training, the majority of participants (above 90%) expressed positive attitudes toward PPC as they perceived its contribution to better symptom management and family support. The authors alluded to the frequent interactions with the PPC team and proposed workplace training offered by this team as a substitute to formal training

(Spruit et al., 2018). As such, experience and interactions with palliative care services may replace formal PPC training, and potentially contribute to positive attitudes towards PPC.

In Europe, investigators of a qualitative study conducted in five pediatric oncology centers in Switzerland explored the conceptual understanding and attitudes toward PPC among 29 pediatric oncology providers using focus groups (De Clercq et al., 2019). On the philosophical level, the majority of participants associated PPC with non-curative treatment and they clearly distinguished it from end-of-life care. However, many participants cited challenges on the operational level such as the timing of integration of PPC. These challenges were primarily attributed to the strong stigma surrounding the term among families, the negative attitudes of providers towards PPC, and the cultural and religious backgrounds of patients and families (De Clercq et al., 2019).

Many studies highlighted that PPC knowledge and attitude toward PPC were positively associated (Atwood et al. 2014; Ghoshal et al., 2018; Haut et al., 2012; Wu et al., 2014; Weaver et al., 2019b; Zuniga-Villanueva et al., 2019). This positive correlation suggests that increasing knowledge in PPC would contribute to a more favorable attitude to endorse such care.

In Lebanon, a recent qualitative study explored pediatric oncology providers' perceptions of the early integration of PPC in children with cancer (Saad et al., 2020). The four focus groups conducted with ten nurses and seven physicians revealed a strong link of PPC with pain relief and psychological support that is mainly integrated at the end-of-life phase, advanced stage of the disease, or in case of treatment failure. The authors attributed the stigma surrounding palliative care to cultural and religious considerations related to cancer itself. In addition, the study findings reiterated the physicians' concern about the parents' acceptance of PPC and difficulties in communicating about the services with patients and their families. The authors emphasized the need for education and formal support for pediatric oncology providers as a means to correct PPC misconception in order to facilitate its early implementation (Saad et al., 2020).

a. Studies merging adult and pediatric providers. Numerous studies explored providers' perspectives toward palliative care as a phenomenon overarching adult and pediatric contexts. Across studies, researchers constantly recommended palliative care education as a basis to improve the services regardless of the extent of palliative care development. A recent systematic review evaluated 39 publications on the experiences of "junior doctors" in five Western countries with developed palliative care services: the United Kingdom, Ireland, Canada, Australia and New Zealand (Bharmal et al. 2019). The thematic analysis of the studies revealed variation in attitudes toward palliative care from valuing such care to "professional disengagement". As for knowledge, the authors pointed to the lack of preparedness for caring for terminal patients and a strong need for training in symptom control, communication and ethical-legal issues, among other topics (Bharmal et al. 2019). Another systematic review of the factors influencing nurses' and nursing students' attitudes toward hospice and palliative care revealed a positive attitude in the majority of selected studies (Jeong, et al., 2020). Yet, the low level of knowledge reflected the need for palliative care education and practical training in nursing curricula. Experience in caring for the dying, career or education level, knowledge and education about hospice and palliative care, religious beliefs, anxiety toward death, and age influenced the nurses' attitudes (Jeong et al., 2020).

Reports from Asian, African and Middle Eastern settings reiterated the need for improving healthcare professional KAB about palliative care, notably in Ethiopia (Kassa et al., 2014), Palestine (Ayed et al., 2015), Qatar (Al-Kindi et al., 2014), Saudi Arabia (Abudari et al., 2014), Iran (Iranmanesh et al., 2014) and India (Gopal & Archana, 2016). In Lebanon, a national cross-sectional descriptive survey compared KAB and palliative care practices of 645 nurses and 223 physicians dealing with terminally ill patients from six different specialties (Abu-Saad Huijer et al., 2009). The section on practices in palliative care covered the domains of communication, decision-making, interdisciplinary collaboration, and managing patients and families' outbursts and concerns. A separate summative score was generated for each survey section. The majority of participants across specialties scored high on knowledge. However, attitude and practice scores were statistically different among specialties. More nurses than physicians in medical and surgical specialties had negative perceptions of patients' and families' outbursts, concerns, and questions. Knowledge scores were associated with palliative care practice scores and the type of profession. Practice scores were positively associated with continuing education in palliative care, exposure to terminally ill patients, and the knowledge and attitude scores. The authors concluded that better knowledge and positive attitudes in palliative care are associated with better palliative care practice (Abu-Saad Huijer et al., 2009). Therefore, the level of education and previous experience with palliative care seem to influence healthcare professional's knowledge and attitudes, which in turn lead to better practice.

2. KAB toward PPC among Primary Caregivers of Pediatric Patients

The perspectives of pediatric patients and their primary caregivers regarding PPC is still an underexplored area where scant research endeavors have been undertaken (Boldt et al., 2006; Lafond et al., 2015; Levine et al, 2017; Dellon et al., 2018). Early researchers have documented a negative connotation of palliative care among pediatric providers as well as parents (Boldt et al., 2006). In a multicenter study, the researchers randomized each of the parents and pediatric staff samples into two groups: one group identified as "palliative care" group and another as "supportive care" group. The authors provided each group with a program description to read, then compared their perceptions of the term palliative care and likelihood to use the program before and after reading the definition and between the two groups in each study sample. At baseline, parents in the supportive care group scored significantly higher on the likelihood to use the program than those in the palliative care group. After reading the description, the group difference disappeared ($p = 0.582$) and more positive feelings toward the PPC program were reported among parents. Reading the PPC program description also increased the pediatric staff's likelihood to use the palliative care program. The authors concluded that educating parents and providers about palliative care may decrease the negative perceptions of the services (Boldt et al., 2006).

Negative parental viewpoints have been cited over time as a barrier to introducing PPC services (Haines et al., 2018). However, studies reporting such a barrier often focused on healthcare providers' perspectives rather than the patient and primary caregivers' own perspectives (Balkin et al. 2017; Davies et al., 2003; Knapp et al., 2012; Spruit et al., 2018). In 2013, Dalberg and colleagues conducted a single-institution study with four focus groups of pediatric oncology providers to explore barriers and facilitators to early integration of PPC for children with cancer. Nearly all the participants (15 physicians, 16 nurses and two social workers) were concerned about an additional parental burden with early PPC (Dalberg et al., 2013). Conversely, a recent quantitative national survey of professional providers revealed that more than half of participants (*N*=1005) disagreed with the concern of additional parental burden with early PPC. The authors argued that this changing perspective reflects the emerging literature in support of PPC and they advocated for additional research of patients' and parents' perspectives (Dalberg et al., 2018).

Parallel to the shift in provider's view, emerging studies conducted among patients and parents also challenge the previously perceived opposition and suggest endorsement of PPC by parents. Lafond and colleagues (2015) examined the willingness to receive PPC among 12 patients and families in the context of hematopoietic stem cell transplant. All participants agreed to enroll in the PPC program, which supported the notion that families are accepting of early PPC (Lafond et al., 2015). These findings are encouraging as they suggest that parents may not be as resistant to PPC as perceived by professionals, and that this barrier to PPC is modifiable. However, the small sample size and patient population warrant caution in the interpretation of results and limits generalizability of findings.

In an attempt to explore the unmet palliative care needs and verify whether pediatric oncology patients and their parents express negative attitudes toward early PPC integration, Levine and colleagues (2017) surveyed 129 patient-parent dyads in three major pediatric oncology centers in the United States. More than 70% of patients experienced nausea, loss of appetite and pain during the first month of diagnosis. A considerable percentage (reaching 52%) reported high levels of suffering from these symptoms during the first month of therapy. As for their attitudes, the majority of participants in both groups had never heard of PPC and none of those familiar with it reported negative attitudes toward early integration. When given a brief definition, less than 2% and 7% of children and parents, respectively, opposed to PPC early integration at diagnosis. Despite the low level of concordance in the responses, the authors concluded that both groups need and endorse early PPC. In contrast to being considered barriers to PPC, children with cancer and their parents “are ready for an integrated model of care” (Levine et al., 2017, p.1219). Cultural bias, lack of in-depth and qualitative reporting of existing knowledge among participants, and the use of non-validated instruments are considerable limitations of the study.

The endorsement of PPC was also reported by parents within the context of cystic fibrosis. A qualitative study explored the knowledge and perceptions of PPC among pediatric patients with cystic fibrosis, parents and professional providers in order to integrate PPC education in routine patient care (Dellon et al., 2018). Individual semi-structured interviews with ten adolescent patients and seven parents were held. Half of the patients and one-third of parents had knowledge deficit about PPC and requested clarification. Patients and parents who were familiar with the term associated PPC with hospice and end of life care. However, after hearing the PPC description provided by the researcher, participants acknowledged that many PPC interventions are provided as routine care and that PPC is helpful in the context of cystic fibrosis. Participants identified barriers to PPC such as its association with end of life (noted by all participants) and patient/family denial and reluctance to discuss palliative care (noted by half of the participants). All respondents agreed on the need for PPC education (Dellon et al., 2018).

Despite these encouraging parents' perspectives, authors are still reporting an inaccurate understanding of PPC within life-threatening and life-limiting conditions. Very recently, Mitchell and colleagues (2021) used a longitudinal qualitative design to investigate the experience with palliative care, among children with life- limiting and life-threatening conditions and their families. After conducting 31 in-depth interviews with parents and children, the authors reported that participants conceptualized PPC as a separate period of child's disease, rather than a comprehensive approach to care (Mitchell et al., 2021). Similar findings were echoed in a more recent qualitative study in India. Parents of children with Duchenne Dystrophy expressed ambiguity about the term "palliative care" and association with "death" (Sadasivan et al., 2021).

In spite of the paucity of literature, the existing studies highlight the possibility of attenuating parents' stigma about PPC through enhancing their knowledge. The recent evidence on PPC misconceptions incite for timely actions.

a. <u>Primary caregivers' beliefs about barriers and facilitators to PPC.</u> Studies addressing parents' beliefs on PPC barriers and facilitators primarily focus on the end-of-life phase and on specific aspects of care, such as decision-making, communication, symptom management and advanced care planning (Davies et al., 2008; Durall et al., 2012; Greenfield et al., 2020; Kars et al., 2010; Mack et al., 2006; Wolfe et al., 2000). Because of the focus on end-of-life, these studies shed light on parents' perspectives of facilitators and barriers to PPC from its narrower angle of end-of-life.

   Recently, Walter and colleagues (2019) developed a conceptual framework for barriers and facilitators to "regoaling", particularly regarding PPC integration in the management of children with serious illness (p.1). In fact, the "regoaling" process is implicated in PPC integration since the latter requires redefining the goals from a solely curative focus to an enhanced attention to quality of life. As such, facilitators and barriers to "regoaling" simulate those of PPC integration. Through their narrative review, Walter and colleagues (2019) identified barriers and facilitators for regoaling. For parents, facilitators to regoaling included: certainty about prognosis, awareness of the child's suffering, support and good communication with the clinical team, knowledge of palliative care or hospice, establishing new attainable hopes, coping skills for negative emotions and congruence with personal "good parent" beliefs (Walter et al., 2019). Barriers to regoaling consisted of: lack of understanding of the medical situation; lack of knowledge about palliative care or and hospice; sense of failure as a parent; uncertainty about the prognosis; unrealistic belief in the probability of cure; overwhelming negative emotions; the desire to shield others from bad news; and lack of trust, support, and communication with the clinical team (Walter et al., 2019). Although the authors suggested a comprehensive list of facilitators and barriers, they overlooked cultural and the spiritual factors.

At the cultural level, researchers identified cultural barriers to PPC integration (Haines et al., 2018; Wiener et al., 2013). Some cultural groups, such as Native Americans and Asians, believe that speaking about the possibility of death can induce it (Wiener et al., 2013). In Lebanon, evoking death remains a taboo (Mouhawej et al., 2017). Within these cultural characteristics, parents who equate PPC with end-of-life care might link PPC integration to the child's death. Additionally, in some cultures, treatment decisions are not solely taken by the concerned patient or family. For example, Native American families engage members from the larger family in making treatment decisions, such that decisions are taken collectively rather than by the caregiver alone (Weiner et al., 2013). Such cultural contexts particularly challenge PPC integration.

On the spiritual and religious level, studies suggest that religious and spiritual beliefs also influence PPC integration. Hexem and colleagues (2011) used a grounded theory approach to investigate how 73 parents of children receiving PPC use religion, spirituality and life philosophy in difficult times. Participants reported that their engagement in religious and spiritual practices helped them accept and understand the child’s condition, make treatment decisions, gain control and feel peace and comfort (Hexem et al., 2011). More recently, Nicholas and colleagues (2017) reported that spirituality enabled parents to accept their child's advanced cancer and experience emotional relief. These findings suggest that the parents’ spiritual and religious engagement may facilitate PPC, which reinforces the importance of the spiritual dimension.

Two very recent qualitative studies reported on facilitators and barriers to PPC from parents’ of children with life-limiting or life-threatening conditions. Facilitators included: availability of specialist services, trust with healthcare professionals (Mitchell et al., 2021). Barriers encompassed difficulty accepting the child's prognosis, as well as lack of emotional acceptance of the child’s condition, lack of open communication between the parents and the child (Sadasivan et al., 2021).

The existing evidence on parents’ beliefs toward PPC integration suggest various facilitating and challenging factors at the individual level. The barriers and facilitators to PPC described by parents encompass their mental, emotional, cultural and spiritual dimensions.

C. KAB toward Palliative Care among Primary Caregivers of Adult Patients

Other studies addressed the perspectives of adult patients' caregivers on palliative care (An et al., 2014; Dionne-Odom et al., 2019; Yoo et al., 2018; Shah, et al., 2020; Zimmermann et al., 2016). Findings from these studies can be extrapolated to primary caregivers' of pediatric oncology patients since they represent non-professional and caregivers' views on palliative care.

Several recent studies conducted among caregivers of adult patients examined their KAB toward palliative care and the influencing factors. Findings from these studies can be extrapolated to pediatric contexts as participants share similar caregiving roles. In fact, a recent national study conducted in USA compared knowledge in palliative care between caregivers of children with serious chronic conditions (N=131) and caregivers of adults (N=109) (Johnston et al., 2020). The proportion of participants who had never heard about palliative care was similar in both groups (59.4% vs 49.1%, p= 0.13). Even among those who are aware of palliative care (N=48) a considerable proportion lacked accurate understanding: 80.3% equated palliative care to hospice care and 81.3% thought that accepting palliative care requires stopping other treatments. Younger age (less than 40 years) and low level of education contributed to lack of awareness (Johnston et al., 2020). Previous reports described similar misconceptions and factors associated with lack of knowledge among caregivers of adult patients with various conditions including cancer (An, et al., 2014; Dionne-Odom et al., 2019; Shah, et al., 2020; Yoo et al., 2018). Quantitative and qualitative findings revealed that even when caregivers are aware of such care, their knowledge is often inaccurate as they associated palliative care to giving-up and death, and confused it with end-of-life care (Dionne-Odom et al., 2019, Zimmermann et al., 2016). Zimmermann and colleagues (2016) reported that such stigma originated from healthcare providers and persisted among primary caregivers despite their positive experience with an early palliative care intervention. Caregivers noted the lack of sufficient information and misconceptions about palliative care among the reasons for opposing the services (An et al., 2014; Yoo et al., 2018). The common factors influencing caregivers' KAB toward palliative care were age, gender, educational level, employment status, and caregiving hours per week (Dionne-Odom et al., 2019; Shah et al., 2020; Yoo et al., 2018). Some authors proposed examining the effect of other variables such as the patient's medical condition including illness severity (Dionne-Odom, et al., 2019) and type of treatment (Yoo et al., 2018).

The limited literature in pediatric contexts call for extrapolation from the adult literature to ensure a comprehensive examination of KAB and their associated factors. The literature suggests similarities between caregivers of adults and children in terms of knowledge about palliative care. Additional studies in the pediatric context are needed to strengthen the evidence on these similarities and inform whether attitudes and beliefs also converge.

D. KAB toward Palliative Care in the General Public

Several studies addressing the perspective of the general public regarding palliative care examined the phenomenon as an overarching concept for both adult and pediatric populations (Alkhudairi, 2019; Collins et al., 2020; Patel & Lyons, 2019).

These studies shed light on the understanding of palliative care among non-healthcare professionals. Moreover, it is possible that among study participants were primary caregivers of children in need of palliative care. Therefore, findings from these studies may be extrapolated to primary caregivers of pediatric patients. Many researchers investigated public awareness regarding palliative care and highlighted caregivers' representation in their samples, however, without specifying patients' age (Collins et al., 2020; Flieger et al., 2020). In the national study conducted in USA, Johnston & colleagues (2020) compared knowledge in palliative care between caregivers of children with serious chronic conditions (N=131) and a sample of general population (N=106). Results revealed similar proportions of participants who reported lack of palliative care knowledge (61.5% vs 60.0%, p= .76) (Johnston et al., 2020). The study also reiterated misconceptions about palliative care found reports from the general population.

In countries with developed palliative care services, general public surveys revealed familiarity with the term "palliative care"; however, this awareness did not preclude inaccurate information (Benini et al., 2011; Claxton-Oldfield et al., 2004; Taber et al., 2019; Westerlund et al. 2018). A recent scoping review examined thirteen articles on knowledge, awareness and perceptions of the general public from various countries including Canada, the United States, New Zealand, Ireland, Scotland, the United Kingdom, Korea, Sweden, and Italy (Patel & Lyons, 2019). The authors reported a consistent poor awareness and knowledge about palliative care over the years. Across the articles, the proportion of participants having no knowledge about palliative care ranged from 32% to 71% of the samples. The studies also highlighted common participants' misperceptions that associated palliative care with end-of-life stages and with cancer. Moreover, the authors summarized several factors associated with increased knowledge, which were gender, age, prior experience with palliative care and higher level of education (Patel & Lyons, 2019). This review focused on knowledge and excluded several reports addressing the general public's attitudes toward palliative care. A careful interpretation of the review findings is warranted since the studies were conducted in numerous countries using different designs and various conceptual definitions, measurement tools and data collection methods.

In Australia, Collins and colleagues (2020) recently described the understanding of and attitudes toward palliative care in a community sample and explored participants' characteristics that were associated with favorable attitudes. The sample consisted of 421 participants, mostly females and middle-aged. Ninety percent reported having heard of palliative care. Yet, only 12% had accurate knowledge about such care as evidenced by the complete correct answers on a previously validated and psychometrically tested scale. Overall, study participants endorsed palliative care. Older age, being in a caregiving role, knowing someone who had received palliative care and more accurate knowledge predicted more favorable attitudes (Collins et al., 2020). The major limitations of the study were selection bias due to self-selection and lack of generalizability, as the sample was restricted to internet users.

In less developed settings, the above findings are echoed with even lower percentages of both familiarity with and accurate knowledge about palliative care (Alkhudairi, 2019; Gopal & Archana, 2016; Joseph et al., 2009). Different contributing factors were also revealed. In India, urban habitants had higher level of knowledge than those living in rural areas (Joseph et al., 2009). In Saudi Arabia, employment status correlated with better palliative care knowledge and more awareness (Alkhudairi, 2019).

Although to a limited extent, findings from general public studies could inform about primary caregivers KAB toward palliative care for children. Therefore, considering these studies in pediatric caregivers' context could enhance a comprehensive examination KAB toward PPC.

E. Instruments Measuring KAB in Palliative Care

Several instruments have been developed and validated to measure knowledge and attitudes in palliative care among adult healthcare providers, the general public, adult patients and caregivers. Despite evidence on their sound psychometric properties, these instruments were not adopted as standardized measures. Moreover in pediatric contexts, existing tools validated in adult palliative care were used, which may overlook specific aspects of PPC.

The Palliative Care Quiz for Nursing (PCQN) was developed for measuring nurses' knowledge of palliative care (Ross et al., 1996). Knapp and colleagues (2009) used the PCQN among 276 pediatric nurses' in Florida. More than half of the sample could correctly answer 12 of the 20 PCQN questions. The mean score of 10.9± 3.77 (range 0-20) on PCQN indicated an average level of knowledge, suggesting the need for improvement. The authors pointed to the inability of the instrument to discriminate participants who completed PPC training, hence they raised the need to develop a more specific instrument to assess pediatric nurses' knowledge in PPC (Knapp et al., 2009).

Most of the studies addressing patients' and caregivers' perspectives on palliative care used tools that were developed by the authors for the study purpose. To our best knowledge, only two validated instruments were specifically designed and psychometrically tested to measure adult patient perceptions (Milne et al., 2013) and patient attitudes toward palliative care (Perry et al., 2020). The Perceptions of Palliative Care Instrument (PPCI) is a 37-item instrument divided into four sections asking patients to rate their feelings upon hearing the term, thoughts upon suggesting palliative care referral, readiness to hear about the concept, areas of palliative care needs and perceptions of burden (Milne et al., 2013). The Palliative Care Attitude Scale (PCAS-9) consists of nine items asking patients to rate their attitude toward palliative care consultation at the emotional, cognitive and behavioral scales (Perry et al., 2020). Both instruments address the palliative care concept from the narrow angle of referral or consultations, without tackling the broader concept and principles. Therefore, they are more appropriate for use in settings where services and specialized teams are well-established. Moreover, none of these tools have been adapted to pediatric contexts.

Authors of studies on general public perspectives also utilized a variety of instruments, each developed to fit the study purpose. These self-developed instruments have, at best, very limited evidence of validity testing. Therefore, comparing the findings is particularly challenging. In an attempt to standardize the measure for palliative care knowledge among non-healthcare professionals, Kozlov and colleagues (2017) developed and validated the Palliative Care Knowledge Scale (PaCKS) composed of 13 items with dichotomous answers. The instrument underwent psychometric testing with adequate results in a sample of 614 community adults and 30 clinicians and researchers (Kozlov et al., 2017). In order to account for the guessing effect, the developers recently added “I don’t know” option to all items of the tool, which yielded better internal consistency (Kozlov et al., 2018). However, these results are limited by sampling bias (Kozlov et al., 2018). As participants were recruited “Amazon’s Mechanical Turk (mTURK) - an online marketplace for survey administration – the sample included younger, more educated and more white subjects than the intended target population. This has limited sample representativeness. It is worth mentioning that the items of PaCKS pertain to palliative care as an overarching concept rather than distinguishing adult from pediatric palliative care. Therefore, additional items addressing specific aspects of PPC will be needed to adapt the instrument to the pediatric context.

F. Instruments Measuring Barriers and Facilitators to PPC

As for measuring beliefs regarding PPC integration, Dalberg and colleagues (2018) developed a 36-item tool soliciting pediatric oncology providers’ perceptions on barriers and facilitators to PPC integration. The items consisted of Likert questions or multiple-choice questions developed based on previous qualitative data. After conducting pilot testing and cognitive interviewing, the developers used the tool in a national study with more than 1000 pediatric oncology providers to elicit their perspectives on barriers and facilitators to early PPC integration (Dalberg, et al., 2018). This tool is specifically designed for healthcare providers and is intended to capture their perspectives, which may differ from the parents’ perspectives. In fact, parents may lack medical background and professional information about the healthcare system. Therefore, a tool soliciting primary caregivers’ beliefs on barriers and facilitators to PPC at the individual level would better reflect their perspectives.

Current available information on primary caregivers’ barriers and facilitators to PPC is scattered in the literature particularly in the pediatric oncology context (Haines et al., 2018). To our best knowledge, a psychometrically validated tool measuring these beliefs remains a need. Yet, the existing literature provides an initial step for developing a psychometrically sound measure addressing primary caregivers' beliefs on barriers and facilitators to PPC.

G. Summary of the Literature

In summary, parental caregiving within PPC of children with cancer encompasses a range of activities including physical, emotional and spiritual care, in addition to decision-making tasks. A comprehensive and psychometrically sound measure of these tasks is needed to capture the involvement of primary caregivers, since diagnosis and throughout the disease journey.

The literature highlights lack of knowledge and negative attitudes toward palliative care that is common among healthcare providers, the general public, patients and their primary caregivers. Across studies, it is obvious that improving knowledge and attitude is needed despite the scattered findings of positive attitudes. Studies suggest that several factors are associated with knowledge and attitudes, including participants' demographic characteristics and patients' clinical information. These factors are worth considering in studies investigating knowledge and attitudes, regardless of whose perspective was. Evidence on primary caregivers' beliefs toward PPC integration are dispersed in the literature. A comprehensive instrument compiling primary caregivers' perspectives on facilitators and barriers to PPC remains a need.

At the conceptual level, many authors focused on the end-of-life dimension of PPC. It is probable that such focus in studying KAB reinforced the link of palliative care with death. Thus, conducting palliative care research without emphasis on terminal phases would redirect the participants' understandings of the correct and broad definition that encompasses the entire disease trajectory. At the operational level, the lack of tools measuring KAB in PPC requires careful adaptation of existing measures.

As for the context, most of the studies focus on health professionals' perspectives. A detailed exploration of primary caregivers' views of PPC has been lacking. In pediatric oncology, there is a serious need to examine caregivers' perspectives as they are partners in decision-making and care. Very little research in this regard has been conducted. Few recent studies from the United States suggest that primary caregivers favor PPC when properly educated about it. Such studies lack in less developed settings, which hinders the possibility of comparing findings or distinguishing potential cultural variations. Considering the limited availability of PPC in LMICs, such as Lebanon, and the crucial involvement of parents in the care, it is pertinent to investigate primary caregivers' perspectives in these settings. To the authors' knowledge, no studies addressing primary caregivers' KAB toward PPC have been conducted in LMICs. Determining primary caregivers' views will form the basis for designing strategies not only to improve their KAB but also to enhance the entire PPC delivery. Table 1 summarizes the literature gaps and how the research addressed these gaps.

Table 1 Summary of Identified Gaps and Addressing the Gaps in the Study

Literature Gaps	Addressing Literature Gaps
1- No studies have examined primary caregivers' KAB towards PPC for children with cancer in LMICs. Reports from healthcare professionals, caregivers of adult patients and general public suggest a lack of knowledge and misconceptions.	Using descriptive analysis, I described the current knowledge, attitudes and beliefs of primary caregivers towards PPC in the Lebanese context. (Aim 1).
2- Few emerging studies conducted among primary caregivers of children with cancer challenge the existing perceived barrier to PPC that they oppose the care.	I described the current attitudes of primary caregivers to strengthen evidence on their endorsement or opposition to the care (Aim 1).
3- Evidence on factors associated with KAB toward palliative care largely rely on studies from healthcare professionals, caregivers of adults and general public.	Using bivariate and multiple regressions analyses, I identified the demographic and clinical factors associated with KAB towards PPC among primary caregivers of children with cancer (Aim 2)
4- Scarce literature on KAB toward PPC solicited information directly from primary caregivers. Existing data rely on healthcare professionals' perspectives.	I recruited primary caregivers of children with cancer.
5- No studies have described the tasks performed by primary caregivers of children with cancer within the broad context of PPC and covering all PPC domains	I identified the PPC tasks performed by primary caregivers regardless of the disease stage (Aim 3)
6- The instruments measuring primary caregivers' KAB towards PPC lack evidence on psychometric properties in pediatric context.	I adapted items from existing instruments and developed new items based on literature to measure KAB and PPC tasks. I tested the measures through expert reviews with calculation of CVI and pilot testing. When applicable, I calculated internal consistency coefficient, item correlations, and conducted item ranges and exploratory factor analysis (Aim 4)

CHAPTER III

CONCEPTUAL FRAMEWORK

The conceptual framework of this study was guided by the study purpose and was based on two theoretical foundations, in addition to the existing literature. The proposed framework combines the Knowledge-Attitude-Behavior model by Allport (1935) and the Theory of Planned Behavior (TPB) by Ajzen (1991) to conceptually define knowledge, attitudes, beliefs, and behaviors and to delineate their relationships.

A. Knowledge-Attitude-Behavior Model

The classic Knowledge-Attitude-Behavior model posits that the three elements are connected in a linear unidirectional manner (Allport, 1935). According to the model, the information acquired about a behavior (knowledge) leads to the formation of a predisposition to respond (attitude), which, in turn, leads to behavior. With this model, it can be hypothesized that the knowledge of primary caregivers about PPC is associated with their attitudes toward it, and that their attitudes affect their actions related to PPC. Literature findings reveal a positive association between knowledge to palliative care and attitudes towards it (Atwood et al., 2014; Boldt et al., 2006; Collins et al., 2020; Jeong et al., 2020; Pasaol, 2019). The literature also suggests a positive association between attitudes and PPC behaviors (Abu-Saad Huijer et al., 2009; Spruit et al, 2018)

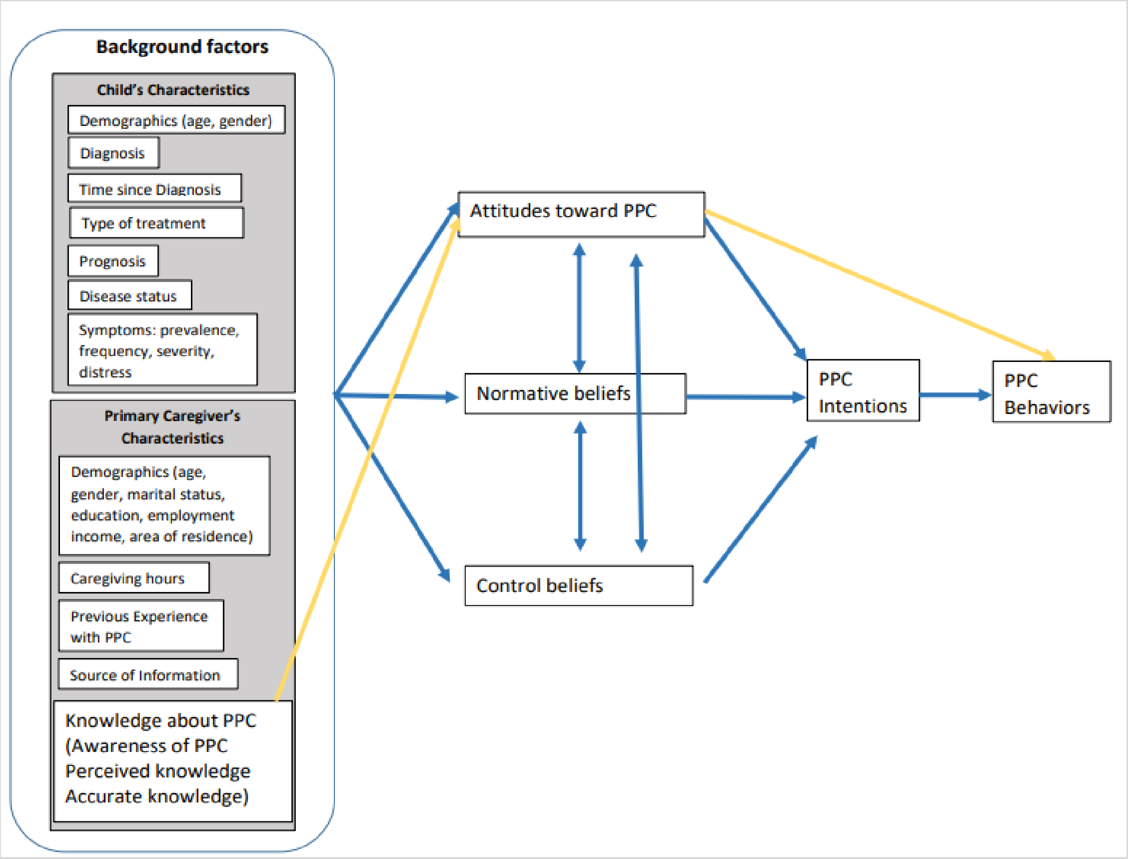
B. Theory of Planned Behavior

The TPB posits that a behavior is predicted by a set of beliefs (Ajzen, 1991). According to the theory, three types of beliefs influence intention that immediately precedes the behavior. The behavioral beliefs pertain to the attitudes toward a behavior. The normative beliefs describe social norms and expectations, and the control beliefs capture the perceived barriers and facilitators to perform the behavior. Ajzen postulates that the three sets of beliefs are connected in a bi-directional manner. As such behavioral beliefs influence control beliefs and vice versa. The same is the case with every two sets of beliefs (Ajzen, 1991). The Theory also posits that the perceived behavioral control, attitude and subjective norms influence intention. In addition, background factors such as demographic data and other characteristics also affect the behavioral, normative and control beliefs. One of these characteristics is the individual’s knowledge about the behavior (Montaño, & Kasprzyk, 2015). The conceptual framework of the current study focuses on attitudes, normative beliefs, control beliefs, intentions, behaviors and background factors. The perceived behavioral control focuses on factors outside the individual’s control such as availability of resources (Montaño, & Kasprzyk, 2015), and therefore are outside the study scope. The subjective norms are the product of normative beliefs and motivation (Azjen, 1991). As motivation is outside the study scope, therefore, subjective norms were omitted from the model. In the current study, the behavioral beliefs were examined through collecting data on primary caregivers’ attitudes toward PPC in the care of children with cancer. In addition, control beliefs were evaluated by examining data related to individual’s perceived barriers and facilitators to PPC. Normative beliefs were evaluated by collecting data on parents’ views regarding the focus of the healthcare team on quality of life of children with cancer. The intentions were evaluated by collecting data on primary caregivers' willingness to try performing PPC tasks. Finally, PPC behavior were examined through information about primary caregivers' performance of PPC activities. In the current study, the PPC behaviors that primary caregivers performed in the previous week were examined to serve as a baseline data for possible future interventions.

The literature on KAB toward PPC reveals relationships in alignment with the TPB. Boldt and colleagues described positive associations between attitudes toward PPC and likelihood to use the services. As for background factors, the literature supports the association of attitudes and beliefs toward palliative care with several factors such as gender (Atwood et al., 2014), age, level of education, employment status (Collins et al., 2019; Dionne-Odom et al., 2019; Shah et al., 2020; Yoo et al., 2018), knowledge and experience in palliative care (Jeong et al., 2020) among others. Therefore, the factors included in the proposed framework were based on previous literature findings.

Figure 4 illustrates the study conceptual framework including the key concepts and their relationships. The yellow and blue arrows represent the relationships between concepts as proposed by Allport (1935) and Azjen (1991) respectively.

Figure 4 Conceptual Framework of the Study



C. Definitions of Key Concepts

1. Metaparadigms

At the most abstract level of the framework, the general conception of the human being is a bio-psycho-social spiritual being that the study seeks to understand as a separate entity from the researcher. In the study context, the human being is viewed as the dyad of parent-child with cancer, where the parent is defined as the primary caregiver and the first line of support for the child with cancer. The primary caregiver is the person who is deeply involved in the healthcare of a child until the age of 18 years (mother or father or significant other). The child with cancer is defined as male or female individual aged below 18 years who is diagnosed with cancer and on active cancer therapy. Nursing care is included within the provision of PPC (which will be defined later in the section). The child's characteristics are the socio-demographic and clinical data describing the child with cancer. Primary caregiver's characteristics are the socio-demographic data describing the primary caregiver and the information describing the caregiving role as well as baseline information about PPC. As for the environment, for the child with cancer residing in Lebanon, a limited resource country, there is a considerable involvement of the primary caregiver in the care as a distinctive cultural expression of close family ties. In Lebanon, PPC is primarily accessible for children with cancer in pediatric oncology centers in the country. Multidisciplinary teams specialized in pediatric oncology offer curative and palliative therapies. At the Lebanese community level, there are two non-governmental organizations that provide home-based adult palliative care, one of which gives limited services to pediatric patients in coordination with the primary care team.

2. Knowledge about PPC

Knowledge is defined as the information that the person possesses related to a given field (Alexander, Jetton & Kulikowich, 1995). In the current study, this concept was defined as the primary caregiver's awareness, perceived knowledge and accurate information regarding PPC.

3. Attitudes toward PPC

The definition of this concept is inspired by the TPB (Ajzen, 1991). Attitude falls under behavioral beliefs and is defined as the degree to which the primary caregiver of the child with cancer has a favorable or unfavorable evaluation or appraisal of PPC.

4. Control Beliefs toward PPC

The definition of this concept is inspired by the TPB (Ajzen, 1991). These are the control beliefs defined as primary caregivers' perceived facilitators and barriers to PPC at the individual level.

5. Normative Beliefs

As defined by Ajzen (1989) normative beliefs refer to the "likelihood that important referent individuals or groups would approve or disapprove of performing the behavior" (p.252). In this study, normative beliefs will be defined as the parents' views on the approval of the healthcare team's on focusing on the child's quality of life.

6. PPC Intentions

The definition of this concept is inspired by the TPB (Ajzen, 1991). PPC intentions are the indications of the willingness to try to perform PPC behaviors or tasks.

7. PPC Behaviors

Actions taken by the primary caregiver in relation to PPC as defined by the WHO. These actions include discussing, seeking information or delivering PPC. According to WHO PPC is:

> “The active total care of the child's body, mind and spirit, and also involves giving support to the family. It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease. Health providers must evaluate and alleviate a child's physical, psychological, and social distress. Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited. It can be provided in tertiary care facilities, in community health centers and even in children's homes” (WHO, 1998, WHO Definition of Palliative Care for Children section).

D. Study Hypotheses

The proposed conceptual framework allows testing the following hypotheses:

1- Accurate knowledge about PPC is associated with positive attitude toward PPC

2- Prior experience with PPC is associated with attitude to PPC

3- Control and normative beliefs are associated with primary caregivers’ attitudes toward PPC.

4-Control beliefs, normative beliefs and attitude toward PPC are associated with PPC intentions.

5- Primary caregivers’ attitude toward PPC is associated with PPC behaviors.

6- Primary caregivers’ intentions are associated with PPC behaviors.

Several assumptions form the basis of the proposed framework. First, it is assumed that children with cancer living in Lebanon receive PPC along with their curative treatment using the available resources. It is also assumed that PPC for children with cancer in Lebanon is provided by the primary multidisciplinary healthcare team at the hospital and by the primary caregiver at home in coordination with the treating team.

CHAPTER IV

METHODS

This chapter presents the study design, and defines the study sample, settings and recruitment procedure. In addition, the chapter explains the data collection procedure with a detailed description of the survey sections. It also depicts the ethical considerations and delineates the analysis plan to address the research aims and the study questions.

A. Research Design

The research was conducted in two phases: the adaptation and pilot testing phase, and the main study phase.

1. Adaptation and Pilot Testing

This phase is an adaptation and pilot testing of all the sections of the survey used to measure the variables of interest. These sections include: demographic data of the primary caregiver and the child; clinical data for the child with cancer; normative beliefs; primary caregivers' knowledge about PPC; primary caregivers' attitudes toward PPC; primary caregivers' control beliefs; PPC intentions and PPC behaviors; and a space for participants' other comments if any. All these sections were tested in the first phase of the research. The sections of the study survey combined previously developed tools, and some items were added, removed or modified based on the literature review to fit the study purpose and the culture. In addition, the survey was administered in Arabic as a target language; therefore, translation and cultural adaptation were needed.

Table 2 illustrates the different sections of the survey with the number of items and reasons for inclusion in the first phase of the research.

Table 2 Description of Survey Sections and Adaptation

Survey Section	Previously developed Items	Source	Number of new items added	Total number of items in the section	Reason for Inclusion in First Phase: Adaptation and Pilot Testing				
					Translation	Modification	Addition of New items	Testing Relevance	Testing Cultural Appropriateness
1. *Demographic data*	13			13				x	x
2. *Child's Clinical Data*	2	Levine et al., 2017	3	17	x	x	x	x	x
	1	National Cancer Institute, 2018							
	10	Portenoy et al., 1994	None					x	
3. *Normative beliefs*	1	Levine et al., 2017	None	1	x	x		x	x
4. *Knowledge about PPC*	2	National Cancer Institute, 2018	None	21	x	x	x	x	x
	2	Levine et al., 2017							
	13	Kozlov et al., 2017	4						
5. *Attitudes*	14	Levine et al., 2017	None	14	x	x		x	x
6. *Control Beliefs*	None		12	13			x	x	x
7. *PPC Intentions and PPC Behaviors*	22	Wells et al., 2002	9	31	x	x	x	x	x
Comments	1			1				x	
				Total=112 items					

PPC=Pediatric Palliative Care

The process of cross-cultural adaptation suggested by Beaton and colleagues (2000) was followed. The steps include translation, synthesis, back translation, expert committee review and survey pretesting (Beaton et al., 2000). According to Beaton and colleagues (2000), cross-cultural adaptation is recommended when a previously developed survey is administered in a new country or culture or language in order to maintain "semantic, idiomatic, experiential, and conceptual equivalence between the source and target questionnaires" (Beaton at al., 2000, p. 3186). All the sections were combined in one survey, translated, back-translated, and validated by a panel of 10 experts to generate a Content Validity Index (*CVI*). The translated and validated version was pretested with 20 primary caregivers and their feedback was sought. A detailed description of the different steps of the process are elaborated in a subsequent section.

2. Main Study

The main study was carried out using a quantitative cross-sectional descriptive design. This design allows for describing variables and examining associations (Hulley et al., 2013). It helps identify the relationships between the child's and participants' characteristics and KAB toward PPC, as well as between KAB and PPC intentions and behaviors. The associations between the key concepts were assessed through a survey conducted with the primary caregivers of children with cancer on active cancer therapy at three major pediatric oncology centers in Lebanon. The survey piloted in the first phase was used. The cross-sectional design is practical and economical since data collection was done at one time point only. Moreover, the cross-sectional design was the most suitable design since the study focuses on the associations between the variables rather than the change of variables over time. Although it is difficult to establish causal relationship, this design helps establish associations between key concepts (Hulley et al., 2013).

Table 3 summarizes the research procedures of the first and second research phases. Details of the procedures was provided in subsequent sections.

Table 3 Research Procedures for the First and Second Phase

Phase	Elements	Subjects	Sampling	Recruitment	Consent	Data Collection
Phase I	Translation	Researcher and two translators	Purposive	Email	Within the recruitment email	Email back the responses
	Content validation of the survey by expert panel	Ten experts	Purposive	Email	Within the recruitment email	Content evaluation grid
	Amendment sent to the IRB before proceeding					
	Pilot testing	20 primary caregivers of children with cancer	Convenience sample from three study sites	Flyers posted in the treatment areas and snowballing	Oral consent conducted remotely	Interview via Whatspp video call. The researcher administered the validated survey and asked for participants' feedback
	Amendment sent to the IRB before proceeding					
Phase II	Main Study	105 primary caregivers of children with cancer (calculated sample size=110 participants)	Convenience sample from three study sites	Direct approach by the researcher or healthcare team member Flyers posted in the treatment areas and snowballing	Oral consent Conducted remotely	Interview via Whatsapp video call. The researcher administered the piloted survey.

B. Population, Sample, Sampling Plan

In the adaptation phase, the researcher selected two native Arabic speaking translators to forward and back translate the compiled survey. The main criteria for selection included being bilingual. For the back translation, the additional condition was to be blinded from the original version of the survey. As for content validation, the researcher selected ten experts. The criteria for selection included being bilingual and being an experienced clinician in pediatric oncology or palliative care. For the translation and content validation, the researcher adopted a purposive sampling plan and agreed with the study team on the suitable subjects. The emails of the translators and experts were obtained from the personal contacts of the researcher or research team.

The pilot testing and main study targeted primary caregivers of children with cancer living in Lebanon and receiving active cancer therapy. A fairly representative subset of this target population is accessible in the three major pediatric oncology centers selected in this study. The distribution of participants among the sites was proportional to the number of patients treated in each site in order to ensure a representative sample.

A non-probability convenience sampling design was followed to recruit 20 and 110 primary caregivers of children with cancer in the pilot and main study phase respectively. This sampling design was cost-effective and practical as children with cancer in Lebanon are treated in specialized centers, making the population of interest accessible through these centers. However, convenience sampling requires subjective judgment and contributes to limited generalizability of the findings (Hulley et al., 2013). Particularly in conducting research among families of children with serious conditions, such as cancer, the researcher considers the ability of the subjects to handle the research burden at the time of recruitment such as their emotional status and time requirement to complete data collection (Crocker et al., 2015).

The same eligibility criteria were used in the pilot and main study phases. Participants were selected, if they were the primary caregivers of a child, who, at the time of data collection, was below 18 years of age, who was diagnosed with cancer since more than two months and who was on active cancer treatment at one of the three selected centers. Previous researchers have recruited parents as early as one month after cancer diagnosis (Abu-Saad Huijer et al., 2013b; Levine et al., 2017). However, the time lapse of two months allowed more time for psychological adjustment and stabilization of the patients' status based on the researcher's clinical experience. Other inclusion criteria for participants entailed being Arabic speaking, and of Lebanese or officially permanent resident in Lebanon. The inclusion of participants with foreign nationalities who are permanently residing in Lebanon enhances sample representation. Moreover, as the study ultimately informs national policy, the input of permanent residents was more conducive to developing national standards than other groups who have transitional stay.

Primary caregivers of children with cancer who were admitted to PICU within one month prior to the study, were excluded due to the participants' psychological status that may interfere with their ability to complete data collection. Primary caregivers of children who completed treatment were also excluded since PPC interventions, at this stage, are significantly decreased due to fewer experienced symptoms and return of children to their usual age-appropriate activities. The inclusion and exclusion criteria selected ensured a reasonably balanced heterogeneity and sample representativeness while reducing the risk of bias.

C. Setting

In both phases of this research, the recruitment activities of primary caregivers took place at the inpatient and outpatient facilities of three pediatric oncology centers in Lebanon: the Children's Cancer Institute (CCI) at the American University of Beirut Medical Center (AUBMC), Saint George Hospital University Medical Center (SGHUMC) and Lebanese Hospital Geitaoui-University Medical Center (LHG-UMC).

The CCI is a regional center pioneering in the treatment of children with cancer affiliated with St. Jude Children's Research Hospital in Memphis, Tennessee, and it functions within AUBMC. Inaugurated in 2002, CCI has treated, to date, more than 1500 children with cancer; and received around 4,500 consultations for complex patients referred from Lebanon and the Region. The inpatient unit's capacity is currently 19 beds. The center currently treats 160 children with various childhood malignancies. The pediatric oncology unit at SGHUMC is one of the largest in Lebanon where the inpatient unit can host up to 10 patients at a time. Currently, 45 children with cancer are under treatment. At LHG-UMC, the pediatric hematology-oncology services are among the largest in the country, with more than 1500 admissions per year and an inpatient capacity of seven beds. Around 35 patients are currently on active treatment at LHG-UMC.

All three centers are equipped with an inpatient and an outpatient facility and they provide state-of-the art cancer therapies for children with various cancer diseases, using a multidisciplinary approach to address the child's and family's needs. They cover a large number of Lebanese and Arab children with cancer from various socioeconomic backgrounds. In all three centers, there is no specialized PPC team. Therefore, PPC provision at the three centers essentially relies on the pediatric oncology multidisciplinary teams who are at the same time providing curative therapy.

D. Recruitment Procedure

For the Adaptation phase, the translators and experts were recruited through email invitations that included an explanation of the procedure. The script of the emails are available in Appendix B for translators and Appendix C for experts.

The recruitment procedure of the primary caregivers included sending an email to the primary oncology treating team ten days before the initiation of data collection. The email informed the primary oncology treating team about the launching of the study (Refer to Sample of email script for oncology treating team in Appendix D).

Participants knew about the study through flyers posted in ambulatory pediatric oncology clinics or inpatient pediatric oncology units at AUBMC-CCI or SGHUMC or LGH-UMC for otherwise scheduled visit or during the patient’s hospitalization. The researcher sent an email to the person responsible for granting administrative approval at each institution, requesting to post the flyers in the treatment areas to make them visible for potential participants (Appendix E: Sample Email script for request for approval to post flyers). The flyers included a phone number for potential participants to call and learn about the study (Appendix F: Copy of the flyer for Pilot Phase-English, Appendix G: Copy of the flyer for Pilot Phase-Arabic, Appendix H: Copy of the flyer for Main Study-English, Appendix I: Copy of the flyer for Main Study-Arabic). An Arabic version of the flyers was used. Interested participants contacted the researcher during their presence in clinic or inpatient. When contacted, the researcher screened subjects for eligibility and explained the study using a verbal script (Appendix J: Verbal Recruitment Script for Pilot Phase-English, Appendix K: Verbal Recruitment Script for Pilot Phase-Arabic). The Arabic version was used with participants. If interested, the researcher shared with the subject an electronic version of the flyer and study brochure (Appendix L: Copy of the Brochure for Pilot Phase-English, Appendix M: Copy of the Brochure for Pilot Phase-Arabic, Appendix N: Copy of the Brochure for Main Study-English, Appendix O: Copy of the Brochure for Main Study-Arabic). The brochure included more details about the study procedure than the flyers. The Arabic versions were used. The researcher and subject agreed on a mutually convenient date and time to complete the consent and data collection procedure.

1. Snowballing Technique

In addition to posting the flyers and brochures, the researcher used a snowballing technique to approach participants. The researcher sent to each participant who completed the survey a short whatsapp written message and asked the participant to forward the message as is to his/her contacts from parents of children with cancer treated at the center (Appendix P: Message forwarded by participants in Snowballing Technique). The message contained a link. Subjects who received the link accessed a single-question electronic anonymous poll upon clicking on the link. The researcher developed the poll using LimeSurvey. The poll included a brief description of the study purpose and a single question asking subjects whether they agree to share their phone number with the researcher. If subjects selected yes, they were asked to enter their phone number in a blank space. If they selected no, the poll ended (Appendix Q: Content of the Electronic Poll in the Snowballing Technique). The researcher then had access to the phone numbers entered by subjects and called to invite them to the study using the Arabic versions of the verbal recruitment scripts (Appendix K: Verbal Recruitment Script for Pilot Phase-Arabic).

2. Amended Recruitment Strategy

Before starting the main study, the researcher included additional measures to recruit participants. The additions entailed using a direct approach by the researcher and by healthcare team members to invite subjects to participate, and posting flyers on social media platforms.

a. Direct approach by the researcher

- The researcher secured the approval of the medical director and nursing management team to be present at each site to approach participants (Refer to Sample Email script for researcher’s presence in treatment areas in Appendix R).
- The researcher wore a pin where it is written “ask me about the research study” (Appendix S) to be distinguished from the treating team members.
- The researcher followed the guidelines for conducting research during COVID-19 pandemic issued on March 22, 2021 by the Institutional Review Board at AUB (Appendix T).
- The researcher asked subjects if they were interested in hearing about the study. If yes, the researcher located a private space to provide the participant with more

details following the verbal script previously approved by the IRB for introducing the study (Please refer Appendix U: Verbal Recruitment Script for Main Study-English and Appendix V: Verbal Recruitment Script for Main Study-Arabic). The Arabic version was used with participants. If interested, the researcher shared with the subject an electronic version of the flyer (Appendices H, I: English and Arabic versions of the flyers for the Main Study) and brochure (Appendices N, O: English and Arabic versions of the brochures for Main Study). The Arabic versions was used. The researcher and subject agreed on a mutually convenient time to complete the consent and data collection procedure.

b. Direct approach by the treating team member

- The researcher sent to the medical director/nursing management team a request to identify one or two members of the treating team to help in directly approaching potential participants (Appendix W)
- The identified member(s) of the treating team was provided with a pin the same as the one used by the researcher (Appendix S) to trigger the participants' interest to ask about the study.
- The identified member(s) of the treating team were provided with the inclusion criteria to follow before approaching subjects.
- The identified member(s) of the treating team followed a script to ask eligible potential participants for permission to share their phone number with the researcher (Appendix X).

- The researcher shared the same link used for snowballing technique with the identified member(s) of the treating team.
- If the potential participant agreed to share his/her number, the identified member(s) of the treating team entered the participant’s phone number on the link.

E. Data Collection Procedures

1. Adaptation and Pilot Testing Procedure

The adaptation procedure was completed in one month. All the sections of the study survey were compiled and validated before use. The procedure encompassed translation, synthesis, back translation, expert committee review and pretesting (Beaton et al., 2000). The compiled English version was forward translated into Arabic independently by two bilingual translators; one of them was the researcher. The two translators synthesized and agreed on one final version in the presence of an auditor who documented the process (Beaton et al., 2000). The translated version agreed upon was translated back to English by a translator who is blinded to the original version. This step ensured validity check to identify inconsistencies or conceptual errors in the translation (Beaton et al., 2000). The researcher evaluated the semantic equivalence through agreement between the original and back translated versions (Varrichio, 2004). An expert panel of ten members was designated to content validate the prefinal version of the survey. The panel included healthcare providers with pediatric oncology and palliative care background. Each member of the committee was given the definition of the concepts and the study survey (Appendix Y: Study Survey-English version, Appendix Z: Study Survey-Translated Arabic Version). The experts were asked to rate each item of the study survey for conceptual relevance and cultural appropriateness on a four-point Likert scale from 1 (not at all) to 4 (very). For this purpose, experts were asked to complete the content validation grid (Appendix AA).This process helped identify areas of omission and areas for improvement to enhance clarity (Lynn, 1986). A Content Validity Index (*CVI*) was obtained. Feedback from experts was also used to refine the questionnaire.

The pilot testing was conducted over one month. The validated version of the study survey (Appendix BB: Study Survey-Validated Arabic Version) was pilot tested with 20 primary caregivers following the same procedures for recruitment, consent, and data collection as in the main study. In addition, the researcher obtained feedback from each participant on the survey sections. At the end of each section, the researcher asked participants to rate each section for level of difficulty, appropriateness of length, clarity, wording, and language used. In addition, the researcher asked participants whether they had any suggestions for improvement by indicating a specific problematic item in a given section or by recommending any addition or deletion of items to the section (Appendix CC: Questions to Obtain Participants Feedback on the Study Survey in the Pilot Phase). The results of the pilot testing are presented in Chapter V. Participants involved in the pilot phase of the research were not included in the sample of the main study.

2. Main Study Procedure

The data collection from primary caregivers followed the same procedure in both pilot testing and main study. The consent and data collection procedures were conducted through remote interviews. Subjects agreeing to take part in the study were invited to an individual structured interview with the researcher via whatsapp video call. Collecting data through interviews gave equal chance for participation for subjects regardless of their level of literacy. Moreover, in PPC research, conducting interviews was found to psychologically relieve parents as they express their thoughts & feelings and they are heard without being judged (Doumit et al., 2019; Weaver et al., 2019a). However, the current COVID-19 pandemic precautions restricted face-to-face encounters for data collection to minimize transmission. Therefore, interviews were conducted remotely via whatsapp video call instead of on-site face-to-face interview. The date and time were mutually agreed upon with each participant. Both researcher and participant, each at an end, used a private quiet room equipped with internet connection to conduct the interview. The participants had the option to be at their home or at the treatment center where the child could be either an inpatient or outpatient at the time of the interview. The researcher asked participants a list of 112 questions included in the proposed survey in Appendix BB. The researcher read each question and response options to the participant. The researcher entered the participant's answers on the computer directly on the electronic version of the survey. Participants had the option to skip any question that made them uncomfortable and to stop the interview at any time. Participants received a thank you electronic card for participating in the study (Appendix DD). In addition, each participant who completed data collection entered a prize draw for one of a total of four cash prizes of 150,000 LBP each. One prize was drawn at the end of the pilot and the remaining three prizes were drawn during and at the end of the main study. The researcher gathered participants' phone numbers in a single document and assigned them to sequential numbers from one to 130. The numbers one to 20 were assigned to participants in the pilot testing and 21 to 130 to participants in the main study. The first prize draw occured at the completion of data collection in pilot testing. The remaining three draws took place at the completion of data collection from each 37 participants and at the end of main study. A computer-generated random draw will be was conducted in due time using https://www.randomresult.com/. The result of the draw determined the sequential number of the phone number to be selected as winner. The researcher called the participant holding the winning phone number and announced him/her being the recipient of the prize. The researcher agreed with each recipient on a mutually convenient date/time to deliver the prize while taking the necessary precautions for COVID-19 prevention (perform hand hygiene before and after the interaction, face-masks worn by researcher and winner, physical distancing of at least 2 meters, ventilation, etc…).

F. Research Instruments

The study variables were measured using a structured survey that combined previously developed tools with items added based on the literature review to fit the study purpose. The entire survey was pilot tested in the first phase of the research. The researcher administered the entire survey to participants during the remote interview. The survey included the following sections: two demographic data sections, one for the primary caregiver and one for the child; a clinical data section for the child with cancer; a section on normative beliefs represented by the primary caregivers' views regarding the approval of the treating team to focus on their child's quality of life; a section on primary caregivers' knowledge about PPC, a section on primary caregivers' attitude toward PPC; a section on primary caregivers' control beliefs represented by the perceived barriers and facilitators to

PPC at the individual level; a section on PPC intentions and behaviors; and a space for participants’ other comments if any. The English version of the survey is available in Appendix Y and the Arabic Version is available in Appendix BB. All information on the survey were collected directly from the participants through interview. The researcher asked the survey questions to each participant and completed the entire survey by entering data provided the participants in the different sections. Table 4 summarizes the different survey sections with the number of items obtained from existing tools, prior psychometric properties and their adaptation process.

Table 4 Summary of the Survey Items, Psychometric Properties and Adaptation Process

Survey Sections	Previously developed items	Prior Reliability and Validity Testing	Adaptation Process	
			Existing Items	New items
Demographic data	13			
Child's Clinical Data	2 (Levine et al., 2017)	Expert reviews, cognitive interviewing, pilot testing	Modification of answer options, Translation	Three items added to cover the type of treatment, disease status and caregiving duration.
	1 (National Cancer Institute, 2018)	Pretesting and cognitive interviewing	Rephrasing, Modification of time period, Translation	
	10 (Portenoy et al., 1994)- Arabic version (Abu-Saad Huijer et al., 2015)	*Cronbach's α* range 0.71-0.83 Convergent validity ($r > -0.5$, $p<0.01$). Principle Component Analysis (4 clusters) CFA: *GFI*=0.59	None	
Normative beliefs	1 (Levine et al., 2017)	Expert reviews, cognitive interviewing, pilot testing	Rephrasing, Translation	
Knowledge about PPC	2 items (National Cancer Institute, 2018)	Pretesting and cognitive interviewing	Rephrasing Translation	
	2 (Levine et al., 2017)		Modification to close-ended Translation	
	13 items (Kozlov et al., 2017)	*KR-20*=0.71; *ICC-agreement for 10-minute interval* =0.70 with 95% *CI*= 0.56-0.80; *CFI* = 0.97, *TLI*= 0.96, *RMSEA* = 0.031 Convergent validity (r=0.37 and r=0.47, $p<0.001$); Known-group validity: $t(55)$ =7.86 , $p < 0.001$; *Cronbach' α*=0.94	Translation	Four items added to cover the pediatric context
Attitudes	14 (Levine et al., 2017)	Expert reviews, cognitive interviewing, pilot testing	Modification, Rephrasing Translation	None
Control Beliefs	None	None	None	12 New items
PPC Intentions and PPC Behaviors	22 (Wells et al., 2002)	Expert reviews, cognitive interviewing test-retest reliability (r=0.90) Cronbach's *α* range 0.90–0.93	Modification Rephrasing Addition of intention scale Translation	Nine items added to cover the palliative care context.

PPC=Pediatric Palliative Care, CFA=Confirmatory Factor Analysis, *GFI*=Goodness of Fit Index, *KR-20*= Kuder-Richardson 20, *ICC*= Inter-Class Correlation, *RMSEA*= Root Mean Square Error of Approximation

1. Demographic Data

This section consisted of 13 items. Eleven items were related to the primary caregivers' gender, age, relation to the child, marital status, the number of individuals living with the child, nationality, level of education, area of residence, religion, employment status and household income. Two items addressed the child's gender and current age in years.

2. Child's Clinical Data

This section was composed of six items related to the child's diagnosis, age at diagnosis, prognosis, current disease status, current type of treatment, caregiving duration in years and caregiving hours per day. Two of these items (child's diagnosis and prognosis) were obtained from the survey used by Levine and colleagues (2017). The two items were content validated as the authors developed these items for their study purposes based on literature, iterative expert reviews, pilot testing and cognitive interviews. Reliability data was not reported (Levine et al., 2017). The item on diagnosis was modified from open-ended to close-ended question with an 'other' option. For the item on prognosis, the answer options were rephrased to align with the question. Three new items were added to this section to cover type of treatment, disease status and caregiving duration. All items were translated into Arabic.

The item of clinical data section pertaining to caregiving hours was obtained from the survey used by the National Cancer Institute (2018) in the Health Information National Trends Survey 5 cycle 2 (HINTS 5 Cycle 2). The item underwent pretesting and cognitive interviewing (Taber et al., 2019). This item was rephrased for simplicity and “hours per week” was replaced by “hours per day”.

In addition, a subsection of the child’s clinical data addressed symptom assessment to capture a more comprehensive representation of the child’s clinical status, as children with cancer experience a list of symptoms due to the disease or treatment during their disease trajectory. The Memorial Symptom Assessment Scale (MSAS) version 10-18 was used to assess symptoms. The MSAS is a 32-item patient-rated multidimensional instrument initially developed in adult patients (Portenoy et al., 1994). Two modified versions were previously validated in children with cancer and adolescents, with evidence of sound psychometric properties (Collins et al., 2000; Collins et al., 2002). Moreover, the child’s and parent’s rating revealed a moderate to strong agreement with Cohen’s Kappa at least 0.42 ($p<0.05$) for most of the symptoms (Collins et al., 2000; Collins et al., 2002).

The tool is available in the Lebanese Arabic language with sound psychometric properties (Abu-Saad Huijer et al., 2015). Evidence of reliability was demonstrated by Cronbach’s *alpha* of the Arabic version and its subscale ranging from 0.71 to 0.83. Convergent validity was illustrated by the moderate correlation of psychological and distress subscales with the emotional subscale of a previously validated quality of life measure (European Organization for Research and Treatment of Cancer Quality of Life Questionnaire-Core 30, EORTC QLQ-C30) ($r > -0.5$, $p<0.01$). In addition, the MSAS items of the Arabic version were moderately to strongly correlated with almost all selected subscales of the validated quality of life measure (correlation coefficients ranged between -0.55 and 0.81, $p<0.01$). In the exploratory factor analysis, the principal component analysis revealed four clusters representing the physical and psychological elements. In the confirmatory factor analysis, fit indices met the acceptable values of a good fit model in the study sample (Abu-Saad Huijer et al., 2015). A symptom score is generated as a mean of the three dimensions: the frequency, severity and distress score (Collins et al., 2000). The MSAS 10-18 generates three subscales. The physical subscale score represents the mean of physical symptoms score. The psychological subscale represents the mean of psychological symptoms scores. The Global Distress Index (GDI) score represents the mean of frequency scores of psychological symptoms and distress scores of physical symptoms (Collins et al., 2000).

Based on the literature on symptoms in pediatric oncology, the ten most prevalent symptoms were listed in the survey, with an additional option for "other" if needed. Following the scoring system suggested by Collins and colleagues (2000), each symptom, if present, was scored as the average of its dimensions. The total MSAS score was computed as the mean ranges and standard deviation of all symptom scores. The distress score was calculated as the mean of frequency scores for psychological symptoms and distress scores for physical symptoms.

3. Normative Beliefs

This section included one item adapted from a previous study addressing patients and parents' views regarding the focus of healthcare team on the quality of life of children with cancer (Levine et al., 2017). The item was previously content validated through literature review, iterative expert reviews, pilot testing and cognitive interviews. Reliability data was not reported. For the current research, the stem was reworded to align with the conceptual definition of normative beliefs. The response options were transformed into a five-point Likert scale. Participants were asked to rate their agreement with approval of healthcare team on focusing on the child's quality of life. A mean score was computed to indicate the approval to focus on quality of life. A higher score indicated more focus on quality of life.

4. Knowledge about PPC

Items in this section were obtained from a previously validated instrument, the Palliative Care Knowledge Scale (PaCKS), and previous questionnaires that were used to assess knowledge of palliative care in the general public, patients and caregivers. The first three items of the section pertained to the participants' awareness about PPC and their perceived level of knowledge about it and source of information they would seek for acquiring palliative care knowledge. Participants who reported having heard about palliative care and having at least some knowledge about it, were asked whether they had previous experience with PPC. The items on awareness and experience about palliative care were obtained from the study of Levine and colleagues (2017). For the current study, the open-ended part of the experience question was removed. The items on perceived knowledge and source of information were taken from the survey HINTS 5 Cycle 2 by the National Cancer Institute (2018). The perceived knowledge question and answer options were rephrased. Instead of describing their level of knowledge, prticipants were asked to rate on a three-point likert scale their level of knowledge they thing they have about PPC, ranging from knowing "nothing at all" to being "very knowledgeable".

Respondents who reported some knowledge about PPC, were asked the items taken from PaCKS to assess the accuracy of their information. The PaCKS is a recently developed 13-items scale assessing general knowledge about facts and principles of palliative such as goals of palliative care (Kozlov et al., 2017). The scale uses dichotomous answer format (true or false) with scores ranging from 0 (lowest knowledge) to 13 (highest knowledge) (Kozlov et al., 2017). As evidence of reliability, PaCKS has adequate internal consistency (*Kuder– Richardson Formula 20 (KR-20)* value=0.71) and acceptable stability over time (*ICC-agreement* for 10-minute interval =0.70 with *95% CI*= 0.56, 0.80). As for structural validity, the exploratory factor analysis revealed two factors: the main factor relates to knowledge of palliative care represented by 13 items, and the bias factor relates to the tendency to answer all items similarly regardless of knowledge about palliative care. The confirmatory factor analysis of the final 13-item scale yielded excellent fit indices *(Comparative Fit Index (CFI)* = 0.97, *Tucker-Lewis Index (TLI)* = 0.96, *Root mean square error of approximation (RMSEA)* = 0.031 (Kozlov et al., 2017). The instrument demonstrated adequate convergent validity since the main factor of PaCKS moderately and positively correlated with health literacy and intelligence measures (r=0.37 and r=0.47, p<0.001 respectively). In addition, PaCKS was able to discriminate between professionals and community members that are known to differ on their palliative care knowledge. As evidence of known-groups validity, PaCKS scores significantly differed between professionals and community members (t(55)=7.86, $p < 0.001$) (Kozlov et al., 2017). Acknowledging the guessing effect of the tool, the authors established a higher internal consistency (*Cronbach α*=0.94) after adding an answer option of “I don’t know”, scored as false answer, to all the items (Kozlov et al., 2018). The PaCKS is designed to assess knowledge about palliative care without distinguishing the pediatric population. Therefore, to fit the study context, four items were added to highlight information about palliative care in the pediatric population. These items reflected the WHO definition of PPC and the timing to start palliative care, the total care approach, the use of available resources and family involvement. In the current study, a summative score was calculated with a range of 0-17. A higher score indicated more accurate knowledge about PPC.

5. Attitudes toward PPC

Items in this section were adapted from a previous study addressing the attitude of parents of children with cancer toward palliative care (Levine et al., 2017). The items were content validated as the authors developed these items for the study purposes based on literature, iterative expert reviews, pilot testing and cognitive interviews (Levine et al., 2017). Reliability data was not reported. For the current study, the questions were modified as follows: stem questions reworded for simplicity purposes, the time restriction to “first month of treatment” was removed, the “PPC team” was replaced by “PPC services” to fit the study context, and the response options were transformed into five-point Likert scale to allow for psychometric testing. The items of the attitude section were asked after giving a brief explanation about PPC. The following statement was used: “The palliative care services treat patients’ symptoms and improve patients’ quality of life”. Participants were asked to rate their level of agreement with each of the 14 items on a five-point Likert scale. The attitude toward PPC was computed as the mean of the 14 items. Reverse coding was performed for applicable items. Mean score above or equal to four indicated a positive attitude. The percentage of participants who reported positive attitude was calculated.

6. Control Beliefs

The items of this section were developed for the study purpose based on the literature addressing barriers and facilitators to PPC at the individual level. The section included 12 facilitators and barriers to PPC described in the literature, with an option for "other". Participants were asked to rate the extent to which the factor described in each of the items makes it difficult or easy for them to integrate PPC in their child's care. The rating used a five-point Likert scale ranging from "very difficult" to "very easy". The items on facilitators to PPC included: "Certainty about my child's prognosis", "Awareness of the child's suffering", "Support and good communication with my child' clinical team", "Knowledge about PPC", "Believing that I am "a good parent", "Religious and spiritual engagement". The items related to barriers to PPC included: "Lack of understanding of my child's medical condition", "Unrealistic belief in the child's probability of cure", "Overwhelming negative emotions", "Desire to shield others from bad news", "Discomfort talking about death" , "Involvement of larger family members in treatment decisions about my child's care". A summative score of all items was calculated to generate the control beliefs score. Higher scores indicated a higher control at the individual level.

7. PPC Intentions and PPC Behaviors

This section is composed of list of 31 PPC caregiving tasks performed by the primary caregiver of the child with cancer. An option for “other” was included to allow for additional tasks if not covered in the list. For each task, participants were asked to answer by yes/no whether they performed the task within the previous week if applicable. For tasks not performed, participants were asked to rate their likelihood to perform the task in the coming week on a five-point Likert scale.

The list of tasks contains 22 items adapted from a previously validated tool, the Care of My Child with Cancer (CMCC), which included a physical and emotional subscale (Wells et al., 2002). This tool measures the 28 caregiving demands through the time required and the degree of effort or difficulty of certain tasks completed by parents in the previous week (Wells et al., 2002). The CMCC was developed based on the literature and expert panel review but not on parents’ input. In several studies the CMCC demonstrated acceptable test-retest reliability (*r*=0.90) and internal consistency (*Cronbach’s alpha*=0.90–0.93) (Kelly et al., 2014; Klassen et al., 2010; Klassen et al., 2011; Wells et al., 2002). Moreover, construct validity was demonstrated by increased demand associated with more intense treatment and poorer child and parent quality of life (Klassen et al., 2011). In the current study, 22 out of 28 tasks were selected to fit the study context. Some items were reworded to enhance clarity such as using “my child” instead of “the child” and “following up with the treating team” instead of “reporting to the treating team”. The answer options were modified to “yes/no/not applicable” instead of rating to the time required and degree of efforts on five-point Likert scale. As CCMC was validated among primary caregivers of children with cancer excluding terminal phases, it partially covers the PPC context.

Therefore, nine items were added based on the literature to meet parental PPC caregiving activities across the different phases of the disease trajectory. The nine items included the following: managing medical devices such as feeding pump, obtaining necessary equipment and medications, praying with my child, taking decisions related to my child's care, sharing my experience with similar parents, reminding my child about medical precautions, telling medical information to my child, getting more information about PPC, and discussing PPC with my child's healthcare team. An option for "other" was also added.

The measure of PPC behavior pertained to the number of tasks performed by the participant in the previous week and ranged from zero to 31. The measure of PPC intentions pertains to the likelihood to perform PPC tasks that were not performed in the previous week. PPC Intentions were scored by computing the mean of participants' likelihood to engage in PPC tasks in the coming week.

G. Ethical Considerations

The study was carried out by qualified researchers who have completed courses on ethical conduct of research (Appendix EE includes a certificate of completion of the course). The study did not directly benefit participants; however, collected data helped understand primary caregivers' perspectives towards PPC in Lebanon, and inform improvement areas in pediatric oncology practice and policy. The social benefits of the study outweighed the risks. The main social benefit was that the results of the study have the potential to influence the development of PPC in Lebanon and other similar LMICs.

The study carried no more than minimal risk except for potential negative emotions in participants and potential unintentional loss of confidentiality. When participants experienced negative emotions upon sharing their experience with their child’s care, the researcher offered opportunities for breaks or stopping the interview. When any participant verbalized feeling anxious and in distress, the researcher reminded him/her to discuss with the child’s primary physician or psychologist at the treatment center. In a pediatric context, especially in pediatric oncology, psychological support is offered automatically to children and parents by the multidisciplinary treating team within a family-centered care approach with no additional charges. To protect confidentiality, the interviews were secured to the extent that technology allows. Only the researcher had access to data that was entirely electronic and saved in a password-protected computer in a private office at the Hariri School of Nursing at AUB. Back-up data was saved in the personal researcher’s laptop which was also password-protected. Private spaces were used for consenting participants and collecting data. Completed surveys were identified by unique codes not linked to the participants’ identity. All primary caregivers, routinely present at the sites, had equal opportunity to participate. Recruitment materials were made available to all potential participants.

Before initiating the study, the researcher sought and obtained the approval of the Institutional Review Board (IRB) and administrative approvals from all three centers. The recruitment flyer and brochures included the information required by the IRBs.

During the development of the proposal and recruitment material, the researcher obtained license for using picture on the flyer/brochure (Appendix FF). In addition, the researcher obtained written permission for using, modifying and translating existing questionnaires from the original developers (Appendix GG). Upon completion of content validation, the researcher sent amendments to IRB to seek approval on the validated version of the survey prior to conducting the main study. An additional admendement was sent to IRB to obtain approval on the additional measures in the recruitment stragety.

1. *Consent Procedure*

The same consent procedure was followed in the pilot testing and main study. Before starting each interview, the researcher sought participant's oral consent via whatsapp call. The researcher read and explained all the content of the consent form (Appendix HH: Oral Consent for Pilot Phase-English, Appendix II: Oral Consent for Pilot Phase-Arabic, Appendix JJ: Oral Consent for Main Study-English, Appendix KK: Oral Consent for Main Study-Arabic). An Arabic version was used. The consent included: contacts of the researcher and IRB, the aim of the study, the risks and benefits, the data collection method, the anonymity and confidentiality of the procedure, the voluntary nature of participation, and freedom to withdraw from the study at any time. After checking the participants' understanding and responding to his/her inquiries, the researcher sent the consent form to participants via whatsapp message. Participants were not be asked to sign the form as an additional measure to protect privacy and confidentiality. When needed, the researcher allowed two hours for the primary caregivers to think about their participation, discuss among family and read the consent.

H. Data Analysis

1. Sample Size Calculation

Two approaches were available to calculate the sample size of the main study. One was based on correlation between outcomes of interest and the other was based on regression analysis. Both approaches are presented in this section with the rational of selecting the first one.

a. Sample size Based on Correlation between Knowledge and Attitude. A previous study used the PaCKS, the same knowledge scale that was used in this study, to describe community understanding about palliative care and identified factors associated with attitudes toward palliative care (Collins et al., 2020). The authors reported a significant positive correlation between palliative care knowledge and attitude ($r=0.314$, $p<0.01$) among other factors. One of current study hypotheses particularly predicted that accurate knowledge about PPC is associated with positive attitude toward PPC. Therefore, the sample size calculation using $r=0.314$ with a *power* of 0.9 yields 102 participants. In order to account for a refusal rate of 8%, 110 participants should be approached.

b. Sample Size Based on Regression Analysis. The regression analysis for the three outcomes of interest (knowledge, attitude and beliefs toward PPC) was conducted using 19 demographic and clinical variables. The categorical variables with more than three categories (such as level of education) were dichotomized. Based on 19 variables on a medium effect size of $R^2= 0.15$, *power*= 0.8 and $\alpha=0.05/3=0.017$ (to account for the three outcomes) a minimum of 188 subjects are needed. The medium effect size was selected due to paucity of literature. In order to account for a refusal rate of 8%, 203 participants should be approached. Sample size calculation using this method was conducted on G*Power version 3.

c. Sample size calculation approach selected. The sample size calculation based on correlation is preferred for several reasons. The literature recurrently emphasized the association between knowledge and attitude about palliative care (Atwood et al., 2014; Boldt et al., 2006; Collins et al., 2020; Jeong et al., 2020; Pasaol, 2019). Many findings suggested that increased knowledge enhances attitude, which in turn improves palliative care practice (Abu-Saad Huijer et al., 2009; Spruit et al, 2018). Therefore, demonstrating the association between the knowledge and attitude toward PPC in the sample formed the basis for planning educational interventions that will lead to better attitudes. A separate hypothesis articulating this relationship was tested in the current study.

Another reason for selecting the first method was that the total number of accessible subjects is 240. The recruitment of a total of 203 subjects accounted for 85% of the population while a reasonably achievable percentage may reach 60%.

With the use of calculation based on correlation, the power was increased to 0.9. This further restricted the probability of type II error (failure to reject the null hypothesis when it is false), while ensuring an adequate sample size for psychometric testing of the scales.

The refusal rate was determined based on prior literature in PPC. In previous quantitative studies conducted among parents of children with cancer in Lebanon, the refusal rate ranged from 3.4% (Abu-Saad Huijer et al., 2013b; Mosleh El-Gharib, Abu-Saad Huijer, & Darwish, 2015) and 19.5% (Saad et al., 2011). The upper limit pertained to participation of bereaved parents. As the current study targets parents of children with cancer on treatment the lower limit of refusal rate was anticipated. A more recent study conducted in USA examined the attitude of parents of children with cancer on treatment toward early PPC and yielded 8% refusal rate (Levine et al., 2017). Therefore, an estimate of 8% refusal was considered appropriate for the study context.

2. *Psychometric Testing*

In line with the study specific aim to psychometrically test KAB instruments, the reliability and validity of the knowledge, attitude and control beliefs scales were tested in the first and second phase of the research.

During the pilot phase, the content validity of the items, survey sections and entire survey were assessed by calculating the Content Validity Index (*CVI*). The *CVI* represents the level of agreement among the ten panel members that each item and the entire survey are relevant. A *CVI* of at least 0.8 is considered acceptable to retain the items and judge the survey as content valid (Lynn, 1986). The detailed results of *CVI* and cultural appropriateness are presented in Chapter V.

The data obtained in the main study allowed for conducting more psychometric analysis for the PPC Attitude, Control Beleifs, and PPC Behaviors scales. Exploratory factor analysis (EFA) was performed to reveal the structure of the PPC Attitude and Control Beleifs scales. Internal consistency was examined by calculating *Cronbach's α* for both scales. A coefficient of at least 0.7 is considered acceptable (Polit & Yang, 2016). In addition, item-tem correlations were assessed to examine relationships between items, and item score ranges were determined to explore ceiling or floor effect of the items. Inter-item correlations were also examined for PPC behavior scale. The detailed results of psychometric analysis are presented in Chapter VI.

3. Analysis of the Study Outcomes

The remaining three specific aims pertain to the main study phase. These aims were addressed using various statistical methods. Data was entered on Statistical Product and Service Solutions (SPSS) version 26 using a coding format. In order to respond to the research main purpose to examine knowledge, attitudes and beliefs toward palliative care, the research questions were addressed through descriptive analysis and correlation analysis. Descriptive data was analyzed using frequencies (counts and percentages) for categorical variables and means and standard deviations for continuous variables.

Associations between knowledge, attitudes and beliefs and demographic, clinical data, and PPC intentions and behaviors were analyzed. Before conducting the analysis, the variables were checked for assumptions of normality to determine the appropriate use of the statistical test. Whenever the number of responses for a given variable was small (for example “personal experience with palliative care”), non-parametric tests were used. If normal distributions were violated, non-parametric tests were used.

When testing categorical variables with a continuous outcome (such as attitudes score), *t-test* or *Mann-Whitney* test were used for dichotomous variables (such as gender), and *ANOVA* or *KrusKall Wallis* were used for variables with more than two groups (such as level of education). When testing the correlations between two continuous variables

Pearson *r* or Spearman *rho* were used (such as correlation between Attitudes score and Beliefs score). Significant associations with the outcomes of interest were set at *p*-value below or equal to 0.05.

The first research question: What is the distribution of knowledge about PPC among primary caregivers of children with cancer? This question was answered by calculating the percentage of participants who report completely correct answers on the PaCKS scale.

The second research question: What are the attitudes of primary caregivers toward PPC for children with cancer? This question was answered by calculating the percentage of participants who reported a mean attitude score above or equal to four. In addition, the question was addressed by computing the percentage of participants who endorsed (agreed or strongly agreed) statements about the benefits of PPC, and percentage of participants who endorsed initiating PPC at the beginning of cancer therapy.

The third research question: What are the barriers and facilitators to PPC reported by primary caregivers at the individual level? This question was answered by calculating the means and standard deviations on each of item listed in the control beliefs section.

The fourth question: What are the associations between demographic variables and child's clinical characteristics and the primary caregiver's KAB towards PPC in children with cancer? This question was answered by running bivariate analysis, each demographic and clinical data with the outcomes (PaCKS score, mean attitudes score and beliefs score). The correlation between continuous independent variables (such as number of prevalent symptoms) was tested for correlation with knowledge, attitudes and beliefs using Pearson *r* correlation coefficient or Spearman *rho* coefficient. The study outcomes were compared based on primary caregivers' characteristics and the child's characteristics (such as gender, level of education current disease status, experience with PPC, etc…) using *t-test*, *ANOVA* or their non-parametric alternatives. All significant predicators (*p*-value <0.05) were entered into a multiple linear regression analysis to determine the strongest association. Separate linear regression analyses were conducted one for knowledge, one for attitude and one for control beliefs.

The fifth question: What are the associations between the primary caregivers' attitudes and beliefs and their PPC intentions and behaviors? This question was assessed by checking the correlations between: mean attitudes score with mean intentions scores, beliefs scores with mean intentions scores. The association between primary caregivers' attitudes and beliefs with their PPC behaviors were tested by assessing the correlation between mean attitudes score with number of PPC behaviors performed in the previous week and beliefs scores with number of PPC behaviors performed in the previous week.

I. Summary

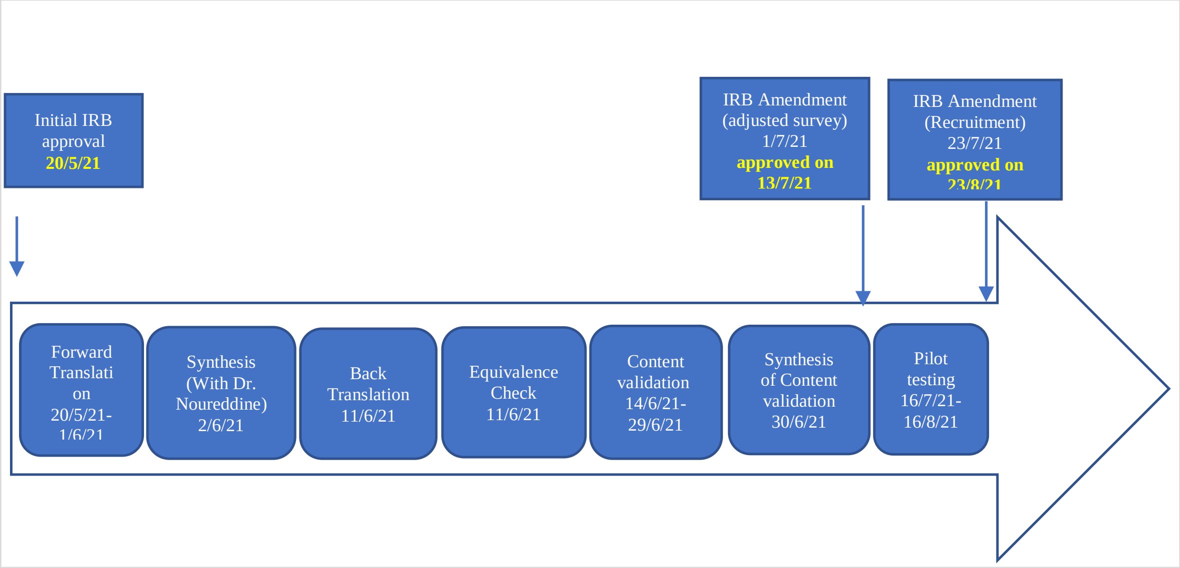
In summary, the methods described in this chapter delineate the systematic and scientific approach to examine KAB toward PPC in the Lebanese context. Throughout the chapter, each study element was detailed and explained. The research methods were followed to obtain the study findings presented and discussed in the subsequent chapters.

CHAPTER V

RESULTS OF CROSS-CULTURAL ADAPTATION AND PILOT TESTING

The first phase of the study entailed adaptation and pilot testing of the questionnaire. The below figure 5 presents a summary of the followed steps along with the dates of completion.

Figure 5 Progress of the Adaptation and Pilot Study



A. Translation and Back Translation

All the sections of the study survey were compiled and validated before use. The procedure encompassed translation, synthesis, back translation, expert committee review and pretesting (Beaton et al., 2000). The compiled English version was forward translated into Arabic independently by two bilingual translators, one of them is the researcher and the other is a sworn translator. The two independent translators synthesized and agreed on one final version in the presence of an auditor (Dr Samar Noureddine) on June 2, 2021.

A PhD nursing student, blinded from the original English version, submitted a back translated version of the questionnaire on June 11, 2021. Upon comparing the original English and back translated versions, the researcher detected agreement, therefore, no changes were made to the questionnaire.

B. Content Validation

A purposive sample of ten experts were invited by email to validate the prefinal version of the survey for content and cultural appropriateness. The panel included healthcare providers with pediatric oncology and palliative care background as illustrated in Table 5.

Table 5 Characteristics of Expert Panel ($N = 10$)

Characteristic	Number	Percentage
Gender		
Female	9	90%
Male	1	10%
Age (years)		
30-39	4	40%
40-50	6	60%
Discipline		
Nurse	7	70%
Nurse Scientist	1	
Nurse Instructor	1	
Nurse Manager	1	
Clinical Nurse Specialist	2	
Bedside Nurse	2	
Physician	2	20%
Psychologist	1	10%
Expertise/Research Focus		
Pediatric Oncology	5	50%
Palliative Care	5	50%

The content validation was carried out over two weeks (between June 14, 2021 and June 29, 2021). Each member of the expert panel was provided with the definition of the concepts and the study survey. The experts used a content validation grid to rate each item of the study survey for conceptual relevance and cultural appropriateness on a four-point Likert scale from 1 (not at all) to 4 (very). A Content Validity Index (*CVI*) was calculated for each item, for each section and for the whole survey. To obtain Item-*CVI*, the number of experts judging the item as relevant (rating 3 or 4) was divided by the total number of content experts (*N*=10). The section-*CVI* and total-*CVI* were computed using the average approach described by Polit and colleagues (2007), where the sum of Item-*CVIs* was divided by the total number of items. Table 6 presents the *CVI* for each section and for the whole survey.

Table 6 Survey Content Validity Index and Cultural Appropriateness (by section and total)

Survey Sections	Content Validation Index	Cultural Appropriateness
Demographic Data	0.99	0.93
Child's Clinical Data	0.96	0.96
Normative Beliefs	1	0.90
PPC Knowledge	0.99	0.96
Awareness, perceived knowledge, Experience, Source of Information	1	0.97
Palliative Care Knowledge Scale (PaCKS)	0.99	0.95
PaCKS with items for pediatrics	0.98	0.97
Attitudes toward PPC	1	0.97
Control Beliefs	0.95	0.92
PPC Behaviors	1	0.92
Whole Survey	0.99	0.95

A *CVI* of at least 0.8 is considered acceptable to retain the items and judge the survey as content valid (Lynn, 1986).

Item *CVI* values ranged between 0.8 and 1, therefore, all the items were retained. The expert reviews revealed an excellent *CVI* for the survey sections (ranging between 0.95

and 1) and for the whole survey (*CVI*=0.99). The same calculations were done for cultural appropriateness. The cultural appropriateness index for almost all the items ranged between 0.7 and 1, highlighting culturally appropriate translations. Only one item ("meeting my own emotional needs") scored 0.6 on cultural appropriateness and the Arabic version was reworded. The feedback from experts was integrated to refine the questionnaire. Rewording of the Arabic version was done as needed. For the example, the translation of "symptom management" was reworded into "symptom treatment" and "meeting emotional needs" was reworded into "emotional support". The adjusted version of the Arabic questionnaire was approved by the IRBs at AUB and Geitaoui Hospital before initiating pilot testing.

C. Pilot Testing

As previously described, the recruitment of the pilot sample was initiated using flyers and snowballing technique. Only one subject called in the first week, which required the submission of an IRB amendment to the recruitment strategy. The change in the recruitment strategy entailed adding a direct approach by the researcher and by healthcare team members to invite subjects to participate, and posting flyers on social media platforms. However, by the time the approval was granted, the pilot study had been completed using the originally approved recruitment strategy. The pilot study was completed within one month (July 16, 2021 to August 16, 2021). Twenty seven subjects were approached either through flyers or snowballing. Twenty primary caregivers of children with cancer completed the interviews through Whatsapp video or voice calls. Three did not reply to the researcher's call, two reported lack of time for the interview and another two were not interested in participating. Participants completed interviews on mutually agreed date and time with the researcher. On average, each interview was completed within one hour (*M*=59.6 ± 17.7 minutes).

1. Demographic Characteristics

The majority (90%) of the pilot sample consisted of mothers, homemakers (65%) and from the Muslim religion (70%). Less than half of the participants (40%) were middle aged (*M*=38.8±11.4 years) and 50% had high school degree or below. The majority of the caregivers (60%) reported a monthly income that meets their basic needs. More than half (55%) of the children of primary caregivers in the pilot sample were female and their age ranged between five and 15 years (60%). Table 7 and Table 8 illustrate the demographic characteristics of the participants and patients.

Table 7 Demographic Characteristics of the Pilot Sample (*N* = 20)

Variable	Number	Percentage
Gender		
Female	18	90%
Male	2	10%
Relationship to the Child		
Biological Parent	18	90%
Grandparent	1	5%
Sister	1	5%
Age (years) (M=38.8±11.4)		
Below 30	5	25%
30-39	6	30%
40-49	5	25%
50-60	3	15%
Above 60	1	5%
Marital Status		
Married	16	80%
Widowed	3	15%
Single	1	5%
Nationality		
Lebanese	20*	100%
Highest Educational Level		
Below Grade School	3	15%
Grade School	3	15%
High School	4	20%
University	8	40%
Graduate School	2	10%
Area of Residence		
Urban	9	45%
Rural	11	55%
Religion		
Christian	3	15%
Muslim	14	70%
Druze	3	15%
Employment Status		
Employed	4	20%
Homemaker	13	65%
Student	1	5%
Other (Freelance)	2	10%
Monthly Income		
Doesn’t meet basic needs	8	40%
Meets basic needs	12	60%
Exceeds basic needs	0	0%

*One participant holds an additional Canadian nationality

Table 8 Children's Demographic Characteristics (*N* = 20)

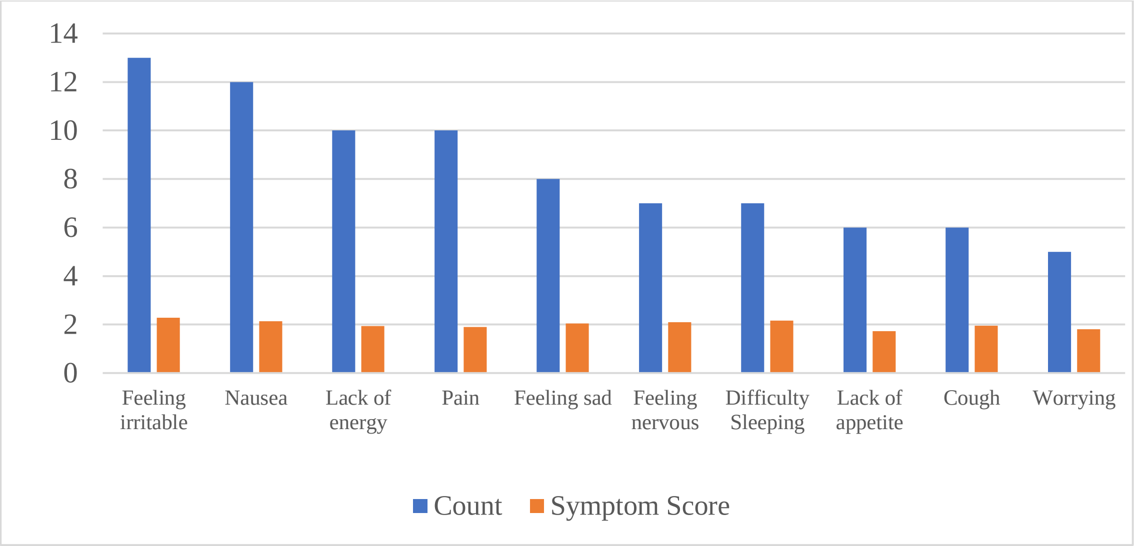
Variable	Number	Percentage
Child's Gender		
Female	11	55%
Male	9	45%
Child's Current Age (years) (M=9.2±4.8 years)		
Below 5	6	30%
5-10	5	25%
11-15	7	35%
Above 15	2	10%

2. *Clinical Data*

Most of the children of participants in the pilot study were diagnosed with Leukemia (70%), receiving chemotherapy (85%), currently in remission (65%) with very high chances for cure (65%). The children's age upon diagnosis ranged between 1.8 years and 14 years (*M*=7.5 ±4.8 years). The caregiving duration ranged from 4 months to 3 years (*M*=1.6 ± 0.9 years). The daily caregiving time ranged between one to 19 hours with an average of six hours per day.

a. Symptom Experience. More than half of the children (*n*=11, 55%) experienced at least four symptoms in the last week. As presented in Figure 6, feeling irritable, nausea, pain and lack of energy were the most common symptoms. The symptom experience was measured using the Memorial Symptom Assessment Scale (MSAS 10-18) (Collins et al., 2000). The scoring system followed the method described by Collins and colleagues (2000): symptom scores were computed as the average of frequency, severity and distress, the total MSAS score was calculated as the average symptoms scores, and the Global Distress Index (GDI) was scored as the average of the frequency scores for feeling sad, worrying, feeling irritable and feeling nervous, and the distress scores of the remaining symptoms. The mean symptoms scores ranged between 1.72 (±0.64) for "lack of appetite" and 2.28(±0.57) for "feeling irritable". The mean of total MSAS score was 1.97 (±0.54) and ranged between 1.22 and 2.93. The mean Global Distress Score was 1.91 (±0.7) representing moderate distress level.

Figure 6 Symptoms Count and Means of the Symptom Scores

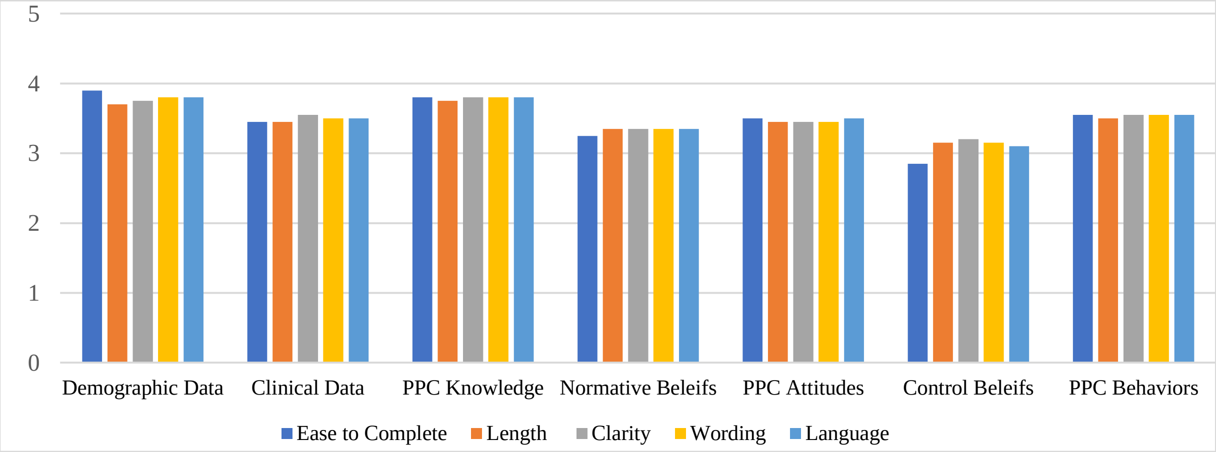


Symptom score is the composite of means of the three symptom dimensions (frequency, severity and distress) (Collins et al., 2000)

3. *Participants' Feedback on the questionnaire*

At the end of each section, the researcher asked the participants to rate each section for level of difficulty, appropriateness of length, clarity, wording, and language used. A four point-Likert scale was used (1=Very difficult, 2=Difficult, 3=Easy, 4=Very easy and 1=Very inappropriate, 2=Inappropriate, 3=Appropriate, 4=Very appropriate). In addition, the researcher inquired whether participants had any suggestions for improvement by indicating any specific problematic item in a given section or by recommending addition or deletion of items to the section. Additionally, the researcher inquired about the participants' understanding of some items to check whether the intended concept was conveyed. As illustrated in Figure 7, the participants positively evaluated the different sections of the questionnaire. Almost all the means of the different survey sections were above three, with a standard deviation ranging between 0.3 and 0.6. Only the "Control Beliefs" section was more difficult than other sections with a mean score of *M*=2.85 ± 0.67. As explained by participants, this section includes "deep items. It makes us think. You asked about what we are living everyday". As such, the section might have elicited participants' reflection on their experience before giving their answer, thus leading to this rating. Table 9 summarizes the participants' comments on the sections and on the entire survey.

Figure 7 Participants' Feedback on the Survey Sections



Rating scale for the ease to complete: 1=Very difficult, 2=Difficult, 3=Easy, 4=Very easy. Rating scale for length: 1=Very inappropriate, 2=Inappropriate, 3=Appropriate, 4=Very appropriate.

Table 9 Participants' Feedback on the Survey Sections (*N*=20)

Survey Sections	Level of Difficulty *M (SD)*	Appropriateness *M (±SD)*				Recommendations/Comments
		Length *M (SD)*	Clarity *M (SD)*	Wording *M (SD)*	Language *M (SD)*	
Demographic Data	3.9 (0.30)	3.7 (0.47)	3.75 (0.44)	3.8 (0.41)	3.8 (0.41)	None
Child's Clinical Data	3.45 (0.51)	3.45 (0.51)	3.55 (0.51)	3.5 (0.51)	3.5 (0.51)	None
PPC Knowledge	3.8 (0.41)	3.75 (0.44)	3.8 (0.41)	3.8 (0.41)	3.8 (0.41)	"Just ask if they (the treating team) are good or not" (P6) "Decrease the length" (P7)
Normative Beliefs	3.25 (0.63)	3.35 (0.67)	3.35 (0.67)	3.35 (0.67)	3.35 (0.67)	None
Attitudes toward PPC	3.5 (0.51)	3.45 (0.51)	3.45 (0.51)	3.45 (0.51)	3.5 (0.51)	"The section brings nice information" (P7) "There is some repetition. PPC should be also implemented after the end-of-life" (P8)
Control Beliefs	2.85 (0.67)	3.15 (0.48)	3.2 (0.52)	3.15 (0.48)	3.1 (0.44)	"Add item: Awareness of parent how to deal with a child" (P3) "Add item: Family problems" (P7) "Add item: Financial issues" "The items are deep, they make you think" (P11) "We need to explain the reason for our answer"(P12) "You are asking about what we are living everyday" (P14) "Add item: Individualized care facilitates PPC" (P17)
PPC Behaviors	3.55 (0.51)	3.5 (0.51)	3.55 (0.51)	3.55 (0.51)	3.55 (0.51)	None
Additional Comments	"I want to say to the parents of other children with cancer to take things positive" (P2) "Questions are very smooth, I enjoyed participating" (P10) "I usually don't pray. Praying now would be strange for my child and maybe he would be afraid that something dangerous will happen"(P12) "We want palliative care to be implemented at the center and for all kids. We perform the task intuitively, training is needed" (P17) "The questions are very beneficial, and increase in difficulty, but I like them. The study is very important for all patients"(P19)					

M=Mean, *SD*=Standard Deviation, PPC=Pediatric Palliative Care, P=participant

4. *Preliminary Analysis of the Outcome of Interest*

In order to respond to the research main purpose to examine knowledge attitudes and beliefs toward palliative care, a preliminary analysis of the outcomes of interest was conducted. The research questions were addressed through descriptive analysis and correlation analysis using non-parametric tests due to the small sample size (*N*=20).

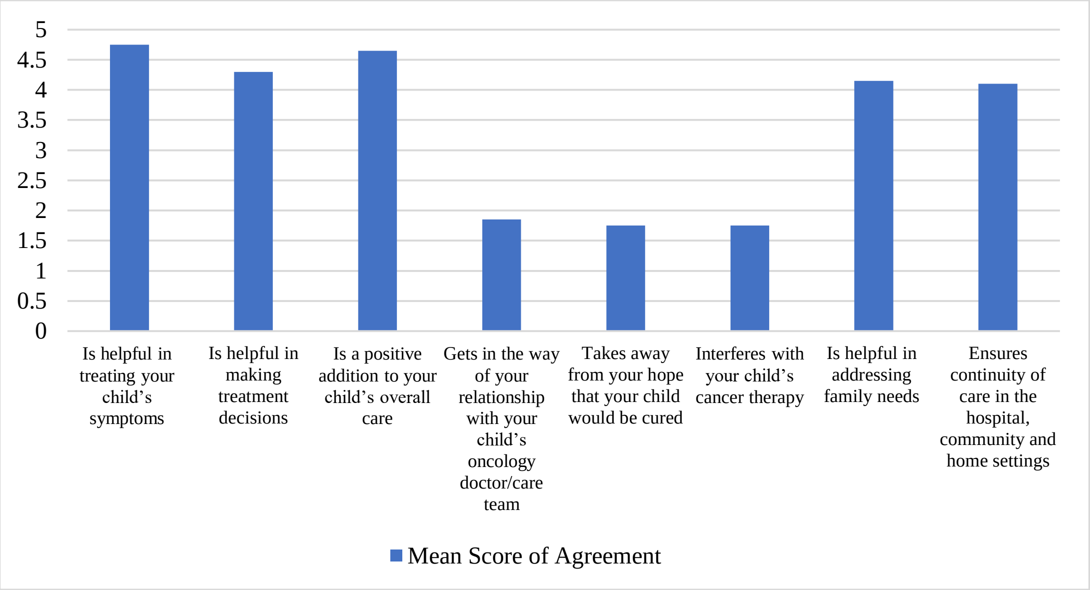
a. <u>Normative beliefs.</u> As defined by Ajzen (1989) normative beliefs refer to the "likelihood that important referent individuals or groups would approve or disapprove of performing the behavior" (p.252). In this study, normative beliefs were defined as the parents' views about the approval of the healthcare team on focusing on the child's quality of life. The participants in the pilot study unanimously agreed or strongly agreed (*N*=20, 100%) that the treating team approves focusing on the quality of life of the child with cancer.

b. <u>Knowledge about PPC.</u> The question about the distribution of knowledge about PPC was addressed by calculating the percentage of participants who reported completely correct answers on the Palliative Care Knowledge Scale (PaCKS) developed by Kozlov and colleagues (2017). The adaptation of the PaCKS required the addition of four items to the initial 13 items to fit the pediatric context. As such the reporting of this scale described the scores of the initial scale (PaCKS-13 items) and the adapted scale (PaCKS-17 items). Out of the 20 participants, only four (20%) have heard about PPC and two of them (10%) had a previous experience with such care. When considering the original PaCKS 13-item version and the version with 17 items, only two of four participants who have heard about PPC had complete correct answers. The PaCKS 17-item version scores ranged from 13 to 17.

The majority of participants (75%) stated that they would seek Internet sites (such as Google) as the first source of information about PPC whereas 25% would seek healthcare providers first.

c. Attitudes about PPC.The second research question pertained to the attitudes of primary caregivers toward PPC for children with cancer. The attitude section included 14 items, eight of which address the PPC benefits and the remaining six pertain to the timing of PPC integration. The 14 items together contribute to the total attitude score. In the presentation of data, PPC benefits and timings were illustrated separately. When given a brief description of PPC, all of the participants (*N*=20, 100%) demonstrated positive attitude (Mean attitude above 4). The median attitude scores was 4.4 and *IQR*= 4.28-4.5 (*M*=4.4±0.2). Participants expressed agreement or strong agreement on statements regarding PPC benefits. Figure 8 displays the mean of agreement of each benefit statement. When computing the PPC attitude score, negatively worded items were reverse coded; however, the initial coding was presented in the picture for clarity purposes.

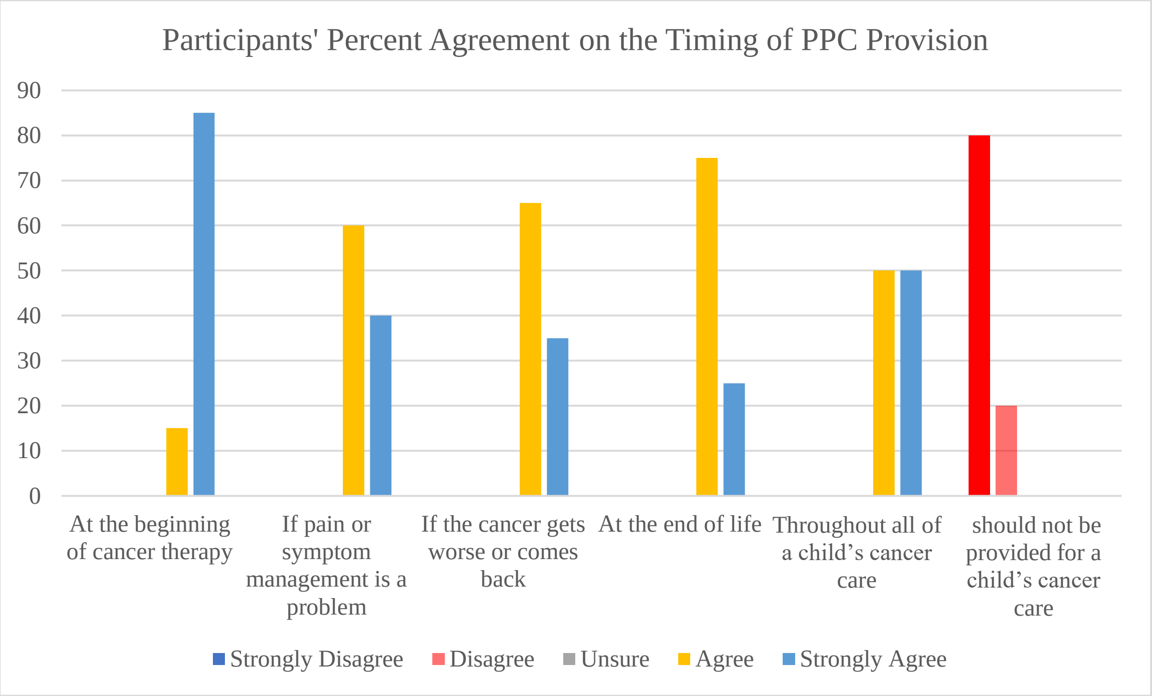
Figure 8 Mean of Agreement on Statements of Attitude toward PPC



Rating scale for PPC Attitude: 1=Strongly disagree, 2=Disagree, 3=Unsure, 4=Agree, 5=Strongly agree

Figure 9 summarizes the distribution of the levels of agreement of participants regarding the timing for providing PPC as recommended by participants. As presented, all of the participants endorsed PPC integration in all phases of treatment and disagreed or strongly disagreed on not providing PPC. Interestingly, 85% strongly agreed on integrating PPC "at the beginning of cancer therapy while 25% strongly agreed on the timing "at the end-of-life".

Figure 9 Participants’ Percent Agreement on the Timing for Providing PPC



d. <u>Control Beliefs.</u> Participants identified several barriers and facilitators to introducing PPC in their child’s care. Participants were asked to rate 12 items on a scale ranging from 1=“makes it very difficult” to 5= “makes it very easy” to integrate PPC. The items with low mean were considered barriers and items with high mean were considered facilitators. “Religious and spiritual commitment” was the most frequent factor rated as “makes it very easy” to integrate PPC”, as rated by 55% of participants as “makes it very easy to integrate PPC”. Fifteen percent rated “Overwhelming negative emotions” as “makes it very difficult”. The mean ratings of facilitators and barriers are presented table 10.

Table 10 Barriers and Facilitators to PPC (*N*=20)

Barrier/Facilitator	*M*	*SD*
Knowledge about PPC	4.45	±0.51
Religious and spiritual engagement	4.45	±0.68
Support and good communication with my child's clinical team	4.4	±0.50
Certainty about my child's prognosis	4.3	±0.47
Believing that I am a good parent	4.2	±0.52
Awareness of the my child's suffering	4.15	±0.48
Desire to shield others from bad news	2.95	±0.88
Involvement of larger family members in treatment decisions about my child's care	2.9	±1.21
Unrealistic belief in probability of cure	2.6	±0.88
Lack of understanding of my child's medical condition	2.45	±0.88
Discomfort talking about death	2.35	±0.81
Overwhelming negative emotions	1.9	±0.44

Rating Scale: 1=Makes it very difficult, 2=Makes it difficult, 3=Unsure, 4=Makes it easy, 5=Makes it very easy

e. <u>PPC Behaviors.</u> When asked about PPC activities performed during the last week, participants described their involvement in various PPC tasks, reported as frequency. On average, participants engaged in 24 out of 31 activities *IQR*=23-27), which implies a considerable involvement in PPC provision. The median of intention to participate in activities not performed over the last week was 3.03 (*IQR*=2.64-3.03). As such, performing PPC was not conditioned by knowing about PPC, as one of the participants mentioned "these tasks are intuitive" and she recommended to train parents to better provide PPC tasks.

f. <u>Factors influencing KAB.</u> Given the small sample size, non-parametric tests were performed to identify the factors influencing KAB. *Fisher's Exact test* was conducted for comparing proportions and *Mann-Whitney* or *Kruskall-Wallis* for comparing means and Spearman *rho* for calculating correlations.

i. PPC Awareness and perceived level of Knowledge. In the pilot sample, the child's current treatment was significantly associated with PPC awareness and perceived level of knowledge (*p*=0.032). Parents of children receiving palliative care perceived that they had "some knowledge about PPC". Likewise, the type of treatment was significantly associated with experience with PPC (*p*=0.032 and 0.01 for chemotherapy and palliative care, respectively). None of the continuous independent variables was found to be associated with PPC awareness. Normality checks were performed between groups and *t-test* was conducted when assumptions were met. The current child's age was significantly lower among participants who have never heard about PPC (*M*=8.4±5.9 years) when compared to those who were familiar with PPC (*M*=12.2±2.0years), with *t(18)*=-2.3 (*p*=0.038), *95% CI* for mean difference (-7.31; -0.23).

ii. Attitude toward PPC. The distribution of attitude scores differed significantly by the child's prognosis (*p*=0.022). Dunn's multiple comparison revealed that participants reporting "very high chance of cure" (*m*=4.42) or "not high chances of cure" (*m*=4.53) for their child expressed significantly higher endorsement to PPC than those who reported that the chance of cure was "somewhat high".

iii. Beliefs about PPC. Correlation analyses were conducted for the continuous demographic and clinical variables to check their associations with beliefs about PPC. Caregiving duration was found to be significantly negatively associated with control beliefs (*rho*=-0.45; *p*=0.04). In addition, the data suggests a significant negative association between normative beliefs and PPC intentions (*rho*=-0.46, *p*=0.04). These results suggest that a longer disease journey may contribute to lower perceived individual control over PPC integration. In addition, caregivers who acknowledge the team's focus on quality of life may be less willing to engage in PPC tasks, possibly due to their reliance on the team.

5. Challenges

The first phase of this research faced several challenges in the recruitment and data collection. Many of these challenges were beyond the researcher's ability to anticipate or control. In particular, the unstable political and economic situation of the country impacted the study process. Table 11 describes the obstacles and solutions implemented or suggested.

Table 11 Challenges and Solutions in Pilot Testing

Challenges	Solutions
Recruitment	
The initially proposed approach used flyers posted in treatment areas and snowballing technique (through electronic poll). - The number of flyers allowed per unit ranged from two to four in specific the spots that, at times, hindered adequate visibility. - Three participants submitted their phone number through snowballing technique (via electronic poll). - The culture of research is still shy in the Lebanese setting, leading to underestimating the contribution of an individual subject to the study. - Subjects lacked the initiative to call a stranger (the researcher), which might have prevented them from participating despite their interest in the study. - The country's circumstances might have contributed to removing participation from subjects' priorities. People are trying to secure basic needs for survival (food, fuel, electricity, medications, etc…). Participating in research seemed to be awkward during the crises.	An amendment to IRB was sent to add the below to the previously approved recruitment strategy: 1- Direct approach by the researcher (while implementing COVID precautions) 2- Recruitment through a member of the treating team 3- Posting on social media platforms
Data collection Procedure	
Data was collected via whatsapp video or voice calls. - Power cuts from the participant or researcher's side delayed participation among five subjects - Many interruptions encountered during interviews due to the suboptimal internet bandwidth - Suboptimal connectivity prevented video calls, so regular whatsapp calls conducted instead. - Several participants actually requested to turn their camera off to enhance privacy. - The duration of three interviews bypassed the limit of 60 minutes. Participants wanted to elaborate on their thoughts and share their experience.	Offer the choice of doing the interview via video or audio whatsapp call based on participant's preference and connectivity.

D. Conclusion

The pilot phase of this study yielded promising results regarding the validity of the instruments measuring KAB toward PPC and shed light on areas for improving the care. The expert review and pilot testing supported the use of the questionnaire in the main study. Feedback for expert panel was integrated to reword some items for clarity. In the pilot study, some participants suggested adding items in the control beliefs section and PPC tasks. However, the researcher opted to keep the same number of items in the questionnaire for two reasons. The questionnaire already included 112 items, therefore additional items may increase participation burden. Moreover, the participant's suggestions varied as highlighted in the qualitative feedback. As such, the availability of "other" option in the control beliefs and PPC tasks and the "comments" sections were deemed adequate alternatives to accommodate additional suggestions as needed.

The pilot study highlighted a lack in PPC knowledge among participants. Nevertheless, all primary caregivers in the pilot study had positive attitude about PPC after receiving a brief definition. Participants identified several barriers and facilitators to integrating PPC and described their involvement in PPC tasks despite their poor or inaccurate knowledge about the care. Participating in the study was by itself a learning experience for the participants and it valued their role in relieving their child's suffering and promoting the child's quality of life.

CHAPTER VI

RESULTS OF PSYCHOMETRIC ANALYSIS

This chapter responds to the specific study aim to test the psychometric properties of instruments used in the study to measure primary caregivers' attitudes and beliefs toward PPC. Specifically, the chapter reports the results of additional psychometric testing related to structural validity and reliability testing of PPC attitude, beliefs and behaviors scales. Psychometric testing was conducted on the data from the 105 participants of the main study. As planned, the Exploratory Factor Analysis (EFA) was conducted to determine structural validity of the PPC attitudes and Control Beliefs scales. In addition, the internal consistency of these sections was examined by calculating Cronbach's alpha (α) reliability coefficients. Inter-item correlations and item ranges were analyzed to explore the relationships between items as well as examine any ceiling or floor effects. For PPC Behaviors and intentions, inter-item correlations and item range were examined.

A. PPC Attitudes Scale

1. Exploratory Factor Analysis (EFA)

For conducting EFA, the following steps were performed: extraction, rotation and interpretation. The data extraction method used for the PPC Attitudes scale was Maximum Likelihood. The number of factors extracted was determined according to eigenvalues above one and an elbow in the scree plot.

As shown in Table 12, five factors have eigenvalue above one, explaining 47% of the total variance. Figure 10 illustrates the scree plot of the eigenvalues of the factors.

Table 12 Total Variance Explained of the PPC Attitudes scale

	Initial Eigenvalues			Extraction Sums of Squared Loadings		
Factor	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %
1	3.117	22.265	22.265	1.414	10.100	10.100
2	1.726	12.332	34.597	1.203	8.594	18.694
3	1.414	10.099	44.696	2.180	15.569	34.264
4	1.192	8.513	53.209	.934	6.675	40.939
5	1.146	8.188	61.396	.858	6.130	47.068
6	.994	7.097	68.494			
7	.864	6.169	74.663			
8	.786	5.617	80.280			
9	.630	4.499	84.779			
10	.547	3.904	88.683			
11	.495	3.533	92.217			
12	.412	2.943	95.160			
13	.372	2.660	97.820			
14	.305	2.180	100.000			

Extraction Method: Maximum Likelihood.

Figure 10 Scree Plot for PPC Attitude Scale

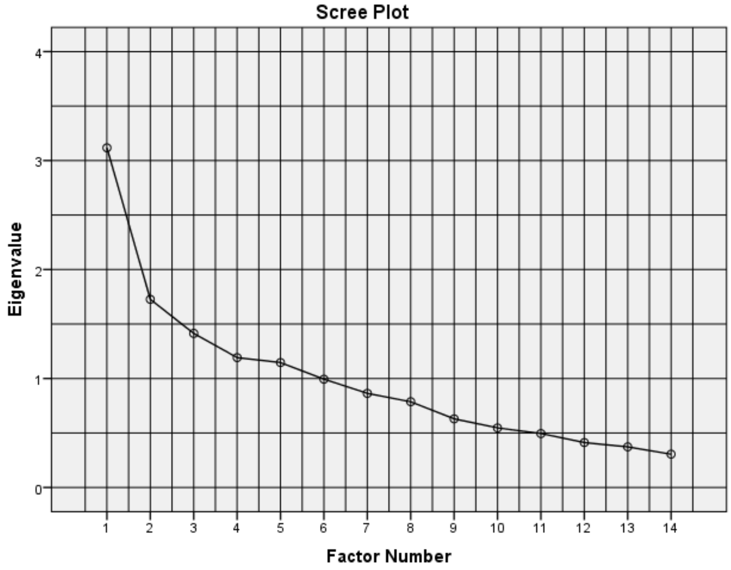


Table 13 illustrates the proportion of variance in each item that can be explained by the factors. For example, 65.4% of the variance in item number 1 ("Including PPC is helpful in treating your child's symptoms") is explained by the factors.

Table 13 Proportion of Variance in Items of the PPC Attitudes Scale

Communalities

	Initial	Extraction
Including PPC is helpful in treating your child's symptoms	.387	.654
Including PPC is helpful in making treatment decisions	.342	.279
Including PPC is a positive addition to your child's overall care	.241	.999
Including PPC is helpful in addressing family needs	.266	.246
Including PPC ensures continuity of care in the hospital, community and home settings	.235	.237
At the beginning of cancer therapy	.348	.999
If pain or symptom management is a problem	.195	.173
If the cancer gets worse or comes back	.263	.294
At the end of life	.422	.776
Throughout all of a child's cancer care	.382	.386
Gets in the way (recoded)	.325	.458
Takes away hope (recoded)	.329	.263
Interferes with therapy (recoded)	.354	.547
Should not be provided (recoded)	.309	.281

The Kaisar-Meyer-Olkin Measure (*KMO*) equals 0.62, and the Bartlett test of sphericity is significant (*p*=0.000). A *KMO* of at least 0.5 is appropriate to conduct EFA (Yong & Pearce, 2013). A significant *Bartlett test* indicates that there is correlation between the items. Oblique rotation was done with Promax. When attempting Varimax (orthogonal) rotation, the same items loaded on the same factors as in oblique rotation. However, Promax was preferred in line with the assumption that the factors may be related. There was a weak to moderate positive correlations between the factors based on the factor correlation matrix as shown in Table 14.

Table 14 Correlations between Factors in PPC Attitude Scale

Factor Correlation Matrix

Factor	1	2	3	4	5
1	1.000				
2	.340	1.000			
3	.090	-.053	1.000		
4	.362	.259	.261	1.000	
5	.160	.158	.032	.257	1.000

Table 15 illustrates results of the EFA with Maximum Likelihood and Promax rotation with Kaiser Normalization; five factors could be retained with their loading values. Factor loading values above 0.4 were bolded.

Table 15 Factor Loading Values in PPC Attitude Scale

Pattern Matrix	Factor				
	1	2	3	4	5
At the end of life	**.935**	-.052	-.105	-.120	-.017
If the cancer gets worse or comes back	**.498**	.065	.092	-.146	.166
Should not be provided (recoded)	**.457**	.034	.000	.111	-.250
If pain or symptom management is a problem	.318	-.016	-.044	.196	-.008
Throughout all of a child's cancer care	.313	-.056	.292	.283	.048
Including PPC is helpful in addressing family needs	.273	.183	-.006	.190	.044
Interferes with therapy (recoded)	-.036	**.719**	-.126	.014	.057
Gets in the way (recoded)	-.014	**.691**	.078	-.015	-.047
Takes away hope (recoded)	.165	**.405**	.071	.049	.009
At the beginning of cancer therapy	-.028	.002	**1.018**	-.078	.016
Including PPC is helpful in treating your child's symptoms	.008	-.080	-.091	**.801**	.127
Including PPC ensures continuity of care in the hospital, community and home settings	-.039	.109	-.025	**.483**	-.075
Including PPC is helpful in making treatment decisions	-.110	.022	.301	.398	-.087
Including PPC is a positive addition to your child's overall care	-.021	.009	.003	.023	**.995**

Extraction Method: Maximum Likelihood. Rotation Method: Promax with Kaiser Normalization.
Bolded numbers represent factor loading value above 0.4

Ten items had loading values more than 0.4 and four items below 0.4: "If pain or symptom management is a problem", "Throughout all of a child's cancer care", "Including PPC is helpful in addressing family needs", "Including PPC is helpful in making treatment decisions". These results warrant reconsidering the inclusion of these four items in the scale. When factor loading value is decreased to 0.3, two additional items would then load on factor 1 ("If pain or symptom management is a problem", "Throughout all of a child's cancer care") and one item on factor 4 ("Including PPC is helpful in making treatment decisions"). Moreover, "Including PPC is helpful in addressing family needs" would be the only item than does not load on any factor. These results suggest removing one item from the scale and attempting EFA with larger sample size. In fact, a larger sample size would allow smaller loading values for a factor to be considered statistically significant. Specifically, larger samples help detect statistically significant lower percentage of overlapping variance, which is the squared factor loading value (Yong & Pearce, 2013). As such, a larger sample size may yield clearer results on the items to be retained.

Moreover, the third and fifth factor had only one item each. These items were included under other factors where they conceptually fit or where they loaded next. Consequently, the final structure includes three factors. The single item loading on the third factor (“At the beginning of cancer therapy”) conceptually fits the timing can be included under factor 1 as all the items loading on this factor reiterate PPC timing. Moreover, the single item loading on the fifth factor (“Including PPC is a positive addition to your child overall care”) can be included under factor 4 as the next factor where it loaded. In addition, this item conceptually relates to PPC benefits and can be included under factor 4 where the items reiterate the same concept.

When aligning EFA results with the conceptual relationships between items, the items can be grouped into a three-factor solution including “PPC timing”, “PPC misconceptions”, and “PPC benefits”. The item that did not load on any factor (“Including PPC is helpful in addressing family needs”) could fit conceptually under “PPC benefits”. The items related to “PPC timing” are: “at the beginning of cancer therapy”, “at the end-of-life”, “if the cancer gets worse or comes back”, “should not be provided for a child with cancer”, “if pain or symptom management is a problem” and, “throughout all of a child’s cancer care”. The items related to “PPC benefits” are: “including PPC is helpful in addressing family needs”, “including PPC is helpful in treating your child’s symptoms”, “including PPC ensures continuity of care in the hospital, community and home settings”, “including PPC is helpful in making treatment decisions”, and “including PPC is a positive addition to your child’s overall care”. The items related to “PPC misconceptions” are: “interferes with therapy”, “gets in the way of cancer treatment”, and “takes away hope”.

To note, the reproduced correlation matrix indicates that the model is fit since there are 14 (15%) nonredundant residuals with absolute value greater than 0.05. The cutoff of nonredundant residuals is 50% (Yong & Pearce, 2013). Accordingly, the results of the EFA are promising, however, further analysis with larger sample size is useful.

2. Internal Consistency, Cronbach Alpha (α).

The PPC Attitudes Scale includes 14 items completed by all study participants (*N*=105). The calculation of Cronbach’s α yielded a coefficient value of 0.702. Table 16 displays that the value of α =0.702 (average measures) was highly statistically significant ($p<0.01$) and *95% CI* is 0.612-0.780. Such results indicate that the items in the PPC Attitudes scale are measuring one latent variable.

Table 16 Internal Consistency Coefficient of PPC Attitudes Scale

	Intraclass	95% Confidence Interval		*F* Test with True Value 0			
	Correlation^b	Lower Bound	Upper Bound	Value	df1	df2	Sig
Single Measures	.144^a	.101	.202	3.359	104	1352	.000
Average Measures	.702^c	.612	.780	3.359	104	1352	.000

When taking into consideration the EFA results, Cronbach α of each factor are not appropriate. Table 17 displays the Cronbach α of each of the three factors identified when factor loading is 0.4 and 0.3 are used respectively, and when items are grouped conceptually and based on EFA. All the Cronbach α coefficients of individual factors are below 0.7 (not acceptable). Therefore, the scale as a whole seems to be more reliable for use since a higher reliability coefficient is obtained when all items are grouped together.

Table 17 Cronbach α of Factors in PPC Attitudes Scale

	Factor Loading = 0.4	Factor Loading = 0.3	Items Grouped Conceptually and Based on EFA
Factor 1 “PPC Timing”	0.604* At the end of life If the cancer gets worse or comes back Should not be provided (recoded)	0.650* At the end of life If the cancer gets worse or comes back Should not be provided (recoded) If pain or symptom management is a problem Throughout all of a child’s cancer care	0.511* At the end of life If the cancer gets worse or comes back Should not be provided (recoded) If pain or symptom management is a problem Throughout all of a child’s cancer care At the beginning of cancer therapy
Factor 2 “PPC Misconceptions”	0.637* Gets in the way (recoded) Takes away hope (recoded) Interferes with therapy (recoded)	0.637* Gets in the way (recoded) Takes away hope (recoded) Interferes with therapy (recoded)	0.637* Gets in the way (recoded) Takes away hope (recoded) Interferes with therapy (recoded)
Factor 3 “PPC Benefits”	0.481* Including PPC is helpful in treating your child’s symptoms Including PPC ensures continuity of care in the hospital, community and home settings	0.478* Including PPC is helpful in treating your child’s symptoms Including PPC ensures continuity of care in the hospital, community and home settings Including PPC is helpful in making treatment decisions	0.534* Including PPC is helpful in treating your child’s symptoms Including PPC ensures continuity of care in the hospital, community and home settings Including PPC is helpful in making treatment decisions Including PPC is helpful in addressing family needs Including PPC is a positive addition to your child’s overall care

*Significant ($p<0.01$)

For further analysis, changes in Cronbach α of the entire scale were checked if we delete any of the items. As shown in Table 18. If we delete the items “Including PPC is helpful in making treatment decisions” and “At the beginning of cancer therapy” alpha becomes 0.712 and 0.705 respectively. Cronbach α of the entire scale became 0.727 (p=0.000) after deleting the two items. As the increase is slight and in order to maintain all the aspects of PPC within the attitude scale, all items will be kept.

Table 18 Cronbach α If Item Deleted of PPC Attitudes Scale

Item-Total Statistics

	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Squared Multiple Correlation	Cronbach's Alpha if Item Deleted
Including PPC is helpful in making treatment decisions	56.98	11.480	.215	.342	.712
At the beginning of cancer therapy	56.26	12.520	.166	.348	.705

3. Inter-Item Correlations

The inter-item correlation coefficients of the entire PPC Attitudes items were calculated as illustrated in Table 19. Every item correlated at least with one other item of the scale, with acceptable correlation values ranging between 0.15 and 0.5 (Paulsen & BrckaLorenz, 2017). This indicates that the items measure the same construct without being repetitive.

The same calculations were performed for the items that loaded on factor 1 “PPC timing”, factor 2 “PPC misconceptions”, and factor 3 “PPC benefits” identified in the EFA (Tables 20, 21 and 22 respectively). All correlations were within the acceptable range.

Table 19 Inter-Item Correlation Matrix for the Entire PPC Attitudes Scale

Inter-Item Correlation Matrix

	1	2	3	4	5	6	7	8	9	10	11	12	13	14
Including PPC is helpful in treating your child’s symptoms	1.000													
Including PPC is helpful in making treatment decisions	**.332***	1.000												
Including PPC is a positive addition to your child’s overall care	**.331***	.021	1.000											
Including PPC is helpful in addressing family needs	**.289***	.106	**.167***	1.000										
Including PPC ensures continuity of care in the hospital, community and home settings	**.333***	**.151***	.068	**.258***	1.000									
At the beginning of cancer therapy	.065	**.364***	.030	.026	.051	1.000								
If pain or symptom management is a problem	**.198***	.122	.089	.128	**.265***	.005	1.000							
If the cancer gets worse or comes back	.109	.006	**.215***	**.235***	-.007	.083	**.151***	1.000						
At the end of life	.143	-.029	.078	**.341***	.055	-.087	**.324***	**.429***	1.000					
Throughout all of a child’s cancer care	**.365***	**.168***	**.175***	.128	**.245***	**.360***	**.225***	**.244***	**.281***	1.000				
Gets in the way (recoded)	.105	.128	.064	**.242***	.076	.019	.065	**.166***	**.154***	.059	1.000			
Takes away hope (recoded)	**.185***	-.138	.116	**.264***	**.172***	.054	.052	.121	**.230***	**.215***	**.327***	1.000		
Interferes with therapy (recoded)	.090	.027	**.170***	**.189***	**.174***	**-.180***	.139	.144	.145	.052	**.477***	**.319***	1.000	
Should not be provided (recoded)	.131	.099	-.145	.109	.088	.029	**.167***	**.197***	**.392***	**.298***	.037	**.272***	.148	1.000

Bolded items with (*) indicate Inter-Item Correlation within the acceptable range of 0.15 to 0.5 (Paulsen & BrckaLorenz, 2017)

Table 20 Inter-Item Correlation Matrix for “PPC timing” Factor in PPC Attitude Scale

	If the cancer gets worse or comes back	At the end of life	Should not be provided (recoded)
If the cancer gets worse or comes back	1.000		
At the end of life	**.429***	1.000	
Should not be provided (recoded)	**.197***	**.392***	1.000

Bolded items with (*) indicate Inter-Item Correlation within the acceptable range of 0.15 to 0.5 (Paulsen & BrckaLorenz, 2017)

Table 21 Inter-Item Correlation Matrix for “PPC misconceptions” in PPC Attitude Scale

	Gets in the way (recoded)	Takes away hope (recoded)	Interferes with therapy (recoded)
Gets in the way (recoded)	1.000		
Takes away hope (recoded)	**.327***	1.000	
Interferes with therapy (recoded)	**.477***	**.319***	1.000

Bolded items with (*) indicate Inter-Item Correlation within the acceptable range of 0.15 to 0.5 (Paulsen & BrckaLorenz, 2017)

Table 22 Inter-Item Correlation Matrix for “PPC Benefits” Factor in PPC Attitudes Scale

	Including PPC is helpful in treating your child’s symptoms	Including PPC ensures continuity of care in the hospital, community and home settings	Including PPC is helpful in making treatment decisions
Including PPC is helpful in treating your child’s symptoms	1.000		
Including PPC ensures continuity of care in the hospital, community and home settings	**.333***	1.000	
Including PPC is helpful in making treatment decisions	**.332***	**.151***	1.000

Bolded items with (*) indicate Inter-Item Correlation within the acceptable range of 0.15 to 0.5 (Paulsen & BrckaLorenz, 2017)

4. Item Range

Ceiling and floor effects of different items of the PPC Attitudes Scale were explored. Only two items had ceiling effect i.e. 75% of participants answered with the highest item scoring. These two items were from the PPC Attitudes section: “Including PPC is a positive addition to the child’s care” (79%), and “I recommend integrating PPC at the beginning of treatment" (75.2%). No floor effect was obtained on any of the tested items.

5. Additional Analysis

In order to explore all the possibilities in the PPC attitude structure, the approach of conducting EFA after reliability analysis was performed. Three items yielding better Cronbach's alpha and items with ceiling effect were removed from the scale. Based on the reliability analysis, the items producing improved alpha were: "Including PPC is helpful in making treatment decisions" and "I recommend integrating PPC at the beginning of cancer therapy". The items with ceiling effect were: "Including PPC is a positive addition to the child's care" and "I recommend integrating PPC at the beginning of cancer therapy". No redundant items were found as the inter-item correlations were all below 0.5.

The EFA using Maximum likelihood with Promax rotation yielded three factors reiterating the same concepts obtained when all items were included (PPC timing, PPC benefits and PPC misconceptions. The *KMO* was 0.718 and the *Bartlett sphericity test* was significant Barlett was significant (*p*=0.000). The structure explained 51.8% of the total PPC attitudes variance. As illustrated in Table 23 seven items had a loading value above 0.4. Two additional items loaded with 0.386 and 0.394, they were: "Should not be provided for a child with cancer" and "PPC Takes away hope". However, two items that did not load on any factor ("Integrating PPC is helpful in addressing family needs", "I recommend to integrate PPC if pain or symptom management is a problem"). Removing the items that did not load or items with weak loading would miss important aspects of the PPC concept. Retaining these items is relevant for the conceptual fit.

Table 23 Factor Loading Values in PPC Attitude Scale with EFA after Reliability Analysis

Pattern Matrix			
	Factor		
	1	2	3
At the end of life	**.998**	-.033	-.128
If the cancer gets worse or comes back	**.445**	.090	-.023
Should not be provided (recoded)	.386	-.009	.131
If pain or symptom management is a problem	.279	-.039	.256
Including PPC is helpful in addressing family needs	.243	.212	.214
Gets in the way (recoded)	-.004	**.756**	-.092
Interferes with therapy (recoded)	-.012	**.660**	-.002
Takes away hope (recoded)	.102	.394	.164
Including PPC is helpful in treating your child's symptoms	-.017	-.014	**.643**
Including PPC ensures continuity of care in the hospital, community and home settings	-.114	.054	**.584**
Throughout all of a child's cancer care	.201	-.098	**.487**

Extraction Method: Maximum Likelihood. Rotation Method: Promax with Kaiser Normalization.
Bolded numbers represent factor loading value above 0.4

Based on the psychometric analysis, the PPC Attitude scale will be used as a whole as one scale, even though, some items had weak loading values or did not load on EFA. The reliability testing highlighted the scale's unidimensionality when the 14 items are measured together. Retaining all items enhanced the inclusiveness of all aspects of PPC and served conceptual fit. Therefore, for the statistical analysis, one PPC Attitude score will be computed based on the means of all items. The items of this scale were adapted from a previous study conducted by Levine and colleagues (2017). No published data was found regarding factor analysis of the original scale. Therefore, the items and scoring system were modified in the current study to allow reliability and validity analysis that was not published for the original scale.

B. Control Beliefs Scale

1. Exploratory Factor Analysis

For the Control Beliefs scale, the factors were extracted using the Maximum Likelihood method also. As shown in Table 24, five factors have eigenvalue above 1, explaining 37.3% of the total variance. The scree plot in shown in Figure 11.

Table 24 Total Variance Explained in Control Beliefs Scale

Total Variance Explained

	Initial Eigenvalues			Extraction Sums of Squared Loadings		
Factor	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %
1	1.854	15.453	15.453	1.255	10.462	10.462
2	1.483	12.355	27.808	1.106	9.219	19.681
3	1.340	11.167	38.975	.883	7.356	27.036
4	1.193	9.943	48.918	.686	5.714	32.750
5	1.007	8.389	57.308	.555	4.623	37.373
6	.975	8.125	65.433			
7	.944	7.865	73.298			
8	.838	6.987	80.286			
9	.735	6.127	86.412			
10	.614	5.113	91.526			
11	.565	4.708	96.234			
12	.452	3.766	100.000			

Extraction Method: Maximum Likelihood.

Figure 11 Scree Plot for Control Beliefs Scale

Table 25 illustrates the proportion of variance in each item that can be explained by the factors. For example 30% of item number 4 "Knowledge about PPC" is explained by the factor.

Table 25 Proportion of Variance in Items of Control Beliefs Scale

Communalities[a]		
	Initial	Extraction
Certainty about my child's prognosis	.111	.170
Awareness of the my child's suffering	.131	.120
Support and good communication with my child's clinical team	.131	.265
Knowledge about PPC	.143	.304
Believing that I am a good parent	.143	.999
Religious and spiritual engagement	.122	.160
Lack of understanding of my child's medical condition	.227	.999
Unrealistic belief in probability of cure	.145	.372
Overwhelming negative emotions	.228	.268
Desire to shield others from bad news	.116	.090
Discomfort talking about death	.103	.183
Involvement of larger family members in treatment decisions about my child's care	.121	.554

Extraction Method: Maximum Likelihood.

The *KMO*=0.497 (below 0.5) and the *Bartlett sphericity test* is significant (*p*=0.01). Thus, although the items seem correlated, the data do not seem to be fit for factor analysis

(Yong & Pearce, 2013). As the scale included barriers and facilitators to PPC, separate EFAs were attempted for each of the subscales separately. All items answered as “making it easy” or “making it very easy” to integrate PPC by at least 50% of participants, were classified as facilitators. For those items, *KMO* was 0.572 and Barlett was not significant (*p*=0.082). Therefore, EFA is not appropriate. The remaining items were classified as barriers since they were answered by at least half participants as “making it difficult” or “making it very difficult” to integrate PPC. The *KMO* was 0.507 and *Barlett* was significant (*p*=0.004). Data of the barriers subscale were extracted using Principal Component Analysis. Table 26 displays that three factors have eigenvalue above one, explaining 63.4% of the total variance. Figure 12 illustrates the scree plot of the factors in PPC barriers.

Table 26 Total Variance Explained for the Barriers to PPC Integration

Total Variance Explained

	Initial Eigenvalues			Extraction Sums of Squared Loadings		
Component	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %
1	1.578	26.302	26.302	1.578	26.302	26.302
2	1.199	19.990	46.291	1.199	19.990	46.291
3	1.030	17.162	63.453	1.030	17.162	63.453
4	.878	14.639	78.091			
5	.762	12.703	90.795			
6	.552	9.205	100.000			

Figure 12 Scree Plot for Barriers to PPC Integration

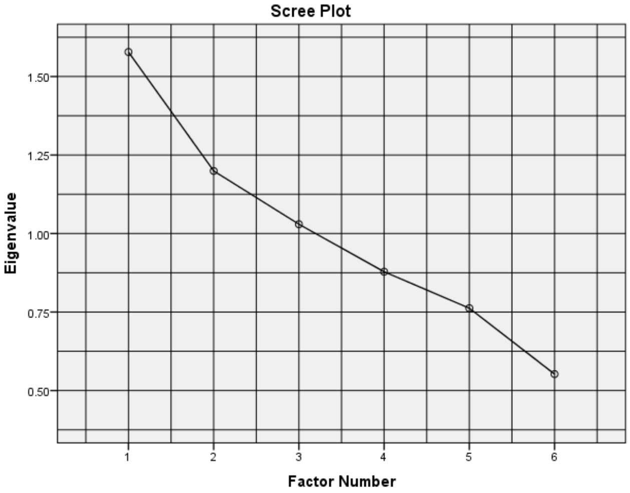


Table 27 illustrates the proportion of variance in each item that can be explained by the factors. For example 70.4% of the variance in item number 1 ("lack of understanding") is explained by the factors.

Table 27 Proportion of Variance in Items of the Barriers scale

Communalities

	Initial	Extraction
Lack of understanding of my child's medical condition	1.000	.704
Unrealistic belief in probability of cure	1.000	.485
Overwhelming negative emotions	1.000	.646
Desire to shield others from bad news	1.000	.707
Discomfort talking about death	1.000	.741
Involvement of larger family members in treatment decisions about my child's care	1.000	.525

The *KMO* of the barriers subscale is considered "miserable" (Kaiser, 1974, p. 35). Moreover, the model was not fit since there are 12 (80%) non-redundant residuals with absolute value greater than 0.05. As such, EFA is not adequate for barriers subscale.

2. Internal Consistency: Cronbach's alpha (α)

The Control Beliefs Scale includes 12 items that measure the barriers and facilitators to integrating PPC at the individual level. The scale was completed by all participants (*N*=105). Cronbach *α* value for the whole scale was 0.278 (95% CI [0.057, 0.476]). Therefore, the same calculations were repeated separately for the items intended to measure facilitators and barriers. The Cronbach *α* values improved, yet, they remained below the desired value (*Cronbach α* for facilitators=0.376, 95% CI [0.171, 0.544], *Cronbach α* for barriers=0.326, 95% CI [0.105, 0.508]). Even if items were deleted the values remained low. These results were expected given the small number of items within each factor. Moreover, the results highlighted that the items measure different concepts. Further testing is needed either by performing item analysis or cognitive interviewing, or increasing the sample size or using other reliability testing methods such as temporal stability.

3. Inter-Item Correlations

As previously planned, testing for the inter-item correlations was conducted on the Control Beliefs Scale. As shown in Table 28, every item correlated at least with one other item of the scale with acceptable but modest correlations ranging from 0.15 to 0.5.

Table 28 Inter-Item Correlation Matrix Control Beliefs Scale

	Certainty about my child’s prognosis	Awareness of the my child’s suffering	Support and good communication with my child’s clinical team	Knowledge about PPC	Believing that I am a good parent	Religious and spiritual engagement	Lack of understanding of my child’s medical condition	Unrealistic belief in probability of cure	Overwhelming negative emotions	Desire to shield others from bad news	Discomfort talking about death	Involvement of larger family members in treatment decisions about my child’s care
Certainty about my child’s prognosis	1.000											
Awareness of the my child’s suffering	-.013	1.000										
Support and good communication with my child’s clinical team	.060	.144	1.000									
Knowledge about PPC	.080	**.196***	**.197***	1.000								
Believing that I am a good parent	**.189***	-.102	-.028	.010	1.000							
Religious and spiritual engagement	**.154***	.104	.090	.081	**.204***	1.000						
Lack of understanding of my child’s medical condition	.104	**-.152***	.025	-.112	.027	-.038	1.000					
Unrealistic belief in probability of cure	.042	-.095	-.147	.107	-.107	-.079	**.177***	1.000				
Overwhelming negative emotions	-.072	-.055	**-.176***	-.137	.092	**-.156***	**.351***	**.164***	1.000			
Desire to shield others from bad news	.082	.135	.107	.012	.073	-.049	**.158***	.081	-.048	1.000		
Discomfort talking about death	.081	-.024	**-.153***	.012	.101	-.060	-.014	**.162***	.104	.007	1.000	
Involvement of larger family members in treatment decisions about my child’s care	**.158***	-.050	-.095	**-.156***	.032	.080	.113	.035	.085	-.117	**.189***	1.000

Bolded items with (*) indicate Inter-Item Correlation within the acceptable range of 0.15 to 0.5 (Paulsen & BrckaLorenz, 2017)

Tables 29 and 30 display the correlation matrices of the facilitators' items and barriers items separately. As expected, few acceptable correlations existed between the items.

Table 29 Inter-Item Correlation Matrix of PPC Facilitators

	Certainty about my child's prognosis	Awareness of my child's suffering	Support and good communication with my child's clinical team	Knowledge about PPC	Believing that I am a good parent	Religious and spiritual engagement
Certainty about my child's prognosis	1.000					
Awareness of the my child's suffering	-.013	1.000				
Support and good communication with my child's clinical team	.060	.144	1.000			
Knowledge about PPC	.080	**.196***	**.197***	1.000		
Believing that I am a good parent	**.189***	-.102	-.028	.010	1.000	
Religious and spiritual engagement	**.154***	.104	.090	.081	.204	1.000

Bolded items with (*) indicate Inter-Item Correlation within the acceptable range of 0.15 to 0.5 (Paulsen & BrckaLorenz, 2017)

Table 30 Inter-Item Correlation Matrix of PPC Barriers

	Lack of understanding of my child's medical condition	Unrealistic belief in probability of cure	Overwhelming negative emotions	Desire to shield others from bad news	Discomfort talking about death	Involvement of larger family members in treatment decisions about my child's care
Lack of understanding of my child's medical condition	1.000					
Unrealistic belief in probability of cure	**.177***	1.000				
Overwhelming negative emotions	**.351***	**.164***	1.000			
Desire to shield others from bad news	**.158***	.081	-.048	1.000		
Discomfort talking about death	-.014	**.162***	.104	.007	1.000	
Involvement of larger family members in treatment decisions about my child's care	.113	.035	.085	-.117	**.189***	1.000

Bolded items with (*) indicate Inter-Item Correlation within the acceptable range of 0.15 to 0.5 (Paulsen & BrckaLorenz, 2017)

4. Item Range for Control Beliefs Scale.

Ceiling and floor effects of different items were explored. No floor or ceiling effect was obtained on any of the tested items. In fact, the highest percentage of participants who answered “makes very difficult” was 33.3% for “overwhelming negative emotions”. In addition, the highest percentage of participants who answered “makes it very easy” to integrate PPC was 71.4% for “Religious and spiritual engagement”.

The analysis did not support the use of control beliefs scale as a measure of one concept. However, a summative total score will be used in the analysis of outcomes to fit the conceptual framework of the study.

C. PPC Behaviors and Intentions

As planned, inter-item correlations between the items of the PPC Behaviors scale were examined. In fact, the items were adapted from “Care of My Child with Cancer” (CMCC) (Wells et al., 2002) and other items added to fit the study purpose. The original CMCC version uses five-point Likert for the amount of time and the degree of effort associated with each caregiving task. As such, the data of the original scale allowed for calculating Cronbach alpha and inter-item correlations for internal consistency analysis. However, in the present study, the scoring of items was binary, therefore, inter-item correlations were more useful to report for internal consistency testing since Cronbach’s alpha is essentially designed for continuous variables (DeVellis, 2017). Table 31 shows that the items have at least one correlation within the acceptable range of 0.15 to 0.5. The item range of the PPC intention part was also evaluated. No items revealed floor or ceiling effect.

Table 31 Inter-Item Correlation Matrix of PPC Behaviors

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	24	26	27	28
Planning activities for the family	1.000																											
Planning activities for the ill child	**.507***	1.000																										
Following up with the treatment team (such as phone calls)	.113	.086	1.000																									
Meeting the emotional needs of my spouse	**.319***	**.320***	.131	1.000																								
Meeting my own emotional needs	-.107	-.102	-.088	.017	1.000																							
Meeting the emotional needs of other children in my family	**.154***	**.193***	.004	.035	.034	1.000																						
Meeting the emotional needs of my extended family	.021	-.094	-.071	.090	.114	.045	1.000																					
Managing painful events	.082	-.018	-.039	**-.204***	.038	-.045	.064	1.000																				
Getting information about the child's illness	.147	**.199***	**.252***	.083	.020	.108	**-.156***	.086	1.000																			
Communicating about the child's illness	**-.191***	-.122	.032	-.111	.100	.064	.025	.139	**.192***	1.000																		
Disciplining the ill child	.026	-.038	-.054	.040	-.124	.134	**.284***	-.004	-.112	**.162***	1.000																	
Managing finances	.062	.018	.107	.126	-.078	.062	-.008	-.108	.078	**-.205***	-.061	1.000																
Managing the side effects of treatment	-.035	-.082	.085	.080	.074	.035	.032	.061	.083	**.190***	.040	.028	1.000															
Giving medications by mouth	-.058	-.037	.133	**.171***	-.046	-.038	-.045	-.095	-.099	-.032	-.061	-.062	**.171***	1.000														
Managing other childhood illnesses	.124	.041	-.032	**.151***	.116	.120	-.006	-.064	.047	**.156***	.073	-.079	.062	.087	1.000													
Attending medical appointments	**.224***	**.227***	-.147	.116	-.094	.068	-.091	-.094	.098	-.065	-.123	-.016	.116	-.020	**.176***	1.000												
Additional household tasks	.090	.023	**-.172***	.035	-.039	.011	.045	**-.213***	**-.284***	.064	**.196***	.000	.035	-.038	**.177***	.068	1.000											
Managing unexpected events	.080	.012	-.049	.063	-.020	-.137	**.165***	**.327***	-.031	-.066	.026	-.129	-.027	.080	.063	-.041	-.023	1.000										
Obtaining child care for the siblings	**.202***	.110	**.159***	.016	.006	**.474***	-.036	-.005	.103	-.042	-.022	-.034	-.035	**.167***	**.212***	-.117	-.103	-.009	1.000									
Obtaining child care for my ill child	-.036	-.018	**.299***	.090	.114	.119	-.073	-.038	.147	.025	-.055	-.008	-.085	**.216***	.096	-.091	-.104	-.093	**.368***	1.000								
Managing medical devices such as feeding pump	.007	-.082	-.076	.059	.062	.010	-.088	.094	-.102	-.043	-.094	**.151***	.120	.042	-.001	.084	.010	.032	-.054	**-.159***	1.000							
Praying with my child	**.155***	.070	-.054	.107	.062	**.284***	-.063	-.065	-.082	-.055	.075	.065	**.167***	-.043	.128	.048	**.208***	**-.169***	**.155***	.006	-.029	1.000						
Taking decisions related to my child's care	**.248***	.123	.099	.140	-.119	.138	.136	.064	**.337***	.003	.039	.098	-.052	-.148	-.001	.132	**-.288***	.135	.058	.082	-.108	.010	1.000					
Sharing my experience with similar parents	.053	.043	**.205***	-.085	-.050	-.038	-.036	-.005	.103	.106	.075	-.083	.016	-.058	.080	.111	.090	-.009	.003	.079	.007	-.022	-.084	1.000				
Reminding my child about medical precautions	.111	.076	-.043	.001	-.094	**.215***	-.091	-.094	**-.201***	-.065	.100	.094	-.114	-.020	-.025	-.040	**.361***	**-.244***	.111	-.091	.084	**.453***	**-.192***	-.003	1.000			
Telling medical information to my child	**.163***	-.059	-.005	-.090	**-.189***	.063	.003	.038	.064	.064	.085	.022	.123	-.052	-.089	.015	.063	-.085	.005	-.119	.032	**.267***	**.151***	**-.154***	**.376***	1.000		
Getting more information about PPC	.102	-.091	-.059	.097	-.033	.020	-.132	.093	**.173***	.099	**.189***	.043	.018	.030	**.210***	.061	-.080	.028	.102	-.041	-.035	-.050	-.055	.024	-.117	-.002	1.000	
Discussing PPC with my child's healthcare team	-.030	-.109	.127	-.034	.081	-.101	.078	-.062	**.173***	.056	-.022	.108	.098	.017	-.036	.034	.067	-.140	-.030	.078	-.073	-.080	.011	.101	.034	.091	**.356***	1.000

Bolded items with (*) indicate Inter-Item Correlation within the acceptable range of 0.15 to 0.5 (Paulsen & BrckaLorenz, 2017)

D. Summary

In conclusion, the study findings yielded useful results on the validity and reliability of the instruments measuring KAB toward PPC and shed light on areas for improving these measures. The EFA of PPC attitude scale revealed a three-factor solution with satisfactory internal consistency coefficient. The data restricted the psychometric analysis on PPC control beliefs items and behavior items. Enhancement of these two sections is needed to improve their performance as research instruments.

CHAPTER VII

RESULTS OF THE MAIN STUDY

The main phase of the research study was conducted using a cross-sectional descriptive quantitative design (Hulley et al., 2013). This chapter presents the findings related to the study outcomes divided into three sections. The first section includes the descriptive analysis and addresses the following two specific aims: to describe the current KAB toward PPC among primary caregivers of children with cancer, and to identify the primary caregivers' tasks in PPC. The second section responds to the study specific aim to determine demographic and clinical factors associated with primary caregivers' KAB toward PPC services. As this aim is exploratory, bivariate analysis and regression analyses are presented. The third section of the chapter presents the participants' overall comments on the study.

A. Descriptive Analysis

The main study phase was carried out between August 16, 2021 and November 1, 2021. One hundred and five out of 110 primary caregivers of children with cancer agreed to participate from the three study sites (response rate=95.4%). Subjects stated lack of time or lack of interest as reasons for refusal. Participants completed interviews via WhatsApp call on mutually agreed date and time with the researcher. On average, the interviews were completed within less than 45 minutes (*M*=42.2 ± 12.2 minutes).

1. Demographic Characteristics

Table 32 and Table 33 illustrate the demographic characteristics of the participants and children respectively. The majority of participants (84.8%) in the main study sample consisted of mothers, homemakers (63.8%) and from the Muslim religion (81%). More than half of the participants (58%) were younger than 40 years (*M*=37.6±7.6 years) and had high school degrees or above (56%). Sixty percent of participants reported a monthly income that doesn't meet their basic needs and around one third reported being able to meet their basic needs. More than half (53.3%) of primary caregivers in the study live in rural areas in Lebanon. Families included, as a median, four members (*IQR*=3-5) were living with the child in the same house.

Table 32 Demographic Characteristics of the Sample (*N* = 105)

Variable	Number	Percentage
Gender		
Female	89	84.8%
Male	16	15.2%
Relationship to the Child		
Biological Parent	103	98.1%
Other (Aunt, Sister)	2	1.9%
Age (years) (Mean=37.6±7.6 years*)*		
Below 30	16	15.2%
30-39	45	42.8%
40-49	37	35.3%
Above 50	7	6.7%
Marital Status		
Married	95	90.5%
Separated/Divorced	7	6.7%
Widowed	2	1.9%
Single	1	0.9%
Nationality		
Lebanese	94*	89.5%
Non-Lebanese (Syrian/Iraqi/Palestinian)	11	10.5%
Highest Educational Level		
Below Grade School	21	20.0%
Grade School	25	23.8%
High School	17	16.2%
University	31	29.5%
Graduate School	11	10.5%
Area of Residence		
Urban	49	46.7%
Rural	56	53.3%
Religion		
Christian	15	14.3%
Muslim	85	81.0%
Druze	5	4.7%
Employment Status		
Employed	23	21.9%
Homemaker	67	63.8%
Unemployed	4	3.8%
Other (Student/Retired/Freelancer)	11	10.5%
Monthly Income		
Doesn't meet basic needs	63	60.0%
Meets basic needs	38	36.2%
Exceeds basic needs	4	3.8%

*Two participants hold other nationalities (Armenian and Syrian) in addition to the Lebanese nationality

As for the children of primary caregivers in the sample, more than half were female (59%) and their age ranged for the majority between 5 and 15 years (*Median*=7, *IQR*=4.5-12 years).

Table 33 Children's Demographic Characteristics (*N* = 105)

Variable	Number	Percentage
Child's Gender		
Female	62	59.0%
Male	43	41.0%
Child's Current Age (years)		
(Median=7, *IQR*=4.5-12 years)		
Below 5	28	26.7%
5-10	40	38.1%
11-15	20	19.0%
Above 15	17	16.2%

2. Clinical Characteristics of Children with Cancer

Almost half of the children of study participants (49.5%) were diagnosed with Leukemia. The majority of children were receiving chemotherapy (93%) and were either in remission or had active disease (78.1%). As reported by the participants, only two children with cancer (1.9%) were receiving palliative therapy. More than three quarters of parents (81%) reported that the chances of cure for their child is either very high (50.5%) or somewhat high (30.5%). The children's age upon diagnosis ranged between 1 month and 16.9 years (*Mean* = 6.2 ± 4.5years). The *Median* caregiving duration was 1.5 years (*IQR*= 0.5-3 years). Children required on average 8.7 hours of care daily (*SD*=5.7 hours).

More than half of the children (*N*=62, 59.1%) experienced at least four symptoms in the last week. As represented in Table 34, feeling irritable, lack of appetite, nausea, and pain were the most prevalent symptoms. The means of symptom scores ranged between 1.2 ± 0.5 for "cough" and 2.1 ± 0.7 for "feeling irritable". The mean of total MSAS score was 1.8 ± 0.45 and ranged between 0.67 and 3.48. The mean Global Distress Score was 1.9 ± 0.4.

Table 34 Symptoms Prevalence and Symptom Scores

Symptom	Prevalence *N* (%)		Symptom Score *Mean* ±*SD*
Feeling irritable	64	(61.0%)	2.1 ± 0.7
Lack of appetite	49	(46.7%)	1.7 ± 0.6
Nausea	47	(44.8%)	1.8 ± 0.6
Pain	44	(41.9%)	2.0 ± 0.6
Worrying	41	(39.0%)	1.9 ± 0.6
Feeling sad	40	(38.1%)	1.8 ± 0.6
Lack of energy	36	(34.3%)	1.8 ± 0.6
Cough	36	(34.3%)	1.2 ± 0.5
Feeling nervous	34	(32.4%)	2.0 ± 0.6
Difficulty Sleeping	18	(17.1%)	2.0 ± 0.7

Symptom score is the composite of means of the three symptom dimensions (frequency, severity and distress) (Collins et al., 2000)

3. Study Outcomes

The study outcomes included categorical and continuous measures. Table 35 illustrates these outcomes with the number of items measuring each outcome, the level of measurement, the scoring system and the number of respondents.

Table 35 Study Outcomes

Primary Outcome	Elements	Number of Items	Level of measurement	Scoring System	Number of respondents
PPC Knowledge	PPC Awareness	1	Categorical	Binary	105
	Perceived level of knowledge	1	Categorical	Three categories	105
	Palliative Care Knowledge Scale (Original scale)	13	Continuous	Summative Score	18
	Palliative Care Knowledge Scale (Adapted version)	17	Continuous	Summative Score	18
	Experience with PPC	1	Categorical	Binary	18
PPC Attitude	-	14	Continuous	Mean Score	105
PPC Beliefs	Normative Beliefs	1	Continuous	Mean Score	105
	Control Beliefs	12	Continuous	Summative Score	105
PPC Behaviors	-	31	Categorical	Summative Score	105
PPC Intentions	-	31	Continuous	Mean Score	105

PPC=Pediatric Palliative Care

a. PPC Knowledge. Out of the 105 participants, only 18 (17.1%) reported having heard about PPC and nine of them (8.6% of the study sample) had a previous experience with such care. More than half of participants (*N*=60, 57.1%) reported that they would seek Internet sites (such as Google) as the first source of information about PPC. On the other hand, over one third (35.2%) would seek healthcare providers first to learn about PPC.

Among participants who have heard about PPC (*n*=18), seventeen (94.4%) reported having some knowledge about PPC and only one participant reported being "very knowledgeable about PPC". The remaining participants (*n*=87) who have never heard about palliative care reported that they "know nothing at all" about the care.

The Palliative Care Knowledge Scale (PaCKS) was completed only by participants who reported knowledge about PPC to measure the accuracy of their knowledge (Kozlov et al., 2017). The adaptation of the PaCKS required the addition of four items to the original 13 items to fit the pediatric context. As such the reporting of this scale included the scores of the initial scale (PaCKS-13 items) and the adapted scale with the four additional items (PaCKS-17 items). One third (*n*=6) of the 18 participants who have heard about PPC had complete correct answers on the PaCKS scale, both when considering the 13 and the 17 scale versions. The PaCKS items scores are illustrated in Table 36. Five items were correctly answered by all 18 participants on the PaCKS 13-item version. The frequency of wrong answers ranged from one to six participants on four items for the 13-item version and six for the 17-item version. The proportion of "I don't know" answers ranged from 5.5% to 27.7% on ten items out of 17 items. One third of participants who have heard about palliative care linked it "exclusively" to the end-of-life period. Five out of 18 participants were unsure whether palliative care helps understanding treatment options. Within the four added items, 11.2% of respondents thought that PPC treats only physical symptoms. Around 17% of participants did not know whether PPC is integration early in cancer diagnosis. A similar proportion also did not know whether PPC can be provided despite limited resources.

Table 36 Palliative Care Knowledge Scale Items Scores (*N* = 18)

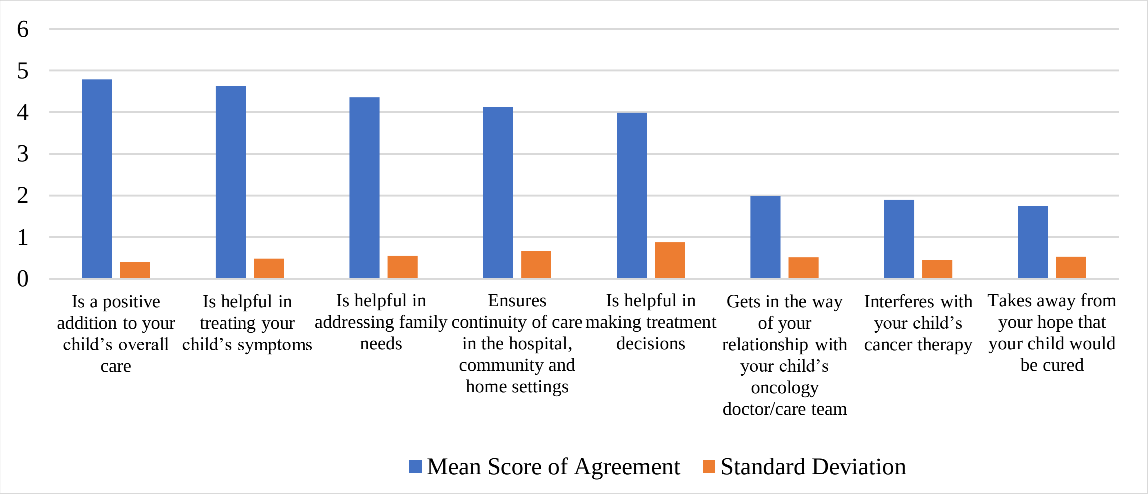
Items	Scores		
	Correct answers	Wrong Answers	I don't know
One goal of palliative care is to address any psychological issues brought up by serious illness (T)	16 (88.8%)	1 (5.5%)	1 (5.5%)
Stress from serious illness can be addressed by palliative care (T)	16 (88.8%)	-	2 (11.2%)
Palliative care can help people manage the side effects of their medical treatments (T)	15 (83.3%)	-	3 (16.7%)
When people receive palliative care, they must give up their other doctors (F)	17 (94.4%)	-	1 (5.5%)
Palliative care is exclusively for people who are in the last months of life (F)	10 (55.5%)	6 (33.4%)	2 (11.2%)
Palliative care is specifically for people with cancer (F)	18 (100%)	-	-
People must be in the hospital to receive palliative care (F)	16 (88.8%)	-	2 (11.2%)
Palliative care is designed specifically for older adults (F)	18 (100%)	-	-
Palliative care is a team-based approach to care (T)	15 (83.3%)	1 (5.5%)	2 (11.2%)
One goal of palliative care is to help people better understand their treatment options (T)	12 (66.8%)	1 (5.5%)	5 (27.7%)
Palliative care encourages people to stop treatments aimed at curing their illness (F)	18 (100%)	-	-
One goal of palliative care is to improve a person's ability to participate in daily activities (T)	18 (100%)	-	-
Palliative care helps the whole family cope with a serious illness (T)	18 (100%)	-	-
	Median score for PaCKS 13-items=12 (*IQR*=10-13)		
Palliative care for children begins when a serious illness is diagnosed (T)	14 (77.7%)	1 (5.5%)	3 (16.7%)
Palliative care for children only alleviates the child's physical suffering (F)	16 (88.8%)	2 (11.2%)	-
Effective palliative care for children is possible even with limited resources (T)	15 (83.3%)	-	3 (16.7%)
Palliative care for children requires family involvement in the care (T)	18 (100%)	-	-
	Median score for PaCKS 17-items=15 (*IQR*=14-17)		

PaCKS=Palliative Care Knowledge Scale, *IQR*=Interquartile Range

The Kuder-Richardson 20 (*KR*-20) coefficient was computed to test the PaCKS reliability in the sample. Unsatisfactory reliability coefficients were obtained with the PaCKS original 13-item version (*KR-20*=0.490, *p*=0.019) and with the adapted 17-item version (*KR-20*=0.634, *p*=0.001). It is worth mentioning that the only 18 participants completed the PaCKS scale. In addition, six items had zero variance as they were correctly answered by all participants who were aware of palliative care. A larger sample size would yield more useful results on the PaCKS reliability.

b. <u>PPC Attitude.</u> When given a brief description of PPC the majority of participants (*N* = 98, 93.3%) demonstrated positive attitudes (*Mean* attitude above 4). The mean attitude score was *M* = 4.3 (*SD* = 0.2). Participants expressed their level of agreement on statements regarding PPC benefits and misconceptions. Figure 13 displays the mean agreement of each statement. When computing the PPC attitude score, negatively worded items were reverse coded, however; the initial coding was presented in the picture for clarity purposes.

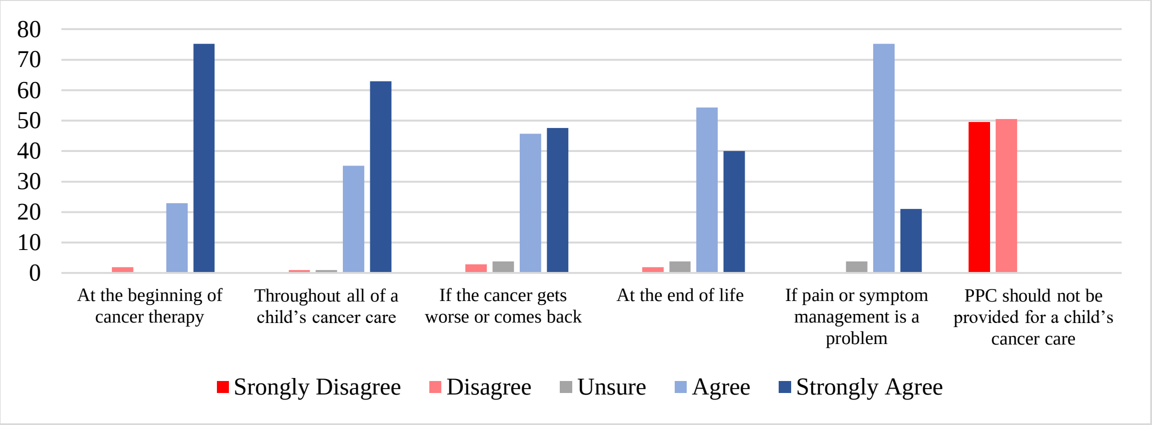
Figure 13 Mean of Agreement and Standard Deviation on Statements of PPC Benefits



Rating scale for PPC Attitude: 1=Strongly disagree, 2=Disagree, 3=Unsure, 4=Agree, 5=Strongly agree

Figure 14 summarizes the distribution of levels of agreement of participants with the timing for providing PPC. As presented, the majority of participants endorsed PPC integration in all phases of the disease trajectory, and disagreed or strongly disagreed on not providing PPC. Interestingly, three quarters of participants strongly agreed on integrating PPC at the beginning of therapy, while less than half (40%) strongly agreed to provide the PPC services at the end-of-life.

Figure 14 Percentage of Participants' Levels of Agreement on PPC Timings



c. <u>Normative Beliefs.</u> As defined by Ajzen (1989) normative beliefs refer to the "likelihood that important referent individuals or groups would approve or disapprove of performing the behavior" (p.252). In this study, normative beliefs were defined as the parents' views on the approval of the healthcare team of focusing on the child's quality of life. The vast majority of the main study participants (*N*=92, 87.6%) agreed or strongly agreed that the treating team approves on focusing on the quality of life of the child with cancer.

d. <u>Control Beliefs.</u> The Control Beliefs score ranged from 34 to 49 (*M* = 39.5±2.9). Participants rated several factors as barriers or facilitators to introducing PPC in their child's care. Participants were asked to rate 12 items on a five-point Likert scale ranging from 1="makes it very difficult" to 5= "makes it very easy" to integrate PPC. The items with low mean were considered barriers and items with high mean were considered facilitators. "Religious and spiritual commitment" was the most frequent factor rated as "makes it very easy" to integrate PPC (*N*= 75, 71.4%). "Overwhelming negative emotions" was the most frequent strong barrier as reported by one third of the participants. Table 37 summarizes the mean scores and standard deviations of each factor in the "Control Beliefs" section.

Table 37 Barriers and Facilitators to PPC (*N*=105)

	M	*SD*
Facilitators		
Religious and spiritual engagement	4.60	±0.70
Support and good communication with my child's clinical team	4.53	±0.52
Knowledge about PPC	4.50	± 0.53
Believing that I am a good parent	4.39	±0.56
Certainty about my child's prognosis	4.27	±0.64
Awareness of the my child's suffering	4.02	±0.63
Barriers		
Desire to shield others from bad news	2.70	±0.96
Involvement of larger family members in treatment decisions about my child's care	2.50	±1.22
Lack of understanding of my child's medical condition	2.14	±0.72
Unrealistic belief in probability of cure	2.08	±0.66
Discomfort talking about death	2.05	±0.68
Overwhelming negative emotions	1.76	±0.70
Summative Control Beliefs Score	39.5	±2.9

PPC=Pediatric Palliative Care

Several participants added other factors that may facilitate or challenge PPC integration. As reported by participants, additional facilitators include: smooth relationship with the child (raised by two participants), marital agreement on how to treat the child, mental and financial support from larger family and friends, emotional support for the parents, peer support for the child, family's level of education, availability of specialized PPC team (raised by two participants), acceptance of the situation by the child, close family ties, support from other parents in similar condition, and adjustment in the chemotherapy protocols for foreigners by using flexibility in the treatment schedule to be able to spend more time at their home country.

The additional barriers reported were: family problems and disagreement between the parents (raised by three participants), the child's young age, inadequate childrearing manners such as neglect or abuse, excessive details about the child's conditions, being surrounded by negative people who always criticize, lack of resources, the parents' overwhelming concerns to meet the basic needs of the child and family, the consecutive country's disasters/instability (strike and revolution, Beirut blast, fuel and economic crisis) (raised by two participants). Adding the above items suggested by participants may help in future improvement of the Control Beliefs scale in terms of structural validity and reliability.

e. PPC Behaviors and Intentions. When asked about PPC tasks performed during the last week, on average, participants reported engaging in 22.1 activities (*SD*=2.8) out of 31. The mean of intentions to participate in activities not performed over the last week was 2.79 (*SD* =0.50) out of 5. Table 38 displays the prevalence of activities and the intention score when activities are not performed.

Table 38 PPC Tasks and PPC Intentions (*N*=105)

PPC Task	Prevalence		PPC Intentions	
	n	*(%)*	*M*	± SD
Meeting the emotional needs of my ill child	105	(100%)	-	-
Maintaining my child's comfort	105	(100%)	-	-
Obtaining necessary equipment and medications	105	(100%)	-	-
Giving medications by mouth	104	(99.0%)	2.00	-
Attending medical appointments	101	(96.2%)	2.50	± 1.732
Reminding my child about medical precautions	101	(96.2%)	2.75	±1.500
Communicating about the child's illness	95	(90.5%)	2.60	± 0.843
Planning activities for the ill child	92	(87.6%)	3.00	± 1.080
Meeting the emotional needs of other children in my family	91	(86.7%)	2.67	± 0.577
Additional household tasks	91	(86.7%)	3.21	± 1.369
Praying with my child	88	(83.8%)	2.77	±1.013
Meeting the emotional needs of my extended family	87	(82.9%)	2.39	± 0.850
Obtaining child care for my ill child	87	(82.9%)	2.00	± 0.816
Meeting my own emotional needs	86	(81.9%)	2.95	± 1.026
Telling medical information to my child	82	(78.1%)	2.31	± 0.630
Managing the side effects of treatment	79	(75.2%)	2.46	± 0.761
Meeting the emotional needs of my spouse	79	(75.2%)	3.12	± 0.928
Planning activities for the family	78	(74.3%)	3.00	± 0.980
Sharing my experience with similar parents	78	(74.3%)	2.33	± 0.961
Obtaining child care for the siblings	78	(74.3%)	1.60	± 0.548
Disciplining the ill child	76	(72.4%)	2.00	± 0.667
Managing finances	75	(71.4%)	2.40	±1.070
Following up with the treatment team (such as phone calls)	68	(64.8%)	2.70	± 0.909
Managing painful events	54	(51.4%)	2.02	± 0.510
Getting information about the child's illness	52	(49.5%)	2.36	± 0.982
Managing other childhood illnesses	46	(43.8%)	2.02	± 0.397
Managing unexpected events	42	(40.0%)	2.54	± 0.803
Taking decisions related to my child's care	32	(30.5%)	2.19	± 0.791
Managing medical devices such as feeding pump	16	(15.2%)	1.86	± 0.378
Getting more information about PPC	9	(8.6%)	3.97	± 0.814
Discussing PPC with my child's healthcare team	3	(2.9%)	3.55	± 0.897

PPC=Pediatric Palliative Care

Participants also added to the above list other activities they performed during the previous week as follows: studying with the child/preparing for school (mentioned by 12 participants), walking in the nature (mentioned by two participants), cooking with the child (mentioned by two participants), doing physiotherapy sessions, visiting grandparents, and talking with the child about the future "dreaming of tomorrow".

B. Factors Associated with Study Outcomes

Bivariate and regression analyses were conducted to identify significant associations of demographic and clinical variables with the outcomes of interest. For the bivariate analysis, parametric tests were used whenever assumptions are met. Non-parametric alternatives were sought in case of small number of respondents or violation in test assumptions. For the regression analysis, variables that had a *p*-value below 0.1 in the bivariate analyses were included in the multivariable models when applicable. The categorical variables with more than two categories were dichotomized as illustrated in Table 39.

Table 39 Dichotomized Variables for Regression Analysis

Categorical variable	Dichotomized Variable	Number of respondents per category
Marital Status	Married	n=95
	Others	n=10
Level of Education	Below high school	n=46
	High or above	n=59
Religion	Muslim	n=90
	Others	n=15
Employment Status	Homemaker	n=67
	Others	n=38
Monthly Income	Doesn’t meet basis needs	n=63
	Others	n=42
Child’s Diagnosis	Leukemia/Lymphoma	n=60
	Solid Tumor	n=45
Disease Status	In Remission	n=58
	Others	n=47
Child’s Prognosis	Very high	n=53
	Others	n=52
Perceived level of PPC knowledge	Know	n=18
	Does not know	n=87

When conducting multiple linear regression for continuous outcomes, models’ assumptions were tested to ensure absence of multicollinearity and homoscedasticity, and presence of linearity and normality. In addition, outliers were reported for the models. Muticollinearity was assessed by computing the Variance Inflation Factors (VIF). A VIF greater than five indicated multicollinearity. Homoscedasticity and linearity were assessed visually by the scatter plot of standardized residuals and predicted standardized residuals. Normality of the residuals of the linear regression models was assessed visually and by the Kolmogorov–Smirnov or Shapiro-Wilk normality tests. Standardized residual absolute values greater than 2 were considered outliers.

1. *Factors Associated with PPC Knowledge*

a. PPC Awareness

i. Bivariate analysis.

Among all demographic variables, the participants' level of education was the only variable significantly associated with PPC awareness (Fisher Exact test significance *p*=0.003). Pairwise comparison was conducted with Bonferroni correction. The awareness is a grouping variable with two categories. The level of education includes five categories. As such, ten comparisons were conducted for testing awareness with level of education. The significance level was decreased to 0.005 (for testing PPC awareness) instead of 0.05 in order to adjust for type I error. Post hoc test revealed a significantly lower proportion of PPC awareness among participants with below grade school degree (0%) compared to those who hold graduate degrees (54.5%), with adjusted *p-value* = 0.001. Moreover, there was significant association between PPC awareness and level of education when the latter is dichotomized (Fisher Exact test significance *p*=0.017).

When analyzing clinical variables, PPC awareness was significantly associated with the type of treatment as receiving PPC. All participants whose children are receiving PPC (n=2) reported having heard about PPC. None of the caregivers of children not receiving PPC have heard about PPC (Fisher Exact test significance *p*=0.028).

When tested with other study outcomes, a significant association between PPC awareness and the perceived level of knowledge. All of the participants who have heard about palliative care (n=18) reported knowing about PPC (17 of them "have some knowledge" and one "knows a lot". Whereas participants who did not hear about PPC (n=87) unanimously reported knowing "nothing at all". The proportion of perceived level of knowledge significantly differed between participants reporting having heard about PPC vs those who did not (Fisher Exact test significance *p*-value=0.00).

ii. Regression analysis.

Based on the bivariate analysis, the PPC awareness was significantly associated with level of education, receiving PPC, and perceived level of knowledge. However, the data was not suitable for regression analysis. Peduzzi and colleagues (1996) proposed a formula for minimum sample needed for logistic regression: "N=10 k / p" where k is number of predictors and p smallest proportion of negative or positive cases. In the current study, three possible predicators were identified (k=3). Eighteen out of 105 participants are aware of palliative care (17%). By applying the formula, 176 subjects are needed for conducting logistic regression analysis.

Moreover, the variance within the variables “perceived level of knowledge” (dichotomized) and “receiving PPC” is nonexistent. All participants who know about PPC and whose child is receiving PPC are aware of PPC. As such, the two variables were removed from the model for lack of variability. The model of PPC awareness included then only one predictor: the level of education.

b. Perceived Level of PPC Knowledge

i. Bivariate Analysis

Among all categorical demographic variables, the participants’ level of education was the only variable significantly associated with the perceived level of knowledge (Fisher Exact test significance *p*=0.004). Pairwise comparison was conducted with Bonferroni correction. The level of knowledge is the grouping variable with two categories. The level of education included five categories. As such, 15 comparisons were conducted for testing level of knowledge, with level of education. The significance level was decreased to 0.003 instead of 0.05 in order to adjust for type I error. Post hoc test revealed a significantly lower proportion of participants who had at least some knowledge about PPC among the group with below grade school degree (0%) compared to graduate group (adjusted *p*-value = 0.001). In addition, there was significant association between perceived level of knowledge and level of education when both are dichotomized (*p*=0.003).

When analyzing clinical variables, the level of knowledge was significantly associated with the type of treatment as receiving PPC. All of the participants whose child was receiving palliative care reported having some knowledge or being very knowledgeable about PPC compared to 23% or less in other treatment groups (Fisher Exact test significance *p*= 0.03).

Among the continuous demographic and clinical variables, there was a significant association between the perceived level of knowledge and lack of appetite score (*p*=0.017). On post hoc analysis, the results approached the adjusted significance level: the symptom score for lack of appetite among those who have some knowledge about PPC was lower than the one among participants who knew nothing (adjusted *p*-value=0.055) or who know a lot (adjusted *p*-value=0.051) about PPC. The appetite scores were 2.1 ± 0.09 among those who knew nothing (*n*=43), 1.5 ± 0.13 among those who had some knowledge (*n*=5) and 3 for the only participant reported being very knowledgeable about PPC.

Among the study outcomes, as previously noted, the perceived level of PPC knowledge was significantly associated with PPC awareness. All of the participants who have at least some knowledge about PPC have heard about PPC compared to those who reported having no knowledge (100% vs 0%, *p*-value=0.00).

ii. Regression Analysis

The regression analysis for "perceived level of knowledge" was not performed. The number of observations needed to conduct a logistic regression analysis for the perceived level of PPC knowledge with four predictors is at least 235 (Peduzzi et al., 1996). Moreover, the variance within the variables "PPC awareness" and "receiving PPC" is nonexistent. All participants who are aware about PPC and whose child is receiving PPC know about PPC. As such, the two variables were removed from the model for lack of variability. The model of perceived PPC level of knowledge included then only one predictor: the level of education.

c. Previous Experience with Palliative Care

i. Bivariate Analysis

The variable "Previous experience with PPC" was completed only by participants who have heard about PPC (*N*=18). The Mann-Whitney *U* test revealed a significant association between PPC intentions and PPC experience (*p*=0.029). Participants who lack of experience in PPC had significantly higher median PPC intentions score (*m*=2.87, *IQR*=2.75-4) than their counterparts (*m*=2.62, *IQR*=2.2-2.72) with *95% CI* between 0.33 and 1.26. While the variable "previous experience in PPC" pertains to past exposure, the concept "PPC intentions" entails willingness to future involvement in PPC tasks. It is possible that the participation in the study and the information received about PPC have boosted the participants' intentions to perform PPC tasks in the coming week.

In addition, the data showed a significant difference in control beliefs scores (*p*=0.04) between participants who had personal experience with palliative care (*m*=38, *IQR*=35-39.5) and those who did not (*m*=41, *IQR*=39-42) with *Mann-Whitney U test*=17.5, *p*=0.04.

ii. Regression analysis.

Only 18 participants completed the item on "previous experience with palliative care". The minimum sample size to run a logistic regression for this outcomes with two predictors is 40 (Peduzzi et al., 1996). In order to run this regression we need at least 40 participants to complete this section. Therefore, the analysis was not conducted due to the small sample size.

d. Palliative Care Knowledge Scale

i. Bivariate Analysis.

The Palliative Care Knowledge Scale (PaCKS) score was the objective measure of PPC knowledge. As the scale was completed only by participants who were aware of PPC (*N*=18), non-parametric tests were used to test the score associations with demographic and clinical variables. The number of persons living with the child, caregiving duration, and nausea score were significantly positively correlated with the PaCKS scores (for the original 13-item version and the adapted version with 17 items). These findings suggest a possible influence of child' family status and clinical status on palliative care knowledge.

Moreover, a significant moderate negative correlation was obtained for number of symptoms in the previous week (*p*=0.01) with the PaCKS scores. These results suggest that when parents lack knowledge about PPC, children may experience more symptoms, thus, they may experience more suffering due to these symptoms. The estimate of the Spearman *rho* correlations are illustrated in Table 40 for the PaCKS-13 items and PaCKS-17 items.

Table 40 Significant Correlations between the PaCKS scores

Demographic /clinical variable	PaCKS (13 items) *n*=18		PaCKS (17 items) *n*=18	
	Spearman *rho* Estimate	*p*	Spearman *rho* Estimate	*p*
Number of persons living with the child	0.479^{*}	0.044	0.473^{*}	0.048
Caregiving duration	0.536^{*}	0.022	0.574^{*}	0.013
Number of symptoms in the previous week	-0.583^{*}	0.011	-0.590^{**}	0.010
Nausea score	0.893^{*}	0.016	0.871^{*}	0.024

Note. * $p<0.05$ (2-tailed). ** $p<0.01$ (2-tailed).
Legend: PaCKS=Palliative Care Knowledge Scale

ii. Regression analysis

Based on the bivariate analysis, four possible predictors were identified for the PaCKS score: number of people living with the child, caregiving duration, number of symptoms, and nausea score. Only N=18 participants completed this section whereas the minimum sample size to run a multiple linear regression is $N \geq 50+8(k)$ (k=the number of independent variables) (Green, 1991). In order to run this regression we need at least 90 participants to complete this section. Therefore, the analysis was not conducted due to the small sample size.

2. Factors Associated with Attitude toward PPC

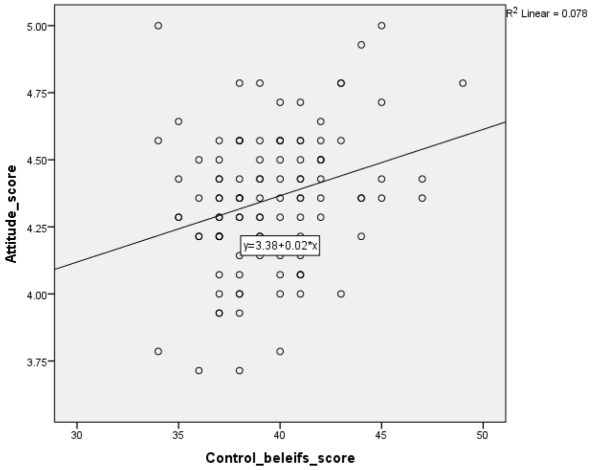
a. Bivariate Analysis.

Among the demographic and clinical variables, PPC attitude scores were significantly correlated with pain scores and this correlation was moderate and negative (r= -0.364, p=0.013). As pain experience increases the attitude toward PPC decreases.

As for correlations with other study outcomes, a significant weak positive correlation was found between “PPC Attitude” and “Normative Beliefs” (*Spearman rho* estimate=0.222, *p*=0.023). These results indicate that when parents recognize that the treating team focuses on quality of life, their attitudes toward PPC is enhanced.

In addition, “PPC Attitude” scores were correlated with “Control Beliefs” scores. Pearson *r* correlation was examined since the scatter plot of the two variables (Figure 15) suggested a linear relationship, and the two variables met the normality assumption. The attitudes scores were highly significantly correlated with control beliefs scores (Pearson *r*=0.279, *p*=0.004). These results indicate that the more parents endorsed palliative care, the higher was their control to integrate it in their child’s care.

Figure 15 Scatter Plot of PPC Attitudes Scores and Control Beliefs Scores



b. Regression Analysis.

The bivariate analysis identified three possible predictors for PPC attitudes: pain score, normative beliefs score, and control beliefs. When dichotomized, religion, had a *p*-value below 0.1 on the bivariate analysis, as such the variable was included in the regression analysis model of PPC attitudes. The initial model was significant

(R^2=0.254, F(4,41)=3.483, p=0.015). However, the variable "religion" was not a statistically significant predictor (p=0.293, 95%CI [-0.114, 0.369]). The variable "religion" was dropped from the model since it did not have an interaction or confounding effect. The regression analysis was conducted again with pain score, normative beliefs score, and control beliefs as predictors. As shown in Table 41 pain score and control beliefs score were significant predictors.

Table 41 Multiple Linear Regression Initial Model for "PPC Attitudes" (N=105)

	Unstandardized Coefficients		Standardized Coefficients		
Variable	B	Std. Error	Beta	*t*	*p*
Pain score	-.151	.058	-.355	-2.620*	.012
Normative beliefs	.012	.040	.042	.308	.760
Control beliefs score	.032	.014	.307	2.238*	.031

Note. Constant=3.354. F(3,42)= 4.252, p=0.010*. R^2=0.233 (adjusted R^2=0.178). * $p< 0.05$ (2-tailed).

Before, removing "normative beliefs" variable, interaction was checked first with pain score then with control beliefs. There was no interaction between normative beliefs and control beliefs (p=0.69, 95%CI [-0.003, 0.085]). The interaction term "normative beliefs*pain score" was significant (p=0.009, 95%CI [0.05, 0.32]). Therefore, an interaction exists between normative beliefs and pain. As such, the interaction term was included in the final model to account for the interaction between the variables. As displayed in Table 42, the new model is highly significant and the variance explained in attitude score was improved to 35.3% when adding the interaction term.

Table 42 Adjusted Multiple Linear Regression Model for PPC Attitudes (*N*=105)

	Unstandardized Coefficients		Standardized Coefficients			95% Confidence Interval for B	
Variable	B	Std. Error	Beta	*t*	*p*	Lower Bound	Upper Bound
Pain score	-.985	.307	-2.314	-3.209**	.003	-1.604	-.365
Control beliefs score	.045	.014	.434	3.198**	.003	.017	.074
Normative beliefs	-.452	.172	-1.572	-2.625*	.012	-.801	-.104
Normative x pain (interaction)	.186	.067	2.627	2.759**	.009	.050	.322

Note. Constant=4.624. $F(4,41)$= 5.595, p=0.001**. R^2=0.353 (adjusted R^2=0.29). * $p< 0.05$ (2-tailed). ** $p< 0.01$ (2-tailed)

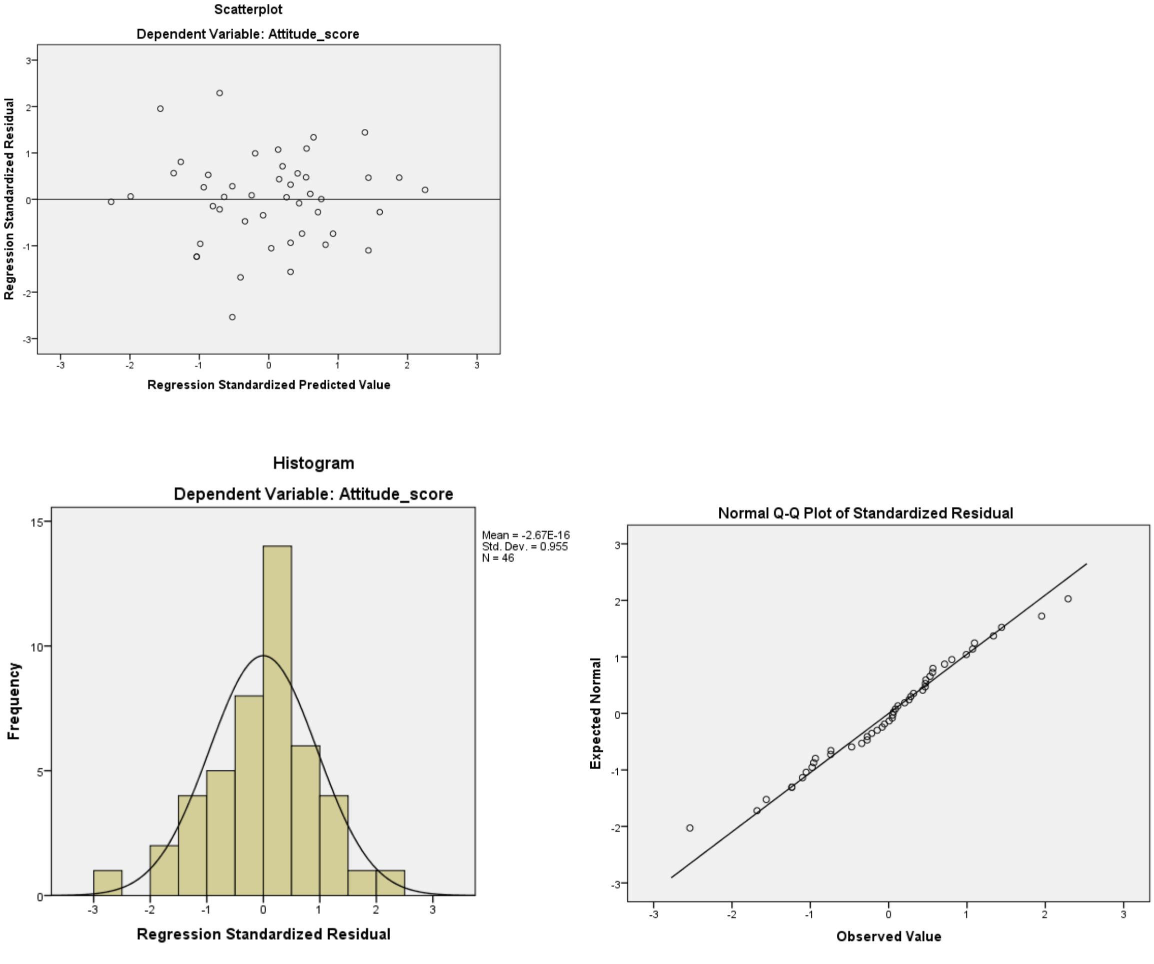
There is an interaction between normative beliefs and pain scores (B4= 0.186, *p*=0.009, 95%CI [0.05, 0.322]). The model equation is: $PPC\ \widehat{Attitudes}$ = 4.952 – 0.985*(pain score) + 0.045*(control beliefs score) – 0.452*(normative beliefs score) + 0.186*(normative*pain). With every one unit increase in control beliefs, PPC attitudes will increase by 0.045 on average, adjusting for pain and normative beliefs scores. To better understand the model pain was dichotomized at the mean level of 2. With a pain score above or equal to 2, the model and predictors become not significant (R^2=0.23, $F(3,21)$=2.087, p=0.133). In contrast, when pain score is below 2, the model explains around 60% of the total variance of PPC attitude (R^2=0.605, $F(3,17)$=8.681, p=0.001). All three variables become significant predictors for PPC attitudes.

The PPC Attitude regression model that includes interaction term is good fit since R^2 value is 0.353, indicating that 35.3% of the variation in PPC attitudes score can be explained by the model. The increase in PPC Attitude score is predicted by the increase in control beliefs and decrease in pain and normative beliefs scores.

Diagnostic tests were conducted to detect outliers, multiple linear regression assumptions (linearity, homoscedasticity and normality). On residual analysis, the scatter plot of the standardized residuals versus predicted values were checked. As illustrated in

Figure 16, the points were randomly scattered around the horizontal line at residual zero, indicating linearity and homoscedasticity. Normality of residuals is also evident in the histogram and QQ plot showing a normal distribution. Kolmogorov-Smirnov and Shapiro-Wilk were both are not significant (*p*-value > 0.05) indicating normality.

Figure 16 Residual Analysis of PPC Attitudes Regression Model



The absolute ranges of standardized and studentized residuals were above 2 but less than 3 (not very large residual). Only two values (4.3%) of the standardized residuals were larger than two. Removing the outliers did not affect the model, therefore, they were kept in the regression model.

As for multicollinearity, the VIF of pain score, normative beliefs and interaction term (normative pain) were above 10, with the highest being the interaction term, indicating multicollinearity. Only “Control belief” variable had a VIF of 1.1 (cutoff is 5). Predictors with high VIF were removed one by one (starting with the highest) and the model was run again. The VIF values obtained for the remaining predictors decreased to below 10; however, the model fit decreased. It worth mentioning that collinearity was expected between pain and normative beliefs scores with their interaction term. As the presence of the interaction term in the regression model helped explain more the predictions in this model, all predictors were retained. In the final model, pain score, normative beliefs score and control beliefs score were strong predictors of PPC attitude score.

3. *Factors Associated with Normative Beliefs*

a. Bivariate analysis

Non-parametric tests were used to analyze the associations of normative beliefs scores since normality assumptions were not met. The number of symptoms was significantly negatively correlated with normative beliefs scores. The estimate of the spearman correlation between the two variables was weak (*Spearman rho*= -0.195, *p*= 0.047). This indicates that with the increase in the number of symptoms, parents perceived less approval of the health team in focusing on the child’s quality of life.

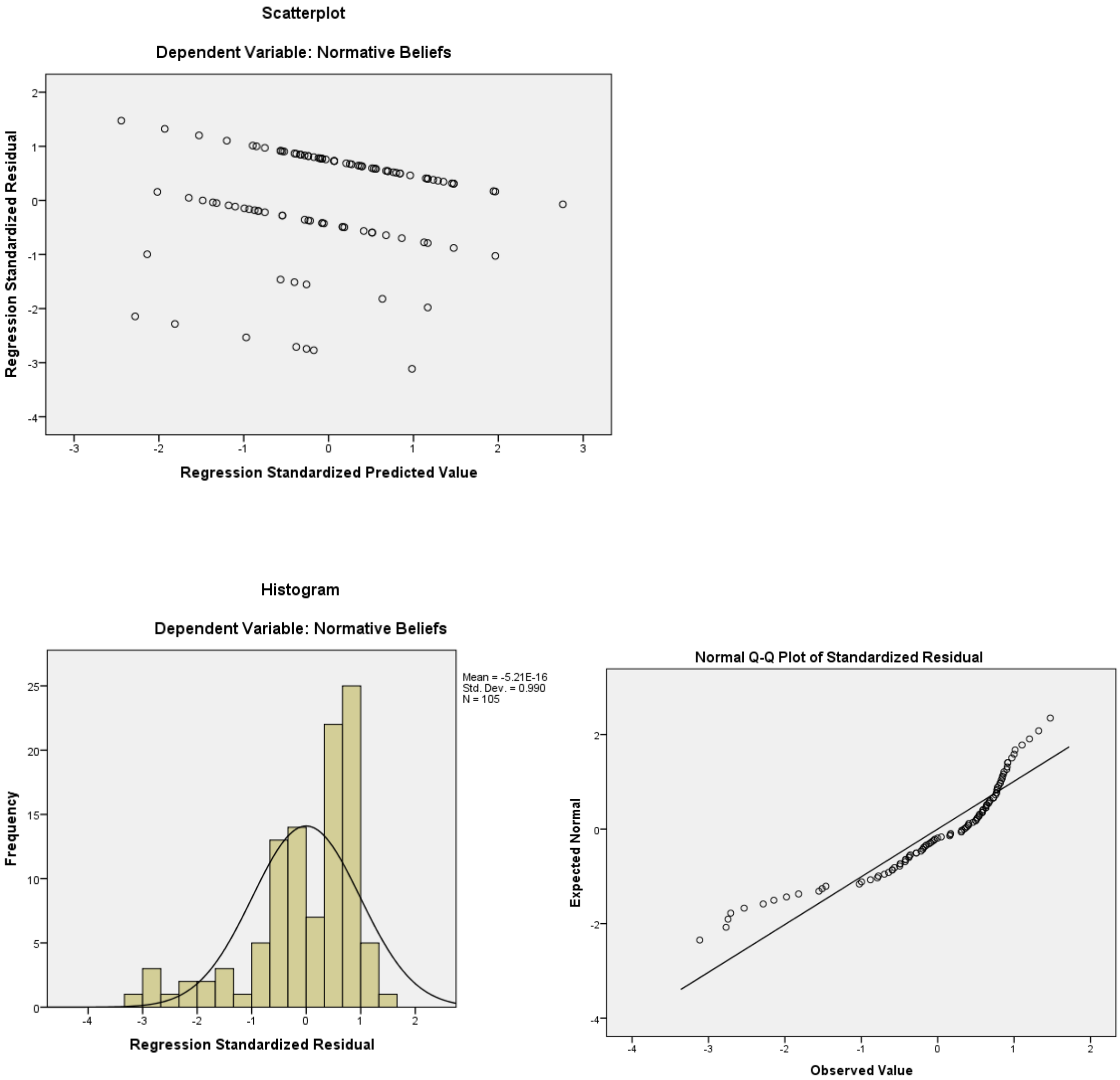
As described earlier, data suggested a weak positive correlation between normative beliefs and PPC attitudes (Spearman *rho* estimate=0.222, *p*=0.023). These results indicate that when parents recognize that the treating team focuses on quality of life, their attitudes toward PPC are enhanced.

b. Regression Analysis

The bivariate analysis of normative beliefs revealed two variables with statistical significance: the number of symptoms and attitudes score. None of the remaining study variables had *p*-value below 0.1. Therefore, the two variables were entered in a multiple regression model. The initial model was significant (R^2=0.083, *F*(2,102)=4.593, *p*=0.012). Only "number of symptoms" was statistically significant (B1= -0.076, *p*=0.02, 95% CI [-0.141, -0.012]. "PPC attitudes" was not a statistically significant predictor (*p*=0.071, 95%CI [-0.051, 1.195]). Interaction and confounding effects did not exist, as such, the variable PPC attitude was removed from the model.

As for the model assumptions, no multicollinearity existed (VIF=1). As shown in Figure 17, the linearity, homoscedasticity and normality assumptions were violated, possibly because the outcome is measured by only one item.

Figure 17 Residual Analysis of Normative Beliefs Regression Model



Seven outliers the standardized residuals were identified with values larger than two. Removing the outliers lowered the total variance explained by the model to 7.7 and did not improve normality. The regression analysis of the data revealed that the number of the child's symptoms in the previous week significantly predicts the normative beliefs scores.

4. *Factors Associated with Control Beliefs toward PPC.*

a. Bivariate Analysis

None of the demographic or clinical variables was significantly associated with control beliefs. Employment status was significantly associated with control beliefs scores (*Mann Whitney U test p*=0.027).

When testing the relationships with other outcomes of interest, as previously noted, there was a significant positive correlation of control beliefs scores with PPC attitudes scores. In addition, a significant difference was found in control beliefs scores (*p*=0.04) between participants who had personal experience with palliative care (*m*=38, *IQR*=35-39.5) and those who did not (*m*=41, *IQR*=39-42).

b. Regression Analysis

The bivariate analysis identified three possible predictors for control beliefs: employment status (dichotomized), previous experience with palliative care, and PPC attitudes scores. Moreover, the level of education (dichotomized) had *p*=0.1 at the bivariate level. All were entered in a multiple linear regression model. However the model was not significant nor the predictors (R^2=0.389, *F*(4,13)=2.070, *p*=0.143). In fact, only 18 participants responded to the variable “previous experience”, thus the regression analysis was not powered in this case. When the variable previous experience is dropped from the model, the regression analysis was powered. Table 43 summarize the findings.

Table 43 Initial Multiple Linear Regression Model for Control Beliefs (*N*=105)

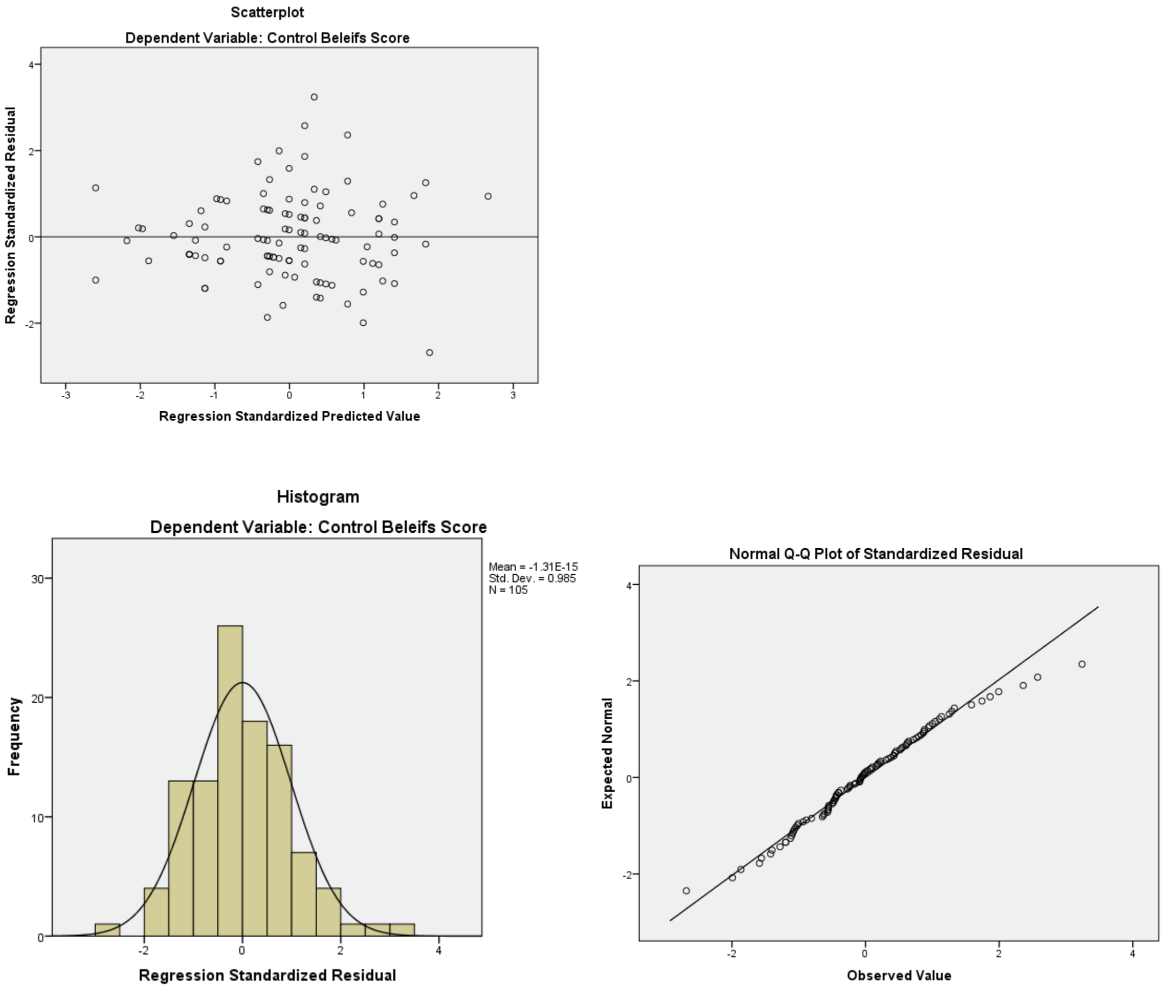
	Unstandardized Coefficients		Standardized Coefficients			95% Confidence Interval for B	
Variables	B	Std. Error	Beta	*t*	*p*	Lower Bound	Upper Bound
Attitude score	3.090	1.054	.274	2.93**	.004	.998	5.181
Education (dichotomized)	-.827	.557	-.139	-1.486	.140	-1.931	.277
Employment (dichotomized)	.970	.576	.158	1.684	.095	-.172	2.111

Note. Constant= 25.943. $F(3,101)=4.888$, $p=0.003$**. $R^2=0.127$ (adjusted $R^2=0.101$). * $p < 0.05$ (2-tailed). ** $p < 0.01$ (2-tailed).

The initial model was significant ($R^2=0.127$, $F(3,101)=4.888$, $p=0.003$). However, only attitude score was a significant predictor. The remaining variables did not have an interaction or confounding effect, thus they were dropped from the model.

The multicollinearity assumption was met since VIF values ranged between 1.011 and 1.019. The linearity, homoscedasticity and normality assumptions were met as shown in the residual analysis (Figure 18). Four outliers were identified with of the standardized residuals larger than two. Removing the outliers did not affect the model, thus they were kept.

Figure 18 Residual Analysis of Control Beliefs Regression Model



The results show that control beliefs are predicted by the “PPC attitude” score of participants. However, a higher number of respondents on “previous experience with palliative care” may yield different results.

5. *Factors Associated with PPC Intentions*

a. <u>Bivariate Analysis</u>

Among the demographic and clinical variables, a significant negative relationship was found between participant's age and PPC intentions (Spearman *rho*= -0.241, *p*=0.013). The lower the participant's age and the higher the likelihood to perform PPC behaviors.

As previously noted, there was a significant association between PPC intentions and PPC experience (Mann-Whitney U test *p*=0.029, 95% CI [0.33, 1.26]). Participants who lacked experience in PPC had significantly higher median PPC intentions score (*m*=2.87, *IQR*=2.75-4) than their counterparts (*m*=2.62, *IQR*=2.2-2.72). Among the other study outcomes, PPC Behaviors and PPC Intentions were positively correlated (Spearman *rho*=0.292) with high significance (*p*=0.003). These results indicate that the higher the likelihood to perform PPC behaviors, the more PPC behaviors the parents performed.

b. Regression Analysis

Based on the bivariate analysis three possible predictors were identified for PPC Intentions. None of the remaining variables had *p*-value below 0.1 at the bivariate level. A regression analysis was conducted with the following variables: "participant's age", "previous experience" and "PPC behaviors". The initial model was not significant nor the predictors (R^2=0.399, *F*(3,14)=3.095, *p*=0.061). In fact, only 18 participants responded to the variable "previous experience". Therefore regression analysis was not powered enough. When "previous experience" was dropped from the model, the model became significant and only "PPC behavior" was a significant predictor (Table 44).

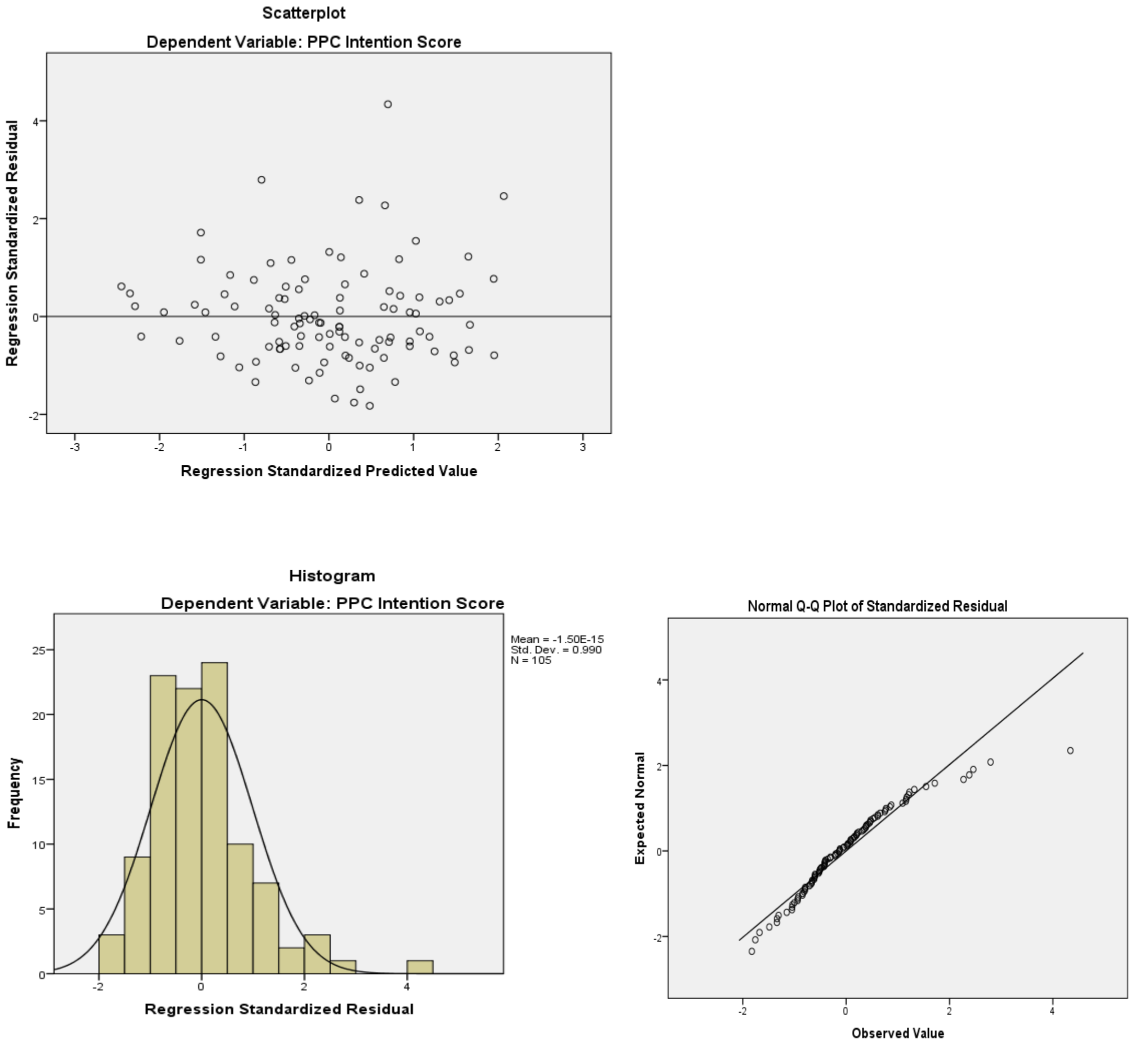
Table 44 Multiple Linear Regression Model for PPC Intentions (N=105)

	Unstandardized Coefficients		Standardized Coefficients			95% Confidence Interval for B	
Variables	B	Std. Error	Beta	t	p	Lower Bound	Upper Bound
Age	-.010	.006	-.155	-1.653	.102	-.023	.002
PPC Behaviors	.051	.017	.282	2.994**	.003	.017	.084

Note. Constant= 2.066. $F(2,102)=6.707$, $p=0.002$**. $R^2=0.116$ (adjusted $R^2=0.099$). * $p< 0.05$ (2-tailed). ** $p< 0.01$ (2-tailed).

The variable “participant’s age” was dropped from the model since it had no interaction or confounding effect with “PPC behaviors”. Linearity and homoscedasticity assumptions are met (Figure 19). There is a slight departure from normality as evident in the histogram and QQ plot.

Figure 19 Residual Analysis of PPC Intentions Regression Model



Five outliers were identified with an absolute standardized residual more than 2. The removal of outliers slightly improved the model (R^2 became 0.121) and enhanced normality of residuals.

Based on the results, “PPC behaviors” is the only significant predictor for “PPC intentions”. However, different results may be revealed with a higher number of respondents on “previous experience with palliative care”.

6. *Factors Associated with PPC Behaviors*

a. Bivariate Analysis

Among the demographic variables, the number of individuals living with the child were positively correlated with PPC behaviors (Spearman *rho*=0.233, *p*=0.017). In addition, when dichotomized marital status is significant (*Mann Whitney U test p*=0.000). The median PPC behaviors performed in the previous week among married was *m*=23 (*IQR*=21-24 PPC behaviors) compared to 19 (*IQR*=18-21) PPC behaviors among other categories (single, separated, divorced, widowed). These results suggest that family status influences the number of PPC behaviors performed by participants.

As for clinical variables, symptoms count was significantly associated with behaviors (Spearman *rho*=0.251, *p*=0.01). The higher the number of symptoms experienced by the child, the more PPC tasks performed.

As previously noted, PPC intentions scores were positively correlated with PPC behaviors scores with high significance (Spearman *rho*=0.292, *p*=0.003). These results indicate that the higher the likelihood to perform PPC behaviors, the more PPC behaviors the parents performed.

b. Regression analysis

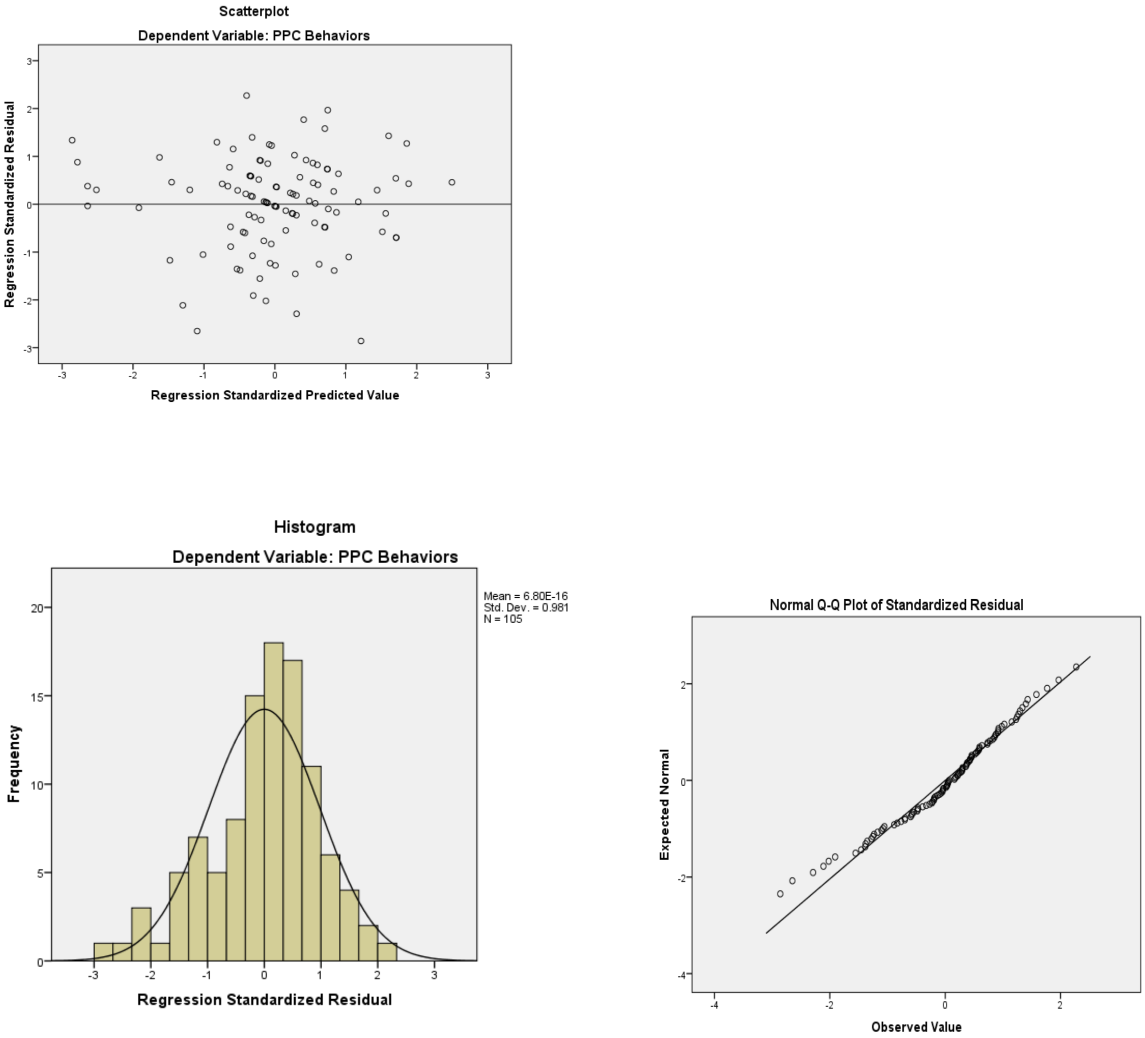
When dichotomized the variable "income" had a *p*-value of 0.067. The regression analysis of PPC behavior score was conducted with five possible predictors: number of individuals living with the child, marital status (dichotomized), symptoms count, PPC intentions, and income (dichotomized). The initial regression model was significant (R^2=0.301, *F*(5,99)=8.528, *p*=0.000). The variable "income" (dichotomized) was dropped from the model since it was not a significant predictor and it had no interaction nor confounding effects on the remaining predictors. The regression analysis was conducted again with the remaining variables. Table 45 illustrates the results. The regression model met the assumptions of absence of homoscedasticity and presence of linearity and normality (Figure 20).

Table 45 Multiple Linear Regression Model for PPC Behaviors (*N*=105)

	Unstandardized Coefficients		Standardized Coefficients			95.0% Confidence Interval for B	
Variables	B	Std. Error	Beta	*t*	*p*	Lower Bound	Upper Bound
Marital status (dichotomized)	2.868	.814	.300	3.522**	.001	1.253	4.484
Number of individual living with the child	.349	.161	.184	2.169*	.032	.030	.669
Symptom count	.291	.094	.262	3.080**	.003	.104	.478
PPC intention score	1.541	.476	.276	3.234**	.002	.596	2.486

Note. Constant= 12.463. $F(4,100)=10.196$, $p=0.000$**. $R^2=0.290$ (adjusted $R^2=0.261$). * $p< 0.05$ (2-tailed). ** $p< 0.01$ (2-tailed). PPC=Pediatric Palliative Care

Figure 20 Residual Analysis of PPC Behaviors Regression Model



Six outliers were detected with an absolute value greater than two but less than three for standardized residual and studentized residual. The outliers were kept in the model to since they did not affect the normality of residuals and their presence enhances sample representativeness. There was no multicollinearity between predictors as VIF values ranged between 1.107 and 1.028.

7. *Summary*

Based on the study findings, the hypotheses stipulated earlier in this study were tested. Two hypothesis were supported by data and four were not. Table 46 summarizes the hypotheses and the decision based on study data including the supporting evidence.

Table 46 Study Hypotheses Testing

Hypothesis	Decision	Supporting Evidence
Accurate knowledge about PPC is associated with positive attitude toward PPC	Reject	No significant correlation between PaCKS and Attitudes Scores
Prior experience with PPC is associated with attitude to PPC	Reject	No significant difference in Attitudes Score between participants who had previous experience with palliative care and those who did not
Control beliefs, normative beliefs and attitude toward PPC are associated with PPC intentions	Reject	No significant correlations between PPC intentions and control beliefs No significant correlations between PPC intentions and normative beliefs No significant correlations between PPC intentions and PPC attitudes scores
Primary caregivers' attitude toward PPC is associated with PPC behaviors.	Reject	No significant correlations between PPC attitudes and PPC behaviors
Primary caregivers' intentions are associated with PPC behaviors.	Retain	Highly significant positive correlation between PPC intentions and PPC behaviors
Control and normative beliefs are associated with primary caregivers' attitude toward PPC	Retain	Significant positive correlation between normative beliefs and PPC attitudes Highly significant positive correlation between control beliefs and PPC attitudes

In addition, the study findings revealed relationships of variables with the study outcomes. Table 47 summarizes the results of bivariate and multiple regression analyses.

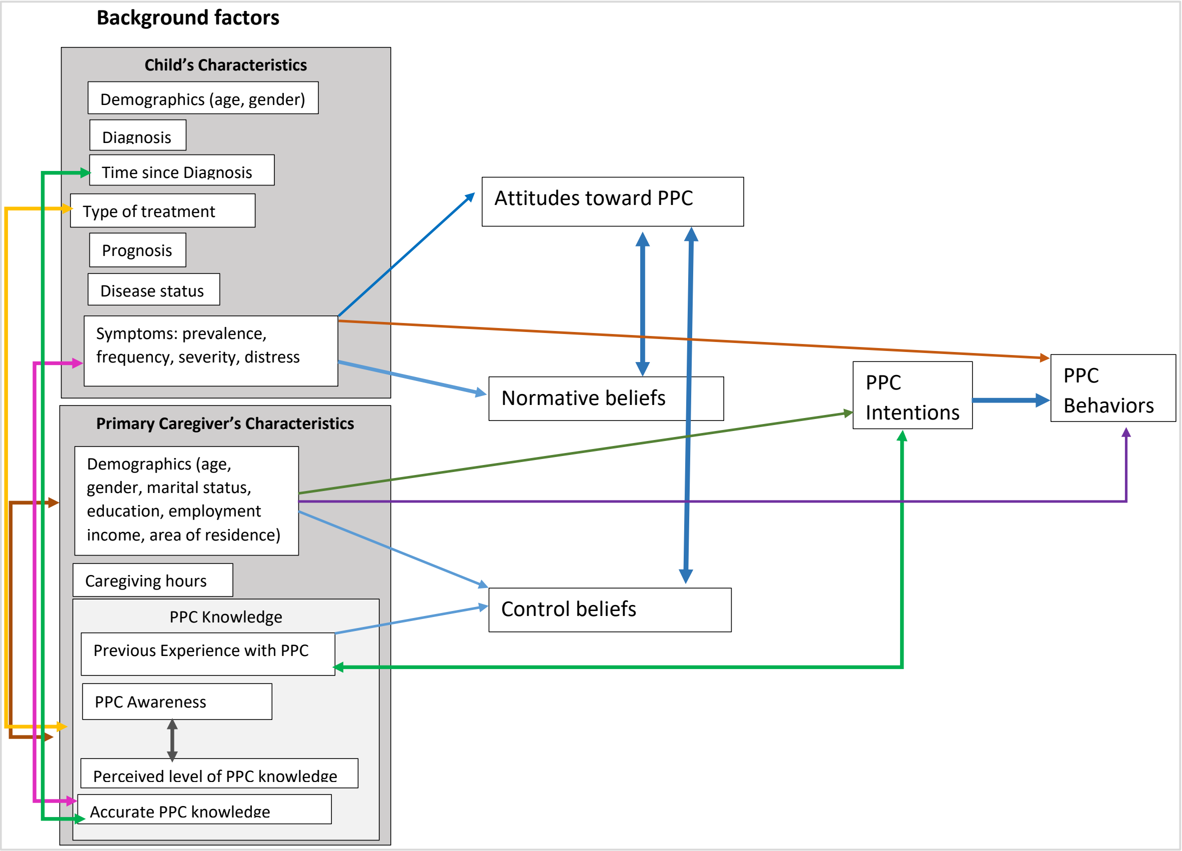
Table 47 Factors Significantly Associated with Study Outcomes

Outcome	Significantly Related Factor (Bivariate Analysis)	Significant Predictors (Regression Analysis)	Model Summary
PPC Awareness	Level of education ** Receiving PPC* Perceived level of PPC knowledge**	-	-
Perceived level of PPC knowledge	Level of education ** Receiving PPC* PPC Awareness**	-	-
Previous experience with PPC	PPC intentions* Control beliefs*	-	-
Palliative Care Knowledge Scale (13-items and 17-items)	Number of people living with child* Caregiving duration* Nausea score* Symptoms count *	-	-
PPC Attitude	Normative beliefs* Pain score * Control beliefs *	Normative beliefs* Pain score ** Control beliefs ** Pain x Normative beliefs (interaction)**	R^2=0.353 *F*(4,41)= 5.595, *p*=0.001**.
Normative Beliefs	Symptoms count* PPC Attitude*	Symptom Count*	R^2=0.083, *F*(2,102)=4.593, *p*=0.012*
Control Beliefs	Employment status (dichotomized)* Previous experience with PPC * PPC Attitude **	PPC Attitude**	R^2=0.127, *F*(3,101)=4.888, *p*=0.003**
PPC Intentions	Age* Previous experience with PPC * PPC Behaviors**	PPC Behaviors**	R^2=0.116 *F*(2,102)=6.707, *p*=0.002**.
PPC Behaviors	Number of people living with child* PPC Intentions ** Symptoms count * Marital Status (dichotomized)**	Number of people living with child* PPC Intentions ** Symptoms count ** Marital Status (dichotomized)**	R^2=0.290 *F*(4,100)=10.196, *p*=0.000**.

Note. – Regression analysis not powered. * $p < 0.05$ (2-tailed). ** $p < 0.01$ (2-tailed).
PPC=Pediatric Palliative Care, PaCKS= Palliative Care Knowledge Scale

Taken together, the hypotheses verified by the data and additional relationships revealed by findings suggested an update for the study conceptual framework, as shown in Figure 21.

Figure 21 Updated Study Conceptual Framework



C. Participants’ Overall Comments

Out of 105 **s**tudy participants 63 participants (60%) provided additional comments and recommendations at the end of their participation. Table 48 presents these comments based on the general themes, with quotes from participants after translation to English, along with the number of participants who discussed each theme.

Table 48 Participants General Comments and Recommendations

Theme	Participants’ Quotes	Number of Participants
PPC is provided by parents without knowing it	“All parents are providing PPC” “PPC is also the role of parents.” “We do PPC by parents' intuition” “We give PPC by instinct to our child; having more information about PPC will help us care better.”	4
Parents enjoyed participation and encouraged to participate in the study Participation in the study brought relief to parents	“Everyone should talk and participate in the study” “Thank you, it was a comfortable discussion, you asked everything.” “I like the idea and PPC should be implemented. We will reach a point where PC is present in all centers like psychologists in schools”. “I support all activities that help relieve suffering in children with cancer” “I would like to know the results of the study” “I was happy & I told you things that I say for the first time. I wish I knew that we could receive PPC from the beginning of the treatment since it was much needed & I thought it was only for end of life” “I really encourage this endeavor. I wish these studies increase, we need this support.” “We pretend humanity but we are so materialistic (please put it in your dissertation). You're talking about something for the humanity not only for your dissertation.” “Thank you for making me comfortable, It relieved me to talk to someone I don't know.” “Thank you so much, I didn't feel the time during the interview” “The study you are doing is very important & so beautiful! Though my child will finish treatment at the end of the month, I feel I want to stay connected with the center (volunteer or so). I want to participate in future research activity.” “Thank you the project is a humanitarian activity” “Thank you. It was very smooth & I will tell my husband how much I liked the participation.” “Thank you, the questions are very nice. Participating in the study was very relieving for me.” “I liked your questions.” “Your questions were very positive.” “This the goal of my participation I talked to benefit from the information.” “Thank you so much for making me speak about what I am living to improve my care for my child”	23

PPC is more relevant at the start of treatment than at the end-of-life	“At EOL PPC is not much needed as in the beginning, it will be too late”. “If PPC is started late the child will be surprised". “At the start parents need PPC since they are devastated, at EOL it's too late” “Give PPC to all children in these circumstances in the Middle East region due to violence and insecurity. For sick children PPC is much needed in certain times of the day (morning 11-12 pm and evening 5-6-7pm) the child is depressed in these times “No need to give PPC at EOL since the situation would be clear that the patient would die” “PPC at start is very important otherwise it will be too late even if at 2 or 3 months it's too late. PPC should continue even after completing treatment. At EOL PPC will give hope for comfort and happy moments” “PPC needs to be started since the beginning of the treatment. It is very much needed!” “PPC should be given a lot in the beginning of treatment it is much more needed than at the EOL” “PPC should be more needed at the beginning especially for parents and also much needed in case of relapse” “PPC should start before treatment and continue to survivorship since the child needs reintegration in society and needs continuous support in life especially if he is an adolescent.” “PPC is something basic to be given to the patient before given the curative treatment and even after treatment” “Very important to be given in the beginning.” “We should start PPC since diagnosis for better commitment with the treatment and having the parents always available for the child. The PPC should be added if the diagnosis is not clear (in case of uncertainty) if PPC is available”	15
Current country circumstances prevent the focus on the quality of life	“Due to COVID the focus on quality of life decreases and we cannot evaluate now if the team approves focusing on quality of life. Pediatric palliative care is also the role of parents.” “There is a lack in resources for PPC due to the blast and to the economic crisis.” “I consider PPC half of the treatment. The healthcare team helped us reach the center during lockdown and during the strike. This was palliative care.” “The focus on quality of life decreased with COVID and the circumstances of the country.” “The team is unable to focus enough on quality of life due to COVID, children cannot gather and interact to each other” “The team doesn't focus on quality of life all the time”	5

PPC facilitates the journey with cancer treatment	“Having PPC makes children love to come to the center and it creates a reason for the treatment work better”. “I recommend having support group at the center and having someone to educate the parents& patient” “PPC makes the patient/family and healthcare team closer, it creates friends” “PPC gives us hope” PPC is very helpful and it is much needed on the physical & emotional level for the child and family.” “PPC is very important to obtain the positive results of the curative treatment” “PPC may interfere. When my son underwent surgery for subcutaneous port insertion I refused to start him on chemotherapy the second day to allow him time to rest and keep him comfortable after the surgery. This way PPC interferes with the chemotherapy treatment. “PPC should be given like the treatment, it is a right. It should be given automatically. Parents can't do things alone, they need guidance & support.” “PPC gives the child confidence. “PPC gives hope. Religious dimension is very important it helped me a lot when the relapse occurred. A religious person talked to me & this relieved my suffering.” “PPC should be always available based on the needs of the family. PPC will help organizing things at home” “We need this type of care psychologically parents are also sick, parents pass by very difficult moments and they need support”	15
Participation corrected misconceptions about PPC	“I had an idea but it was a misconception. Thank you so much for correcting. People who work in PPC don't do a job, they "really care" “I need a reference to read more about PPC. I enjoyed participating. If there are more studies I would like to participate.” “I wish I knew that we would have received PPC from the beginning of the treatment since it was much needed & I thought it was only for end-of- life.” “Thank you for clarifying about PPC”	5
Recommendations can help facilitate the care logistically	“I wish schooling can be done during the visit on Wednesday” “In the 4th floor there was nothing to entertain the child. If the team provides PPC this will be an asset for the treating team. “In USA they give PPC automatically we highly recommend teaching it in university to transmit it to the parents to do it”. “Keep Dr Farah she was a very nice person” “Playroom should be available in each center” “They don't know how to disclose bad news. The team doesn't explain as they consider parents ignorant. Parents need PPC more than patients. I insist to have a psychologist on the team to be present on a daily basis, for the patient and fro the family. PPC is not available although it is much needed. “Allocation of resources is needed. The hospital should consider more resources for PPC.” “PPC needs time to be provided. My child does lumbar punctures without anesthesia because the team provides PPC. PPC should be depending on the need more difficult cases need more time.” “Take into consideration the foreigners like giving Methotrexate orally instead of intravenous to allow patients and families go back to their country for a while. This is a great facilitator.” “The team has to take into consideration the child’s condition to speed up the process of blood sampling and results, noise is very high, we get very tired.” The team should give more importance to PPC.” “It is very important to be given in the beginning PPC it should be accessible to all with no cost” “Hope to make PPC happen because it is needed and it should not be optional” “We follow medical advice regarding treatment decision not PPC.	14

D. Conclusion

The study findings assessed the current KAB toward PPC among primary caregivers of children with cancer. Although participants' knowledge about PPC was limited, participating in the study was, by itself, a venue to express their attitudes and views on barriers and facilitators of such care. The study helped explain some predictors to attitudes and beliefs toward PPC, which helped better understand parents' perspectives regarding PPC. Participants' comments equally highlight their role in relieving their child's suffering and promoting the child's quality of life. Using the study findings will contribute to enhancing primary caregivers' abilities to provide and advocate for their child's palliative care.

CHAPTER VIII

DISCUSSION

To the best of the researchers' knowledge, the present two-phase study is the first to be conducted in Lebanon and in LMICs, to examine KAB toward PPC among primary caregivers of children with cancer. This research took place in three major pediatric oncology centers that collaborate nationally and internationally to provide advanced childhood cancer treatments in Lebanon and the Arab region. The first phase set the stage for the main study through following a rigorous process of cross-cultural adaptation, content validation, and pilot testing of the survey sections. Useful data helped in refining the survey while providing preliminary results on the concepts of interest. The main study phase followed a cross-sectional quantitative correlational design with 105 primary caregivers of children with cancer. The sample size in the main study allowed for exploring the construct validity and internal consistency of the scales used.

Although, the main study findings highlighted a suboptimal primary caregivers' knowledge about pediatric palliative care, a strong endorsement to PPC was demonstrated after giving a brief definition of palliative care. Interestingly, the largest proportion of primary caregivers of children with cancer recommended integrating PPC at the start of cancer treatment. At the individual level, participants distinguished several barriers and facilitators to providing PPC. In particular, “religious and spiritual engagement” and “overwhelming negative emotions” were the most commonly rated facilitator and barrier, respectively. In addition, participants reported their engagement in a list of PPC tasks despite their lack of awareness of PPC as a medical term and specialty. The bivariate analysis yielded significant associations of demographic and clinical variables with the different outcomes of interest. Finally, the regression analyses of attitudes, normative beliefs, and control beliefs toward PPC helped in identifying significant predictors in each model. Despite the quantitative nature of the study, participants' comments and recommendations enriched the research with additional data, highlighting the cultural and circumstantial considerations of PPC provision in Lebanon.

A. Psychometric Testing

1. Cross-Cultural Adaptation and Pilot Testing

The cross-cultural validation of the study survey included translation, back-translation, expert review, and pilot testing (Beaton et al., 2000). The same process was followed in several previous PPC studies conducted in Lebanon (Abu-Saad Huijer et al., 2013a; Abu-Saad Huijer et al., 2013b; Al-Gharib et al., 2015; Saad et al., 2011). The survey validation followed rigorous strategies throughout various testing phases.

First, the inclusion of a professional sworn translator in the forward translation accentuated objectivity and reflected the spoken language in the cultural setting. In fact, Beaton and colleagues (2000) recommend a "naïve translator" for the second forward translation, to prevent bias due to medical background or academic involvement.

Moreover, this study involved ten experts in the content validation and 20 participants in the pilot testing, whereas previous studies conducted in Lebanon recruited, at best, four experts and five participants, respectively. Besides optimizing variability in professional backgrounds, increasing the number of experts controlled the agreement by chance while restricting the risk for error (Lynn, 1986). The experts' rating encompassed content validity and cultural appropriateness of the survey items, sections and entire survey. Having the experts from the Lebanese nationality yielded an excellent *CVI* and a measurable feedback on cultural appropriateness that allowed survey refinement.

According to Beaton et al. (2000) the ideal pilot sample should include 30 to 40 participants. However, cancer in children is a rare disease, especially in a small country like Lebanon (Johnston et al., 2021, Steliarova-Foucher et al., 2017). Therefore, a pilot sample of 20 was deemed adequate to maintain a balance between the limited study population and rigor. Although cognitive interviewing was not possible due to the length of the survey, participants in the pilot sample provided quantitative and qualitative feedback that enabled verification that they understood the items as intended by the researcher. Consequently, the process yielded an Arabic content-valid and culturally-appropriate questionnaire for measuring KAB toward PPC for the primary caregivers of children with cancer. The two sections below discuss the findings of the psychometric testing of the PPC attitude and control beliefs scales.

2. PPC Attitude Scale

Levine and colleagues (2017) pioneered in quantitatively examining the attitude of parents and children with cancer toward PPC in USA. Our study transformed the items used in Levine’s study into a coherent measurement scale with sound psychometric properties. To note, no published data was found regarding factor analysis of the original scale. The items and scoring system were modified in the current study to allow reliability and validity analysis that was not published for the original scale. In the current study, the Exploratory Factor Analysis (EFA) clarified the scale’s structure and the reliability testing (*Cronbach's alpha* and inter-item correlations) supported the measure of one latent concept without redundancy.

In the EFA, a decrease in factor loading value to 0.3 instead of 0.4 better explained the scale structure. The factor loading of an item is a measure of the relationship of that item with the factor (Yong & Pearce, 2013). The typical threshold of loading factor value of 0.4 infers moderate correlation (Guadagnoli & Velicer, 1988). A factor loading values (in other term the correlation coefficients) of 0.3 infers a weaker but moderate association of the item with the factor. Stevens (2002) argues that larger sample sizes allow smaller loading values. In order to maintain power and significance levels, smaller correlation coefficients would require larger sample sizes. According to Comrey & Lee (1992) a sample size of 100 is considered poor, 200 is fair, 300 is good, 500 is very good, and 1,000 is excellent. Administering the PPC Attitude scale in a larger sample would allow more flexibility in lowering the loading values and would yield clearer results on items to retain. Yet, in a larger sample, the loading values of 0.3 still indicates moderate associations of the items with the factors. These results would highlight the need for improving the items. On the other hand, it is possible that loading values of 0.4 are obtained in a larger sample. In this case, the researchers' scientific judgment is essential to draw the correct conclusions. In fact, these findings may provide evidence of sound psychometric, but, they may also yield statistical significance due to large sample size. It is worth mentioning that larger samples may be challenging the Lebanese context; however, a collaborative regional or international research endeavor remains a valuable opportunity.

The study findings suggest satisfactory internal consistency coefficient. The internal consistency coefficient of the entire PPC attitude scale was satisfactory

(α=0.702) (DeVellis 1991; Nunnally & Bernstein 1994). Within the factors identified in EFA, every item correlated with the remaining items with desirable values (between 0.15 and 0.5) (Paulsen & BrckaLorenz, 2017). As the correlations did not change dramatically when removing any of the items, the researchers opted to retain all items in the scale to comprehensively address the conceptual definition of PPC.

A ceiling effect was detected in two items: “Including PPC is a positive addition to the child’s care” (79%), and “I recommend integrating PPC at the beginning of treatment” (75.2%). Yet, this effect did not distort the whole measure, and the PPC attitude scores were normally distributed among participants. A pronounced ceiling effect contributing to skewed scores often leads to inaccurate identification of predictors and warrant remedial action by adopting different approaches (Huang et al., 2008).

This research endeavor yielded a psychometrically sound PPC attitude scale available in English and Arabic. To the best of our knowledge in PPC literature, this is the first validated instrument measuring parents’ attitude toward PPC. The literature on palliative care cited many attitudes scales validated among healthcare providers (Al Ansari et al., 2019; Balkin et al., 2017; Docherty et al., 2007; Ehrlich et al., 2020; Frommelt et al., 1991) or the adult patients (Milne et al., 2013; Perry et al., 2020). Within the scarcity of validated tools, this study provides a unique and useful scale to measure PPC attitude among parents of pediatric oncology patients.

3. Control Beliefs Scale

The psychometric tests conducted on the control beliefs scale were limited. The study data were inappropriate to conduct EFA. On the conceptual level, the results suggest that the items in the control beliefs section may not measure a single latent construct (Watkins, 2018). Moreover, the internal consistency coefficient revealed poor results on the entire scale and on the barriers subscale (DeVellis 1991; Nunnally & Bernstein 1994). Prior scales measuring barriers and facilitators to PPC were based on literature, pilot testing, expert reviews, and cognitive interviewing (Dalberg et al., 2018; Ehrlich et al., 2020). The scale in the present study was developed based on the literature and validated using expert reviews and pilot testing. In-depth cognitive interviewing and using temporal stability can produce additional data on the scale validity and reliability.

Another explanation of the results is the possibility of missed important barriers and facilitators to PPC on the parents' individual level. In fact, the items in the "Control Beliefs" section were compiled based on the existing literature. It is worth mentioning that, as a study population, the caregivers' views on barriers and facilitators to PPC is underexplored compared to that of healthcare providers. To account for the literature gap, the participants' feedback was solicited on the possibility to add items to the control beliefs section. Conducting future research while adding the suggested items to the scale may improve the measure.

In addition, a possible bias in the sample may have contributed to suboptimal psychometric data of control beliefs scale. In fact, few participants (*n*=18) were aware about PPC and very few (*n*=9) had experience with such care. Different results may have been obtained if more participants were aware of or had experience with PPC. Although they received a brief PPC definition, participants who were initially unaware of PPC responded on the spur of the moment. Thus, participants' response may have differed after time lapse of informed experience with PPC.

Based on the above explanations, the psychometric analysis of the control beliefs section highlights the absence of one underlying construct. Different methods for testing validity and reliability may yield clearer results. Nevertheless, the section items shed lights on important factors that could be either facilitating or hindering the integration of PPC at the individual level. A future step in improving the control beliefs measure would be through revising the section while including the participants' suggestions and adopting different validity and reliability approaches. In addition, a more heterogeneous sample in terms of PPC awareness and experience, and the use of cognitive interviewing may yield clearer results.

B. Demographic and Clinical Characteristics

1. Demographic Characteristics

As expected, the majority of participants in the pilot and main study were mothers and homemakers. Nonetheless, fathers' participation in this study is commendable as the proportion of fathers exceeds that reported by prior authors in the PPC context. Fifteen percent of the study sample were fathers as opposed to below 10% in prior studies (Al Omari, 2021; Bingen et al., 2011; Levy et al., 2020; Shattnawi et al., 2021; Shortman et al., 2013). It is possible that the current COVID-19 pandemic and the recent employment crisis in Lebanon may have contributed to increased fathers' involvement in the child care due to their extended presence at home. As a result, fathers participated in the study. The literature conducted among parents of children with cancer aligns with the traditional gender roles, where mothers are often at home and provide the care, whereas fathers are employed and ensure the family revenue (Clarke et al., 2009). The Arab culture further accentuates the role of mothers as natural primary caregivers in health or illness (Al Omari et al., 2021). Authors investigating parents’ perspectives in PPC constantly report an overrepresentation of mothers across settings (Abu-Saad Huijer et al., 2013b; Al-Gharib et al., 2015; Doumit et al., 2019; Khoury et al., 2011; Lazzarin et al, 2018; Sick et al., 2019; Wolfe et al., 2000; Verberne et al., 2019). Other authors completely exclude fathers from the samples (Al Omari, 2021; Shattnawi et al., 2021; Shortman et al., 2013). Historically, mothers account for 75% of the overall sample of parents participating in PPC research (McDonald et al., 2010). To address this flaw, several investigators emphasized the unique fathers’ stressors and gender differences in psychological distress, coping mechanisms and their experience and challenges with children with cancer and other life-limiting conditions (Clark et al., 2009; Fisher, Fraser & Taylor, 2021; Jones et al., 2010; Postavaru, et al., 2021; McNeil et al., 2021a). The investigators called for more inclusion of fathers in PPC practice and in research.

Recently, researchers are increasingly focusing on the fathers’ views for a more comprehensive understanding of the PPC phenomenon (Leemann et al., 2020; Robinson et al., 2019). Nicholas and colleague (2020) explored barriers and facilitators to fathers’ engagement in PPC research and proposed strategies to enhance paternal recruitment. Facilitators included the perceived personal and social benefits, the follow-up and flexibility in data collection timings, the credibility of the research team, and the focus solely on fathers. The authors reported that when healthcare providers act as study recruiters, they avoid approaching fathers out of their concern about the fathers’ well-being. Moreover, the suboptimal rapport with fathers and the outdated contacts impeded paternal participation. Fathers in the study described other challenging factors such as lack of time, other priorities and coping issues (especially bereaved fathers). According to Nicholas and colleagues (2020), a proactive consideration of these factors in designing recruitment strategies in future PPC research is needed to potentially enhance participation of fathers and bridge the gap in knowledge about their views. The present study anticipated and addressed many of these factors through using several recruitment strategies, arranging data collection with fathers and valuing their contribution to the child's care and to the study.

Other demographic characteristics of study participants were similar to those of the Lebanese population, in terms of age, religion, level of education, number of people living with the child, and employment status. The religious distribution of the study sample reflects that of Lebanon where, currently, 61.3% of the population are Muslims and 38.2% are Christians (Lebanon Population Clock, 2021). The education level split in half at high school degree is a realistic representation of the general population. As reported by the United Nations Developmental Program (n.d.), 54.9% of the general Lebanese population have at least some secondary school education. The majority of participants reported not being able to afford basic needs with their monthly income. These figures are not surprising within the current aggravating rates of unemployement in Lebanon (The World Bank, 2021).

2. *Clinical Characteristics*

a. Epidemiological Findings. The global incidence of childhood cancers is 10% higher in boys than in girls in childhood and adolescence (Williams et al., 2019). These figures differed in the present research. In the pilot and main study samples, more females than males with cancers were reported. Prior researchers in Lebanon identified this discrepancy (Abu-Saad Huijer et al., 201b; Al-Gharib et al., 2015). These findings reflect the actual gender distribution in Lebanon, with a higher female proportion in the general population (Lebanon Population Clock, 2021).

The majority of children in the study were diagnosed with leukemia, followed by central nervous system tumors. These findings reiterate the current childhood cancer statistics where leukemia accounts for 28% of the cases followed by brain and other nervous system tumors which account for 27% of pediatric oncology cases (Siegel et al., 2021). These figures also reflect the distributions of childhood cancer in Lebanon (National Cancer Registry, 2015).

Around 80% of participants reported high cure rate or somewhat high cure rate. These results accurately reflect the overall cure rates of children with cancer in High Income Countries (HICs) (Lam et al., 2019; Siegel et al., 2021). The World Bank (2021) classifies Lebanon among LMICs where 5-year childhood cancer survival rates barely reach 30%. Moreover, in the last couple of years, the country endured countless impediments on the security, economy, and health levels. Despite these unprecedented challenges that are hindering access to medications including chemotherapy, the participants reported noticeable favorable prognosis. The findings of this study are promising and reflect the high quality of care for children with cancer in the study settings. A plausible clarification of this finding is that all three study sites rigorously follow state-of-the-art protocols in treating childhood cancers and collaborate with outside partners to ensure provision of treatments to their patients despite the current economic crisis. Recently, the World Health Organization (2020) launched a worldwide initiative to improve survival rates for all children with cancer to 60% and reduce suffering by the year 2030 (WHO, 2020). Lebanon has been working in this direction years before the WHO initiative due to ongoing robust partnerships with world-class pediatric oncology centers. Additionally, pediatric oncology providers in Lebanon strived to establish national collaborations and standardized regimens for treating common childhood diseases.

b. Caregiving duration & Caregiving hours. The caregiving duration in the main study sample ranged from two months up to 12 years. In fact, all children who have been diagnosed since more than three years (*n*=22, 20.9%) were either in relapse or had metastatic disease. The numbers align with the overall five-year remission estimate in childhood cancers (Lam et al., 2019).

The average number of daily caregiving hours in this study was six hours in the pilot study and 8.7 (±5.7) hours in the main study. A previous report from Italy highlighted that parents spend an average of nine hours daily in caregiving activities for their children with life-limiting conditions (Lazzarin et al., 2018). In a more recent similar study in the USA, the authors reported a mean of five hours per day (Johnston, et al., 2020). It is worth mentioning that the former study, recruited parents of children with advanced illness, whereas the latter included various diseases and stages of the diseases. Caregiving time in children on palliative care clearly exceeds the times previously reported in the adult palliative care from various countries (Dionne-Odom et al., 2019; Shah et al., 2020; Yoo et al., 2018). Naturally, children would require more time to care for, due to the age-related complexity added to their medical condition. The longer caring hours in the present study may be also attributed to the cultural traits of caring within the Arab and Lebanese culture. Spending more time in caring for the sick person aligns with valuing family commitments especially among mothers.

c. Symptoms Experience. More than half of the primary caregivers reported that their children experienced on average four symptoms in the previous week, with irritability, lack of appetite, nausea and pain being the most prevalent symptoms. Other researchers from Lebanon and western countries used the same parent-report symptom assessment scale (MSAS) and described somewhat similar prevalent symptoms (Abu-Saad Huijer et al, 2013b; Baggott et al., 2014; Collins et al., 2000; Feudtner et al., 2021b; Montgomery et al., 2021; Pöder et al., 2010; Wolfe et al., 2015; Zhukovsky et al., 2015).

A previous study conducted in Lebanon examined symptom prevalence and quality of life of children with cancer from the parents' perspectives (Abu-Saad Huijer et al. 2013b). Our findings align with Huijer's study in terms of the most prevalent symptom ("feeling irritable") and Global Distress Score (*M* =1.9). These similarities may be attributed to conducting the study in the same Lebanese context. In particular, the largest study site in the current study was the same setting where Huijer's study took place. On the other hand, the mean Total MSAS was higher in the previous research (*M*=1.94±0.5) compared to our results (*M*=1.8±0.045). The nine-year lapse in conducting both studies could explain these difference. During this period, an improvement in practice could have occurred, which could have positively reflected on symptom experience.

Very recently, Montgomery and colleagues (2021) longitudinally assessed symptoms among 48 children with advanced cancers and their parents. Children and parents reported pain, fatigue, nausea, and sleeping difficulties as the most common symptoms. However, the authors noted a discordance between children and parents in estimating prevalence, frequency and severity of some symptoms such as feeling nervous (*Cohen's Kappa*=0.39), irritability (*K*=0.40) and fatigue (*K*=0.44). Baggott and colleagues (2014) had previously identified similar discordance. Based on these findings, the authors called for soliciting symptom experience from the child when possible (Baggott et al., 2014; Montgomery et al., 2021). With the current technological advancement, PPC researchers advocated for the innovative use of toys and mobile applications to involve children in reporting and managing their symptoms (Brock et al., 2018). The implementation of such novel approaches may be challenging in resource-limited settings due to restricted technology literacy or unexpected connectivity issues. A vigilant design taking into consideration these obstacles is warranted.

C. Study Outcomes

1. PPC Knowledge

The present study examined PPC knowledge through four outcomes. The subjective component of knowledge was assessed by participants' report on PPC awareness, perceived level of knowledge, and previous experience with palliative care. The objective component of PPC knowledge was assessed through a previously validated instrument, the Palliative Care Knowledge Scale (PaCKS) (Kozlov et al., 2017). The original version of PaCKS consists of 13 items. During the adaptation process, four items were added to the initial 13 items to fit the pediatric context. As such the reporting of this scale described the scores of the initial scale (PaCKS-13 items) and the adapted scale (PaCKS-17 items).

On the subjective level, only a minority of participants were aware about PPC (20% and 17.1 % in the pilot study and main study respectively). These results fall below the range reported in previous pediatric studies where the percentage of participants who reported having heard about PPC varied between 30% and 38% (Boldt et al., 2006; Dellon et al., 2018, Johnston et al., 2020; Levine et al., 2017). These discrepancies may be attributed to the variations in the level of development of PPC services in Lebanon. In fact, previous statistics originate from USA where the PPC services are at an "advanced stage of integration" compared to Lebanon that witnesses "isolated provision" of PPC (Clark et al. 2020, p. 796).

Despite the lack of resources in the Lebanese context, specialized palliative care services are available; however, in few institutions only. Even when available, these services are often sought at the terminal stages of the disease and in the context of adult oncology. In all three study sites, PPC is provided by the primary treating team, throughout the disease stages. The consultation of specialized palliative care services typically occurs whenever curative treatments are exhausted. Whether in adult or pediatric populations, healthcare providers introduce the term "palliative care" predominantly toward the end-of-life. As such, study participants may have reported their experience with palliative care as specialized services typically in the terminal phases of a loved one. Within this context of narrow use of palliative care, it was not surprising to find that a marginal number of participants reported previous experience with palliative care.

The World Health Organization (1998) called for integrating PPC since diagnosis. The World Health Assembly (2014) affirms the right for palliative care within the universal health coverage plan (World Health Assembly, 2014). To align with WHO statements, a “paradigm shift” must occur (Silbermann et al., 2012). As a first step, it is crucial to market PPC as a natural and integral approach to comprehensive pediatric oncology care. In clinical settings, pediatric oncology teams need to voice out the term “palliative care” more often as they are actually providing PPC. More public awareness campaigns can explain the essence of palliative care as a focus on quality of life. The creation of “PPC sound” through the use of the term and raising awareness is pivotal in transforming palliative care into a norm in childhood cancer care.

Participants who were aware of PPC had suboptimal level of knowledge. Only six out of 18 had accurate information about palliative care as evidenced by PaCKS scores. Reports from USA, Australia, Africa and India described that caregivers of pediatric patients previously voiced the need to increase their information about PPC even if they are already receiving PPC and if they are familiar with the term (Mitchell, et al., 2021; Monterosso et al., 2007, Sadasivan et al., 2021; Visagie & Pillay., 2017). As in the present study, the lack of knowledge and confusion of PPC with end-of-life care were common findings in the pediatric literature (Dellon et al., 2018; Johnston et al., 2020; Sadasivan et al., 2021), adult literature (An, et al., 2014; Dionne-Odom et al., 2019; Shah, et al., 2020; Yoo et al., 2018), and general public studies (Alkhudairi, 2019; Benini et al., 2011; Claxton-Oldfield et al. 2004; Flieger et al., 2020; Gopal & Archana, 2016; Joseph et al., 2009; Taber et al., 2019; Patel & Lyons, 2019). In the latter group, the figures varied depending on the level of development of palliative care services.

The bivariate analysis shed light on several factors influencing PPC knowledge. Specifically, PPC awareness and perceived level of knowledge were significantly influenced by the participant’s level of education and the child’s type of treatment. Other authors previously identified that level of education influenced palliative care knowledge (Alkhudairi, 2019; Chen et al., 2021; Johnston et al., 2020; Dionne-Odom et al., 2019; Flieger et al., 2020; Kozlov et al., 2018; Shah et al., 2020; Yoo et al., 2018; Patel & Lyons, 2019). As expected, receiving palliative care was significantly positively associated with awareness and level of knowledge, since the participants would have received an explanation about the care from the treating team.

The conceptual definition of PPC knowledge also includes “previous experience with palliative care”. The bivariate analysis revealed a significant negative association between PPC experience and intention to perform palliative care, which may be attributed to the conceptual definition of intention in this study and to the sequence of the questionnaire sections. In fact, PPC intentions was defined as the willingness to try to perform PPC behaviors or tasks in the coming week. The intention section is the last part of the questionnaire. Participants are asked about their intentions after the brief definition of PPC within the attitude section. It is possible that participating in the study and receiving information about PPC boosted participants’ willingness to engage in PPC tasks in the coming week.

In addition, participants who had personal experience with palliative care had lower control beliefs score than those who lacked palliative care experience. These results indicate that participants with previous experience in palliative care perceive more barriers to integrating such care. In fact, a summative score is computed for the control beliefs section. Items reported as barriers to PPC integration are given lower scores (“makes it very difficult”=1, “makes it difficult”=2). It is possible that respondents with experience may have reflected their previous struggle with palliative care integration. To note that only 18 participants were asked about previous experience. Therefore, a larger sample may provide a clearer understanding.

The PaCKS scores were positively associated with the number of people in the family. Previous reports using PaCKS were conducted among adults or the general population (Collins et al., Kozlov et al., 2017, Kozlov et al., 2018). None of these reports identified similar results, possibly due to the scale being used in different contexts. Nevertheless, our unique findings may be explained in light of the culture aspect. A closer look at the data shows that among participants who are aware of PPC, seven out of the 18 live with the child’s grandparents or other relatives. This reflects the close family ties in Lebanese society, highlights the support parents receive especially in the time of sickness, and aligns with the previous call to educate the “three-generation family” on palliative care (Daher et al., 2008, p. 74). Within this context, it is common to see that the whole family is aware about the child’s condition and care received. Any family member who acquire a new helpful information would directly share it with the rest of the family. As such, raising more awareness campaigns may be an efficient venue to spread PPC knowledge in Lebanon.

On the clinical level, the PaCKS scores positively correlated with caregiving duration (moderately) and nausea score (strongly). These findings suggest that longer caregiving duration enhance information about palliative care. In fact, longer caregiving durations imply more opportunities to interact with the healthcare team. The continuous encounters of caregivers with the treating team may have facilitated the transmission of PPC knowledge.

The study results also highlighted a strong positive correlation of PaCKS scores with nausea score. Previous authors described nausea as one of the most prevalent symptoms in children with cancer (Ameringer et al., 2015; Miller et al., 2011). In a study conducted in Lebanon, 85 parents of children with cancer identified nausea as the most treated symptom (treatment rate = 80.6%) with the treatment success rate of 72.1% (Abu-Saad Huijer et al., 2013). The present study was conducted within the same Lebanese setting where nausea is highly treated. As such, the focus on treating nausea infers more interaction with the healthcare team. During these encounters clinicians may have conveyed information about PPC, thus, may have contributed to more accurate PPC knowledge. However, caution in interpreting these results is warranted due to the small number of respondents on PaCKS.

Moreover, The PaCKS scores negatively correlated with the number of the child's symptoms in the previous week. The present study builds on previous recommendations to examine the associations of palliative care knowledge within a comprehensive picture of the patient's condition (Dionne-Odom et al., 2019). Importantly, the negative moderate correlation between PaCKS scores and the number of symptoms suggests that the lack of accurate knowledge regarding PPC contributes to a more intense symptom experience. This finding emphasizes the need for strengthening caregivers' knowledge to proactively and effectively manage their children's symptoms in order to decrease symptom burden among children with cancer.

2. PPC Attitude

For PPC attitude, descriptive and bivariate analyses were conducted, followed by multiple linear regression to determine the significant predictors of the PPC attitude.

At the descriptive level, most of the participants endorsed PPC as they acknowledged its benefits. Most importantly, participants highly recommended PPC integration at the beginning of cancer treatment. These findings echo earlier scattered reports underscoring the absence of caregivers' opposition to integrate PPC when informed about the care (Lafond et al., 2015; Levine et al., 2017). More precisely, participants in the present study recognized a higher need for PPC at the beginning of treatment than at the end-of-life as they elaborated in the overall comments on the study. As such, the study offers strong evidence contradicting previous healthcare providers' reports that parents oppose PPC integration. For many years, healthcare providers from different countries, commonly reported that parents of children with cancer are reluctant or "not ready" to integrate PPC (Davies et al., 2008; Dalberg et al., 2013; Kaye et al., 2015; Haines et al., 2018; Nyirő et al., 2018; Thompson et al., 2009; Wentlandt et al. 2014). Zimmermann and colleagues (2016) argued that such "stigma" about palliative care among patients and caregivers was derived from healthcare providers and persisted among primary caregivers despite their positive experience with an early palliative care intervention (p.E225). Emerging studies from the USA underline a shift into more favorable attitude toward PPC among healthcare providers and among parents of children with cancer (Dalberg et al., 2018; Falk et al., 2021; Parisio et al., 2021; Spruit et al., 2018). However, this shift is still lagging behind in other regions of the world. Pediatric oncology providers still describe parents' reluctance in many LMICs in Eurasia and the Middle East (Ehrlich et al., 2021; Saad et al., 2020). More research among caregivers of children with cancer, especially in LMICs, may better capture their attitude toward PPC.

The main study yielded unique results regarding significant predictors of caregivers’ attitude toward PPC in children with cancer. Importantly, the pain score were negatively associated with PPC attitude. In fact, pain is one of the most prevalent and distressing symptoms among children with cancer (Abu-Saad et al., 2013b; Wolfe et al., 2000; Linder & Hooke, 2019; Saad et al., 2011). In addition, alleviating pain is at the core of PPC as it entails relieving suffering by definition (WHO, 1998). Therefore, the presence of pain may impede a major PPC pillar, leading to less endorsement of PPC integration. On an another note, many international statements designate pain management and palliative care as a human right (Brennan et al., 2019; International Pain Summit of the International Association for the Study of Pain, 2011; International Association For Hospice And Palliative Care, & Worldwide Palliative Care Alliance, 2008; Lipman, 2004; Mpanga Sebuyira et al., 2003; Pallium India, International Association For Hospice And Palliative Care, & Pain Policy Studies Group, 2012; Radbruch et al., 2013a; Radbruch et al., 2013b). Healthcare professionals have the moral obligation to alleviate pain and suffering (World Health Assembly, 2014). Our study findings prompt pediatric oncology clinicians to immediately address pain, not only as an ethical duty, but also as a strategy to gain primary caregivers’ positive attitude toward PPC.

To further emphasize the above, the prediction model underscored the moderating effect of pain on the relationship between normative beliefs and PPC attitude. In fact, the normative beliefs variable became a significant predictor only after including the interaction term with pain. Furthermore, the direction and intensity of the relationship changed depending of the pain score. Additional analysis showed that the prediction model of PPC attitudes was significant only when pain scores are below 2.

These findings further highlighted the need to address pain at low intensity, frequency and distress level. A recent study conducted among children with sickle cell disease and their caregivers also documented the moderator role of pain (Sil et al., 2021). The authors described that chronic pain exaggerated the negative association between parenting stress and the child's quality of life (Sil et al., 2021). The results noted by Sil and colleagues (2021) may be extrapolated to childhood cancer due to some commonalities in disease management such as symptom treatments. In the presence of pain, the parenting stress negatively predicted the child's quality of life, the core of PPC. Furthermore, in clinical practice, severe pain is more complicated to manage than mild or moderate pain. Our findings prompt for addressing pain at low scores not only for better management but also for predicting PPC attitude. The prediction model of PPC attitude becomes irrelevant in the context of severe pain.

The study results also suggested that normative and control beliefs are associated with PPC attitudes. These relationships align with the study's conceptual framework developed based on the Theory of Planned Behavior (Ajzen, 1991). The increased focus on quality of life by clinicians enhances the primary caregivers' PPC attitude. As such, by focusing on the child's quality of life, the approach of healthcare professionals will positively reflect on primary caregivers' PPC attitude. In other terms, integrating PPC in the management of childhood cancer is a way to gain primary caregivers' endorsement of such care.

The significant positive association between control beliefs and PPC attitudes denote another strategy to enhance primary caregivers' PPC attitude. Promoting caregivers' control beliefs will improve their PPC attitude. Enhancing control beliefs would be through fostering perceived facilitators and addressing the perceived barriers.

For example, improving PPC knowledge or nurturing spiritual and religious engagement can promote control beliefs. Likewise, attending to overwhelming negative emotions or clarifying the child's medical condition can improve primary caregivers' control.

3. Normative Beliefs

The current study explored normative beliefs toward PPC. Although normative beliefs were measured using one item, the data shed light on primary caregivers' views in this regard. All participants in the pilot study and the majority of participants in the main study perceived the focus on the child's quality of life in healthcare providers' practice. However, in the comments section of the survey, participants explained that the COVID-19 pandemic and the country's circumstances prevented the effective focus on quality of life. Very recently, McNeil and colleagues (2021b) described the challenges of PPC teams during the pandemic in 56 countries around the world. Despite the enhanced use of technology and telehealth, more than half (55%) of the sample (N=156) described deficient personal interactions and suboptimal empathetic expressions during the pandemic (McNeil et al., 2021b). In addition to the outbreak, consecutive disasters devastated Lebanon in the last couple of years. Starting October 17, 2019, intermittent revolutionary movements have impeded access to treatment centers among both patients and healthcare providers. Since then, a sharp economic decline within continuous political quarrels left the country in severe medication shortage including chemotherapy agents and supportive drugs. Furthermore, on August 4, 2020, an unprecedented explosion dramatically destroyed Beirut, the capital of Lebanon, and intensely damaged the three study centers due to their proximity to the blast site. Such extraordinary circumstances have affected the healthcare providers' ability to sustain the usual pace of PPC due to the reasonable collective shift toward survival mode. Two recent references provide tools for implementing palliative care during crises. The World Health Organization (2018) published a guide for implementing palliative care during conflicts, natural disasters, forced displacement and disease outbreaks. Very recently Benini and colleagues (2022) developed PPC standards for humanitarian emergencies.

In addition, the number of symptoms significantly negatively predicted normative beliefs. With the increase in the number of symptoms experienced by their children, parents perceived less attention of health care providers to the child's quality of life. By definition, palliative care improves the quality of life through the prevention and relief of suffering using early and correct assessment and treatment of symptoms (WHO, 1998a; WHA, 2014). As such, symptom management, starting at the prevention level, is essential in palliative care. These findings urge practitioners to implement symptom prevention strategies in order to align with the PPC goal.

4. Control Beliefs

The present study examined barriers and facilitators to PPC integration, at the individual level and regardless of the phase of treatment. Previous reports addressing barriers and facilitators to PPC focused on the end-of-life phase and on specific aspects of care, such as decision-making, communication, symptom management and advanced care planning (Davies et al., 2008; Durall Zurakawski, & Wolfe, 2012; Greenfield et al., 2020; Kars, et al., 2010; Mack et al., 2006; Wolfe et al., 2000). In other disease conditions (Cystic Fibrosis and Duchenne Dystrophy), primary caregivers described the following barriers to early PPC integration: linking PPC to end-of-life, denial of poor prognosis and lack of communication with the child (Dellon et al., 2018; Sadasivan et al., 2021).

In the current study, the majority of participants rated "Religious and spiritual commitment" as a strong facilitator. These findings reflect the prominent religious commitment in a multi-religious country, such as Lebanon, with more than 17 different religious sects representing Christians, Muslims and Druze. Doumit and Khoury (2017) also reported strong religious beliefs as facilitators to coping among parents of children with cancer. These findings from the Lebanese context concur with earlier reports describing that religious and spiritual practices enable acceptance of the child's condition, decision-making and emotional relief (Hexem, et al., 2011; Nicholas et al., 2017). As the spiritual dimension is essential in PPC, encouraging religious and spiritual engagement, particularly in the Lebanese context, may promote PPC integration.

Among the listed barriers, primary caregivers commonly identified "overwhelming negative emotions" as a strong obstacle to integrating PPC. Previous authors identified the importance of "affect" in deciding the goals of care and proposed a balance of positive and negative affect to facilitate transition from one set of goals to another (Hill et al., 2014, p. 4).

In the main study, the control beliefs' scores were associated with employment status. Homemakers had higher control beliefs scores than other categories (employed, freelancers, retired and students). The presence of the caregivers permanently at home may enhance their ability to integrate PPC. Prior authors reported that being employed increased palliative care awareness and attitudes among non-healthcare professionals

(Alkhudairi, 2019; Collins et al., 2020). In contrast, Yoo et al. (2018) found that employment was associated with negative attitude among patients in Korea. To the best of our knowledge no study reported the association of employment status with control beliefs. Our findings should be interpreted with caution given the suboptimal psychometric data of the control beliefs measure.

Furthermore, the main study results suggest significantly higher control beliefs scores among participants who lacked personal experience with palliative care. Previous research conducted among healthcare providers, the public and caregivers of adult patients documented that personal experience improved PPC knowledge and PPC attitude (Abu-Saad Huijer et al., 2009; Jeong et al., 2020; Patel & Lyons, 2019). None of these studies examined the relationship of experience with control beliefs, particularly in primary caregivers of children with cancer. In healthcare providers, Jünger & colleagues (2010) reported that inexperienced pediatricians rated financial, emotional and attitudinal barriers to PPC integration more frequently than their counterparts. Therefore, logically, with higher rating of barriers lower control scores are expected. However, our study results contradict these findings and warrant further research for a clearer understanding.

5. PPC Behaviors and Intentions

The PPC intentions and behaviors section emphasized the extensive primary caregivers' involvement in PPC provision regardless of prior knowledge or exposure. Our findings concur with the existing literature highlighting the role of parents in PPC delivery. The performed care tasks encompass direct physical care and emotional support, managing symptoms, monitoring the patient's status, and making treatment decisions (Bingen et al., 2011; Dionne-Odom et al., 2019; Klassen et al., 2010; Lazzarin et al., 2018; Levy et al., 2020; McLean et al., 2016; Verberne et al., 2017; Wells et al., 2002). Furthermore, many study participants commented that their engagement in PPC was not conditioned by prior orientation since they provide “PPC by parents' intuition” to their child. At the same time, participants acknowledged their need for PPC education for a better performance. Many recent studies described the educational needs among parents of children with cancer (Aoun et al., 2020; Kookhan et al., 2019; Motlagh et al., 2019; Winger et al., 2020). These educational needs pertain to the child’s condition, disease and symptom management including physical and mental care, communication with the child and the healthcare team.

As the child’s comfort is an integral component of palliative care, the involvement of parents in the care becomes natural and instinctive due to their role in comforting the child. As such, PPC is provided by both parents and professionals (Classen, 2012). From this standpoint, enhancing caregivers’ training in PPC promotes their ability to deliver the care, thus, paves the way to the child’s comfort and quality of life goals.

As for factors associated with PPC intentions, the data revealed a negative correlation with age and positive correlation with PPC behaviors. These findings suggest that younger caregivers may be more open for performing PPC tasks than older caregivers. Previous authors reported a higher comprehension of palliative care among younger categories of caregivers (Shah et al., 2020) and community samples (Bennini et al., 2011; Taber et al., 2019). The current study results are useful in designing PPC training for caregivers.

Moreover, the data highlighted a significant positive association between PPC behaviors and intentions. The higher the number of PPC tasks performed in the previous week, the higher the intention to perform other PPC tasks in the coming week. It is possible that caregivers have learned about PPC tasks through their participation in the study. Thus, they may have expressed their intentions based on acknowledging the importance of their contribution to PPC provision. These findings are also helpful in designing educational interventions with caregivers.

The PPC behaviors were more prevalent among married caregivers than other categories. PPC behaviors also increased with the number of persons living with the child. These two results reflect an evident impact of family life on the child's care. The majority of caregivers in the sample were females and mothers. Being married facilitates the performance of PPC tasks in congruence with the social role of a mother. In addition, within the Lebanese context, a big family living together share household tasks. As such, the caregiver may have more time to perform PPC tasks for the child with cancer. Marital status and number of persons living with the child predicted PPC behaviors. Taken together, the predictors of PPC behaviors highlight an important cultural aspect of caring for a child with cancer at home.

The study data also revealed that symptom count predicted PPC behaviors. These findings align with previous reports that underscore symptom experience as a fundamental aspect determining PPC needs (Benini et al., 2022; Donnelly et al., 2017; Lazzarin et al., 2021; Shaw et al., 2018). The "Paediatric Palliative Screening Scale (PaPaS Scale), examines the number of symptoms experienced by the child among the screening criteria for eligibility to PPC (Bergstraesser et al., 2013a). The existing tools assist healthcare providers' in their clinical practice. Our findings reiterated the close link between the child's clinical status and PPC interventions from the caregivers' perspectives.

D. Conceptual Framework

The study conceptual framework combines two theoretical foundations: the Knowledge-Attitude-Behavior model by Allport (1935) and the Theory of Planned Behavior (TPB) by Ajzen (1991). The current study tested hypotheses deriving from these two theories, particularly regarding the relationships between the concepts of interest. The study results only supported two of the six hypotheses tested.

In congruence with the TPB (Ajzen, 1991), control and normative beliefs were associated with, and predicted PPC attitudes. The novelty in our study resides in identifying pain score as a moderator in the prediction model of PPC attitudes.

In addition, PPC intentions correlated with, and predicted PPC behaviors. These findings corroborated the proposed conceptual framework. In order to enhance primary caregivers' involvement in PPC provision, interventions should target fostering their intentions to do so.

On the other hand, the study data failed to support the two hypotheses testing accurate PPC knowledge and previous PPC experience with PPC attitudes. In fact, only the participants who have heard about PPC (*n*=18) were asked about the accuracy of PPC information and previous experience. It is possible that with more respondents data would produce different associations. Collins and colleagues (2020), examined knowledge and attitudes toward palliative care in a community sample (*N*=421). The authors used the PaCKS to measure palliative care knowledge. The reported results revealed that prior experience with palliative care and more accurate knowledge of palliative care significantly predicted favorable attitudes to palliative care (*adjusted* $R^2 = 0.24$, $F(8, 333) = 13.2$, $p < 0.001$).

Furthermore, our study data failed to support the relationship of attitudes and beliefs on one hand with intention and behaviors on the other hand. Some methodological issues related to the questionnaire might have blurred the relationships. The study questionnaire included several newly developed or adapted scales. The PPC attitudes scale was borrowed from Levine and colleagues (2017) after modifying the structure of the items, response options and scoring. The normative beliefs section included only one item. The control beliefs section is novel and developed solely based on the literature. The PPC intentions and behaviors section was adapted from a previously validated measure to fit the study purposes. Changes in response options and scoring systems were made. These changes might have affected the validity of the measures. Although the scales had an excellent content validity index, further analysis, particularly cognitive interviewing might have strengthened their psychometric properties. Using a refined version may yield different results.

According to Haddock and Maio (2008), an attitude predicts a behavior is particular circumstances. The authors have argued that the correspondence between attitudes and behavioral measures is required to produce relationships; particularly, the correspondence of items in terms of breadth, action, target, context and time (Haddock & Maio, 2008). In the present study, the PPC attitudes scale contains broad items related to the general philosophy of PPC. Contrarily, the PPC behaviors scale is very specific in time and actions in performing PPC. In addition, the relationship between attitude and behaviors depends on the behavior domain. A behavior may be more difficult to process than simply expressing an attitude (Haddock & Maio, 2008). Within the study context, caregivers face more challenges in providing PPC than simply articulating their PPC attitudes. In the current study, most participants were not aware of or had little experience with PPC. Haddock and Maio (2008) also noted that the participants' personal characteristics such as personality traits might affect the attitude-behavior relationship. The current study recruited a diverse sample of caregivers with heterogeneous personalities. Measuring personality traits was beyond the scope of this research.

On the conceptual level, PPC behaviors examined the past behavior or tasks performed in the previous week. According to Ajzen (1991) the TPB postulates that attitudes and beliefs predict future behaviors. Moreover, a past behavior has an effect on future behavior that is different from the effects of attitudes and beliefs (Ajzen, 1991). Longitudinal study design would capture future PPC behaviors.

The intent of this study was exploratory, primarily, focusing on the existing KAB in order to plan future interventions fostering the role of caregivers in PPC. The study conceptual framework included some concepts from TPB and excluded others. Notably, the "perceived behavioral control" was excluded. According to Azjen (1991), performance of a behavior is a combined function of intentions and perceived behavioral control. The concept of "perceived behavioral control" relates to the perception of the ease or difficulty of the behavior (Ajzen, 1991). Therefore, this concept accounts for factors outside the individual's control (Montaño, & Kasprzyk, 2015). Whereas, the concept measured in the current study was "control beliefs". The latter concerns the presence or absence of facilitators and barriers to the behavior at the individual level (Ajzen, 1991). Perceived behavioral control is the sum of control beliefs factors "weighted by their perceived power" to facilitate or impede the behavior

(Montaño, & Kasprzyk, 2015, p.98). As such, the inclusion of “perceived behavioral control” in future research may clarify the relationships.

In summary, the data partially corroborated the hypotheses proposed in the study conceptual framework. Conceptual and methodological issues might have shielded the hypothesized relationships between the study outcomes. The study findings suggest the use of an inclusive conceptual framework, longitudinal design, and more psychometrically sound measures. A future research combining these characteristics may better support the assumed hypotheses.

E. Limitations

The present study filled a literature gap regarding primary caregivers’ knowledge, attitude and beliefs toward palliative care for children with cancer in Lebanon. However, some limitations warrant careful attention in the interpretation of the results.

First, the use of a convenience sample might have weakened the representativeness of the sample and thus limited the generalizability of the results. To enhance representativeness, the study took place in three major pediatric oncology treatment centers receiving a diverse population of caregivers of children with cancer in Lebanon. Furthermore, relaxing eligibility criteria enabled the inclusion of different nationalities and prevented the restriction to terminal disease stages.

Additionally, some response biases might be present since the researcher interviewed the primary caregivers. Hawthorne effect and interviewer's subjectivity are possible. Participants may have chosen the answers that are more socially accepted. The researcher emphasized the objectivity in addressing the items of the questionnaire and the option of skipping items if needed. Although a self-administered format may lessen Hawthorne effect, the current study used close-ended questions in the entire survey to balance the social desirability effect and cultural considerations for the study population.

Moreover, the topic by itself is sensitive and it might have induced emotional involvement on the interviewed primary caregivers since it is related to child's disease and possible suffering during the struggle with cancer. This might have influenced the answers, which required researcher's expertise in communicating with the primary caregivers of children with cancer. Participants were informed about the potential emotional burden during the consent procedure. Two participants, cried during the interview and they were offered the option to take a break or stop the participation. However, the two participants opted to continue the interview. They expressed being relieved since their participation allowed them to talk about their caregiving experience. In addition, they were reminded of the availability of the treating team for psychological support as needed.

In addition, as the questionnaire is lengthy. The average duration of interviews was 42.2 (±12.2) minutes. The time needed to complete participation might have induced participant's burden. During the interview, the researcher gave opportunities for breaks as needed and continuously expressed appreciation for the time given by participants.

Finally, despite the rigorous methods of testing validity and reliability of the instruments used, cognitive interviewing lacked due to the length of the survey. Willis (1999) detailed the procedure of cognitive interviewing through "think aloud" and "verbal probing" techniques. These techniques yield robust insight of participants' understanding. However, adopting this approach was practically a challenge, which required other strategies. As an alternative, the expert panel supported the content validity and cultural appropriateness of the survey sections. Moreover, the researcher solicited participants' feedback about survey sections with additional insight about problematic items as needed. These measures helped ensure alignment of the participants' and researcher's understandings of the intended meanings of items. A potential future endeavor would be to conduct cognitive interviews for the PPC attitude and Control Beliefs sections separately.

F. Conclusion

In summary, the study findings share similarities with previous literature while advancing knowledge in an underexplored research area of primary caregivers' knowledge, attitude and beliefs toward palliative care for children with cancer. Despite the limitations, a major study contribution reside in presenting a psychometrically sound measure of PPC attitude instrument that can be used among parents of children with cancer, although further testing is needed. The study also initiated the development of another instrument measuring barriers and facilitators to PPC integration. Regardless of their lack in knowledge, participants endorsed PPC integration in their child's care after receiving a brief description about the care. In addition to identifying some barriers and facilitators to integrating PPC, primary caregivers in the study reported their remarkable involvement in PPC tasks. Finally, the study provided valuable evidence on the factors associated with KAB, which inform the design of future improvement strategies.

CHAPTER IX

CONCLUSIONS

The present study is among the very initial research endeavors conducted worldwide to examine primary caregivers' KAB toward PPC for children with cancer. Being the first undertaken in Lebanon, the study brings distinctive perspectives from LMICs. The study implications address the PPC field at the research, policy, education and practice levels, particularly, in a limited-resource setting.

A. Implications for Research

The study presented the initial psychometric testing of an Arabic PPC attitude scale. In addition, it compiled initial efforts to develop a measure for barriers and facilitators to PPC for use among parents of children with cancer. Several research implications can be drawn:

- Cognitive interviewing is recommended to ensure aligned understanding of items between the researcher and participants.
- Rasch analysis would allow the assessment of the survey items' quality in terms of measuring a trait and determining the most productive items in the scale.
- As an alternative to structured interviews, self-administred surveys could minimize the effect of the researcher's presence in data collection.
- Replication of the study in different countries and using different languages would allow further analysis equally serving comparison of data and cross-cultural validation.

- A larger sample size is recommended to inform further psychometric properties, particularly the structural validity and reliability of the PPC attitude scale and control beliefs scale.
- Based on the participants’ comments, a qualitative study is needed for better understanding primary caregivers’ insight about PPC and to allow the elaboration on participants’ views.
- Building on the study data, experimental and longitudinal research designs would help explore relationships of primary caregivers’ KAB toward PPC with patient outcomes such as quality of life. Studying interventions using longitudinal designs will help test the long term effectiveness of a structured multifaceted program on knowledge, attitudes, and beliefs of parents.

B. Implications for Policy

The current study aligns with the international and national calls for palliative care integration (WHA, 2014; Soueidan et al., 2018). However, in Lebanon, a pediatric-specific palliative care policy remains a need. Several policy implications are recommended.

- A national strategy is needed to structure the implementation of PPC in childhood cancer and other serious conditions.
- The inclusion of primary caregivers is crucial in policy development. To fit the pediatric Lebanese context, the role of primary caregivers is indispensable since the initial phases of strategy design. A judicious strategy not only delineates the professional standards but also honors the primary caregivers’ rights and responsibilities in the child’s care.

C. Implications for Practice

The study provided important findings emphasizing the need for early PPC integration. To align with WHO statements, PPC should be an integral layer of care for children with cancer instead of seeking it as an extra layer of support. Many approaches can be considered.

- In the absence of specialized PPC teams in Lebanon, capacity-building initiatives can focus on developing effective strategies for managing physical and psychological symptoms. Establishing PPC practice guidelines within the healthcare systems can facilitate integration. The guidelines would support pediatric oncology healthcare professionals in PPC delivery at the primary level. Within these guidelines, it is recommended to delineate various procedures encompassing proactive symptom management, communication, psychosocial support, spiritual care, bereavement care and care for survivors and their families.
- The study highlighted the robust contribution of primary caregivers in PPC delivery. Involving the parents in the care management process is key in pediatric contexts. Particularly in childhood cancers, enhancing and praising parents' involvement in the care would strengthen their role as experts in their child's care and potentially promote patients' outcomes.
- The success of partnership in care relies on parents' training on PPC skills and bridging the hospital with the home setting through outreach programs. In the presence of appropriate internet connectivity, telemedicine may strongly support

care delivery at home. Such initiatives enhance accessibility and efficiency in PPC provision in LMICs.

D. Implications for Education

In the domain of education, the study results underline a sharp deficiency in PPC knowledge in terms of awareness and accuracy of information. The study findings are also helpful on the educational level.

- Perhaps the most compelling implication to education is creating a “PPC sound” at the public level. The healthcare sector should collaborate with the media sector to promote palliative care as a human right. Public awareness campaigns encompass television spots, radio broadcast and social media platforms to ensure general dissemination.
- Our study data constitute an educational needs assessment informing the design of formal and informal educational activities for parents of children with cancer. Very recently, Benini (2022) affirmed that “parents and other family members should be trained and supported 24/7 in caring for their child at home whenever possible”.
- Based on the participants’ comments, training workshops may promote theoretical understanding of PPC and enhance technical skills in performing tasks.
- In alignment with electronic advancements, creating user-friendly mobile applications may sustain easy access and retrieval of information when needed.
- The continuous interactions with the healthcare teams would be the most natural educational encounter. However, ensuring proper PPC training for healthcare

providers arises as a prerequisite. Launching interdisciplinary educational/training programs for health professionals would enhance PPC knowledge and skills.

E. Conclusion

Examining the primary caregivers' KAB toward PPC for children with cancer provides a better understanding of PPC provision within a resource-limited setting. The study findings form the basis for future interventions targeting the improvement of primary caregivers' knowledge, attitudes and beliefs towards PPC, which mediates the enhancement of palliative care provision of children with cancer. Despite its limitations, the study brings to light an underexplored perspective for studying PPC and fills a gap in the literature regarding primary caregivers' views about such care. Hence, the study findings provide evidence on the need to optimize primary caregivers' role in PPC and the potential factors to consider when designing improvement strategies. Above all, the study paves the way toward impactful improvement in research, policy, education, and practice of PPC by valuing the primary caregivers' views in the care trajectory.

APPENDIX A

Summary of Reviewed Articles

Studies conducted among healthcare professionals

	Title/Author/year	Country	Purpose	Design	Data Collection method	Sample	Key Findings
1.	Palliative care in the community for children with cancer in South East England (Spencer & Battye, 2001)	South England	Establish how health-care professionals interpreted palliative care, and identify initiatives for service improvement.	Qualitative	In-depth interviews	N=40 community healthcare professionals providing PPC	Palliative care refers to the care which is not aiming for a cure. Interpretations varied in terms of the duration of palliative care and the type of support it involves.
2.	Practices in paediatric palliative care in Lebanon (Abu-Saad Huijer et al., 2008)	Lebanon	Find out about the knowledge of, attitudes to and practices in paediatric palliative care among doctors and nurses in Lebanon.	Quantitative cross-sectional descriptive	self-administered survey (French and English)	n=96 Paediatric nurses n=27 paediatricians	*Knowledge:* Few of paediatric nurses (20.2%) and paediatricians (3.7%) reported receiving continuing education in palliative care. Both paediatric nurses and paediatricians scored highly in PPC knowledge (mean 14.22; possible range 8–16). The majority were able to identify correctly the goals, components and assumptions of palliative care. *Attitude:* Participants had average scores in the section on PPC attitudes (mean 74.077; possible range 61–86). Paediatric nurses more likely to consider that a patient’s family to be involved in the treatment choice (p=0.003). A high percentage pf participants endorsed informing family and patient on prognosis. *Barriers:* Lack of development, lack of training, communication *Facilitators:* sharing the same religious beliefs *Practice:* Average practices scores (mean 159.89; possible range 114–189).
3.	Pediatric Palliative Care: a Qualitative Study of Physicians' Perspectives in a Tertiary Care University Hospital (St-Laurent-Gagnon et al., 2008)	Canada	Assess the concept of palliative care for a group of physicians in a tertiary care pediatric university hospital.	Qualitative Grounded theory	Semi-structured interviews	N=12 physicians	Palliative care is defined as the relief of physical symptoms. PPC is equated to comfort care. The definition varied between physicians. None of the physicians referred to the internationally accepted WHO definition. Some physicians who had more involvement with palliative care evoked a team approach (focusing on physical symptom management), family-oriented care, quality of life of the child, participation of the sick child in his usual activities (school, play, birthday parties, etc.). The timing of PPC integration varied.
4.	Pediatricians’ Perceptions of and Preferred Timing for Pediatric Palliative Care (Thompson et al., 2009)	USA (Florida & California)	Investigate physicians’ definitions of palliative care and their perceptions regarding the timing of referrals to PPC for 13 common diseases	Quantitative cross-sectional descriptive	Mailed and online survey	N=303 pediatricians (random sample)	*Knowledge*: 41.9% defined PPC as hospice care, 31.9% offered alternative definitions. Some respondents (3.1%–35.6%) stated either that palliative care was not indicated or that they did not know when to refer patients. *Factors associated with knowledge:* working in academic institution *Attitudes:* One half (44.3%–59.7%) of the respondents indicated that they would refer patients during the course of an illness (early or middle stage), with one third to one half (29.6%– 44.2%) preferring to refer patients when curative therapy was no longer the goal, at the end of life. *Factors associated with attitude:* Hispanic and having a larger proportion of patients with Medicaid (51% of patients), were associated with earlier referrals. *Practice:* (49.3%) had ever made a referral

	Title/Author/year	Country	Purpose	Design	Data Collection method	Sample	Key Findings
5.	Pediatric Residents' and Fellows' Perspectives on Palliative Care Education (Michelson et al., 2009)	USA	Determine the extent of training, knowledge, experience, comfort and competence in palliative care communication and symptom management. Obtain residents' and fellows' views on key palliative care concepts. Identify topics and methods for palliative care education.	Quantitative cross-sectional descriptive	Survey adapted from previous study	N=52 Residents N=44 Fellows	*Knowledge:* Fifty four percent of participants received previous training *Attitude*: Residents and fellows disagreed that palliative care is best left to oncologists, critical care specialists, or palliative care specialists and that initiating palliative care feels like ''you have given up'' on the patient. Education makes them more comfortable, they all acknowledge that PPC would improve patient care
6.	Paediatricians' perceptions on referrals to paediatric palliative care (Knapp et al., 2009)	USA (Florida & California)	Estimate the association between paediatrician characteristics and the decision to refer children to palliative care and the preferred timing of referrals. Determine how those associations vary across several illness trajectories.	Quantitative cross-sectional descriptive	Mailed and online survey	N=303 pediatricians	*Attitude:* 92% and 98% of paediatricians would refer a child to paediatric palliative care across all the illness trajectories. Between 54% and 92% of paediatricians would refer prior to the end of life, with trajectories 1 (child with a potentially curable disease but has significantly high risk of mortality) and 2 (child who will likely die from a severe congenital anomaly) *Factors associated with referrals:* years of experience, practice setting, Hispanic race, percentage of Medicaid patients
7.	Paediatric palliative home care by general paediatricians: a multimethod study on perceived barriers and incentives (Jünger et al., 2010)	Germany	Examine potential barriers, incentives, and the professional self-image of general paediatricians with regard to paediatric palliative care.	Phase I: Qualitative Exploratory Phase II: Quantitative cross-sectional	Phase I: semi=structured interviews Phase II: self-administered survey	Phase I: n=5 Phase II: N=293	*Knowledge*: 55.2% (N=293) had no experience (81.1%) agreed with the statement that palliative care should be involved early in the disease trajectory. *Attitude:* 75.1% willing engage in PPC *Barriers:* Reluctance on part of the parents, lack of experience restrictions (40.7%) financial burden (31.6%), sole responsibility without team support (31.1%), formal requirements such as forms and prescriptions (26.6%) inhibition in confrontation with death and dying (10.7%) *Facilitators:* Support by local specialist services such as home care nursing service (83.0%), access to a specialist paediatric palliative care consultation team (82.4%), as well as an option of exchange with colleagues (60.1%). Education (especially in communication) *Factors associated with barriers and facilitators*: willing to engage in PPC, gender (in some barriers), experience (in some barriers and facilitators)
8.	A study investigating the need and impact of pediatric palliative care education on undergraduate medical students in Japan (Kato et al., 2011)	Japan	Identify and explore the need for PPC education and the impact of that education on, medical students in Japan.	Quantitative Prospective Cohort	Survey administered before, during, and after a small group lecture on PPC. A second survey administered after six months	N=30 (fifth year medical students)	*Knowledge*: In the first survey, none of the students reported any exposure to PPC. All participants defined PPC as pain management in end-of-life care for children with cancer. *Factor associated with improved knowledge*: the intervention (PPC education) *Attitude*: Attitude toward the lecture was positive
9.	Pediatric Palliative Care Instruction for Residents: An Introduction to Initiative for Pediatric Palliative Care (Carter & Swan, 2012)	USA	Report the development and intervention of a 1-day pediatric palliative care education experience.	Quantitative Pre/posttest	Survey administered before and after PPC education	N=26 residents	*Factor associated with knowledge, skills and attitude*: participants reported having gained new knowledge (M=4.1±0.8), having enhanced my own pediatric palliative care knowledge, skills, and attitude toward PPC after the training (M=3.9± 0.9) out of 5

	Title/Author/year	Country	Purpose	Design	Data Collection method	Sample	Key Findings
10.	Paediatric palliative care services in Queensland: an exploration of the barriers, gaps and plans for service development (Bradford et al., 2012)	Australia	Identify barriers and gaps and to plan for the future of the pediatric palliative care service.	Qualitative	Focus groups	N=38 healthcare professionals	*Barriers*: Equity in access to services; awareness, understanding and fear from clinicians and families; experience of health professionals; funding and resources, lack of respite options, lack of resources and lack of coordination.
11.	Factors associated with perceived barriers to pediatric palliative care: a survey of pediatricians in Florida and California (Knapp & Thompson., 2012)	USA (Florida & California)	Describe the barriers to PPC as reported by a group of pediatricians practicing in two large States in the US. Identify factors associated with these perceived barriers.	Quantitative cross-sectional descriptive	Mailed and online survey	N=303 pediatricians	*Barriers:* families' reluctance to accept palliative care (95%) and families viewing palliative care as giving up (94%). *Factors associated with barriers:* race/ethnicity of pediatrician practice setting, and the percentage of low-income patients.
12.	Paediatric palliative home care in areas of Germany with low population density and long distances: a uestionnaire survey with general paediatricians (Kremeike et al., 2012)	Germany	Evaluate involvement in and contribution of general paediatricians in paediatric palliative care and their cooperation with other paediatric palliative care providers.	Quantitative cross-sectional descriptive	Self-administered questionnaire	N=141 general pediatricians	*Knowledge:* 90.8% had professional experience with PPC and 20.6% were aware of the PPC home services. The reasons for consulting PPC providers: supportive therapy: 84 (59.6%) pain and symptom management 78 (55.3%), psychosocial support: 101 (71.6%) *Attitude*: and adolescents, more than half (74, 52.5%) of the paediatricians said they would engage in palliative home care for children. *Barriers:* time-consuming 41 (29.6%), lack of opportunities to exchange information with colleagues 36 (25.5%), discontinuity of care (22, 15.6%); feeling overwhelmed (19, 13.5%) *Facilitators*: Education in basic palliative medicine 119 (84.4%) sufficient information exchange 116 (82.3%), availability of 24/7 on-call telephone service for PPC 105 (74.5%).
13.	Implementing a Program to Improve Pediatric and Pediatric ICU Nurses' Knowledge of and Attitudes Toward Palliative Care (Haut et al., 2012)	USA	Investigate pediatric nurses' knowledge and attitudes about pediatric palliative care	Quantitative pretest-posttest, pre-experimental design	Self-administered Survey	N=25 pediatric ICU nurses	*Knowledge:* The mean score for knowledge significantly increased afterg the educational program (paired *t-test:* $t24 = 2.48$, $p = .021$). Mean *Attitude:* The mean score for attitude significantly increased after the educational program (paired *t-test:* $t24 = 6.38$, $p = .001$).
14.	The needs of professionals in the palliative care of children and adolescents (Bergstraesser et al., 2013)	Switzerland	Describe the needs of pediatric healthcare professionals taking care of children with palliative care needs. Develop a concept for the first center of competence for PPC in Switzerland.	Qualitative	Semi-structured interview	part I, N=21 part II, N=55	*Knowledge*: The participants defined PPC according to the World Health Organization and the Association of Children with terminal illness definition. PPC is linked with disease progression and complex needs.. *Attitudes:* Participants expressed that PPC entails collaborative efforts. Many staff members felt that there were a multitude of myths around PPC. *Barriers:* uncertainty about when to start palliative care, uncertainty about prognoses in many children, and difficulty communicating with parents.
15.	Pediatric oncology providers' perceptions of barriers and facilitators to early integration of pediatric palliative care (Dalberg et al., 2013)	USA	Investigate pediatric oncology providers' perceptions of barriers and facilitators to early integration of PPC	Qualitative	Four focus groups	N= 15 physicians, seven nurse practitioners, two social workers, and nine inpatient and outpatient nurses.	*Barriers:* Provider role, conflicting philosophy, patient readiness, emotional influence *Facilitators*: Patient eligibility and timing, overall benefit, education of providers and families, evidence-based medicine, enhanced communication

Title/Author/year	Country	Purpose	Design	Data Collection method	Sample	Key Findings
16. Attitudes About Palliative Care: A Comparison of Pediatric Critical Care and Oncology Providers (Atwood et al. 2014)	USA	Compare oncology and critical care providers' attitudes regarding palliative care.	Quantitative cross-sectional descriptive	Electronic survey	N=152	*Attitude*: Critical care physicians were more likely to incorporate palliative care for psychosocial support. Oncologists consult PPC for symptom control. *Factors associated with attitude*: PC education, gender (women are more likely to integrate PPC and integrate it earlier)
17. Underlying barriers to referral to paediatric palliative care services: knowledge and attitudes of health care professionals in a paediatric tertiary care centre in the United Kingdom (Twamley et al. 2014)	United Kingdom	Investigate knowledge and attitudes towards palliative care amongst health care professional.	Quantitative cross-sectional descriptive	Online and paper survey	N=132 healthcare professionals	*Knowledge:* 48% reported the need to refer children to PPC at diagnosis. 68% reported prior referral to PPC team over the last year. *Attitude:* 63% disagreed with the statement 'palliative care is primarily about providing care at the end of life' (22% agreed and 15% neither agreed nor disagreed). 75% agreed with the statement 'palliative care is as important as curative and 66% disagreed with the statement 'referring to palliative care services too early will undermine the parents' hope'.. *Barriers:* The most commonly cited reason for not referring to palliative care was that 'referral would not be acceptable to the parents' (39%).
18. Paediatric palliative care in Malaysia: Survey of knowledge base and barriers to referral (Chong, & Khalid, 2014)	Malaysia	Explore the knowledge and practice of healthcare providers and their barriers to referral for palliative care prior to development of a nationwide service.	Quantitative cross-sectional descriptive	Self-administered survey.	N=292 pediatricians and pediatric nurses	*Knowledge:* more paediatricians (40.5%) than nurses (25.1%) had basic knowledge in palliative care ($p = 0.02$). Misconceptions exist mainly among nurses about the concept of palliative care and the use of morphine *Barriers:* For all participants, the common perceived barriers for referral is the family's understanding of illness and issues within the family. Among pediatricians: 79.4% reported the lack of accessible palliative care services. More than half of paediatricians thought that 'uncertain prognosis' (50%) and 'unsure when to refer' (51.5%) were barriers. Among the paediatricians, the lack of accessible paediatric palliative care services was the predominant perceived barrier to referral. More paediatricians than nurses perceived that communication between the staff and the family and cultural differences were barriers to PPC.
19. Referral practices of pediatric oncologists to specialized palliative care (Wentlandt et al., 2014)	Canada	Describe the attitudes and referral practices of pediatric oncologists specialized palliative care and to compare them with those of adult oncologists	Quantitative cross-sectional descriptive	Self-administered paper questionnaire	N=646 adult and pediatric oncologists	*Knowledge:* 96% of pediatric oncologists had access to inpatient PPC services (vs. 48 % in adult oncology). Only 27 % reported having access to an outpatient palliative care clinic (vs. 73 % adult oncology). Fewer pediatric oncologists than adult oncologists reported prior rotation in palliative care during training (26 vs. 51 %, p=0.0009). *Attitude*: Pediatric oncologist were more likely to agree that they would refer earlier if palliative care were renamed "supportive care" (58 vs. 33 %, p<0.0001), that palliative care adds too many providers (17 vs. 7 %, p=0.002), and that palliative care was perceived negatively by their patients (60 vs. 43 %, p=0.02). *Practice:* POs referred at the diagnosis of metastatic disease, or during the course of chemotherapy (40.4 and 46.8 %, respectively), with only 13 % stating that they tended to refer after chemotherapy or transfusions had been stopped (vs. 30 % of adult oncologists, p= 0.01).

	Title/Author/year	Country	Purpose	Design	Data Collection method	Sample	Key Findings
20.	The impact of a palliative care team on residents' experiences and comfort levels with pediatric palliative care (Wu et al., 2014)	USA	Evaluate the impact of a palliative care team on pediatric and internal medicine/pediatric (IM/Peds) residents knowledge, comfort level and experience providing pediatric palliative care (PPC).	Quantitative cross-sectional descriptive	Electronic questionnaire.	N=294 Pediatric and IM/Peds residents at	*Knowledge:* nearly 2/3 of participants selected a description of PPC that describes palliative care as starting at the time of diagnosis regardless of treatment goals. *Factors associated with knowledge*: Participants who reported the presence of a PPC team at their institution selected accurate description of PPC more often than those who did not report the presence of a PCT (72.3% vs. 53.3%; $p<0.001$, *Fisher's Exact Test*). *Attitude:* Overall, 55.3% (95% CI: 49.2, 61.3) were comfortable providing PPC. *Factors associated with attitude*: presence of a PPC team at the institution
21.	Physician Perspectives on Palliative Care for Children With Neuroblastoma: An International Context (Balkin et al., 2016)	International	Explore physicians' perceptions or knowledge of palliative care	Quantitative cross-sectional descriptive	Online survey	N=53 pediatric oncologists	*Knowledge*: Fifty-eight percent of participants responded initiating PPC when curative treatment have failed of curative options and 33% responded that palliative care is initiated within the last six months of the child's life. Less commonly chosen inappropriate answers were "Initiated only after curative therapy has stopped" (17%) and "Initiated after a DNR order is in place" (13%). 17% of respondents inappropriately considered palliative care as that initiated only after curative therapy is stopped.
22.	Pediatric Cardiology Provider Attitudes About Palliative Care: A Multicenter Survey Study (Balkin et al. 2017)	USA	Describe attitudes towards PPC consultation. Identify barriers to PPC. Characterize physician perceived competence PPC	Quantitative cross-sectional descriptive	E-mailed survey	N=155 pediatric cardiologist in 19 centers	*Knowledge:* 30% received training, level of knowledge: (5 point likert scale) mean of 2.94 ± 0.77. Over 90% percent reported no role for palliative care involvement unless the patient is expected to die within weeks to months or if he/she is actively dying *Factors associated with knowledge*: training and number of patients *Attitude:* 85% agreed that palliative care consultations are helpful. *Barriers:* undermining parents' hope (45%) and parents views as giving-up (56%), parents' refusal to refer to PPC (27%), lack of availability (22%) *Practice:* 60% felt competent caring for children with heart disease around end-of-life, and 80% felt competent discussing goals of care and code status.
23.	Palliative care in paediatric oncology in nursing education (Guimarães et al., 2017)	Brazil	Identify the view of students regarding palliative care in paediatric oncology during a graduate programme.	Qualitative Exploratory	Semi-structured interviews	N=20 nursing students	*Knowledge*: PPC perceived as care when there is no possibility for cure *Attitude:* students reported being unprepared and avoid this specialty
24.	Towards culturally competent paediatric oncology care. A qualitative study from the perspective of care providers (Suurmond et al., 2017)	Netherland	Explore obstacles in paediatric cancer care that lead to barriers in the care process for ethnic minority patients.	Qualitative framework approach	Semi-structured interviews	N=12 paediatric oncologists and 13 nurses of two different paediatric oncology wards	*Barriers:* language barriers between care provider and parents hindered the exchange of information. Cultural barriers between care provider and parents about sharing the diagnosis and palliative perspective hindered communication
25.	Physician Perspectives on Palliative Care for Children with Advanced Heart Disease: A Comparison between Pediatric Cardiology and Palliative Care Physicians (Balkin et al., 2018)	USA	Compare the perspectives of PPC physicians and pediatric cardiologists regarding palliative care in pediatric heart disease.	Quantitative cross-sectional descriptive	Web-based survey	N=183 pediatric cardiologists N= 49 PPC physicians	Forty-eight percent of PPC physicians and 63% of pediatric cardiologists agreed that availability of PPC is adequate ($p = 0.028$). The majority of both groups indicated that PPC consultation occurs "too late." *Barriers:* PPC physicians overestimated how much pediatric cardiologists worry about PPC introducing inconsistency in approach (60% vs. 11%, $p < 0.001$), perceive lack of added value from PPC (30% vs. 7%, $p < 0.001$), believe that PPC involvement will undermine parental hope (65% vs. 44%, $p = 0.003$), and perceive that PPC is poorly accepted by parents (53% vs. 27%, $p < 0.001$).

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26.	Building Bridges, Paediatric Palliative Care in Belgium: A secondary data analysis of annual paediatric liaison team reports from 2010 to 2014 (Friedel et al., 2018)	Belgium	Describe the characteristics of children cared for by Pediatric Liaison Team and the different activities provided by Pediatric Liaison Team in order to document how continuity of care is ensured in Belgium.	Qualitative	Secondary data analysis Thematic analysis	Annual reports of five specialized pediatric liaison teams	*Knowledge:* Difficulty expressed by pediatric liaison team to define when palliative care starts. There is a need for continuous PPC training for pediatric liaison team. Family confusion with death require clear explanation of PPC since the beginning of treatment. *Barriers:* "palliative" frightens the families and may represent an obstacle to accessing palliative care services
27.	Perceptions of barriers and facilitators to early integration of pediatric palliative care: A national survey of pediatric oncology providers (Dalberg et al., 2018)	USA	Assess pediatric oncology providers' perceptions of palliative care to validate previously identified barriers and facilitators to early integration of a pediatric palliative care team (PCT) in the care of children with cancer.	Quantitative cross-sectional descriptive	Electronic survey	N= 1005 pediatric oncology providers	*Barriers:* Over half agreed on overlapping roles between the oncology team and the PPC team. *Facilitators:* All participants moderately agreed that introducing PC early does not create an overall burden for parents. All participants largely disagreed with the statement that PC is not consistent with curative care All participants moderately agreed that evidence-based literature regarding early integration of PC is needed. Slightly over half of physicians and social workers, and nearly three quarters of RNs and APRNs, said they would not limit who receives a PC consult based on prognosis.
28.	Providing Pediatric Palliative Care Education Using Problem-Based Learning (Moody et al., 2018)	USA	Test the effectiveness of a PPC module on third year medical students' and pediatric faculty's declarative knowledge, attitudes toward, perceived exposure, and self-assessed competency in PPC objectives.	Quantitative prospective cohort study	Self-administered survey at 3 time points (baseline, follow-up and end of rotation)	N=190 medical students	*Knowledge*: Declarative knowledge and perceived exposure improved significantly on each objective after the intervention ($p = 0.002$) Self-assessed competency and students' perceived exposure improved significant ($p<0.001$) after the intervention
29.	Awareness of pediatric palliative care among health care workers (Detsyk et al., 2018)	Ukraine	Assess the awareness of pediatric palliative care among healthcare workers providing medical services to children.	Quantitative cross-sectional descriptive	Structured interviews	N=578 healthcare workers	*Knowledge*: One fourth respondent (25.3%) did not know the definition of pediatric palliative care. 71.5% linked PPC with cancer. Only 59.7% of respondents knew that palliative care should begin with the diagnosis of an incurable disease, and not at the end of life. The majority of respondents recognized their lack of their knowledge regarding PPC (85.8%) and almost all 94.5%) expressed their desire for PPC education. *Factors associated with knowledge:* position of respondents.
30.	Impact of Educational Training in Improving Skills, Practice, Attitude, and Knowledge of Healthcare Workers in Pediatric Palliative Care: Children's Palliative Care Project in the Indian State of Maharashtra (Ghoshal et al., 2018)	India	Evaluate the impact of PPC education and training on skills, practice, attitude, and knowledge of healthcare workers	Quantitative Pre/post test	Researcher-administered survey	N=62 healthcare workers	*Knowledge*: 43% of the doctors and 45% of the nurses had shown a good level (70 and above) while 45% of others showed a medium level of knowledge with a score of 50 and above 73% of them believed palliative care should be started at the time of diagnosis, 18% felt that it should be started during the treatment phase, and 9% felt that it should be started when treatment fails. *Factors associated with knowledge*: Training improved knowledge and. More than 80% of the nurses felt that, with the training provided to them, they have now the knowledge to provide palliative care to children. *Attitude*: 64% of doctors and 67% of nurses endorsed PPC after the training

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31.	The timing and circumstances of the implementation of pediatric palliative care in Hungarian pediatric oncology (Nyirő et al., 2018)	Hungary	Explore physician's attitudes and practices concerning pediatric PC	Qualitative: Inductive analysis	Structured Interviews	N=22 pediatric oncologists	*Knowledge:* Most physicians (n = 21) equated palliation with end-of-life care. *Attitude:* The majority of respondents voiced distrust concerning the early implementation of PC, citing parental anxiety and possible detrimental effects on the doctor-family-patient relationship. *Barriers*: conceptualization of palliation equated with end-of-life care. *Practice:* the common practice of timing is still at the end of curative treatment.
32.	National Impact of the EPEC-Pediatrics Enhanced Train-the-Trainer Model for Delivering Education on Pediatric Palliative Care (Widger et al., 2018)	Canada	Examine the impact of an enhanced implementation of the Education in Palliative and End-of-Life Care for Pediatrics curriculum on, knowledge dissemination, health professionals' knowledge, practice change, and quality of PPC.	Quantitative pretest-posttest	Electronic survey	N= 3475 health professionals in 15 sites	*Knowledge*: the majority (96.7%) agreed that their PPC knowledge improved *Quality of care*: 10/15 sites achieved practice change quality improvement goals. The only improvements in care quality were an increased number of days from referral to PPC teams until death by a factor of 1.54 (95% CI = 1.17-2.03) and from first documentation of advance care planning until death by a factor of 1.50 (95% CI = 1.06-2.11), after adjusting for background variables.
33.	Knowledge, Beliefs, and Behaviors Related to Palliative Care Delivery Among Pediatric Oncology Health Care Providers (Spruit et al., 2018)	USA	Evaluate the knowledge and beliefs of pediatric oncology HCPs regarding involvement of PPC. Assess potential barriers that interfered with its utilization.	Quantitative cross-sectional descriptive	Electronic survey	N=156 pediatric oncology providers	*Knowledge*: Physicians received more didactic (0.25 ± 4.34, *p* = .002) and clinical (.09 ± .286, *p* = .012) education than nurses. More than half of nurses reported no palliative care education or training, compared to 22% of physicians. Twenty percent of participants defined PPC as EOL *Attitude:* 99.4% felt that involving PPC benefits children and their families. More than 90% agreed that PPC improves symptom management, patient and family outcomes, and family support When asked if PPC involvement led to less hope for families, 71% of respondents disagreed. *Barriers:* misconception of PPC as "giving-up" (49%), misunderstandings of PPC definition on behalf of the HCPs (46%), family resistance to PPC (38%), and discomfort discussing PPC or limited knowledge regarding PPC services (36%). Nurse reported barriers at higher frequency. *Practice:*56% of providers stated they never or rarely involve PPC
34.	Pediatric Oncology Providers' Perceptions of a Palliative Care Service: The Influence of Emotional Esteem and Emotional Labor (Szymczak, et al., 2018)	USA	Explore how pediatric oncology providers at one institution perceived the hospital's PPC service and the way these perceptions may influence the timing of consultation.	Qualitative modified grounded theory approach	Semi-structured interviews	N=16 pediatric oncology providers	*Attitude:* PPC service offers a diverse range of valuable contributions to the care of children with advancing cancer. Favorable opinions about the PPC services. *Barriers*: emotional labor involved in early PPC consultation
35.	Factors Associated With Knowledge and Comfort Providing Palliative Care: A Survey of Pediatricians in Mexico (Zuniga-Villanueva et al., 2019)	Mexico	Examine what factors determine the degree of knowledge and level of comfort Mexican pediatricians have providing pediatric palliative care.	Quantitative cross-sectional descriptive	Electronic survey	N=242 pediatricians	*Factors associated with Knowledge*: exposure to oncologic patients (*p* = .01) and previous palliative care education (*p* = .02), pediatrician's age (*p* = .01). The final model explains 8.64% of the variation in the final score of PC knowledge *Factors associated with attitude:* PPC knowledge (*p* < .01) , exposure to oncology patients, prior PPC education *Barriers:* feeling uncomfortable when addressing these issues with patients and families

	Title/Author/year	Country	Purpose	Design	Data Collection method	Sample	Key Findings
36.	Training in pediatric palliative care in Italy: still much to do (Benini et al., 2019)	Italy	Determine the availability of training programs in PPC and EOL care for Italian postgraduates specializing in Pediatric Medicine and how the knowledge and skills offered as part of their training is structured	Quantitative cross-sectional descriptive	Web-based survey	n = 14 Directors of Italian postgraduate pediatric medicine programs n = 116 postgraduate students in pediatric medicine	*Knowledge:* 33.6% of the students (n = 39) were aware of local PPC services. 96.6% correctly defined PPC as "the care addressed to children with life-limiting and chronic illnesses, who need high levels of care, regardless of the expected survival time". In 65.5% of the cases, PPC was correctly defined as a care that should start when the diagnosis of incurability. Between 90% and 100% of participants denied several PPC misconceptions. *Attitude:* 68.1% of students did not feel ready to care for a pediatric patient with life-limiting disease. *Practice*: 68.1% (n = 79) did not feel ready to care for a pediatric patient with life-limiting disease.
37.	The conceptual understanding of pediatric palliative care: a Swiss healthcare perspective (De Clercq et al., 2019)	Switzerland	Examine understanding of and attitudes towards pediatric palliative care from the perspective of health care providers working in pediatric oncology.	Qualitative (Thematic coding)	Mixed focused group	N=29 pediatric oncology providers	*Knowledge*: Most participants associated PPC with non-curative treatment. *Barriers:* difficulties in addressing palliative care services to families due to the strong stigma surrounding this term. *Facilitators:* use synonyms such as comfort or supportive care and positive "word of mouth"
38.	A survey demonstrates limited palliative care structures in paediatric nephrology from the perspective of a multidisciplinary healthcare team (Thumfart et al., 2019)	Germany	Investigate the attitudes and expectations of a multidisciplinary paediatric nephrology team, towards palliative care	Quantitative cross-sectional descriptive	Online survey	N=52 healthcare professionals.	*Knowledge*: The majority of participants (96%) responded that the timing of PPC is at EOL, 17% throughout the disease. Two thirds the nephrology care team agreed on integrating PPC at EOL and for patients with high morbidity. Only one-sixth of the respondents felt that palliative care should be provided to patients in stable condition. *Attitude:* physicians rated the importance of PPC as 1.8, nurses as 1.6 and psychosocial health professionals as1.9 (1=very important) *Barriers:* lack of expertise (74%), lack of adequate funding(47%) and lack of specialized care teams (42%)
39.	Use of an Electronic Journal Club to Increase Access to and Acceptance of Palliative Care Literature across General Pediatricians and Pediatric Subspecialties. (Weaver et al., 2019b)	USA	Explore the impact of a monthly electronic journal club to increase the number of palliative care-relevant articles read and discussed and to enhance provider comfort with the integration and introduction of palliative care.	Quantitative predesign-post-design	Online survey	One cohort	*Attitude:* The journal club intervention increased participant personal comfort with integrating palliative care principles at the bedside ($p < 0.0001$) and introducing pediatric palliative care to patients and families ($p < 0.0001$)
40.	Defining the Boundaries of Palliative Care in Pediatric Oncology (Cuviello et al., 2020)	USA	Assess pediatric oncology practitioners' understanding of PPC. Describe the extent to which PPC is integrated into current care via primary PPC delivered by the oncologist. Describe reported barriers to PC provision to pediatric oncology patients	Mixed-method	semi-structured interviews content analysis	N=76 pediatric oncology providers	*Knowledge:* PPC was not limited to EOL as reported by 75% of respondents. All participants acknowledged primary PPC skills as part of their daily clinical activities some reported confusion about the benefits of PC consultation. *Practice:* variation in the comfort and time spent performing primary PPC tasks *Barriers:* Discomfort providing primary pc, tensions between subspecialty palliative care and oncology.

	Title/Author/year	Country	Purpose	Design	Data Collection method	Sample	Key Findings
41.	A multicountry assessment in Eurasia: Alignment of physician perspectives on palliative care integration in pediatric oncology with World Health Organization guidelines (Ehrlich et al., 2020)	Eurasia (Armenia, Azerbaijan, Belarus, Kazakhstan, Kyrgyzstan, Moldova, Mongolia, Russia, Tajikistan, Ukraine, and Uzbekistan)	Assess the perspectives and knowledge of physicians caring for children with cancer on palliative care in 11 countries in Eurasia.	Quantitative and Qualitative items	Electronic survey with paper-based option	N=424 responses from 11 countries in Eurasia	*Knowledge:* The mean alignment between provider perspectives and WHO recommendations was 70% (range, 7%-100%). More than 90% of respondents reported the role palliative care as pain and symptom management (97%) and psychological support (92%) and addressing quality of life. The most common regional misconceptions was early consultation with palliative care causes increased parental burden and anxiety. *Factors associated with knowledge:* prior palliative care education *Attitude:* Two-thirds of respondents (67%) reported not feeling confident about delivering at least 1 component of palliative care. The majority indicated that palliative care is administered when no other curative options are available (57%) and at the end of life (36%). A minority of respondents described palliative care more positively (7.7%) as a celebration of life. Participants responded being confident about managing the physical (57%) and emotional needs of their patients (63%). *Practice:* Access to PPC consultation was reported in 54% of the cases.
42.	The effect of web-based pediatric palliative care education on the palliative care knowledge level and practices of nursing students (Akdeniz Kudubes & Bektas, 2020)	Turkey	Investigate the effect of web-based pediatric palliative care education on nursing students' knowledge level and practices related to palliative care	Quantitative Case-control Pre-post training	Electronic survey	N=265 nursing students	*Knowledge:* The difference between pre-post test scores was statistically significant in the intervention and control groups ($p < .05$). The PPC education program explained 9.6% ($R^2 = 0.096$) of the increase in the level of knowledge, receiving the education increased the level of knowledge by 0.310 times ($\beta = .310$). *Practice:* The difference between the pretest and posttest score on PPC practice was statistically significant in the intervention and control groups ($p < .05$).The education program explained 36% ($R^2 = 0.360$) of the increase in the level of the change in self-reported palliative care practices, while receiving the education increased the level of change in self-reported palliative care practices by 0.600 times ($\beta = .600$).
43.	Paediatric oncology providers' perspectives on early integration of paediatric palliative care (Saad et al., 2020)	Lebanon	Explore the perceptions of paediatric oncology providers regarding the integration of early PPC in the management of children with cancer.	Qualitative descriptive	Focus Group discussions Semi-structure interviews	n=10 pediatric oncology nurses n=7 pediatric oncologists	*Knowledge:* palliative care is understood as pain relief and psychological support, mainly at the EOL. The timing of integrating PPC is linked to EOL, advanced disease or treatment failure *Attitude:* The benefits of early integration were raised by nurses *Barriers:* Parents' views as giving-up, lack of training and specialization, Difficulties in communication with patients/ families, emotional attachment to patients *Facilitators*: Respecting religious beliefs, team approach/ collaboration, Involvement of trained nurses
44.	Perceptions of Pediatric Palliative Care among Physicians Who Care for Pediatric Patients in South Korea (Yu et al., 2020)	South Korea	Explore physicians' perceptions of PPC and the differences therein between non-oncologists and oncologists.	Quantitative cross-sectional descriptive	Electronic Survey	N=141 physicians	*Attitude:* Oncologists showed higher confidence levels in decision making and communication with patients and families with poor prognosis ($p = 0.041$) and education and providing end-of-life care ($p < 0.001$). oncologists preferred earlier referrals than did non-oncologists. *Barriers*: Lack of resources in PPC (60.2%), patients' or caregivers' negative recognition (55.9%)

	Title/Author/year	Country	Purpose	Design	Data Collection method	Sample	Key Findings
45.	Feasibility, Acceptability, and Education of Pediatric Oncology Providers Before and After an Embedded Pediatric Palliative Oncology Clinic (Falk et al., 2021)	USA	Explore whether an embedded pediatric palliative oncology (PPO) clinic is associated with improved pediatric oncology provider palliative care comfort, knowledge, and attitudes toward PPC and if the model is feasible for both clinical care and education of providers	Quantitative Cohort	Electronic survey (baseline, six months, and one year after the start of an embedded PPO clinic)	N=29 oncologists, advanced practice providers, and fellows.	*Knowledge:* Embedded clinic: The non-PPO group had a greater mean change over 1 year in self-efficacy ($p = .003$) and knowledge ($p = .01$) *Attitude:* All providers reported positive attitudes about PPC, seeing it as essential to patient care, helpful in relieving suffering, and beneficial for a comprehensive patient care.
46.	Congenital Cardiothoracic Surgeons and Palliative Care: A National Survey Study (Morell et al., 2021)	USA	Describe perspectives of pediatric cardiothoracic surgeons regarding palliative care in pediatric heart disease.	Quantitative cross-sectional descriptive	Web-based survey	N=31 cardiothoracic surgeons	*Attitude*: Forty five percent would refer to PPC upon prenatal diagnosis and 30% would refer when treatment options fail. *Barriers:* perception of "giving-up" (40%) and concern for undermining parental hope (36%). *Practice:* Around 83% initiated or encouraged PPC. Reasons for consultation included setting the goals of care (87%) end-of-life care (90%), symptom and pain management (74%)
47.	Qualitative Analysis of Family-centered Care for Children with Cancer in Palliative Wards: An Evaluation of Needs and Barriers in Resource-limited Settings (Endah Purnamaningsih Maria Margaretha et al. 2021)	Indonesia	Assess the perspectives of nurses regarding family-centered treatment in Indonesia's palliative wards for children with cancer.	Qualitative Content analysis	Semi-structured Interview	N=10 nurses	*Barriers:* Limited information regarding the timing introduction of palliative and family centered care, inconsistency in patient classification lack of palliative and family centered care awareness, and lack of awareness, lack of practice skills about palliative and family centered care, *Facilitators*: multidisciplinary collaboration
48.	Attitudes and Practices of Pediatric Oncologists Regarding Palliative Care Consultation for Pediatric Oncology Patients (Parisio et al. 2021)	USA	Describe palliative care services available to children with cancer along with pediatric oncologists' current and ideal practices of palliative care involvement in children with cancer	Quantitative cross-sectional descriptive	Electronic survey	N=265	*Attitude*: more than half of oncologists agreed that palliative care should "always" be consulted for the following scenarios: new diagnosis of advanced/metastatic disease (53%), uncontrolled symptoms (65%), BMT (55%), relapsed/refractory disease (73%), and end of life (89%). No one felt that palliative care should "never" be consulted for all scenarios outlined in the survey. More than 90% reported that PPC services should be consultations more frequently.
49.	Palliative care for children with complex cardiac conditions: survey results (Vemuri et al., 2021)	United Kingdom	Examine current practices, attitudes, confidence and perspectives of participants on providing palliative care to children with complex cardiac conditions.	Quantitative cross-sectional descriptive with open-ended questions	Electronic survey	n=86 Palliative Care Practitioners n=91 Cardiac Care Practitioners	*Knowledge*: Both groups reported that palliative care extended beyond the end of life phase, the last weeks of life, and could be instituted even when management had not yet been decided. *Attitude:* Significant difference between groups regarding the acceptability of PPC and the effect of early PPC on parental hope. Both groups agreed on its value as a support to clinicians and in managing symptoms. *Practice:* The most common reasons for PPC referral were: assistance with preferred place of death discussions, advance care planning, symptom management. Both groups reported confidence in discussing goals of Care and providing end-of-life care.

Studies conducted among non-healthcare professionals

	Title/Author/year	Country	Purpose	Design	Data Collection method	Sample	Key Findings
50.	Perceptions of the Term Palliative Care (Boldt et al., 2006)	USA	Assess parents' and health care providers' perceptions of the name and description of a PPC program.	Quantitative randomized, parallel-group survey	Written survey Before and after reading description	N=105 Parents N=79 healthcare providers	*Knowledge:* At baseline, more parents in the supportive care group (57.6%) reported knowledge about the program definition than in PPC group (36.4%), (Chi^2= 4.562, *p*= 0.033). Reading the description significantly increased awareness in both groups (100% in supportive care vs 89.7% in PPC group (*p*=0.02). Among providers reading the description significantly increased awareness within the supportive care group only (*p* = 0.016). *Attitude:* At baseline, parents in PPC group were less likely to use program than supportive care group (*p*<0.05). The likelihood to use the program increased in both groups after reading the program description. Both likelihood increased after reading description. Among providers the likelihood to use the program increased significantly in PC group after reading the description.
51.	Awareness, understanding and attitudes of Italians regarding palliative care (Benini et al., 2011)	Italy	Examine the level of public awareness, understanding and attitudes of the Italian population regarding PC	Quantitative cross-sectional descriptive	Structured Interviews	N= 1897 individuals from the general public	*Knowledge:* Around 40% of participants have never heard about palliative care. Of those who have heard, only 23.5% reported adequate level of knowledge and 27% did not know or had a mistaken idea about the nature of PC. When articulating their own definition participants linked palliative care to final phase of life. *Factors associated with knowledge*: gender (women were more aware), age, level of education, geographic location, income. *Barriers*: In Pediatric population the main concern was: being "separated" from family, friends, home and toys.
52.	How Parents of Children Receiving Pediatric Palliative Care Use Religion, Spirituality, or Life Philosophy in Tough Times (Hexem et al., 2011)	USA	Clarify and illustrate the role of religion, spirituality, or life philosophy in the lives of parents of children with life-threatening conditions.	Qualitative research approach nested in a prospective cohort study	Semi-structured interviews	N=73 parents	*Facilitator:* Religious beliefs and commitment
53.	Establishing Feasibility of Early Palliative Care Consultation in Pediatric Hematopoietic Stem Cell Transplantation (Lafond et al., 2015)	USA	Establish the feasibility of integrating palliative care early in the trajectory of HSCT (at the time of referral or admission to the HSCT program) and to measure the outcomes of such care. experience	Longitudinal, descriptive cohort design	Structured Interviews	n=12 Families (caregivers and patients) n=20 healthcare providers	*Attitude:* Families (100%) rated the PC as helpful or very helpful in managing symptoms and stresses. All families indicated it was very important to offer palliative care services and that they were very likely to recommend the palliative care team to others. Families (70%) were also very likely to recommend the institution to other patients and families based upon their experiences with the palliative care team.
54.	Patients' and Parents' Needs, Attitudes, and Perceptions About Early Palliative Care Integration in Pediatric Oncology (Levine et al., 2017)	USA	Determine the perception of symptom burden early in treatment. Assess attitudes toward early integration of palliative care in pediatric oncology patient-parent pairs.	Quantitative cross-sectional descriptive	Self-administered survey	N=129 dyads (Patients=10-17 years and parents)	*Knowledge:* The majority of both patients (n = 127; 98.4%) and parents (n = 90; 69.8%) reported that they had never heard the term "palliative care," *Attitude:* none of those familiar have negative attitude. When given a brief description: Very few children (n = 2; 1.6%) or parents (n = 8; 6.2%) opposed early PPC integration. Children were significantly more likely than parents to endorse that including PC around the time of diagnosis would have been helpful for treating symptoms (40.3% vs 17.8% *p* < .001)

	Title/Author/year	Country	Purpose	Design	Data Collection method	Sample	Key Findings
55.	Needs and challenges of lay community health workers in a palliative care environment for orphans and vulnerable children (Visagie & Pillay, 2017)	South Africa	Explore the role of lay health workers in a community organization located in rural Bronkhorstspruit, Gauteng Province of South Africa.	Qualitative descriptive phenomenological case study design	Individual interviews Focus group discussions Observations	N=25 lay community workers N=21 in FGD	*Knowledge*: participants reported lack of knowledge in term of palliative care itself.
56.	Exploring knowledge and perceptions of palliative care to inform integration of palliative care education into cystic fibrosis care (Dellon et al., 2018)	USA	Explore knowledge and perceptions of palliative care among patients with cystic fibrosis, caregivers, and care providers. Solicit opinions about incorporating palliative care into routine cystic fibrosis care and recommendations for cystic fibrosis -specific palliative care education	Qualitative Descriptive	Semi-structured interviews	n=10 Patients n=10 caregivers n= 8 Providers	*Knowledge:* half of patients and one third of parents had no knowledge Those familiar with PPC associated it with end-of-life. Most of participants used "comfort" and “quality of life” in their description *Attitude:* After hearing description participants reported that PPC is helpful *Barriers:* association with end-of-life, patient/family denial and reluctance to discuss palliative care.
57.	Public awareness of palliative care in Sweden (Westerlund et al., 2018)	Sweeden	Investigate the awareness of palliative care in a general Swedish population	Quantitative cross-sectional descriptive	Electronic survey	N=2020 individuals from the general public	*Knowledge:* Around 84% have ‘no’ or ‘some’ knowledge about palliative care. The aims of palliative care were most frequently identified as ‘care before death’ and ‘pain relief’. The most common sources of information included: media, close friends and relatives receiving PC. *Factors associated with knowledge:* gender, age, level of education, work setting and knowing someone receiving palliative care *Barriers:* fear, shame, taboo, perceived lack of information
58.	Palliative Care Knowledge and Characteristics in Caregivers of Chronically Ill Children (Johnston et al., 2020)	USA	Describe palliative care awareness among caregivers of children with children with chronic conditions. Compare awareness to the whole survey population, the non-caregiver population, and the adult caregiver population. Identify socio-demographic and clinical factors associated with lack of palliative care awareness.	Secondary Data Analysis (HINTS 5 cycle 2)	Self-administered mailed survey	N=131 caregivers of children with chronic conditions	*Knowledge:* 62% never heard (comparable to non-caregivers and adult caregivers). More than 90% of participants reported that palliative care help coping emotional support and symptom management. and 80% think that PPC is the same as hopice *Factors associated with knowledge:* age and level of education
59.	Experiences of healthcare, including palliative care, of children with life- limiting and life- threatening conditions and their families: a longitudinal qualitative investigation (Mitchell et al., 2021)	United Kingdom	Understand the experiences and perceptions of healthcare services of children with life- limiting and life- threatening conditions and their family members, including palliative care.	Longitudinal qualitative	In-depth interviews (up to three interviews per participant)	N=31 participants (including 10 children)	*Knowledge:* Palliative care conceptualized as a distinct service or phase of a child’s condition, rather than a broad approach. *Facilitators:* availability of specialist services, trust with healthcare professionals

	Title/Author/year	Country	Purpose	Design	Data Collection method	Sample	Key Findings
60.	Palliative Care in Duchenne Muscular Dystrophy: A Study on Parents' Understanding (Sadasivan et al., 2021)	India	Explore the parent's understanding of palliative care services available for children with Duchenne Muscular Dystrophy and the challenges faced by them in utilizing the same.	Qualitative exploratory Grounded theory	Semi-structured interviews	N=six parents	*Knowledge:* Participants are aware of the term and aim of palliative care. But palliative care for children was not clear. The term palliative care is associated with ambiguity and death. This association created stigma for the parents unless they have prior experience with the condition. Participants were unsure regarding the timing and indications of PPC. *Barriers:* difficulty accepting the child's prognosis, lack of emotional acceptance of the child's condition, lack of open communication between the parents and the child

APPENDIX B

Invitation to Participate in a Research Study

This notice is for an AUB-IRB Approved Research Study for

Principle Investigator: Dr Samar Noureddine
Co-Investigator: Dr Huda Abu-Saad Huijer

(Rafic Hariri School of Nursing, Email address: hh35@aub.edu.lb, sn00@aub.edu.lb
Telephone: 961-1-374374 extension 5953-5966)

It is not an Official Message from AUB

Hello. My name is Rima Saad. I am a PhD student working with Dr Huijer and Dr Noureddine at the Hariri School of Nursing at the American University of Beirut. I would like to invite you to participate in a research study about parents' views regarding palliative care for children with cancer. The purpose of the study is to examine the parents' knowledge, attitudes and beliefs toward palliative care in order to uncover areas for improvement. I am doing this study as part of my PhD dissertation at AUB. I will be conducting the study in two phases. The first phase encompasses cultural adaptation and pilot testing of the survey and the second phase includes the main study.

This email is to invite you to participate as a translator of the survey. The procedure consists of translating the attached survey from English to Arabic *(or Arabic to English for back-translation)* and sending it back within two weeks *(ie before dd/mm/year).* I will use the information in the first phase of my dissertation study. I may also use this information in articles that might be published, as well as in academic presentations. Your individual privacy and confidentiality of the information you provide will be maintained in all published and written data analysis resulting from the study. I will be the only one who will have access to the data you provide. The information you provide will not be linked to your identity. You will not be asked to provide any identifying information. Your privacy will be further protected by not asking you to sign any consent form.

Please understand your participation is entirely on a voluntary basis and you have the right to withdraw your consent or discontinue participation at any time without penalty. You will not be asked any personal or sensitive question. The risks of participating in the study are minimal. There are no direct benefits to you from participating in the study, however, the information you provide will contribute to developing culturally-adapted measures that help in conducting palliative care research. You will receive a thank you note as a token of appreciation for your participation. If you agree to participate, your reply to this email by sending the translated survey within the timeline implies your consent.

If you have any questions, you may contact me at my phone number: 03-998548 or email "rms57@mail.aub.edu". If you have questions about your rights as a participant in this research, you can contact the AUB Social and Behavioral Sciences Review Board Telephone: **01-350000, Ext: 5444/5455, Email: irb@aub.edu.lb**

Thank you.

Rima Saad, MSN RN CPHON
PhD Candidate
Hariri School of Nursing
American University of Beirut

APPENDIX C

Invitation to Participate in a Research Study

This notice is for an AUB-IRB Approved Research Study for

Principle Investigator: Dr Samar Noureddine
Co-Investigator: Dr Huda Abu-Saad Huijer

(Rafic Hariri School of Nursing, Email address: hh35@aub.edu.lb,sn00@aub.edu.lb
Telephone: 961-1-374374 extension 5953-5966)

It is not an Official Message from AUB

Hello. My name is Rima Saad. I am a PhD student working with Dr Huijer and Dr Noureddine at the Hariri School of Nursing at the American University of Beirut. I would like to invite you to participate in a research study about parents' views regarding palliative care for children with cancer. The purpose of the study is to examine the parents' knowledge, attitudes and beliefs toward palliative care in order to uncover areas for improvement. I am doing this study as part of my PhD dissertation at AUB. I will be conducting the study in two phases. The first phase encompasses cultural-adaptation and pilot testing of the survey and the second phase includes the main study.

This email is to invite you to participate in the first phase as content expert to validate the survey in terms of relevance and cultural appropriateness. The procedure consists of rating each item of the attached survey for relevance and cultural appropriateness using the attached grid and sending it back within two weeks *(ie before dd/mm/year)*. I will use the information in the first phase of my dissertation study. I may also use this information in articles that might be published, as well as in academic presentations. Your individual privacy and confidentiality of the information you provide will be maintained in all published and written data analysis resulting from the study. I will be the only one who will have access to the data you provide. The information you provide will not be linked to your identity. You will not be asked to provide any identifying information. Your privacy will be further protected by not asking you to sign any consent form.

Please understand your participation is entirely on a voluntary basis and you have the right to withdraw your consent or discontinue participation at any time without penalty. You will not be asked any personal or sensitive question. The risks of participating in the study are minimal. There are no direct benefits to you from participating in the study, however, the information you provide will contribute to developing culturally-adapted measures that help in conducting palliative care research. You will receive a thank you note as a token of appreciation for your participation. If you agree to participate, your reply to this email by sending the completed grid within the timeline implies your consent.

If you have any questions, you may contact me at my phone number: 03-998548 or email "rms57@mail.aub.edu". If you have questions about your rights as a participant in this research, you can contact the AUB Social and Behavioral Sciences Review Board Telephone: **01-350000, Ext: 5444/5455, Email: irb@aub.edu.lb**

Thank you.

Rima Saad, MSN RN CPHON
PhD Candidate
Hariri School of Nursing
American University of Beirut

APPENDIX D

Sample of Email Script for Oncology Treating Team to Inform about the Study

“This is not an official message from AUB”

This email message is sent on behalf of Dr Samar Noureddine with regards to a research study she plans to conduct at the American University of Beirut Medical Center (AUBMC)-Children’s Cancer Institute (CCI), Saint George Hospital University Medical Center (SGHUMC) and Lebanese Hospital Geitaoui-University Medical Center (LHG-UMC). Dr Noureddine’s email address: sn00@aub.edu.lb, Telephone: 961-1-374374 (ext: 5966).

Dear Colleagues,

We are about to launch a study entitled:

“Primary caregivers’ knowledge, attitudes and beliefs toward palliative care for children with cancer”

The goal of this study is to examine primary caregivers’ knowledge, attitudes and beliefs towards pediatric palliative care for children with cancer in order to uncover areas for improvement.

This email is to inform you that primary caregivers of your patients will be invited to partake in the study. The study involves no more than minimum risk to the participants, consent will be sought. The procedure consists of remotely interviewing primary caregivers of children with cancer treated at the *(AUBMC-CCI or SGHUMC or LHG-UMC)* regarding the different concepts of interest. .

Thank you.

Samar Noureddine, PhD, RN, FAHA, FAAN
Professor,
Associate Dean for Academic Affairs
Convener of the Graduate Division
Hariri School of Nursing,
American University of Beirut
Honorary Professor: University of Dundee, Scotland
Adjunct faculty: Johns Hopkins University, USA

Rima Saad, MSN RN CPHON
PhD Candidate
Hariri School of Nursing
American University of Beirut

APPENDIX E

Sample Email Script for Approval Request to Post Flyers

“This is not an official message from AUB”

This email message is sent on behalf of Dr Noureddine with regards to a research study she plans to conduct at American University of Beirut Medical Center (AUBMC)- Children’s Cancer Institute (CCI), Saint George Hospital University Medical Center (SGHUMC) and Lebanese Hospital Geitaoui-University Medical Center (LHG-UMC) Dr Noureddine’s email address: sn00@aub.edu.lb, Telephone: 961-1-374374 (ext: 5966).

Dear *(Name of the person responsible for granting administrative approval to post the flyers at each institution)*,

We are starting data collection for a study entitled:

“Primary caregivers’ knowledge, attitudes and beliefs toward palliative care for children with cancer”

The goal of this study is to examine primary caregivers’ knowledge, attitudes and beliefs towards pediatric palliative care for children with cancer in order to uncover areas for improvement.

This email is to seek your approval to post the attached flyer in the treatment areas of the pediatric oncology ambulatory clinic and pediatric oncology inpatient unit at *(AUBMC-CCI or SGHUMC or LHG-UMC).*

The flyer is intended as initial approach to invite primary caregivers to partake in the study. The study involves no more than minimum risk to the participants. The procedure consists of remotely interviewing primary caregivers of children with cancer treated at the *(AUBMC-CCI or SGHUMC or LHG-UMC)* regarding the different concepts of interest
Your approval is highly appreciated to post the flyers in the above mentioned areas.

Thank you.

Samar Noureddine, PhD, RN, FAHA, FAAN
Professor,
Associate Dean for Academic Affairs
Convener of the Graduate Division
Hariri School of Nursing,
American University of Beirut
Honorary Professor: University of Dundee, Scotland
Adjunct faculty: Johns Hopkins University, USA

Rima Saad, MSN RN CPHON
PhD Candidate
Hariri School of Nursing
American University of Beirut

APPENDIX F

Copy of the Flyer for Pilot Phase (English)

Call for participation in research

Pilot Phase

Are you a primary caregiver of a child with cancer?

We invite you to participate in the study on:

Primary Caregivers' Knowledge Attitudes and Beliefs toward Palliative Care for Children with Cancer

Principle Investigator: Dr Samar Noureddine, PhD, Hariri School of Nursing, American University of Beirut
Co-Investigator: Dr Huda Abu-Saad Huijer, PhD, Rima Saad, MSN, PhD Candidate, Hariri School of Nursing, American University of Beirut

This is a study about examining primary caregivers' perspectives toward palliative care for children with cancer in Lebanon in order to uncover areas for improvement.

We invite you to participate in the first phase of the study which entails describing your views about palliative care and pilot testing the survey used. 20 Primary caregivers are being recruited in three major pediatric oncology centers in Lebanon.

Your participation will bring valuable information that help improve the care of children with cancer in Lebanon.

If you decide to participate you will be invited to an interview via whatsapp video call (45-60 minutes). You can choose to be at home or at the treatment center. You will use a quiet room with internet connection. You will be asked questions on your views regarding pediatric palliative care and your feedback on the survey used. A thank you note will be sent to you after the interview and you will enter a prize draw for one of four cash prizes of 150 000 LBP each.

For any questions/clarifications or for participation you can contact or ask your healthcare provider to help you contact Rima Saad (tel: 03-998548, email: rms57@mail.aub.edu).

APPENDIX G

Copy of the Flyer for Pilot Phase (Arabic)

مرحلة الإختبار

دعوة للمشاركة في بحث علمي

هل أنت معتني رئيسي
بطفل مصاب بالسرطان؟

ندعوك للمشاركة
في بحث علمي عن:

معرفة المعتنين الرئيسيّن ومواقفهم
وإعتتقاداتهم تجاه العناية التلطيفية للأطفال
المصابين بالسرطان

الباحثة الرئيسية: الدكتورة سمر نورالدين، مدرسة الحريري للتمريض ، الجامعة الأمريكية في بيروت
الباحثة المشاركة: الدكتورة هدى أبو سعد هاير، ريما سعد، مدرسة الحريري للتمريض ، الجامعة الأمريكية في بيروت

تتمحورهذه دراسة حول فحص وجهات نظر المعتنين الرئيسيّن تجاه الرعاية التلطيفية للأطفال المصابين بالسرطان من أجل الكشف عن مجالات التحسين.

ندعوك للمشاركة في المرحلة الأولى من الدراسة التي تتضمّن وصف آرائك حول الرعاية التلطيفية وتعليقك على قائمة الأسئلة المستخدمة. يشارك في هذه الدراسة 20 معتني رئيسيّ في ثلاثة مراكز لعلاج سرطان الأطفال في لبنان.

ستجلب مشاركتك معلومات قيمة تساعد في تحسين رعاية الأطفال المصابين بالسرطان في لبنان.

إذا قررت المشاركة ، فستتم دعوتك لإجراء مقابلة عبر مكالمة فيديو واتساب مدتها 45-60 دقيقة. يمكنك اختيار أن تكون في المنزل أو في مركز العلاج. سوف تستخدم غرفة هادئة مجهزه بالإنترنت. ستطرح عليك أسئلة حول آرائك بخصوص الرعاية التلطيفية للأطفال وتعليقك على قائمة الأسئلة المستخدمة. سيتم إرسال رسالة شكر إليك بعد المقابلة وستدخل في سحب على واحده من أربع جوائز نقدية كل منها بقيمة 150000 ليره لبنانية.

لأية أسئلة / توضيحات أو للمشاركة ، يمكنك الاتصال أو طلب المساعدة من مقدم الرعاية الصحية الخاص بك لمساعدتك في الاتصال بالسيدة ريما سعد:
رقم الهاتف: 03-998548 أو البريد الالكتروني: rms57@mail.aub.edu

APPENDIX H

Copy of the Flyer for Main Study (English)

Call for participation in research

Are you a primary caregiver of a child with cancer?

We invite you to participate in the study on:

Primary Caregivers' Knowledge Attitudes and Beliefs toward Palliative Care for Children with Cancer

Principle Investigator: Dr Samar Noureddine, PhD, Hariri School of Nursing, American University of Beirut
Co-Investigator: Dr Huda Abu-Saad Huijer, PhD, Rima Saad, MSN, PhD Candidate, Hariri School of Nursing, American University of Beirut

This is a study about examining primary caregivers' perspectives toward palliative care for children with cancer in Lebanon in order to uncover areas for improvement.

110 Primary caregivers are being recruited in three major pediatric oncology centers in Lebanon.

Your participation will bring valuable information that help improve the care of children with cancer in Lebanon.

If you decide to participate you will be invited to an interview via whatsapp video call (45-60 minutes). You can choose to be at home or at the treatment center. You will use a quiet room with internet connection. You will be asked questions on your views regarding pediatric palliative care. A thank you note will be sent to you after the interview and you will enter a prize draw for one of four cash prizes of 150 000 LBP each.

For any questions/clarifications or for participation you can contact or ask your healthcare provider to help you contact Rima Saad (tel: 03-998548, email: rms57@mail.aub.edu).

APPENDIX I

Copy of the Flyer for Main Study (Arabic)

دعوة للمشاركة في بحث علمي

هل أنت معتني رئيسي
بطفل مصاب بالسرطان؟

ندعوك للمشاركة
في بحث علمي عن:

معرفة المعتنين الرئيسيّن ومواقفهم
وإعتقاداتهم تجاه العناية التلطيفية للأطفال
المصابين بالسرطان

الباحثة الرئيسية: الدكتورة سمر نورالدين، مدرسة الحريري للتمريض ، الجامعة الأمريكية في بيروت
الباحثة المشاركة: الدكتورة هدى أبو سعد هاير، ريما سعد، مدرسة الحريري للتمريض ، الجامعة الأمريكية في بيروت

تتمحورهذه دراسة حول فحص وجهات نظر المعتنين الرئيسيّن تجاه الرعاية التلطيفية للأطفال المصابين بالسرطان من أجل الكشف عن مجالات التحسين.

يشارك في هذه الدراسة 110 معتنين رئيسيّن في ثلاثة مراكز لعلاج سرطان الأطفال في لبنان.

ستجلب مشاركتك معلومات قيمة تساعد في تحسين رعاية الأطفال المصابين بالسرطان في لبنان.

إذا قررت المشاركة ، فستتم دعوتك لإجراء مقابلة عبر مكالمة فيديو واتساب مدتها 45-60 دقيقة. يمكنك اختيار أن تكون في المنزل أو في مركز العلاج. سوف تستخدم غرفة هادئة مجهزة بالإنترنت. ستطرح عليك أسئلة حول آرائك بخصوص الرعاية التلطيفية للأطفال. سيتم إرسال رسالة شكر إليك بعد المقابلة وستدخل في سحب على واحده من أربع جوائز نقدية كل منها بقيمة 150000 ليره لبنانية.

لأية أسئلة / توضيحات أو للمشاركة ، يمكنك الاتصال أو طلب المساعدة من مقدم الرعاية الصحية الخاص بك لمساعدتك في الاتصال بالسيدة ريما سعد:
رقم الهاتف: 03-998548 أو البريد الالكتروني: rms57@mail.aub.edu

APPENDIX J

Verbal Recruitment Script for Pilot Phase (English)

Hello - My name is Rima Saad and I am a PhD candidate working with Dr Noureddine at the Hariri School of Nursing at the American University of Beirut. Before doing my PhD I worked with children with cancer for 15 years.

Thank you for your interest in my research study titled "Primary caregivers' knowledge, attitudes and beliefs towards palliative care for children with cancer". I am interested about your views about pediatric palliative care for children with cancer. There will be no direct benefit to your child; however, the information you provide will help to improve the care of children with cancer. I would like to confirm that

- you are the primary caregiver of a child with cancer being currently treated at [*site name*].
- you are Lebanese or a permanent resident in Lebanon, currently living in Lebanon
- you can speak Arabic
- the child with cancer under your care is currently below 18 years
- the diagnosis with cancer occurred longer than 2 months ago,
- the child was not admitted to intensive care within the last month.

(If any of the above is not confirmed by the subject)
I am sorry, but it looks like my study is not for you. Thank you for your time and for listening to me. I hope to talk with you in the future about other research studies you might be interested in.

(If all of the above is confirmed by the subject)
In this study, I will be interviewing mothers, fathers, or other caregivers of children with cancer via whatsapp video call. The participants may choose to be at their home or at the treatment center at the time of the interview. They will be asked to use a private room equipped with internet connection. A thank you note will be sent after the interview and participants will enter a prize draw for one of four cash prizes of 150 000 LBP each.

The first phase of the study encompasses pilot testing of the survey in order to refine it before its use in the main study. I will be asking about your knowledge, attitudes and beliefs about pediatric palliative care for children with cancer. I will also ask for your feedback and recommendations on the different sections of the survey. If you are interested, I would like to talk to you more about the study, answer any questions you might have, and take your consent if you want to be involved.
All information will be confidential and only accessible to the research team at all times. Remember, your participation is completely voluntary. Refusal to participate will not affect you, your child's or your relationship with the treatment center or with the treating physician nor the quality of care that your child is receiving at the center.

If you'd like to participate, we can go ahead and schedule a time for the interview. If you need more time to decide, you may also call or email me with your decision. Do you have any questions for me at this time?

If you have any more questions about the study or if you need to contact me about participation, I may be reached at [03-998548, email: rms57@mail.aub.edu]. Thank you so much.

APPENDIX K

Verbal Recruitment Script for Pilot Phase (Arabic)

مرحبا- إسمي ريما سعد وأنا طالبة دكتوراه مع الدكتورة سمر نورالدين في مدرسة الحريري للتمريض في الجامعة الأمريكية في بيروت. قبل دراسة الدكتوراه ، اشتغلت مع الأطفال المصابين بالسرطان لمدة 15 سنة.

شكراً لإهتمامك ببحثي العلمي بعنوان :" معرفة المعتنين الرئيسيّن ومواقفهم وإعتتقاداتهم تجاه العناية التلطيفية للأطفال المصابين بالسرطان ".

أنا مهتمة بنظرتك حول العناية التلطيفية للأطفال المصابين بالسرطان. ما رح يكون في استفادة مباشرة لإبنك/بنتك ، إنما، المعلومات يلي بتعطيها رح تساعد على تحسين العناية بالأطفال المصابين بالسرطان في لبنان.

بحب أكّد معك:

- إنك المعتني(ة) الرئيسيّ(ة) بطفل مصاب بالسرطان حالياً عم يتعالج ب(إسم المركز)
- إنك لبناني(ة) أو مقيم(ة) دائم(ة) بلبنان وحالياً عايش(ة) بلبنان
- إنك بتحكي اللغة العربية
- الطفل المصاب بالسرطان حالياً عمره أقل من 18 سنة
- تم التشخيص بالسرطان قبل أكثر من شهرين
- ما دخل الطفل على العناية المركزة خلال الشهر الماضي.

(If any of the above is not confirmed by the subject)

بعتذر، بس كأن دراستي مش إلك. شكراً على وقتك وعلى إنك سمعتلّي. إنشالله بالمستقبل إحكي معك بغير أبحاث علمية ممكن تهمّك.

(If all above is confirmed by the subject)

بهالدراسة، رح كون عم قابل أمات وبيات أو غير معتنين بالأطفال المصابين بالسرطان عبر اتصال واتساب فيديو.

المشاركين فين يكونو ببيتن أو بمركز العلاج بوقت المقابلة. رح ينطلب منن يكونوا بغرفة خاصة مجهزة بإنترنيت .

رح ينبعث رسالة شكر بعد المقابلة ورح يدخل المشاركون بسحب على وحدة من أربع جوائز نقدية كل منها 150000 ليرة لبنانية.

المرحلة الأولى من الدراسة بتشمل اختبار للأسئلة الموجودة باللإستمارة لتنقيحها قبل استخدامها بالدراسة الرئيسية.

رح إسأل عن معرفتك ومواقفك وإعتقاداتك تجاه العناية التلطيفية للأطفال المصابين بالسرطان . ورح أطلب ملاحظاتك وتوصياتك حول الأقسام المختلفة من إستمارة الأسئلة لتحسينها.

إذا مهتم بحب إحكيك أكتر عن الدراسة، جاوب على أسئلة ممكن تسألها وآخذ موافقتك على المشاركة.

كل المعلومات رح تكون كل الوقت سرية وبس فريق البحث ممكن يطّلع عليها. تّذكر إنو مشاركتك طوعية تماماً.

رفض المشاركة ما رح يأثرعليك ، على علاقة الولد أو علاقتك بمركز العلاج أو بالطبيب المعالج ولا على نوعية العناية يللي عم يتلقاها الولد بالمركز.

إذا بتحب(ي) تشارك(ي) فينا نحدد موعد للمقابلة. إذا محتاج(ة) وقت زيادة لتقرر(ي)، فيك تدقللي أو تبعتلي بريد إلكتروني عن قرارك. عندك أي سؤال بالوقت الحاضر؟

إذا كان عندك أي أسئلة زيادة بخصوص الدراسة أو إذا احتجت تتصل(ي) فيّ بخصوص المشاركة، أنا موجودة على

الرقم: 03-998548 أو البريد إلكتروني :

"rms57@mail.aub.edu"

شكراً!

APPENDIX L

Copy of the Brochure for Pilot Phase (English)

Call for participation in research

Pilot Phase

Are you a primary caregiver of a child with cancer?

We invite you to participate in the study on:

Primary Caregivers' Knowledge Attitudes and Beliefs toward Palliative Care for Children with Cancer

Principle Investigator: Dr Samar Noureddine, PhD, Hariri School of Nursing, American University of Beirut
Co-Investigator: Dr Huda Abu-Saad Huijer, PhD, Rima Saad, MSN, PhD Student, Hariri School of Nursing, American University of Beirut

This is a study about examining primary caregivers' perspectives toward palliative care for children with cancer in Lebanon in order to uncover areas for improvement.

We invite you to participate in the first phase of the study which entails describing your views about palliative care and pilot testing the survey used. 20 Primary caregivers are being recruited in three major pediatric oncology centers in Lebanon.

Your participation will bring valuable information that help improve the care of children with cancer in Lebanon.

If you decide to participate you will be invited to an interview via whatsapp video call (45-60 minutes). You can choose to be at home or at the treatment center. You will use a quiet room with internet connection. You will be asked questions on your views regarding pediatric palliative care and your feedback on the survey used. A thank you note will be sent to you after the interview and you will enter a prize draw for one of four cash prizes of 150 000 LBP each.

Pilot Phase

You can choose to be in the study or not to participate

If you decide to participate in this study, you will be completing a consent process before the interview.

If you agree to take part in this study, you will be invited in one individual interview via whatsapp video call with Ms Rima Saad, the co-investigator. The co-investigator will ask you a list of questions about you, your child, your child's cancer, and your views about palliative care for children with cancer in Lebanon. You will be also asked for your feedback on the different parts of the questionnaire which will help in refining it. The co-investigator will type down your answers to the questions on the soft copy of the survey. You may skip any question that makes you uncomfortable and you can stop the interview at any time without affecting the treatment of your child or your relationship with the treatment center.

All information will be confidential and only accessible by the research team at all times.

Remember, your participation is completely voluntary.

For any questions/clarifications or for participation you can contact or ask your healthcare provider to help you contact Rima Saad (tel: 03-998548, email: rms57@mail.aub.edu).

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APPENDIX M

Copy of the Brochure for Pilot Phase (Arabic)

مرحلة الإختبار

دعوة للمشاركة في بحث علمي

هل أنت معتني رئيسي
بطفل مصاب بالسرطان؟

ندعوك للمشاركة
في بحث علمي عن:

معرفة المعتنين الرئيسيّن ومواقفهم
وإعتتقاداتهم تجاه العناية التلطيفية للأطفال
المصابين بالسرطان

الباحثة الرئيسية: الدكتورة سمر نورالدين، مدرسة الحريري للتمريض ، الجامعة الأمريكية في بيروت
الباحثة المشاركة: الدكتورة هدى أبو سعد هاير، ريما سعد، مدرسة الحريري للتمريض ، الجامعة الأمريكية في بيروت

تتمحورهذه دراسة حول فحص وجهات نظر المعتنين الرئيسيّن تجاه الرعاية التلطيفية للأطفال المصابين بالسرطان من أجل الكشف عن مجالات التحسين.

ندعوك للمشاركه في المرحله الأولى من الدراسة التي تتضمّن وصف آرائك حول الرعاية التلطيفية وتعليقك على قائمة الأسئلة المستخدمة. يشارك في هذه الدراسة 20 معتني رئيسيّ في ثلاثة مراكز لعلاج سرطان الأطفال في لبنان.

ستجلب مشاركتك معلومات قيمة تساعد في تحسين رعاية الأطفال المصابين بالسرطان في لبنان.

إذا قررت المشاركة ، فستتم دعوتك لإجراء مقابلة عبر مكالمة فيديو واتساب مدتها 45-60 دقيقة. يمكنك اختيار أن تكون في المنزل أو في مركز العلاج. سوف تستخدم غرفة هادئة مجهزه بالإنترنت. ستطرح عليك أسئلة حول آرائك بخصوص الرعاية التلطيفية للأطفال وتعليقك على قائمة الأسئلة المستخدمة. سيتم إرسال رسالة شكر إليك بعد المقابلة وستدخل في سحب على واحده من أربع جوائز نقدية كل منها 150000 ليره لبنانية.

مرحلة الإختبار

يمكنك اختيار المشاركة أو
عدم المشاركة في الدراسة

إذا قررت المشاركة في هذه الدراسة ، فستستكمل عملية الموافقة قبل المقابلة.

إذا وافقت على المشاركة في هذه الدراسة ، فستتم دعوتك في مقابلة فردية عبر مكالمة فيديو واتساب مع الباحثة المشاركة ريما سعد. ستطرح عليك الباحثة المشاركة قائمة بالأسئلة المتعلقة بك وبطفلك وبمرض طفلك وآرائك حول الرعاية التلطيفية للأطفال المصابين بالسرطان في لبنان. سيُطلب منك أيضًا تقديم ملاحظاتك حول الأجزاء المختلفة من قائمة الأسئلة مما سيساعد في تنقيحها. ستقوم الباحثة المشاركة بكتابة إجاباتك على الأسئلة الموجودة في النسخة الإلكترونية من قائمة الأسئلة . يمكنك تخطي أي سؤال يجعلك غير مرتاح ويمكنك إيقاف المقابلة في أي وقت دون التأثيرعلى معاملة طفلك أو علاقتك بمركز العلاج.

ستكون جميع المعلومات سرية ولا يمكن الوصول إليها إلا من قبل فريق البحث في جميع الأوقات.

تذكر أن مشاركتك طوعية تمامًا.

لأية أسئلة / توضيحات أو للمشاركة ، يمكنك الاتصال أو طلب المساعدة من مقدم الرعاية الصحية الخاص بك لمساعدتك في الاتصال بالسيدة ريما سعد:
رقم الهاتف: 03-998548 أو البريد الالكتروني: rms57@mail.aub.edu

Photo source: https://stock.adobe.com/images/alegria/225582305 -Standard License

APPENDIX N

Copy of the Brochure for Main Study (English)

Call for participation in research

Are you a primary caregiver of a child with cancer?

We invite you to participate in the study on:

Primary Caregivers' Knowledge Attitudes and Beliefs toward Palliative Care for Children with Cancer

Principle Investigator: Dr Samar Noureddine, PhD, Hariri School of Nursing, American University of Beirut
Co-Investigator: Dr Huda Abu-Saad Huijer, PhD, Rima Saad, MSN, PhD Student, Hariri School of Nursing, American University of Beirut

This is a study about examining primary caregivers' perspectives toward palliative care for children with cancer in Lebanon in order to uncover areas for improvement.

110 Primary caregivers are being recruited in three major pediatric oncology centers in Lebanon.

Your participation will bring valuable information that help improve the care of children with cancer in Lebanon.

If you decide to participate you will be invited invited to an interview via whatsapp video call (45-60 minutes). You can choose to be at home or at the treatment center. You will use a quiet room with internet connection. You will be asked questions on your views regarding pediatric palliative care. A thank you note will be sent to you after the interview and you will enter a prize draw for one of four cash prizes of 150 000 LBP each.

You can choose to be in the study or not to participate

If you decide to participate in this study, you will be completing a consent process before the interview.

If you agree to take part in this study, you will be invited in one individual interview via whatsapp video call with Ms Rima Saad, the co-investigator. The co-investigator will ask you a list of questions about you, your child, your child's cancer, and your views about palliative care for children with cancer in Lebanon. The co-investigator will type down your answers to the questions on the soft copy of the survey. You may skip any question that makes you uncomfortable and you can stop the interview at any time without affecting the treatment of your child or your relationship with the treatment center.

All information will be confidential and only accessible by the research team at all times.

Remember, your participation is completely voluntary.

For any questions/clarifications or for participation you can contact or ask your healthcare provider to help you contact Rima Saad (tel: 03-998548, email: rms57@mail.aub.edu).

Photo source: https://stock.adobe.com/images/alegria/225582395 -Standard License

APPENDIX O

Copy of the Brochure for Main Study (Arabic)

دعوة للمشاركة في بحث علمي

هل أنت معتني رئيسي
بطفل مصاب بالسرطان؟

ندعوك للمشاركة
في بحث علمي عن:

معرفة المعتنين الرئيسيّن ومواقفهم
وإعتنقاداتهم تجاه العناية التلطيفية للأطفال
المصابين بالسرطان

الباحثة الرئيسية: الدكتورة سمر نورالدين، مدرسة الحريري للتمريض ، الجامعة الأمريكية في بيروت
الباحثة المشاركة: الدكتورة هدى أبو سعد هاير، ريما سعد، مدرسة الحريري للتمريض ، الجامعة الأمريكية في بيروت

تتمحورهذه دراسة حول فحص وجهات نظر المعتنين الرئيسيّن تجاه الرعاية التلطيفية للأطفال المصابين بالسرطان من أجل الكشف عن مجالات التحسين.

يشارك في هذه الدراسة 110 معتنين رئيسيّن في ثلاثة مراكز لعلاج سرطان الأطفال في لبنان.

ستجلب مشاركتك معلومات قيمة تساعد في تحسين رعاية الأطفال المصابين بالسرطان في لبنان.

إذا قررت المشاركة ، فستتم دعوتك لإجراء مقابلة عبر مكالمة فيديو واتساب مدتها 45-60 دقيقة. يمكنك اختيار أن تكون في المنزل أو في مركز العلاج. سوف تستخدم غرفة هادئة مجهزة بالإنترنت. ستطرح عليك أسئلة حول آرائك بخصوص الرعاية التلطيفية للأطفال. سيتم إرسال رسالة شكر إليك بعد المقابلة وستدخل في سحب على واحده من أربع جوائز نقدية كل منها 150000 ليره لبنانية.

يمكنك اختيار المشاركة أو
عدم المشاركة في الدراسة

إذا قررت المشاركة في هذه الدراسة ، فستستكمل عملية الموافقة قبل المقابلة.

إذا وافقت على المشاركة في هذه الدراسة ، فستتم دعوتك في مقابلة فردية عبر مكالمة فيديو واتساب مع الباحثة المشاركة ريما سعد. ستطرح عليك الباحثة المشاركة قائمة بالأسئلة المتعلقة بك وبطفلك وبمرض طفلك وآرائك حول الرعاية التلطيفية للأطفال المصابين بالسرطان في لبنان. ستقوم الباحثة المشاركة بكتابة إجاباتك على الأسئلة الموجودة في النسخة الإلكترونية من الاستبيان. يمكنك تخطي أي سؤال يجعلك غير مرتاح ويمكنك إيقاف المقابلة في أي وقت دون التأثير على معاملة طفلك أو علاقتك بمركز العلاج.

ستكون جميع المعلومات سرية ولا يمكن الوصول إليها إلا من قبل فريق البحث في جميع الأوقات.

تذكر أن مشاركتك طوعية تمامًا.

لأية أسئلة / توضيحات أي للمشاركة ، يمكنك الاتصال أو طلب المساعدة من مقدم الرعاية الصحية الخاص بك لمساعدتك في الاتصال بالسيدة ريما سعد:
رقم الهاتف: 03-998548 أو البريد الالكتروني: rms57@mail.aub.edu

Photo source: https://stock.adobe.com/images/alegria/225582305 -Standard License

APPENDIX P

Script of the Message forwarded by Participants in Snowballing Technique

If you are interested in participating in a research, please click on the following link:
Link address

إذا كنت مهتمًا بالمشاركة في بحث علمي ، فالرجاء إضغط على الرابط التالي:
الرابط

APPENDIX Q

Content of the Electronic Poll in Snowballing Technique

A study is being conducted at the *(Name of the Treatment Center)* regarding parents' knowledge, attitudes and beliefs toward palliative care for children with cancer. The researcher is Ms Rima Saad, a former clinical nurse specialist in pediatric oncology and currently a PhD student working with Dr Samar Noureddine at the Hariri School of Nursing at the American University of Beirut. You are eligible to participate, if:

- you are the primary caregiver of a child with cancer being currently treated at [*site name*].
- you are Lebanese or a permanent resident in Lebanon, currently living in Lebanon
- you can speak Arabic
- your child with cancer under your care is currently below 18 years
- the diagnosis with cancer occurred longer than 2 months ago,
- the child was not admitted to intensive care within the last month.

Please indicate if you agree or disagree to share your phone number with the researcher to hear more about the study:

☐ Yes, I agree to share my phone number with the researcher
☐ No, I disagree to share my phone number with the researcher
(Appears only if "yes" is selected)
Please type your phone number here: _____________. The researcher will call you to tell you more about the study.

يتم إجراء دراسة في المركز حول :"معرفة المعتنين الرئيسيّن ومواقفهم وإعتنقاداتهم تجاه العناية التلطيفية للأطفال
المصابين بالسرطان". الباحثة هي السيدة ريما سعد ، وهي ممرضة متخصصة في سرطان الأطفال وطالبة دكتوراه
تعمل مع الدكتورة سمر نورالدين في كلية الحريري للتمريض في الجامعة الأمريكية في بيروت. أنت مؤهل للمشاركة إذا:
- كنت المعتني(ة) الرئيسيّ(ة) بطفل مصاب بالسرطان يتعالج حالياً في(إسم المركز)
- كنت لبناني(ة) أو مقيم(ة) دائم(ة) بلبنان وحالياً تعيش(ين) بلبنان
-كنت تتكلم اللغة العربية
- الطفل المصاب بالسرطان حالياً عمره أقل من 18 سنة
- تم التشخيص بالسرطان قبل أكثر من شهرين
- لم يدخل الطفل إلى العناية المركزة خلال الشهر الماضي.

يرجى اختيار ما إذا كنت توافق أو لا توافق على مشاركة رقم هاتفك مع الباحثة لسماع المزيد عن الدراسة:
☐ نعم، أوافق على مشاركة رقم هاتفي مع الباحثة.
☐ كلا، لا أوافق على مشاركة رقم هاتفي مع الباحثة.
(Appears only if "yes" is selected)
الرجاء إدخال رقم هاتفك هنا:_______________. ستتصل بك الباحثة لتخبرك المزيد عن الدراسة.

APPENDIX R

Sample Email Script for Researcher's Presence in Treatment Areas

"This is not an official message from AUB"

This email message is sent on behalf of Dr Samar Noureddine with regards to a research study she is conducting at the American University of Beirut Medical Center (AUBMC)-Children's Cancer Institute (CCI), Saint George Hospital University Medical Center (SGHUMC) and Lebanese Hospital Geitaoui-University Medical Center (LHG-UMC). Dr Noureddine's email address: sn00@aub.edu.lb, Telephone: 961-1-374374 (ext: 5966).

Dear Colleagues (medical director and nursing management team),

We are collecting data for the study that you previously approved entitled:

"Primary caregivers' knowledge, attitudes and beliefs toward palliative care for children with cancer"

The goal of this study is to examine primary caregivers' knowledge, attitudes and beliefs towards pediatric palliative care for children with cancer in Lebanon in order to uncover areas for improvement.

This email is to seek your permission on the presence of the researcher, Ms Rima Saad at the center to directly approach and invite primary caregivers of your patients to partake in the study. The study involves no more than minimum risk to the participants, consent will be sought. The procedure consists of remotely interviewing primary caregivers of children with cancer treated at the (AUBMC-CCI or SGHUMC or LHG-UMC) regarding the different concepts of interest.

The researcher, Ms Rima Saad, will be present at center during working hours and implement the necessary COVID-19 precaution measures to approach potential participants in the treatment areas of the inpatient and outpatient units. The researcher will wear a pin where it is written "ask me about the research study" to be distinguished from the treating team members.

The researcher will approach the subject if:
- he/she is the primary caregiver of a child with cancer being currently treated at [site name].
- he/she is Lebanese or a permanent resident in Lebanon, currently living in Lebanon
- he/she can speak Arabic
- the child with cancer under your care is currently below 18 years
- the diagnosis with cancer occurred longer than 2 months ago,
- the child was not admitted to intensive care within the last month.

For further questions/clarifications about the study, please contact Ms Rima Saad (Telephone: 03-998548, Email: rms57@mail.aub.edu) or Dr Samar Noureddine (Telephone: 961-1-374374 (ext: 5966), Email: sn00@aub.edu.lb).

Looking forward for your approval.
Thank you.

Samar Noureddine, PhD, RN, FAHA, FAAN
Professor,
Associate Dean for Academic Affairs
Convener of the Graduate Division
Hariri School of Nursing,
American University of Beirut
Honorary Professor: University of Dundee, Scotland
Adjunct faculty: Johns Hopkins University, USA

Rima Saad, MSN RN CPHON
PhD Candidate
Hariri School of Nursing
American University of Beirut

APPENDIX S

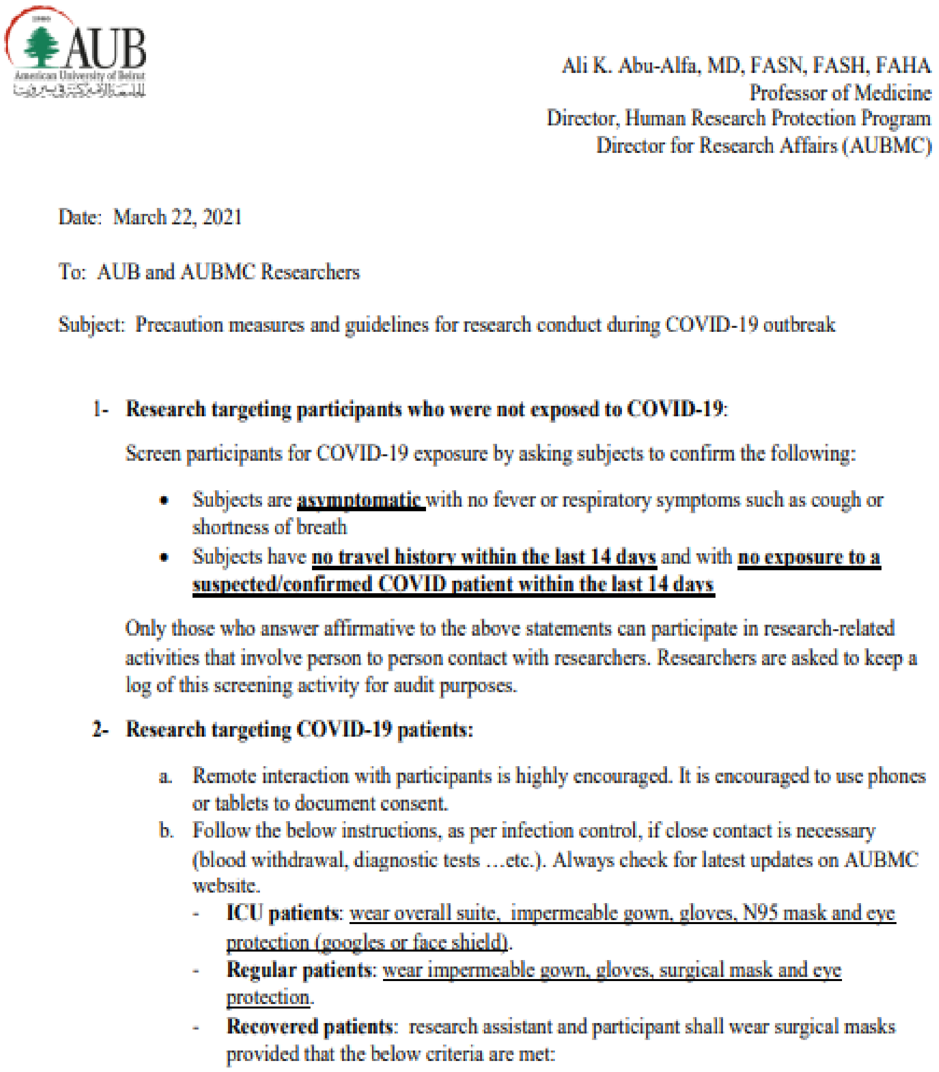
Pin

Verbal Recruitment Script for Main Study (English)

Hello - My name *is* Rima Saad *and I am a* PhD candidate working with Dr Noureddine at the Hariri School of Nursing *at the American* University of Beirut. Before doing my PhD I worked with children with cancer for 15 years.

APPENDIX T

Precaution Measures and Guidelines for Research Conduct during COVID-19 Outbreak



Ali K. Abu-Alfa, MD, FASN, FASH, FAHA
Professor of Medicine
Director, Human Research Protection Program
Director for Research Affairs (AUBMC)

Date: March 22, 2021

To: AUB and AUBMC Researchers

Subject: Precaution measures and guidelines for research conduct during COVID-19 outbreak

1- **Research targeting participants who were not exposed to COVID-19**:

Screen participants for COVID-19 exposure by asking subjects to confirm the following:

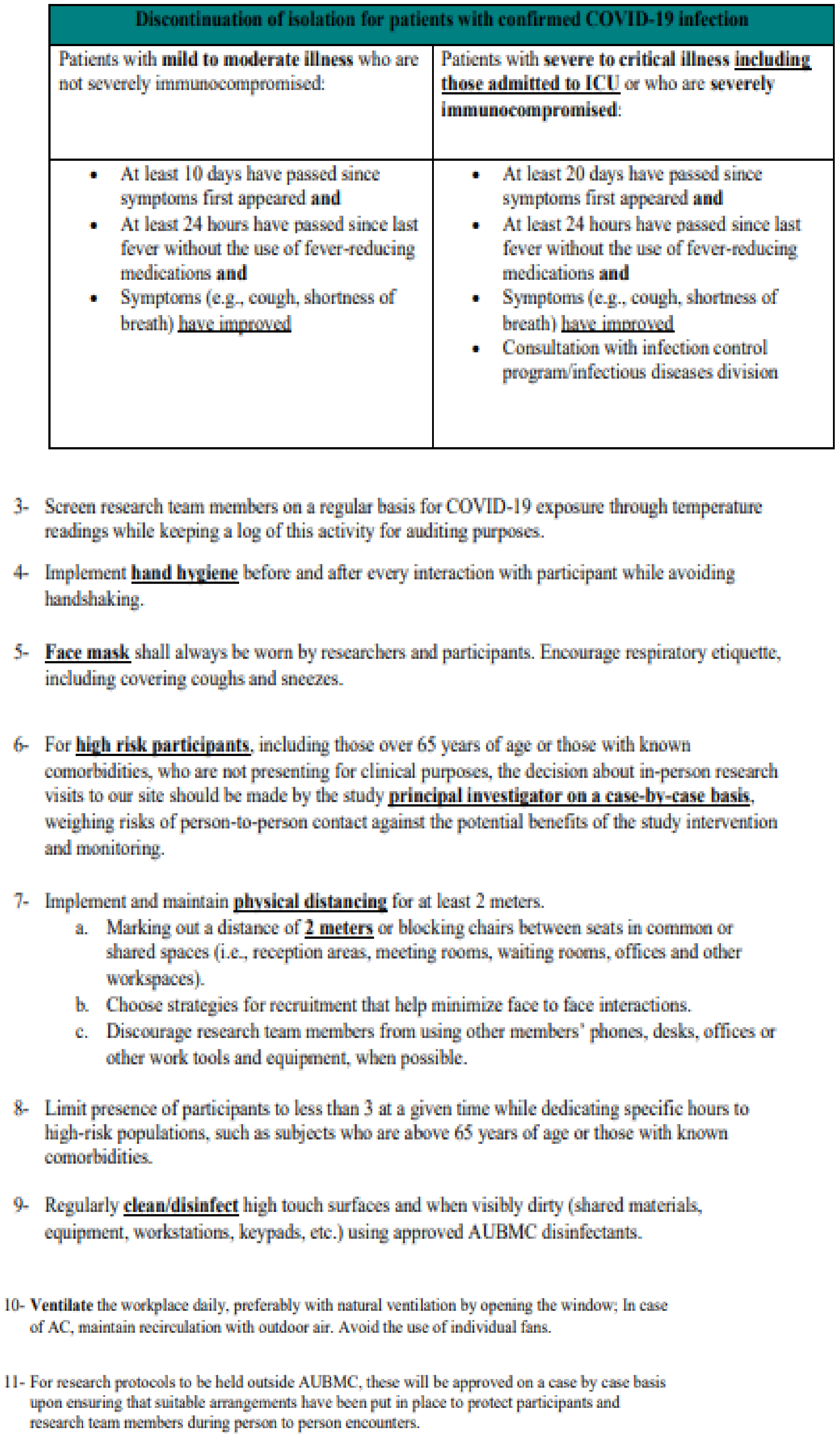
- Subjects are **asymptomatic** with no fever or respiratory symptoms such as cough or shortness of breath
- Subjects have **no travel history within the last 14 days** and with **no exposure to a suspected/confirmed COVID patient within the last 14 days**

Only those who answer affirmative to the above statements can participate in research-related activities that involve person to person contact with researchers. Researchers are asked to keep a log of this screening activity for audit purposes.

2- **Research targeting COVID-19 patients:**

a. Remote interaction with participants is highly encouraged. It is encouraged to use phones or tablets to document consent.

b. Follow the below instructions, as per infection control, if close contact is necessary (blood withdrawal, diagnostic tests …etc.). Always check for latest updates on AUBMC website.
   - **ICU patients**: wear overall suite, impermeable gown, gloves, N95 mask and eye protection (googles or face shield).
   - **Regular patients**: wear impermeable gown, gloves, surgical mask and eye protection.
   - **Recovered patients**: research assistant and participant shall wear surgical masks provided that the below criteria are met:



Discontinuation of isolation for patients with confirmed COVID-19 infection	
Patients with **mild to moderate illness** who are not severely immunocompromised:	Patients with **severe to critical illness** **including those admitted to ICU** or who are **severely immunocompromised**:
• At least 10 days have passed since symptoms first appeared **and** • At least 24 hours have passed since last fever without the use of fever-reducing medications **and** • Symptoms (e.g., cough, shortness of breath) have improved	• At least 20 days have passed since symptoms first appeared **and** • At least 24 hours have passed since last fever without the use of fever-reducing medications **and** • Symptoms (e.g., cough, shortness of breath) have improved • Consultation with infection control program/infectious diseases division

3- Screen research team members on a regular basis for COVID-19 exposure through temperature readings while keeping a log of this activity for auditing purposes.

4- Implement **hand hygiene** before and after every interaction with participant while avoiding handshaking.

5- **Face mask** shall always be worn by researchers and participants. Encourage respiratory etiquette, including covering coughs and sneezes.

6- For **high risk participants**, including those over 65 years of age or those with known comorbidities, who are not presenting for clinical purposes, the decision about in-person research visits to our site should be made by the study **principal investigator on a case-by-case basis**, weighing risks of person-to-person contact against the potential benefits of the study intervention and monitoring.

7- Implement and maintain **physical distancing** for at least 2 meters.
   a. Marking out a distance of **2 meters** or blocking chairs between seats in common or shared spaces (i.e., reception areas, meeting rooms, waiting rooms, offices and other workspaces).
   b. Choose strategies for recruitment that help minimize face to face interactions.
   c. Discourage research team members from using other members' phones, desks, offices or other work tools and equipment, when possible.

8- Limit presence of participants to less than 3 at a given time while dedicating specific hours to high-risk populations, such as subjects who are above 65 years of age or those with known comorbidities.

9- Regularly **clean/disinfect** high touch surfaces and when visibly dirty (shared materials, equipment, workstations, keypads, etc.) using approved AUBMC disinfectants.

10- **Ventilate** the workplace daily, preferably with natural ventilation by opening the window; In case of AC, maintain recirculation with outdoor air. Avoid the use of individual fans.

11- For research protocols to be held outside AUBMC, these will be approved on a case by case basis upon ensuring that suitable arrangements have been put in place to protect participants and research team members during person to person encounters.

APPENDIX U

Verbal Recruitment Script for Main Study (English)

Thank you for your interest in my research study titled “Primary caregivers’ knowledge, attitudes and beliefs towards palliative care for children with cancer”. I am interested about your views about pediatric palliative care for children with cancer. *There will be no direct benefit to your child; however, the information you provide will help to improve the care of children with cancer.*

I would like to confirm that:

- you are the primary caregiver of a child with cancer being currently treated at [*site name*].
- you are Lebanese or a permanent resident in Lebanon, currently living in Lebanon
- You can speak Arabic
- the child with cancer under your care is currently below 18 years
- the diagnosis with cancer occurred longer than 2 months ago,
- the child was not admitted to intensive care within the last month.

(If any of the above is not confirmed by the subject)

I am sorry, but it looks like my study is not for you. Thank you for your time and for listening to me. I hope to talk with you in the future about other research studies you might be interested in.

(If all of the above is confirmed by the subject)

In this study, I will be interviewing mothers, fathers, or other caregivers of children with cancer via whatsapp video call. The participants may choose to be at their home or at the treatment center at the time of the interview. They will be asked to use a private room equipped with internet connection. A *thank you note will be sent after the interview* and participants will enter a prize draw for one of four cash prizes of 150 000 LBP each.

I will be asking about your knowledge, attitudes and beliefs about pediatric palliative care for children with cancer. *If you are* interested, I would like to talk to you more about the study, answer any questions you might have, and take your consent if you want to be involved.

All information will be confidential and only accessible to the research team at all times. Remember, your participation is completely voluntary. Refusal to participate will not affect you, your child’s or your relationship with the treatment center or with the treating physician nor the quality of care your child is receiving at the center.

If you'd like to participate, we can go ahead and schedule a time for the interview. If you need more time to decide, you may also call or email me with your decision. Do you have any questions for me at this time?

If you have any more questions about the study or if you need to contact me about participation, I may be reached at [03-998548, email: rms57@mail.aub.edu]. Thank you so much.

APPENDIX V

Verbal Recruitment Script for Main Study (Arabic)

مرحبا- إسمي ريما سعد وأنا طالبة دكتوراه مع الدكتورة سمر نورالدين في مدرسة الحريري للتمريض في الجامعة الأمريكية في بيروت. قبل دراسة الدكتوراه ، اشتغلت مع الأطفال المصابين بالسرطان لمدة 15 سنة.

شكراً لإهتمامك ببحثي العلمي بعنوان :" معرفة المعتنين الرئيسيّن ومواقفهم وإعتنقاداتهم تجاه العناية التلطيفية للأطفال المصابين بالسرطان ".

أنا مهتمة بنظرتك حول العناية التلطيفية للأطفال المصابين بالسرطان. ما رح يكون في استفادة مباشرة لإبنك/بنتك ، إنما، المعلومات يلي بتعطيها رح تساعد على تحسين العناية بالأطفال المصابين بالسرطان في لبنان.

بحب أكّد معك:

- إنك المعتني(ة) الرئيسيّ(ة) بطفل مصاب بالسرطان حالياً عم يتعالج ب(إسم المركز)
- إنك لبناني(ة) أو مقيم(ة) دائم(ة) بلبنان وحالياً عايش(ة) بلبنان
- إنك بتحكي اللغة العربية
- الطفل المصاب بالسرطان حالياً عمره أقل من 18 سنة
- تم التشخيص بالسرطان قبل أكثر من شهرين
- ما دخل الطفل على العناية المركزة خلال الشهر الماضي.

(If any of the above is not confirmed by the subject)

بعتذر، بس كأن دراستي مش إلك. شكراً على وقتك وعلى إنك سمعتلّي. إنشالله بالمستقبل إحكي معك بغير أبحاث علمية ممكن تهمّك.

(If all above is confirmed by the subject)

بهالدراسة، رح كون عم قابل أمات وبيات أو غير معتنين بالأطفال المصابين بالسرطان عبر اتصال واتساب فيديو.
المشاركين فين يكونو ببيتن أو بمركز العلاج بوقت المقابلة. رح ينطلب منن يكونوا بغرفة خاصة مجهزة بإنترنيت .
رح ينبعث رسالة شكر بعد المقابلة ورح يدخل المشاركون بسحب على وحدة من أربع جوائز نقدية كل منها 150000 ليرة لبنانية.
رح إسأل عن معرفتك ومواقفك وإعتقاداتك تجاه العناية التلطيفية للأطفال المصابين بالسرطان .
إذا مهتم بحب إحكيك أكتر عن الدراسة، جاوب على أسئلة ممكن تسألها وآخذ موافقتك على المشاركة.
كل المعلومات رح تكون كل الوقت سرية وبس فريق البحث ممكن يطّلع عليها. تّذكر إنو مشاركتك طوعية تماماً.
رفض المشاركة ما رح يأثرعليك ، على علاقة الولد أو علاقتك بمركز العلاج أو بالطبيب المعالج ولا على نوعية العناية يللي عم يتلقاها الولد بالمركز.
إذا بتحب(ي) تشارك(ي) فينا نحدد موعد للمقابلة. إذا محتاج(ة) وقت زيادة لتقرر(ي)، فيك تدقللي أو تبعتلي بريد إلكتروني عن قرارك. عندك أي سؤال بالوقت الحاضر؟

إذا كان عندك أي أسئلة زيادة بخصوص الدراسة أو إذا احتجت تتصل(ي) فيّ بخصوص المشاركة، أنا موجودة على
الرقم: 03-998548 أو البريد إلكتروني:
"rms57@mail.aub.edu"

شكراً!

APPENDIX W

Sample Email Script for identifying a treating team member to help in recruitment

"This is not an official message from AUB"

This email message is sent on behalf of Dr Samar Noureddine with regards to a research study she is conducting at the American University of Beirut Medical Center (AUBMC)-Children's Cancer Institute (CCI), Saint George Hospital University Medical Center (SGHUMC) and Lebanese Hospital Geitaoui-University Medical Center (LHG-UMC). Dr Noureddine's email address: sn00@aub.edu.lb, Telephone: 961-1-374374 (ext: 5966).

Dear Colleague (Medical director/Nursing management team),

We are collecting data for the study that you previously approved entitled:

"Primary caregivers' knowledge, attitudes and beliefs
toward palliative care for children with cancer"

The goal of this study is to examine primary caregivers' knowledge, attitudes and beliefs towards pediatric palliative care for children with cancer in Lebanon in order to uncover areas for improvement.

This email is to seek your help in identifying one or two members from the treating team to ask primary caregivers of your patients for permission to share their phone number with the researcher. The study involves no more than minimum risk to the participants, consent will be sought. The procedure consists of remotely interviewing primary caregivers of children with cancer treated at the (AUBMC-CCI or SGHUMC or LHG-UMC) regarding the different concepts of interest.

The identified team member (s) will be provided with the script to use for seeking subjects' permission, and the procedure to enter the subjects' phone number after obtaining permission.

Looking forward for your collaboration.

Thank you.

Samar Noureddine, PhD, RN, FAHA, FAAN
Professor,
Associate Dean for Academic Affairs
Convener of the Graduate Division
Hariri School of Nursing,
American University of Beirut
Honorary Professor: University of Dundee, Scotland
Adjunct faculty: Johns Hopkins University, USA

Rima Saad, MSN RN CPHON
PhD Candidate
Hariri School of Nursing
American University of Beirut

APPENDIX X

Script for treating team members to obtain permission

“A research study is being conducted at the center entitled: "Primary Caregivers' Knowledge, Attitudes and Beliefs toward Palliative Care for Children with Center". The flyers are posted on the unit for more details. The purpose of the study is to uncover areas for improvement. One hundred and ten primary caregivers are being recruited in three major pediatric oncology centers in Lebanon. Your participation will bring valuable information that help improve the care of children with cancer in Lebanon.

You are eligible to participate since:
- you are the primary caregiver of a child with cancer being currently treated at [site name].
- you are Lebanese or a permanent resident in Lebanon, currently living in Lebanon
- you can speak Arabic
- the child with cancer under your care is currently below 18 years
- the diagnosis with cancer occurred longer than 2 months ago,
- the child was not admitted to intensive care within the last month.

If you decide to participate you will be invited to an interview via whatsapp video call (45-60 minutes). You can choose to be at home or at the treatment center. You will use a quiet room with internet connection. You will be asked questions on your views regarding pediatric palliative care. A thank you note will be sent to you after the interview and you will enter a prize draw for one of four cash prizes of 150.000 LBP each.

The researcher Ms Rima Saad is interested in contacting you to tell you more about the study. Do you agree on sharing your phone number with the researcher?
Thank you!”

في بحث علمي عم بصير بالمركز بعنوان :
"معرفة المعتنين الرئيسيين ومواقفهم واعتقاداتهم حول العناية التلطيفية للاطفال المصابين بالسرطان." الإعلان معلّق بالقسم لتفاصيل إضافية. بتهدف الدراسة لكشف مجالات التحسين. بيشارك في هالدراسة 110 معتنين رئيسيّن في ثلاثة مراكز لعلاج سرطان الأطفال في لبنان. مشاركتك رح توفر معلومات قيمة بتساعد في تحسين رعاية الأطفال المصابين بالسرطان في لبنان. إنت مؤهل(ة) للمشاركة لأنك:
- المعتني(ة) الرئيسيّ بطفل مصاب بالسرطان عم يتعالج حاليا في(إسم المركز)
- بتعيش(ي) بلبنان
- لبناني(ة) أو حالياً مقيم(ة) دائم(ة) بلبنان
- بتحكي اللغة العربية
- الطفل المصاب بالسرطان حالياً عمره أقل من 18 سنة
- تم التشخيص بالسرطان قبل أكثر من شهرين
- لم يدخل الطفل إلى العناية المركزة خلال الشهر الماضي.

إذا قررت المشاركة ، رح تدُعى لإجراء مقابلة عبر فيديو واتساب مدتها 45-60 دقيقة .
فيك تختار(ي) أن تكون(ي) في المنزل أو في مركز العلاج. رح تستخدم(ي) غرفة هادئة مجهزة بالإنترنت. ستطرح عليك أسئلة حول آرائك بخصوص الرعاية التلطيفية للأطفال. رح يتم إرسال رسالة شكر إلك بعد المقابلة وستدخل(ي) في سحب على واحدة من أربع جوائز نقدية كل منها بقيمة 150000 ليرة لبنانية.

بهمّ الباحثة ريما سعد الإتصال فيك لإخبارك أكثرعن الدراسة. هل بتوافق على إعطاء رقم هاتفك للباحثة ؟
شكرا!"

APPENDIX Y

Study Survey English Version

Section 1: Demographic Data

Primary caregiver's characteristics	
1. Gender:	☐Male ☐Female
2. What is your relationship to the patient?	☐ Biological Parent ☐Step-parent ☐Adoptive Parent ☐Grandparent ☐Other:_______
3. How old are you?	_________years old
4. Are you currently:	☐Married ☐ Separated ☐ Divorced ☐ Widowed ☐Other:____________________
5. Who does your child live with? *Please check all the boxes that apply*	☐ Mother ☐ Father ☐Sisters/Brothers ☐ Grandparent ☐ Step-parent ☐ Other: _______
6. What is your nationality:	☐ Lebanese ☐Non-Lebanese (please specify):_
7. What is the highest level of education that you have completed?	☐ graduate school ☐college ☐high school ☐grade school ☐below grade school
8. Where do you live?	Area of residence (urban/rural):_________________
9. What, if any, is your religious preference?	☐ Christian ☐ Muslim ☐ Druze ☐prefer not to answer ☐ Other (please specify): ___________ ☐None
10. What is your current occupational status?	☐Employed ☐Unemployed ☐Homemaker ☐Student ☐Retired ☐Other – Specify:____________________
11. What is the range of your monthly household total income?	☐ Below or equal to 675000 LBP ☐ Above 675000 but below or equal to 1000000 LBP ☐ Above 1000 000LBP but below or equal to 1500000 LBP ☐ Above 1500000 LBP but below or equal to 2000000 LBP ☐ Above 2000000 LBP ☐ I don't know
Child's Demographic Data	
12. What is your child's gender?	☐ Male ☐ Female
13. What is your child's current age?	__________years

Section 2: Child's Clinical Data

14. What is your child's diagnosis?	☐ Leukemia ☐Lymphoma ☐Medulloblastoma ☐Neuroblastoma ☐Osteosarcoma ☐ Ewing Sarcoma ☐ Retinoblastoma ☐Rhabdomyosarcoma ☐Other:____________________
15. What was your child's age at diagnosis?	___________years (caregiving duration)
16. Think of a regular day, how many hours do you dedicate for your child's illness?	__________(caregiving hours)
17. What type of treatment is your child currently receiving?	☐Chemotherapy ☐Radiotherapy ☐Surgery ☐Palliative care
18. What is your child's current disease status?	☐In remission ☐active disease ☐metastatic disease
19. What has your child's doctor told you about the chances of a child with this type of cancer being cured (being cured means not having cancer any more)?	☐ My child's doctor has not discussed the chance of a cure with me ☐ The doctor said: The chance of cure is very high ☐ The doctor said: The chance of cure is somewhat high ☐ The doctor said: The chance of cure is not high ☐ I am not sure what the doctor said

Memorial Symptom Assessment Scale (MSAS):

Symptom Did your child have any of the following symptoms **In the past week?**	**Present** (yes/no)	**Frequency** **(if yes)** **How OFTEN did he/she have it?** 1 Almost never 2 Sometimes 3 A lot 4 Almost always	**Severity** **(if yes)** **How SEVERE was it usually?** 1 Slight 2 Moderately 3 Severe 4 Very severe	**Distress** **(if yes)** **How much did it DISTRESS or BOTHER him/her?** 0 Not at all 1 A little bit 2 Somewhat 3 Quite a bit 4 Very much
20. Feeling irritable	☐Yes ☐No	1 2 3 4	1 2 3 4	0 1 2 3 4

21. Feeling nervous	☐Yes ☐No	1 2 3 4	1 2 3 4	0 1 2 3 4
22. Feeling sad	☐Yes ☐No	1 2 3 4	1 2 3 4	0 1 2 3 4
23. Worrying	☐Yes ☐No	1 2 3 4	1 2 3 4	0 1 2 3 4
24. Difficulty sleeping	☐Yes ☐No	1 2 3 4	1 2 3 4	0 1 2 3 4
25. Lack of energy	☐Yes ☐No	1 2 3 4	1 2 3 4	0 1 2 3 4
26. Lack of appetite	☐Yes ☐No	1 2 3 4	1 2 3 4	0 1 2 3 4
27. Pain	☐Yes ☐No	1 2 3 4	1 2 3 4	0 1 2 3 4
28. Nausea	☐Yes ☐No	1 2 3 4	1 2 3 4	0 1 2 3 4
29. Cough	☐Yes ☐No	1 2 3 4	1 2 3 4	0 1 2 3 4
30. Others: ______________	☐Yes ☐No	1 2 3 4	1 2 3 4	0 1 2 3 4

Section 3: Normative beliefs

31. The child's oncology care team approves on focusing on the quality of life of the child with cancer (the child's ability to participate in and enjoy daily activities)

☐ strongly disagree ☐ disagree ☐ neutral ☐ agree ☐ strongly agree

Section 4: Knowledge about PPC

32. Have you heard of palliative care? *(awareness)*	☐ Yes ☐ No *(go to "Source of information" section)*
33. How much knowledge you think you have about PPC: *(perceived knowledge)*	☐ I know nothing at all *(go to "Source of information" section)* ☐ I have some knowledge ☐ I am very knowledgeable
34. Imagine you had a strong need to get information about palliative care. Where would you go first to get information? *(only one)* *(Source of information)*	☐ Printed materials (for example, newspapers, magazines) ☐ Health care provider (doctor, nurse, social worker) ☐ Conversations with people you trust (friends, relatives, or co-workers) ☐ Internet (Google or another search engine, WebMD or another medical website) ☐ Social Media (Facebook, Instagram, Twitter)
35. Do you have any personal experience with PC? (*Only for those who report having knowledge)*	☐ No, I don't have personal experience with palliative care ☐ Yes

Palliative Care Knowledge Scale (PaCKS) *Only for those who report having knowledge*

	True	False	I don't know
36. One goal of palliative care is to address any psychological issues brought up by serious illness.			
37. Stress from serious illness can be addressed by palliative care			
38. Palliative care can help people manage the side effects of their medical treatments.			
39. When people receive palliative care, they must give up their other doctors.			
40. Palliative care is exclusively for people who are in the last six months of life.			
41. Palliative care is specifically for people with cancer.			
42. People must be in the hospital to receive palliative care.			
43. Palliative care is designed specifically for older adults.			
44. Palliative care is a team-based approach to care			
45. One goal of palliative care is to help people better understand their treatment options.			
46. Palliative care encourages people to stop treatments aimed at curing their illness.			
47. One goal of palliative care is to improve a person's ability to participate in daily activities.			
48. Palliative care helps the whole family cope with a serious illness.			
49. Palliative care for children begins when a serious illness is diagnosed			
50. Palliative care for children only alleviates the child's physical suffering			
51. Effective palliative care for children is possible even with limited resources			
52. Palliative care for children requires family involvement in the care			

Section 5: Attitudes toward PPC

The palliative care services treat patients' symptoms and improve patients' quality of life. How much do you agree with the following statements?

Including palliative care services in your child's care	1 Strongly disagree 2 disagree 3 Unsure 4 Agree 5 Strongly Agree
53. is helpful in treating your child's symptoms	1 2 3 4 5
54. is helpful in making treatment decisions	1 2 3 4 5
55. is a positive addition to your child's overall care	1 2 3 4 5
56. gets in the way of your relationship with your child's oncology doctor/care team	1 2 3 4 5
57. takes away from your hope that your child would be cured	1 2 3 4 5
58. interferes with your child's cancer therapy	1 2 3 4 5
59. is helpful in addressing family needs	1 2 3 4 5
60. ensures continuity of care in the hospital, community and home settings	1 2 3 4 5

How much do you agree with the following statements regarding the timing of Palliative care for children with cancer?

I would recommend that palliative care services are provided for a child with cancer	1 Strongly disagree 2 disagree 3 Unsure 4 Agree 5 Strongly Agree
61. At the beginning of cancer therapy	1 2 3 4 5
62. If pain or symptom management is a problem	1 2 3 4 5
63. If the cancer gets worse or comes back	1 2 3 4 5
64. At the end of life	1 2 3 4 5
65. Throughout all of a child's cancer care	1 2 3 4 5
66. They should not be provided for a child's cancer care	1 2 3 4 5

Section 6: Control Beliefs

To what extent does each of the factors below make it difficult or easy to integrate PPC in your child's care? (Very Difficult to Very easy)

	Very difficult	difficult	Unsure	Easy	Very Easy
67. Certainty about my child's prognosis					
68. Awareness of the my child's suffering					
69. Support and good communication with my child's clinical team					
70. Knowledge about PPC					
71. Believing that I am a good parent					
72. Religious and spiritual engagement					
73. Lack of understanding of my child's medical condition					
74. Unrealistic belief in probability of cure					
75. Overwhelming negative emotions					
76. Desire to shield others from bad news					
77. Discomfort talking about death					
78. Involvement of larger family members in treatment decisions about my child's care					
79. Others:________________					

Section 7: PPC Intentions and PPC Behaviors

Which of the activities listed below (if applicable) did you perform for your child's care in the past week?
For the activities not performed, how likely would you perform each of them in the coming week?

Activity	N/A	Yes	No	If "No", Intention to perform 1=Very unlikely 2=Unlikely 3=Unsure 4=Likely 5=Very likely
Care for My Child With Cancer (CMCC) 22 out of 28 items used				
80. Meeting the emotional needs of my ill child				1 2 3 4 5
81. Planning activities for the family				1 2 3 4 5
82. Planning activities for the ill child				1 2 3 4 5
83. Following up with the treatment team (such as phone calls)				1 2 3 4 5
84. Meeting the emotional needs of my spouse				1 2 3 4 5
85. Meeting my own emotional needs				1 2 3 4 5
86. Meeting the emotional needs of other children in my family				1 2 3 4 5
87. Meeting the emotional needs of my extended family				1 2 3 4 5
88. Managing painful events				1 2 3 4 5
89. Getting information about the child's illness				1 2 3 4 5
90. Communicating about the child's illness				1 2 3 4 5
91. Disciplining the ill child				1 2 3 4 5
92. Managing finances				1 2 3 4 5
93. Maintaining my child's comfort				1 2 3 4 5
94. Managing the side effects of treatment				1 2 3 4 5
95. Giving medications by mouth				1 2 3 4 5
96. Managing other childhood illnesses				1 2 3 4 5
97. Attending medical appointments				1 2 3 4 5
98. Additional household tasks				1 2 3 4 5
99. Managing unexpected events				1 2 3 4 5
100. Obtaining child care for the siblings				1 2 3 4 5
101. Obtaining child care for my ill child				1 2 3 4 5
102. Managing medical devices such as feeding pump				1 2 3 4 5
103. Obtaining necessary equipment and medications				1 2 3 4 5
104. Praying with my child				1 2 3 4 5
105. Taking decisions related to my child's care				1 2 3 4 5
106. Sharing my experience with similar parents				1 2 3 4 5
107. Reminding my child about medical precautions				1 2 3 4 5
108. Telling medical information to my child				1 2 3 4 5
109. Getting more information about PPC				1 2 3 4 5
110. Discussing PPC with my child's healthcare team				1 2 3 4 5
111. Other:_________________________________				1 2 3 4 5

112. **Other comments:**

____
____
____
____

Thank you for participating in the study!

APPENDIX Z

Study Survey Translated Version

دراسة استقصائية – النسخة العربية

الفقرة الأولى: البيانات الديموغرافية

خصائص المعتني الرئيسي	
1- الجنس	☐ ذكر ☐ أنثى
2- ما علاقتك بالمريض؟	☐الوالد(ة) البيولوجي(ة) ☐زوج(ة) الوالد(ة) ☐الوالد(ة) بالتبني ☐الجد(ة) ☐غيره: ______
3- كم عمرك؟	________سنة
4- هل أنت حالياً:	☐متزوج(ة) ☐منفصل(ة) ☐ مطلق ☐أرمل(ة) ☐غيره: ______
5- مع من يعيش الطفل(ة)؟ (اختر كل ما ينطبق)	☐الوالد ☐الوالدة ☐الإخوة/الأخوات ☐الجد/الجدة ☐زوج(ة) الوالد(ة) ☐غيره: __________
6- ما هي جنسيتك؟	☐لبناني ☐ غير لبناني (الرجاء التحديد): ____________
7- ما هو أعلى مستوى علمي أكملته؟	☐دراسات عليا ☐جامعة ☐ المدرسة الثانوية ☐ بروفيه ☐أقل من بروفيه
8- أين تسكن؟	مكان السكن: (مدينة/ريف): ___________
9- ماهو تفضيلك الديني، إذا وجد؟	☐مسيحي(ة) ☐مسلم(ة) ☐درزي(ة) ☐أفضل عدم الإجابة ☐غيره ☐لا تفضيل ديني
10- ما هو وضعك المهني حالياً؟	☐موظف ☐ عاطل عن العمل ☐رب(ة)منزل ☐طالب (ة) ☐ متقاعد(ة) ☐غيره (الرجاء التحديد): ____________
11- ما هو نطاق الدخل الإجمالي الشهري لأسرتك؟	☐أقل أو يساوي 675000 ليرة لبنانية ☐أكثر من 675000 لكن أقل أو يساوي 1000000 ليرة لبنانية ☐أكثر من 1000000 لكن أقل أو يساوي 1500000 ليرة لبنانية ☐أكثر من 1500000 لكن أقل أو يساوي 2000000 ليرة لبنانية ☐أكثر من 2000000 ليرة لبنانية ☐لا أعرف
البيانات الديموغرافية للطفل(ة)	
12- ما هو جنس الولد؟	☐ ذكر ☐ أنثى
13- كم عمر ابنك/ابنتك حالياً ؟	____________سنة

الفقرة الثانية: البياناتالطبية للولد

14- ما هو تشخيص مرض ابنك/ابنتك ؟	☐ سرطان الدم ☐سرطان الغدد اللمفاوية ☐سرطان في الرأس ☐سرطان في العصب Neuroblastoma ☐ سرطان في العظم ☐سرطان إوينغ ☐ سرطان في العين ☐ سرطان في العضل ☐غيره: ________________
15- كم كان عمر ابنك/ابنتك عند التشخيص؟	____________سنة/سنوات
16- فكّر بيوم عادي، كم ساعة تخصصها لرعاية مرض ابنك/ابنتك ؟	____________ساعة
17- ما نوع العلاج الذي يتلقاه ابنك/ابنتك حالياًّ؟	☐علاج كيميائي ☐ علاج بالأشعة ☐جراحة ☐عناية تلطيفية
18- ما هي حالة المرض - لابنك/ابنتك حالياً؟	☐لا خلايا سرطانية ☐مرض نشط ☐مرض منتشر
19- ماذا أخبرك طبيب ابنك/ابنتك عن فرص شفاء طفل مصاب بهذا النوع من السرطان؟	☐ لم يناقش طبيب طفلي(تي) فرصة الشفاء معي ☐ قال الطبيب: إن فرصة الشفاء عالية جدًا ☐ قال الطبيب: فرصة الشفاء عالية نوعا ما ☐ قال الطبيب: فرصة الشفاء غيرعالية ☐ غير متأكد (ة) مما قاله الطبيب

مقياس تقييم الأعراض				
هل اختبر ابنك/ابنتك أي من الأعراض التالية <u>في الاسبوع الماضي</u> ؟	اختبر ابنك/ابنتك هذا العارض نعم/كلا	**التردّد** (**إذا الجواب نعم**) كم من الوقت اختبر ابنك/ابنتك هذا العارض؟ 1- تقريبا أبداً 2- أحياناً 3- كثيراً 4- تقريبا دائماً	**الحدّة** (**إذا الجواب نعم**) ما مدى شدة العارض في العادة؟ 1- خفيف 2- معتدل 3- شديد 4- شديد جداً	**المحنة/المعاناة**(**إذا الجواب نعم**) كم سبّب هذا العارض من معاناة أو انزعاج لابنك/ابنتك ؟ 1- أبداً 2- قليلاً 3- بعض الشيء 4- كثيراً 5- بشكل هائل

20- سرعة الإنفعال	☐نعم ☐كلا	1 2 3 4	1 2 3 4	1 2 3 4 5
21- الشعور بالتوتر	☐نعم ☐كلا	1 2 3 4	1 2 3 4	1 2 3 4 5
22- الشعور بالحزن	☐نعم ☐كلا	1 2 3 4	1 2 3 4	1 2 3 4 5
23- الشعور بالقلق	☐نعم ☐كلا	1 2 3 4	1 2 3 4	1 2 3 4 5
24- صعوبة بالنوم	☐نعم ☐كلا	1 2 3 4	1 2 3 4	1 2 3 4 5
25- نقص بالطاقة	☐نعم ☐كلا	1 2 3 4	1 2 3 4	1 2 3 4 5
26- نقص بالشهية	☐نعم ☐كلا	1 2 3 4	1 2 3 4	1 2 3 4 5
27- الألم	☐نعم ☐كلا	1 2 3 4	1 2 3 4	1 2 3 4 5
28- الغثيان	☐نعم ☐كلا	1 2 3 4	1 2 3 4	1 2 3 4 5
29- السعال	☐نعم ☐كلا	1 2 3 4	1 2 3 4	1 2 3 4 5
30- غيره:__________	☐نعم ☐كلا	1 2 3 4	1 2 3 4	1 2 3 4 5

الفقرة الثالثة: الإعتقادات المعيارية(المتعارف عليها/المعتمدة)

31- يوافق الفريق المعالج لابنك/ابنتك على التركيز على جودة حياة الطفل المصاب بالسرطان (قدرة الطفل على المشاركة في الأنشطة اليومية والاستمتاع بها)
☐ أعارض بشدة ☐ أعارض ☐ محايد ☐أوافق ☐أوافق بشدة

الفقرة الرابعة: المعرفة حول العناية التلطيفية

32- هل سمعت بالعناية التلطيفية؟	☐ نعم ☐كلا *(إذهب إلى سؤال #34)*
33- باعتقادك، ما مقدار معرفتك عن العناية التلطيفية؟	☐لا أعرف أيّ شيء *(إذهب إلى سؤال #34)* ☐ أعرف عنها القليل ☐أنا أعرف عنها كثيراً
34- تخيل أن لديك حاجة ماسة للحصول على معلومات حول العناية التلطيفية. إلى أين/إلى من تتّجه/تتّجهين أوَّلاً؟ للحصول على المعلومات؟ *(اختر إجابة واحدة فقط)*	☐المطبوعات (مثل الصحف والمجلات) ☐مقدّم الرعاية الصحية (طبيب ، ممرض ، عامل(ة) اجتماعي(ة)) ☐ محادثات مع أشخاص تثق/تثقين بهم (أصدقاء أو أقارب أو زملاء في العمل) ☐ الإنترنت (Google أو WebMD أو موقع إلكتروني طبي آخر) ☐ وسائل التواصل الاجتماعي (Facebook و Instagram و Twitter)
35- هل لديك أي تجربة شخصية في العناية التلطيفية؟ *(فقط لمن لديه معرفة عن العناية التلطيفية)*	☐كلا، ليس لدي أي تجربة شخصية في العناية التلطيفية ☐ نعم

مقياس المعرفة بالرعاية التلطيفية (PaCKS) *(فقط لمن لديه معرفة عن العناية التلطيفية)*			
	صح	**خطأ**	**لا أعرف**
36- أحد أهداف العناية التلطيفية هو معالجة أي مشاكل نفسية تنشأ عن مرض خطير			
37- يمكن معالجة الضغط النفسي الناتج عن مرض خطير عن طريق العناية التلطيفية			
38- يمكن أن تساعد العناية التلطيفية الناس على إدارة الآثار الجانبية للعلاجات الطبية			
39- عندما يتلقى الناس العناية التلطيفية ، يجب عليهم التخلي عن أطبائهم الآخرين			
40- العناية التلطيفية مخصصة حصراً لمن هم في الأشهر الستة الأخيرة من حياتهم			
41- العناية التلطيفية مخصصة للأشخاص المصابين بالسرطان تحديداً			
42- يجب أن يكون الناس في المستشفى لتلقي العناية التلطيفية			
43- العناية التلطيفية مخصصة لكبار السن			
44- العناية التلطيفية هي عمل فريق لتقديم الرعاية			
45- أحد أهداف العناية التلطيفية هو مساعدة الناس على فهم خيارات العلاج بشكل أفضل			
46- العناية التلطيفية تشجع الناس على التوقف عن العلاجات التي تهدف للشفاء من مرضهم			
47- أحد أهداف العناية التلطيفية هو تحسين قدرة الشخص على المشاركة في الأنشطة اليومية			
48- تساعد العناية التلطيفية الأسرة بأكملها على التأقلم مع مرض خطير.			
49- تبدأ العناية التلطيفية للأطفال عند تشخيص مرض خطير			
50- تخفف العناية التلطيفية للأطفال معاناة الطفل الجسدية فقط			
51- العناية التلطيفية الفعالة للأطفال ممكنة حتّى إذا كانت الموارد محدودة			
52- تتطلب العناية التلطيفية للأطفال مشاركة الأسرة في الرعاية			

الفقرة الخامسة: المواقف من العناية التلطيفية

تعالج خدمات العناية التلطيفية أعراض المرضى وتحسن نوعية حياة المرضى. إلى أي مدى توافق على العبارات التالية					
إدراج خدمات العناية التلطيفية في رعاية ابنك/ابنتك	1= أعارض بشدة 2 =أعارض =لست متأكد(ة) 4=أوافق 5=أوافق بشدة				
53- يساعد في معالجة أعراض طفلك	1	2	3	4	5
54- يساعد في اتخاذ قرارات العلاج	1	2	3	4	5

55- هو إضافة إيجابية للرعاية الإجمالية لطفلك	1	2	3	4	5
56- يعيق علاقتك بطبيب الأورام / الفريق المعالج لابنك/ابنتك	1	2	3	4	5
57- يقلل أملك في شفاء ابنك/ابنتك	1	2	3	4	5
58- يتعارض مع علاج سرطان ابنك/ابنتك	1	2	3	4	5
59- يساعد في تلبية حاجات الأسرة	1	2	3	4	5
60- يضمن استمرارية الرعاية بين المستشفى والمجتمع والمنزل	1	2	3	4	5

إلى أي مدى توافق/توافقين على العبارات التالية بخصوص توقيت العناية التلطيفية للأطفال المصابين بالسرطان؟ أوصي بتوفير خدمات الرعاية التلطيفية لطفل مصاب بالسرطان					
61- في بداية علاج السرطان	1	2	3	4	5
62- إذا كان إدارة الألم أو الأعراض مشكلة	1	2	3	4	5
63- إذا تفاقم السرطان أو عاد ظهوره	1	2	3	4	5
64- في الفترة الأخيرة من حياة المريض	1	2	3	4	5
65- في جميع مراحل رعاية الطفل المصاب بالسرطان	1	2	3	4	5
66- لا يجب توفيرها لرعاية الطفل من السرطان	1	2	3	4	5

الفقرة السادسة: إعتقادات السيطرة

إلى أي مدى كل من العوامل التالية تسهّل أو تصعّب دمج خدمات العناية التلطيفية في رعاية ابنك/ابنتك ؟					
1= تصعّب كثيراً 2 = تصعّب 3= غير متأكد 4= تسهّل 5= تسهّل كثيراً					
67- التأكد من إحتمال الشفاء لابني/ابنتي	1	2	3	4	5
68- -إدراك معاناة ابني/ابنتي	1	2	3	4	5
69- الدعم والتواصل الجيد مع الفريق المعالج لابني/ابنتي	1	2	3	4	5
70- المعرفة عن العناية التلطيفية للأطفال	1	2	3	4	5
71- الإعتقاد بأنني والد(ة) صالح(ة)	1	2	3	4	5
72- الإلتزام الديني والروحي	1	2	3	4	5
73- نقص في فهم الحالة الطبية لابني/ابنتي	1	2	3	4	5
74- الاعتقاد غير الواقعي باحتمال الشفاء	1	2	3	4	5
75- كثرة المشاعر السلبية	1	2	3	4	5
76- الرغبة في حماية الآخرين من الأخبار السيئة	1	2	3	4	5
77- الإنزعاج عند الحديث عن الموت	1	2	3	4	5
78- إشراك أفراد الأسرة الكبيرة (الأقارب) في قرارات العلاج المتعلقة برعاية ابني/ابنتي	1	2	3	4	5
79- غيره:____________________________	1	2	3	4	5

الفقرة السابعة: النوايا والسلوكيات في العناية التلطيفية

أي من الأنشطة التالية (إن تنطبق) أنجزتها لرعاية طفلك في الأسبوع الماضي؟ **بالنسبة للأنشطة التي لم يتم إجراؤها، ما مدى احتمال /إنجازها في الأسبوع القادم؟**								
النشاط	لا ينطبق	نعم	كلا	1= مستبعد جداً 2 = مستبعد 3= غير متأكد 4= محتمَل 5= محتمَل جداً				
80- تلبية الحاجات العاطفية لابني/ابنتي المريض(ة)				1	2	3	4	5
81- تخطيط الأنشطة للأسرة				1	2	3	4	5
82- التخطيط لأنشطة لابني/ابنتي المريض(ة)				1	2	3	4	5
83- المتابعة مع فريق العلاج (مثل /الإتصالات الهاتفية)				1	2	3	4	5
84- تلبية حاجات زوجي/زوجتي العاطفيّة				1	2	3	4	5
85- تلبية حاجاتي العاطفية				1	2	3	4	5
86- تلبية الحاجات العاطفية لأولادي الآخرين				1	2	3	4	5
87- تلبية الاحتياجات العاطفية لأسرتي الكبيرة (الأقارب)				1	2	3	4	5
88- إدارة الأحداث المؤلمة				1	2	3	4	5
89- الحصول على معلومات عن مرض ابني/ابنتي				1	2	3	4	5
90- التواصل حول مرض ابني/ابنتي				1	2	3	4	5
91- تأديب الطفل المريض				1	2	3	4	5
92- إدارة /الأمور الماليّة				1	2	3	4	5
93- الحفاظ على راحة ابني/ابنتي				1	2	3	4	5
94- إدارة الآثار الجانبية للعلاج				1	2	3	4	5
95- إعطاء الأدوية عن طريق الفم				1	2	3	4	5
96- إدارة أمراض الطفولة الأخرى				1	2	3	4	5

97- الحضور إلى المواعيد الطبية				1	2	3	4	5
98- القيام بمهام منزلية إضافية				1	2	3	4	5
99- إدارة أحداث -مفاجئة				1	2	3	4	5
100- تأمين الرعاية للإخوة				1	2	3	4	5
101- تأمين الرعاية لابني/ابنتي المريض(ة)				1	2	3	4	5
102- تشغيل الأجهزة الطبية مثل آلة التغذية				1	2	3	4	5
103- الحصول على المعدات والأدوية الضروريّة				1	2	3	4	5
104- الصلاة مع ابني/ابنتي				1	2	3	4	5
105- اتخاذ القرارات المتعلقة برعاية ابني/ابنتي				1	2	3	4	5
106- مشاركة تجربتي مع أهالٍ وضعهم مماثل لوضعي				1	2	3	4	5
107- تذكير ابني/ابنتي بالاحتياطات الطبية				1	2	3	4	5
108- إطلاع ابني/ابنتي على معلومات طبية				1	2	3	4	5
109- الحصول على مزيد من المعلومات حول العناية التلطيفية				1	2	3	4	5
110- مناقشة العناية التلطيفية مع فريق الرعاية الصحية لابني(تي)				1	2	3	4	5
111- غيره:__________________				1	2	3	4	5

112- تعليقات أخرى:

____

____

____

شكراً على مشاركتك في هذه الدراسة!!

APPENDIX AA

Content Validation Grid

Dear Content Expert,

Thank you for taking the time to validate the content of the study survey that will be used in examining primary caregivers’ knowledge, attitudes and beliefs toward palliative care of children with cancer. The survey contains 7 sections with a total of 112 items. Please refer to the attached Arabic version of the survey. You are kindly asked to rate each item for relevance to the related section and for cultural appropriateness. Your review should be based on the provided definitions of the different concepts of interest. Please be as objective and as constructive as possible in your review and use the following rating scale:

Degree of Relevance	Cultural Appropriateness
1= the item is not relevant to the measured concept	1= the item is not appropriate
2= the item is somewhat relevant to the measured concept	2= the item is somewhat appropriate
3= the item is relevant to the measured concept	3= the item is appropriate
4= the item is very relevant to the measured concept	4= the item is very appropriate

In case you have any comment or suggestion to improve the item, please indicate it in the comment/suggestion space.

Section 1: Demographic Data										
Definitions: ***Primary Caregiver:*** The child’s parent who is the first line of support and who is deeply involved in the healthcare of the child until the age of 18 years (mother or father or significant other). ***Child with Cancer:*** The child with cancer is defined as male or female individual aged below 18 years who is diagnosed with cancer and on active cancer therapy.										
Items		**Relevance**				**Cultural Appropriateness**				**Comments/Suggestions**
Primary caregiver’s characteristics										
1.	الجنس	1	2	3	4	1	2	3	4	
2.	ما علاقتك بالمريض؟	1	2	3	4	1	2	3	4	
3.	كم عمرك؟	1	2	3	4	1	2	3	4	
4.	هل أنت حالياً؟(الوضع العائلي)	1	2	3	4	1	2	3	4	
5.	مع من يعيش الطفل(ة)؟ (اختر كل ما ينطبق)	1	2	3	4	1	2	3	4	
6.	ما هي جنسيتك؟	1	2	3	4	1	2	3	4	
7.	ما هو أعلى مستوى علمي أكملته؟	1	2	3	4	1	2	3	4	
8.	أين تسكن؟	1	2	3	4	1	2	3	4	
9.	ماهو تفضيلك الديني، إذا وجد؟	1	2	3	4	1	2	3	4	
10.	ما هو وضعك المهني حالياً؟	1	2	3	4	1	2	3	4	
11.	ما هو نطاق الدخل الإجمالي الشهري لأسرتك؟	1	2	3	4	1	2	3	4	
Child’s demographic data										
12.	ما هو جنس الولد؟	1	2	3	4	1	2	3	4	
13.	كم عمر ابنك/ابنتك حالياّ ؟	1	2	3	4	1	2	3	4	
Section 2: Child’s Clinical Data										
Items		**Relevance**				**Cultural Appropriateness**				**Comments**
14.	ما هو تشخيص مرض ابنك/ابنتك؟	1	2	3	4	1	2	3	4	
15.	كم كان عمر ابنك/ابنتك عند التشخيص؟	1	2	3	4	1	2	3	4	
16.	فكّر بيوم عادي، كم ساعة تخصصها لرعاية مرض ابنك/ابنتك؟	1	2	3	4	1	2	3	4	
17.	ما نوع العلاج الذي يتلقاه ابنك/ابنتك حالياً؟	1	2	3	4	1	2	3	4	
18.	ما هي حالة المرض لابنك/ابنتك	1	2	3	4	1	2	3	4	

	حالياً؟			
19.	ماذا أخبرك طبيب ابنك/ابنتك عن فرص شفاء طفل مصاب بهذا النوع من السرطان؟	1 2 3 4	1 2 3 4	
Memorial Symptom Assessment Scale (MSAS):				
هل اختبر ابنك/ابنتك أي من الأعراض التالية في الاسبوع الماضي ؟ ***(إذا اختبر العارض)*** **كم من الوقت اختبر ابنك/ابنتك هذا العارض؟(إذا اختبر العارض)** **ما مدى شدة العارض في العادة؟** **كم سبّب هذا العارض من معاناة أو انزعاج لابنك/ابنتك ؟**		1 2 3 4	1 2 3 4	
20.	سرعة الإنفعال	1 2 3 4	1 2 3 4	
21.	الشعور بالتوتر	1 2 3 4	1 2 3 4	
22.	الشعور بالحزن	1 2 3 4	1 2 3 4	
23.	الشعور بالقلق	1 2 3 4	1 2 3 4	
24.	صعوبة بالنوم	1 2 3 4	1 2 3 4	
25.	نقص بالطاقة	1 2 3 4	1 2 3 4	
26.	نقص بالشهية	1 2 3 4	1 2 3 4	
27.	الألم	1 2 3 4	1 2 3 4	
28.	الغثيان	1 2 3 4	1 2 3 4	
29.	السعال	1 2 3 4	1 2 3 4	
30.	غيره:__________	1 2 3 4	1 2 3 4	

Section 3: Normative Beliefs

Definition:

Normative Beliefs:

The primary caregiver’s views on the approval of the healthcare team on focusing on the child’s quality of life.

Items		**Relevance**	**Cultural Appropriateness**	**Comments**
31.	(Level of agreement with the below statement) يوافق الفريق المعالج لابنك/ابنتك على التركيز على –جودة حياة الطفل المصاب بالسرطان (قدرة الطفل على المشاركة في الأنشطة اليومية والاستمتاع بها)	1 2 3 4	1 2 3 4	

Section 4: Knowledge about Pediatric Palliative Care (PPC):

Definition:

Knowledge about PPC:

The primary caregiver’s awareness, perceived knowledge and accurate information regarding PPC.

Items		**Relevance**	**Cultural Appropriateness**	**Comments**
32.	هل سمعت بالعناية التلطيفية؟	1 2 3 4	1 2 3 4	
33.	باعتقادك، ما مقدار معرفتك عن العناية التلطيفية؟	1 2 3 4	1 2 3 4	
34.	تخيل أن لديك حاجة ماسة للحصول على معلومات حول العناية التلطيفية. إلى أين/إلى من تتّجه/تتّجهين أوًلا؟ للحصول على المعلومات؟ *(اختر إجابة واحدة فقط)*	1 2 3 4	1 2 3 4	
35.	هل لديك أي تجربة شخصية في العناية التلطيفية؟ *(فقط لمن لديه معرفة عن العناية التلطيفية)*	1 2 3 4	1 2 3 4	
Palliative Care Knowledge Scale (PaCKS)- Yes/No/I don’t know *(فقط لمن لديه معرفة عن العناية التلطيفية)*				
36.	أحد أهداف العناية التلطيفية هو معالجة أي مشاكل نفسية تنشأ عن مرض خطير	1 2 3 4	1 2 3 4	

37.	يمكن معالجة الضغط النفسي الناتج عن مرض خطير عن طريق العناية التلطيفية	1 2 3 4	1 2 3 4	
38.	يمكن أن تساعد العناية التلطيفية الناس على إدارة الآثار الجانبية للعلاجات الطبية	1 2 3 4	1 2 3 4	
39.	عندما يتلقى الناس العناية التلطيفية ، يجب عليهم التخلي عن أطبائهم الآخرين	1 2 3 4	1 2 3 4	
40.	العناية التلطيفية مخصصة حصراً لمن هم في الأشهر الستة الأخيرة من حياتهم	1 2 3 4	1 2 3 4	
41.	العناية التلطيفية مخصصة للأشخاص المصابين بالسرطان تحديداً	1 2 3 4	1 2 3 4	
42.	يجب أن يكون الناس في المستشفى لتلقي العناية التلطيفية	1 2 3 4	1 2 3 4	
43.	العناية التلطيفية مخصصة لكبار السن	1 2 3 4	1 2 3 4	
44.	العناية التلطيفية هي عمل فريق لتقديم الرعاية	1 2 3 4	1 2 3 4	
45.	أحد أهداف العناية التلطيفية هو مساعدة الناس على فهم خيارات العلاج بشكل أفضل	1 2 3 4	1 2 3 4	
46.	العناية التلطيفية تشجع الناس على التوقف عن العلاجات التي تهدف للشفاء من مرضهم	1 2 3 4	1 2 3 4	
47.	أحد أهداف العناية التلطيفية هو تحسين قدرة الشخص على المشاركة في الأنشطة اليومية	1 2 3 4	1 2 3 4	
48.	تساعد العناية التلطيفية الأسرة بأكملها على التأقلم مع مرض خطير.	1 2 3 4	1 2 3 4	
49.	تبدأ العناية التلطيفية للأطفال عند تشخيص مرض خطير	1 2 3 4	1 2 3 4	
50.	تخفف العناية التلطيفية للأطفال معاناة الطفل الجسدية فقط	1 2 3 4	1 2 3 4	
51.	العناية التلطيفية الفعالة للأطفال ممكنة حتّى إذا كانت الموارد محدودة	1 2 3 4	1 2 3 4	
52.	تتطلب العناية التلطيفية للأطفال مشاركة الأسرة في الرعاية	1 2 3 4	1 2 3 4	

Section 5: Attitudes toward PPC

Definition:

Attitude toward PPC:

The degree to which the primary caregiver of the child with cancer has a favorable or unfavorable evaluation or appraisal of PPC.

Items		**Relevance**	**Cultural Appropriateness**	**Comments**
تعالج خدمات العناية التلطيفية أعراض المرضى وتحسن نوعية حياة المرضى. إلى أي مدى توافق على العبارات التالية: إدراج خدمات العناية التلطيفية في رعاية ابنك/ابنتك		1 2 3 4	1 2 3 4	
53.	يساعد في معالجة أعراض طفلك	1 2 3 4	1 2 3 4	
54.	يساعد في اتخاذ قرارات العلاج	1 2 3 4	1 2 3 4	
55.	هو إضافة إيجابية للرعاية الإجمالية لطفلك	1 2 3 4	1 2 3 4	
56.	يعيق علاقتك بطبيب الأورام / الفريق المعالج لابنك/ابنتك	1 2 3 4	1 2 3 4	
57.	يقلل أملك في شفاء ابنك/ابنتك	1 2 3 4	1 2 3 4	

58.	يتعارض مع علاج سرطان ابنك/ابنتك	1 2 3 4	1 2 3 4	
59.	يساعد في تلبية حاجات الأسرة	1 2 3 4	1 2 3 4	
60.	يضمن استمرارية الرعاية بين المستشفى والمجتمع والمنزل	1 2 3 4	1 2 3 4	
إلى أي مدى توافق/توافقين على العبارات التالية بخصوص توقيت العناية التلطيفية للأطفال المصابين بالسرطان؟ أوصي بتوفير خدمات الرعاية التلطيفية لطفل مصاب بالسرطان		1 2 3 4	1 2 3 4	
61.	في بداية علاج السرطان	1 2 3 4	1 2 3 4	
62.	إذا كان إدارة الألم أو الأعراض مشكلة	1 2 3 4	1 2 3 4	
63.	إذا تفاقم السرطان أو عاد ظهوره	1 2 3 4	1 2 3 4	
64.	في الفترة الأخيرة من حياة المريض	1 2 3 4	1 2 3 4	
65.	في جميع مراحل رعاية الطفل المصاب بالسرطان	1 2 3 4	1 2 3 4	
66.	لا يجب توفيرها لرعاية الطفل من السرطان	1 2 3 4	1 2 3 4	

Section 6: Control Beliefs toward PPC

Definition:

Control Beliefs toward PPC

The primary caregivers’ perceived facilitators and barriers to PPC at the individual level.

Items		**Relevance**	**Cultural Appropriateness**	**Comments**
إلى أي مدى كل من العوامل التالية تسهّل أو تصعّب دمج خدمات العناية التلطيفية في رعاية ابنك/ابنتك ؟		1 2 3 4	1 2 3 4	
67.	التأكد من إحتمال الشفاء لابني/ابنتي	1 2 3 4	1 2 3 4	
68.	إدراك معاناة ابني/ابنتي	1 2 3 4	1 2 3 4	
69.	الدعم والتواصل الجيد مع الفريق المعالج لابني/ابنتي	1 2 3 4	1 2 3 4	
70.	المعرفة عن العناية التلطيفية للأطفال	1 2 3 4	1 2 3 4	
71.	الإعتقاد بأنني والد(ة) صالح(ة)	1 2 3 4	1 2 3 4	
72.	الإلتزام الديني والروحي	1 2 3 4	1 2 3 4	
73.	لابني/ابنتي نقص في فهم الحالة الطبية	1 2 3 4	1 2 3 4	
74.	الاعتقاد غير الواقعي باحتمال الشفاء	1 2 3 4	1 2 3 4	
75.	كثرة المشاعر السلبية	1 2 3 4	1 2 3 4	
76.	الرغبة في حماية الآخرين من الأخبار السيئة	1 2 3 4	1 2 3 4	
77.	الإنزعاج عند الحديث عن الموت	1 2 3 4	1 2 3 4	
78.	(الأقارب) في إشراك أفراد الأسرة الكبيرة قرارات العلاج المتعلقة برعاية ابني/ابنتي	1 2 3 4	1 2 3 4	
79.	غيره:_________________	1 2 3 4	1 2 3 4	

Section 7: PPC Intentions and PPC Behaviors

Definition:

PPC Intentions

The indications of the willingness to try to perform PPC behaviors or tasks.

PPC Behaviors

Actions taken by the primary caregiver in relation to PPC as defined by the World Health Organization (WHO). These actions include discussing, seeking information or delivering PPC. According to WHO PPC is: “the active total care of the child's body, mind and spirit, and also involves giving support to the family. It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease. Health providers must evaluate and alleviate a child's physical, psychological, and social distress. Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community.”

Items	**Relevance**	**Cultural Appropriateness**	**Comments**

أي من الأنشطة التالية (إن تنطبق) أنجزتها لرعاية طفلك في الأسبوع الماضي؟ بالنسبة للأنشطة التي لم يتم إجراؤها، ما مدى احتمال إنجازها في الأسبوع القادم؟		1	2	3	4	1	2	3	4	
80.	تلبية الحاجات العاطفية لابني/ابنتي المريض(ة)	1	2	3	4	1	2	3	4	
81.	تخطيط الأنشطة للأسرة	1	2	3	4	1	2	3	4	
82.	التخطيط لأنشطة لابني/ابنتي المريض(ة)	1	2	3	4	1	2	3	4	
83.	المتابعة مع فريق العلاج (مثل /الإتصالات الهاتفية)	1	2	3	4	1	2	3	4	
84.	تلبية حاجات زوجي/زوجتي العاطفيّة	1	2	3	4	1	2	3	4	
85.	تلبية حاجاتي العاطفية	1	2	3	4	1	2	3	4	
86.	تلبية الحاجات العاطفية لأولادي الآخرين	1	2	3	4	1	2	3	4	
87.	تلبية الاحتياجات العاطفية لأسرتي الكبيرة (الأقارب)	1	2	3	4	1	2	3	4	
88.	إدارة الأحداث المؤلمة	1	2	3	4	1	2	3	4	
89.	الحصول على معلومات عن مرض ابني/ابنتي	1	2	3	4	1	2	3	4	
90.	التواصل حول مرض ابني/ابنتي	1	2	3	4	1	2	3	4	
91.	تأديب الطفل المريض	1	2	3	4	1	2	3	4	
92.	إدارة /الأمور الماليّة	1	2	3	4	1	2	3	4	
93.	الحفاظ على راحة ابني/ابنتي	1	2	3	4	1	2	3	4	
94.	إدارة الآثار الجانبية للعلاج	1	2	3	4	1	2	3	4	
95.	إعطاء الأدوية عن طريق الفم	1	2	3	4	1	2	3	4	
96.	إدارة أمراض الطفولة الأخرى	1	2	3	4	1	2	3	4	
97.	الحضور إلى المواعيد الطبية	1	2	3	4	1	2	3	4	
98.	القيام بمهام منزلية إضافية	1	2	3	4	1	2	3	4	
99.	إدارة أحداث -مفاجئة	1	2	3	4	1	2	3	4	
100.	تأمين الرعاية للإخوة	1	2	3	4	1	2	3	4	
101.	تأمين الرعاية لابني/ابنتي المريض(ة)	1	2	3	4	1	2	3	4	
102.	تشغيل الأجهزة الطبية مثل آلة التغذية	1	2	3	4	1	2	3	4	
103.	الحصول على المعدات والأدوية الضروريّة	1	2	3	4	1	2	3	4	
104.	الصلاة مع ابني/ابنتي	1	2	3	4	1	2	3	4	
105.	اتخاذ القرارات المتعلقة برعاية ابني/ابنتي	1	2	3	4	1	2	3	4	
106.	مشاركة تجربتي مع أهالٍ وضعهم مماثل لوضعي	1	2	3	4	1	2	3	4	
107.	تذكير ابني/ابنتي بالاحتياطات الطبية	1	2	3	4	1	2	3	4	
108.	إطلاع ابني/ابنتي على معلومات طبية	1	2	3	4	1	2	3	4	
109.	الحصول على مزيد من المعلومات حول العناية التلطيفية	1	2	3	4	1	2	3	4	
110.	مناقشة العناية التلطيفية مع فريق الرعاية الصحية لابني(تي)	1	2	3	4	1	2	3	4	
111.	غيره:__________________	1	2	3	4	1	2	3	4	

112. General Comments on the survey:

Thank you for completing the content validation grid!!

APPENDIX BB

Study Survey-Validated Arabic

دراسة استقصائية – النسخة العربية

الفقرة الأولى: البيانات الديموغرافية

خصائص المعتني الرئيسي	
1- الجنس	☐ ذكر ☐ أنثى
2- ما علاقتك بالمريض؟	☐الوالد(ة) البيولوجي(ة) ☐زوج(ة) الوالد(ة) ☐الوالد(ة) بالتبني ☐الجد(ة) ☐غيره: ______
3- كم عمرك؟	__________سنة
4- هل أنت حالياً:	☐متزوج(ة) ☐منفصل(ة) ☐ مطلق ☐أرمل(ة) ☐غيره: ______
5- مع من يعيش الولد ؟ (اختر كل ما ينطبق)	☐الوالد ☐الوالدة ☐الإخوة/الأخوات ☐الجد/الجدة ☐زوج(ة) الوالد(ة) ☐غيره: __________
6- ما هي جنسيتك؟	☐لبناني ☐ غير لبناني (الرجاء التحديد): ____________
7- ما هو أعلى مستوى علمي أكملته؟	☐دراسات عليا ☐جامعة ☐ المدرسة الثانوية ☐ بروفيه ☐أقل من بروفيه
8- أين تسكن؟	مكان السكن: (مدينة/ريف): ____________
9- ماهي ديانتك؟	☐مسيحي(ة) ☐مسلم(ة) ☐درزي(ة) ☐أفضل عدم الإجابة ☐غيره ☐لا تفضيل ديني
10-ما هو وضعك المهني حالياً؟	☐موظف ☐ عاطل عن العمل ☐رب(ة)منزل ☐طالب (ة) ☐ متقاعد(ة) ☐غيره (الرجاء التحديد): ____________
11- كيف تقيّمالدخل الإجمالي الشهري لأسرتك؟	☐ لا يكفي حاجات الأسرة الأساسية ☐ يكفي حاجات الأسرة الأساسية ☐ يفوق حاجات الأسرة الأساسية ☐لا أعرف
البيانات الديموغرافية للولد	
12-ما هو جنس الولد؟	☐ ذكر ☐ أنثى
13-كم عمر الولد حالياّ ؟	____________سنة/شهر

الفقرة الثانية: البياناتالطبية للولد

14-ما هو تشخيص مرض الولد ؟	☐ سرطان الدم ☐سرطان الغدد اللمفاوية ☐سرطان في الرأس ☐سرطان في العصب Neuroblastoma ☐ سرطان في العظم ☐سرطان إوينغ ☐ سرطان في العين ☐ سرطان في العضل ☐ غيره: ____________
15-كم كان عمر الولد عند التشخيص؟	____________سنة/سنوات/أشهر
16-فكّر بيوم عادي، كم ساعة تخصصها لرعاية مرض الولد ؟	____________ساعة
17-ما نوع العلاج الذي يتلقاه الولد حالياّ؟ (اختر كل ما ينطبق)	☐علاج كيميائي ☐ علاج بالأشعة ☐جراحة ☐عناية تلطيفية ☐علاج موجّه Targeted therapy
18-ما هي حالة مرض الولد حالياً؟	☐لا خلايا سرطانية ☐مرض نشط ☐مرض منتشر ☐لا أعرف
19- ماذا أخبرك طبيب الولد عن فرص شفاء طفل مصاب بهذا النوع من السرطان؟	☐ لم يناقش طبيب الولد فرصة الشفاء معي ☐ قال الطبيب: إن فرصة الشفاء عالية جدًا ☐ قال الطبيب: فرصة الشفاء عالية نوعا ما ☐ قال الطبيب: فرصة الشفاء غيرعالية ☐ غير متأكد (ة) مما قاله الطبيب

مقياس تقييم الأعراض				
هل اختبر الولد أي من الأعراض التالية في الاسبوع الماضي ؟	اختبر الولد هذا العارض نعم/كلا	**التردّد (إذا الجواب نعم)** كم من الوقت اختبر الولد هذا العارض؟ 1- تقريبا أبداً 2- أحياناً 3- كثيراً 4- تقريبا دائماً	**الحدّة (إذا الجواب نعم)** ما مدى شدة العارض في العادة؟ 1- خفيف 2- معتدل 3- شديد 4- شديد جداً	**المحنة/المعاناة(إذا الجواب نعم)** كم سبّب هذا العارض من معاناة أو انزعاج للولد ؟ 0- أبداً 1-قليلاً 2-بعض الشيء 3-كثيراً 4-بشكل هائل
20- سرعة الإنفعال	☐نعم ☐كلا	1 2 3 4	1 2 3 4	0 1 2 3 4
21-الشعور بالتوتر	☐نعم ☐كلا	1 2 3 4	1 2 3 4	0 1 2 3 4
22-الشعور بالحزن	☐نعم ☐كلا	1 2 3 4	1 2 3 4	0 1 2 3 4
23-الشعور بالقلق	☐نعم ☐كلا	1 2 3 4	1 2 3 4	0 1 2 3 4
24-صعوبة بالنوم	☐نعم ☐كلا	1 2 3 4	1 2 3 4	0 1 2 3 4
25-نقص بالطاقة	☐نعم ☐كلا	1 2 3 4	1 2 3 4	0 1 2 3 4
26-نقص بالشهية	☐نعم ☐كلا	1 2 3 4	1 2 3 4	0 1 2 3 4
27- الألم	☐نعم ☐كلا	1 2 3 4	1 2 3 4	0 1 2 3 4
28- الغثيان	☐نعم ☐كلا	1 2 3 4	1 2 3 4	0 1 2 3 4

29-السعال	☐نعم ☐كلا	1 2 3 4	1 2 3 4	0 1 2 3 4
30-غيره:__________	☐نعم ☐كلا	1 2 3 4	1 2 3 4	0 1 2 3 4

الفقرة الثالثة: الإعتقادات/المعتقدات؟ المعيارية/المتعارف عليها/المعتمدة

31-يدْعم الفريق المعالج للولد التركيز على جودة حياة الطفل المصاب بالسرطان (قدرة الولد على المشاركة في الأنشطة اليومية والاستمتاع بها)
☐ أعارض بشدة ☐ أعارض ☐ محايد ☐أوافق ☐أوافق بشدة

الفقرة الرابعة: المعرفة حول العناية التلطيفية

32-هل سمعت بالعناية التلطيفية؟	☐ نعم ☐كلا *(إذهب إلى سؤال #34)*
33- باعتقادك، ما مقدار معرفتك عن العناية التلطيفية؟	☐لا أعرف أيّ شيء *(إذهب إلى سؤال #34)* ☐ أعرف عنها القليل ☐أعرف عنها كثيراً
34-افترض (ي) أن لديك حاجة ماسة للحصول على معلومات حول العناية التلطيفية. إلى أين/إلى من تتّجه/تتّجهين أوًلا؟ للحصول على المعلومات؟ *(اخترإجابة واحدة فقط)*	☐المطبوعات (مثل الصحف والمجلات) ☐أحد أفراد فريق الرعاية الصحية (طبيب ، ممرض ، عامل(ة) اجتماعي(ة)) ☐ محادثات مع أشخاص تثق/تثقين بهم (أصدقاء أو أقارب أو زملاء في العمل) ☐ الإنترنت (Google أو WebMD أو موقع إلكتروني طبي آخر) ☐ وسائل التواصل الاجتماعي (Facebook و Instagram و Twitter) ☐عائلة مريض آخر
35-هل لديك أي تجربة شخصية في العناية التلطيفية؟ *(فقط لمن لديه معرفة عن العناية التلطيفية)*	☐كلا، ليس لدي أي تجربة شخصية في العناية التلطيفية ☐ نعم

مقياس المعرفة بالرعاية التلطيفية (PaCKS) *(فقط لمن لديه معرفة عن العناية التلطيفية)*			
	صح	**خطأ**	**لا أعرف**
36-أحد أهداف العناية التلطيفية هو معالجة أي مشاكل نفسية تنشأ عن مرض خطير			
37-يمكن معالجة الضغط النفسي الناتج عن مرض خطير عن طريق العناية التلطيفية			
38-يمكن أن تساعد العناية التلطيفية المرضى على معالجة الآثار الجانبية للعلاجات الطبية			
39-عندما يتلقى المرضى العناية التلطيفية ، يجب عليهم التخلي عن أطبائهم الآخرين			
40-العناية التلطيفية مخصصة حصراً لمن هم في الأشهر الأخيرة من حياتهم			
41-العناية التلطيفية مخصصة تحديداً للأشخاص المصابين بالسرطان			
42-يجب أن يكون المرضى في المستشفى لتلقي العناية التلطيفية			
43-العناية التلطيفية مخصصة للمسنّين			
44-تعتمد العناية التلطيفية على عمل فريق من مُقدّمي الرعاية الصحية			
45-أحد أهداف العناية التلطيفية هو مساعدة المرضى على فهم خيارات العلاج بشكل أفضل			
46-العناية التلطيفية تشجع المرضى على التوقف عن العلاجات التي تهدف للشفاء من مرضهم			
47-أحد أهداف العناية التلطيفية هو تحسين قدرة المريض على المشاركة في الأنشطة اليومية			
48-تساعد العناية التلطيفية الأسرة بأكملها على التأقلم مع مرض خطير.			
49-تبدأ العناية التلطيفية للأطفال عند تشخيص مرض خطير			
50-تخفف العناية التلطيفية للأطفال معاناة الطفل الجسدية فقط			
51-العناية التلطيفية الفعالة للأطفال ممكنة حتّى إذا كانت الموارد محدودة			
52-تتطلب العناية التلطيفية للأطفال مشاركة الأسرة في الرعاية			

الفقرة الخامسة: المواقف من العناية التلطيفية

تعالج خدمات العناية التلطيفية أعراض المرضى وتحسن نوعية حياة المرضى. إلى أي مدى توافق على العبارات التالية	
إدراج خدمات العناية التلطيفية في رعاية الولد	1= أعارض بشدة 2 =أعارض 3= لست متأكد(ة) 4=أوافق 5=أوافق بشدة
53-يساعد في معالجة أعراض الولد	1 2 3 4 5
54-يساعد في اتخاذ قرارات العلاج	1 2 3 4 5
55-هو إضافة إيجابية للرعاية الإجمالية للولد	1 2 3 4 5
56-يعيق علاقتك بطبيب الأورام / الفريق المعالج للولد	1 2 3 4 5
57- يقلل أملك في شفاء الولد	1 2 3 4 5
58-يتعارض مع علاج سرطان الولد	1 2 3 4 5
59-يساعد في تلبية /حاجات الأسرة	1 2 3 4 5
60-يضمن استمرارية الرعاية بين المستشفى والمجتمع والمنزل	1 2 3 4 5

إلى أي مدى توافق/توافقين على العبارات التالية بخصوص توقيت العناية التلطيفية للأطفال المصابين بالسرطان؟ أوصي بتوفير خدمات الرعاية التلطيفية لطفل مصاب بالسرطان	
61-في بداية علاج السرطان	1 2 3 4 5
62-إذا كان هناك مشكلة مي معالجة الألم أو الأعراض	1 2 3 4 5
63-إذا تفاقم السرطان أو عاد ظهوره	1 2 3 4 5
64-في الفترة الأخيرة من حياة المريض	1 2 3 4 5
65-في جميع مراحل رعاية الطفل المصاب بالسرطان	1 2 3 4 5
66-لا يجب توفيرها لرعاية الطفل من السرطان	1 2 3 4 5

الفقرة السادسة: إعتقادات السيطرة

إلى أي مدى كل من العوامل التالية تسهّل أو تصعّب دمج خدمات العناية التلطيفية في رعاية الولد ؟					
1= تصعّب كثيراً 2 = تصعّب 3= غير متأكد 4= تسهّل 5= تسهّل كثيراً					
67-التأكد من إحتمال الشفاء للولد	1	2	3	4	5
68--إدراك معاناة الولد	1	2	3	4	5
69-الدعم والتواصل الجيد مع الفريق المعالج للولد	1	2	3	4	5
70-المعرفة عن العناية التلطيفية للأطفال	1	2	3	4	5
71-الإعتقاد بأنني والد(ة) صالح(ة)	1	2	3	4	5
72-الإلتزام الديني والروحي	1	2	3	4	5
73-نقص في الفهم الدقيق للحالة الطبية للولد	1	2	3	4	5
74-الاعتقاد غير الواقعي باحتمال الشفاء	1	2	3	4	5
75-كثرة المشاعر السلبية	1	2	3	4	5
76-الرغبة في حماية الآخرين من الأخبار السيئة	1	2	3	4	5
77-الإنزعاج عند الحديث عن الموت	1	2	3	4	5
78-إشراك أفراد الأسرة الكبيرة في قرارات العلاج المتعلقة برعاية الولد	1	2	3	4	5
79-غيره:________________________	1	2	3	4	5

الفقرة السابعة: النوايا والسلوكيات في العناية التلطيفية

أي من الأنشطة التالية (إن تنطبق) أنجزتها لرعاية طفلك في الأسبوع الماضي؟ **بالنسبة للأنشطة التي لم يتم إجراؤها، ما مدى احتمال /إنجازها في الأسبوع القادم؟**								
النشاط	لا ينطبق	نعم	كلا	1= مستبعد جداً 2 = مستبعد 3= غير متأكد 4= محتمَل 5= محتمَل جداً				
80-تلبية /الحاجات العاطفية للولد المريض(ة)				1	2	3	4	5
81-تخطيط الأنشطة للأسرة				1	2	3	4	5
82-التخطيط لأنشطة للولد المريض				1	2	3	4	5
83-المتابعة مع فريق العلاج (مثل /الإتصالات الهاتفية)				1	2	3	4	5
84- إعطاء الدعم العاطفي لزوجي/زوجتي				1	2	3	4	5
85-تلبية حاجاتي العاطفية				1	2	3	4	5
86-تلبية الحاجات العاطفية لأولادي الآخرين				1	2	3	4	5
87-إعطاء الدعم العاطفي لأسرتي الكبيرة (الأقارب)				1	2	3	4	5
88-التعامل مع الأحداث المؤلمة				1	2	3	4	5
89-البحث عن معلومات عن مرض الولد				1	2	3	4	5
90-التحدث عن مرض الولد				1	2	3	4	5
91-تأديب الطفل المريض				1	2	3	4	5
92-إدارة الأمورالماليّة				1	2	3	4	5
93-الحفاظ على راحة الولد				1	2	3	4	5
94-معالجة الآثارالجانبية للعلاج				1	2	3	4	5
95-إعطاء الأدوية عن طريق الفم				1	2	3	4	5
96-معالجة أمراض الطفولة الأخرى				1	2	3	4	5
97-الحضور إلى المواعيد الطبية				1	2	3	4	5
98-القيام بمهام منزلية إضافية				1	2	3	4	5
99-التعامل مع أحداث مفاجئة				1	2	3	4	5
100- تأمين الرعاية للإخوة				1	2	3	4	5
101-تأمين الرعاية للولد المريض				1	2	3	4	5
102-تشغيل الأجهزة الطبية مثل آلة التغذية				1	2	3	4	5
103-تأمين المعدات والأدوية الضروريّة				1	2	3	4	5
104-الصلاة مع الولد				1	2	3	4	5
105-اتخاذ القرارات المتعلقة برعاية الولد				1	2	3	4	5
106-مشاركة تجربتي مع أهالٍ وضعهم مماثل لوضعي				1	2	3	4	5
107-تذكيرالولد بالاحتياطات الطبية				1	2	3	4	5
108- إعطاء معلومات طبية للولد				1	2	3	4	5
109-البحث عن مزيد من المعلومات حول العناية التلطيفية				1	2	3	4	5
110-مناقشة العناية التلطيفية مع فريق الرعاية الصحية لابني(تي)				1	2	3	4	5
111-غيره:__________________				1	2	3	4	5

112-تعليقات أخرى:

____

____

شكراً على مشاركتك في هذه الدراسة!!

APPENDIX CC

Questions to Obtain Participants’ Feedback on the Study Survey in the Pilot Phase

	1=Very difficult	**2=Difficult**	**3=Easy**	**4=Very easy**
How easy was it to answer the items of this section?				
How appropriate is this section’s	**1=Inappropriate**	**2=Somewhat**	**3=Appropriate**	**4=Very appropriate**
- **Length**				
- **Clarity**				
- **Wording**				
- **Language**				
What are your recommendations to improve this section? *please indicate if there is any problematic item in the section and whether we need to remove or add any item*				

	1=كتير صعب	2=صعب	3=سهل	4= كتير سهل
قدي كان سهل تجاوب على الأسئلة بهذا القسم؟				
قدي مناسب هذا القسم من ناحية	1= غير مناسب	2=نوعاً ما مناسب	3=مناسب	4=كتير مناسب
الطول				
الوضوح				
الكلمات				
اللغة				
شو هي توصياتك لتحسين هالقسم؟ الرجاء تحديد إذا فيه مشكلة بأي عنصر إذا كنا بحاجة إلى إزالة أو إضافة أي عنصر.				

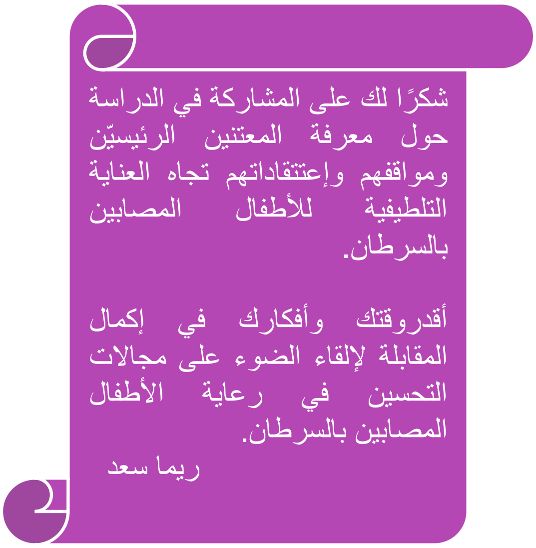
APPENDIX DD

Thank You Electronic Card

Thank you for participating in this study about Primary Caregivers' Knowledge Attitudes and Beliefs toward Palliative Care for Children with Cancer.

I appreciate your time and thoughts in completing the interview to highlight areas for improvement in the care of children with cancer.

Rima Saad



شكرًا لك على المشاركة في الدراسة حول معرفة المعتنين الرئيسيّن ومواقفهم وإعتتقاداتهم تجاه العناية التلطيفية للأطفال المصابين بالسرطان.

أقدروقتك وأفكارك في إكمال المقابلة لإلقاء الضوء على مجالات التحسين في رعاية الأطفال المصابين بالسرطان.

ريما سعد

APPENDIX EE

CITI

CITI PROGRAM

Completion Date 27-Apr-2020
Expiration Date 27-Apr-2023
Record ID 36383319

This is to certify that:

Rima Saad

Has completed the following CITI Program course:

Not valid for renewal of certification through CME. Do not use for TransCelerate mutual recognition (see Completion Report).

Social & Behavioral Research - Basic/Refresher (Curriculum Group)
Social & Behavioral Research - Basic/Refresher (Course Learner Group)
1 - Basic Course (Stage)

Under requirements set by:

American University of Beirut

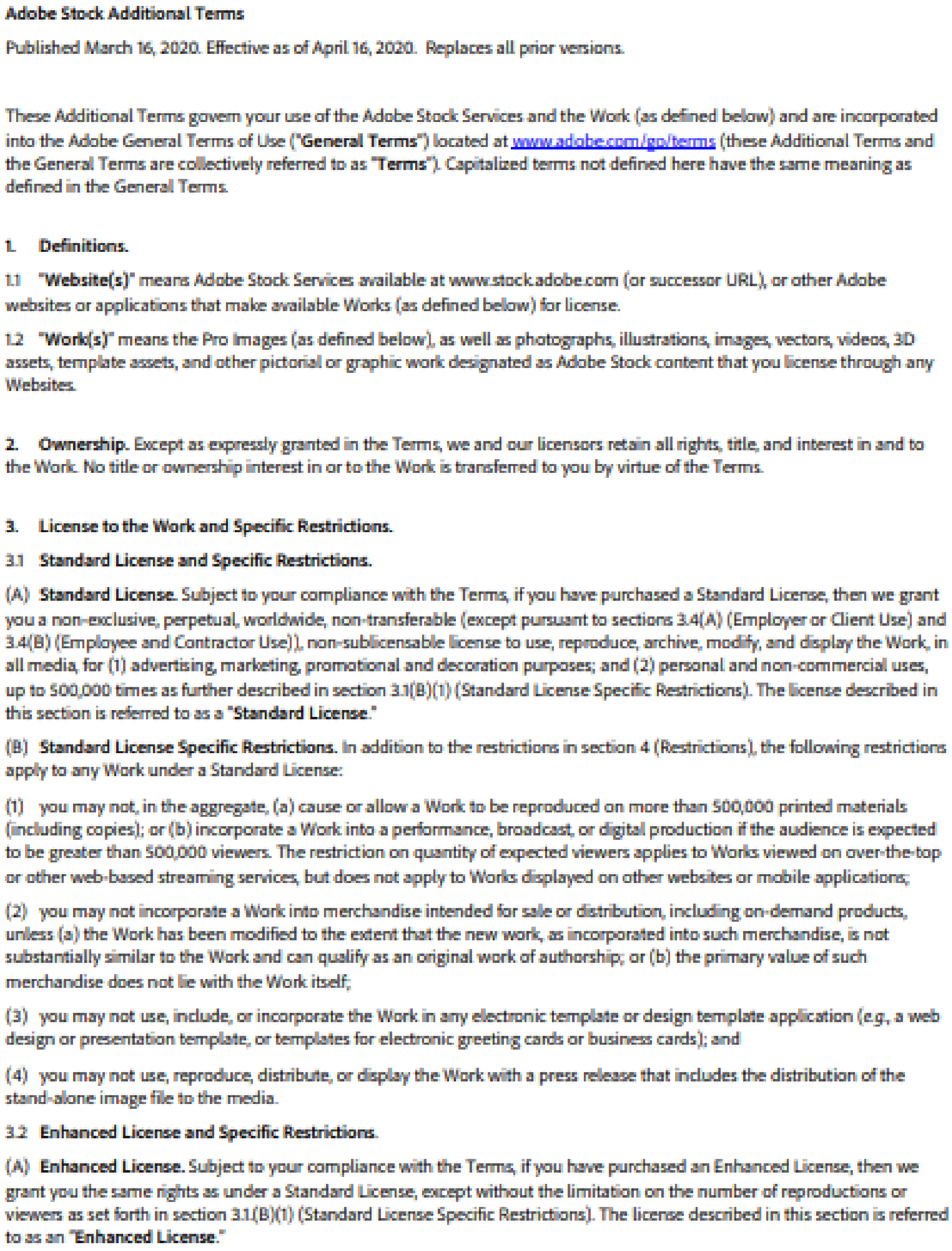
CITI
Collaborative Institutional Training Initiative

Verify at www.citiprogram.org/verify/?w064278cc-3812-4688-a577-feac0791808e-36383319

APPENDIX FF

License to Use Picture

Photo source: https://stock.adobe.com/images/alegria/225582395 -Standard License



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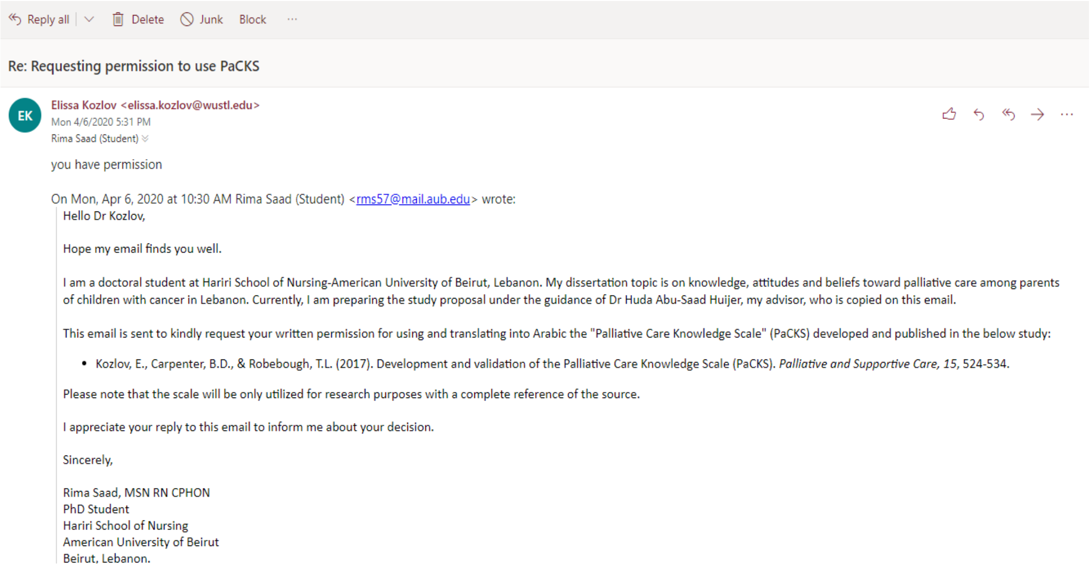
APPENDIX GG

Permission to use Questionnaires



Re: Requesting permission to use PaCKS

Elissa Kozlov <elissa.kozlov@wustl.edu>
Mon 4/6/2020 5:31 PM
Rima Saad (Student)

you have permission

On Mon, Apr 6, 2020 at 10:30 AM Rima Saad (Student) <rms57@mail.aub.edu> wrote:

Hello Dr Kozlov,

Hope my email finds you well.

I am a doctoral student at Hariri School of Nursing-American University of Beirut, Lebanon. My dissertation topic is on knowledge, attitudes and beliefs toward palliative care among parents of children with cancer in Lebanon. Currently, I am preparing the study proposal under the guidance of Dr Huda Abu-Saad Huijer, my advisor, who is copied on this email.

This email is sent to kindly request your written permission for using and translating into Arabic the "Palliative Care Knowledge Scale" (PaCKS) developed and published in the below study:

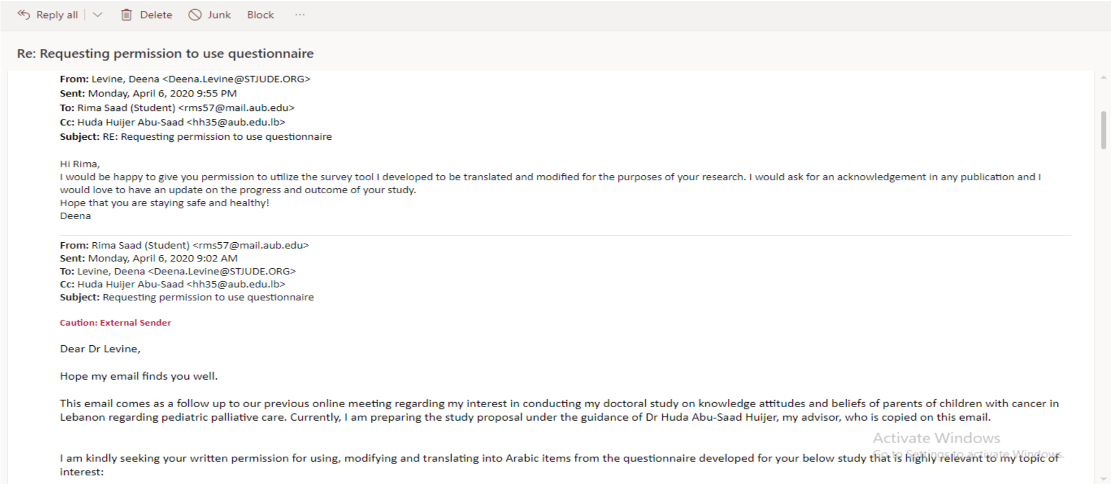
- Kozlov, E., Carpenter, B.D., & Robebough, T.L. (2017). Development and validation of the Palliative Care Knowledge Scale (PaCKS). *Palliative and Supportive Care, 15*, 524-534.

Please note that the scale will be only utilized for research purposes with a complete reference of the source.

I appreciate your reply to this email to inform me about your decision.

Sincerely,

Rima Saad, MSN RN CPHON
PhD Student
Hariri School of Nursing
American University of Beirut
Beirut, Lebanon.



Re: Requesting permission to use questionnaire

From: Levine, Deena <Deena.Levine@STJUDE.ORG>
Sent: Monday, April 6, 2020 9:55 PM
To: Rima Saad (Student) <rms57@mail.aub.edu>
Cc: Huda Huijer Abu-Saad <hh35@aub.edu.lb>
Subject: RE: Requesting permission to use questionnaire

Hi Rima,
I would be happy to give you permission to utilize the survey tool I developed to be translated and modified for the purposes of your research. I would ask for an acknowledgement in any publication and I would love to have an update on the progress and outcome of your study.
Hope that you are staying safe and healthy!
Deena

From: Rima Saad (Student) <rms57@mail.aub.edu>
Sent: Monday, April 6, 2020 9:02 AM
To: Levine, Deena <Deena.Levine@STJUDE.ORG>
Cc: Huda Huijer Abu-Saad <hh35@aub.edu.lb>
Subject: Requesting permission to use questionnaire

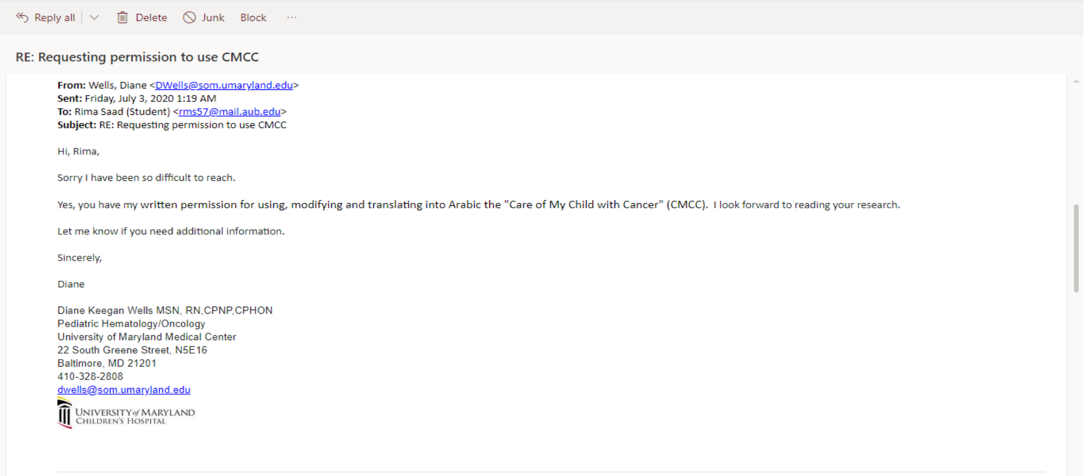
Caution: External Sender

Dear Dr Levine,

Hope my email finds you well.

This email comes as a follow up to our previous online meeting regarding my interest in conducting my doctoral study on knowledge attitudes and beliefs of parents of children with cancer in Lebanon regarding pediatric palliative care. Currently, I am preparing the study proposal under the guidance of Dr Huda Abu-Saad Huijer, my advisor, who is copied on this email.

I am kindly seeking your written permission for using, modifying and translating into Arabic items from the questionnaire developed for your below study that is highly relevant to my topic of interest:



RE: Requesting permission to use CMCC

From: Wells, Diane <DWells@som.umaryland.edu>
Sent: Friday, July 3, 2020 1:19 AM
To: Rima Saad (Student) <rms57@mail.aub.edu>
Subject: RE: Requesting permission to use CMCC

Hi, Rima,

Sorry I have been so difficult to reach.

Yes, you have my written permission for using, modifying and translating into Arabic the "Care of My Child with Cancer" (CMCC). I look forward to reading your research.

Let me know if you need additional information.

Sincerely,

Diane

Diane Keegan Wells MSN, RN,CPNP,CPHON
Pediatric Hematology/Oncology
University of Maryland Medical Center
22 South Greene Street, N5E16
Baltimore, MD 21201
410-328-2808
dwells@som.umaryland.edu
UNIVERSITY of MARYLAND
CHILDREN'S HOSPITAL

APPENDIX HH

Oral Consent for Pilot Phase (English)

Oral Consent for Pilot Phase

Primary Caregivers' Knowledge Attitudes and Beliefs toward Palliative Care for Children with Cancer

Principle Investigator: Dr. Samar Noureddine at AUB.
Co-Investigator: Dr Huda Abu-Saad Huijer
Student Investigator: Rima Saad

Hello. My name is Rima Saad. I am a PhD student working with Dr Huijer and Dr Noureddine at the Hariri School of Nursing at the American University of Beirut. I would like to invite you to participate in a **research study** about parents' views regarding palliative care for children with cancer. The **purpose** of the study is to examine the parents' knowledge, attitudes and beliefs toward palliative care in order to uncover areas for improvement. **You are one of 20 participants recruited through flyers posted in the treatment center or electronic poll.**

Before we begin, I would like to take a few minutes to explain why I am inviting you to participate and what will be done with the information you provide. You will be asked to participate in an interview via whatsapp video call. You will be asked questions on information about you, your child, your child's cancer, and your views about palliative care for children with cancer. Please stop me at any time if you have questions about the study.

I am doing this study as part of my PhD dissertation at AUB. I will be conducting the study in two phases. The first phase encompasses pilot testing of the survey in order to refine it before its use in the main study. In this phase, I will be interviewing 20 primary caregivers of children with cancer from three major pediatric oncology centers in Lebanon. If you agree to participate, I will ask you the list of questions in the survey. I will also ask for your feedback and recommendations on the different sections to refine the survey. I will type your answers to the questions on the soft copy of the survey.

I will use the information of the pilot testing in my dissertation study. I may also use this information in articles that might be published, as well as in academic presentations. Your individual privacy and **confidentiality** of the information you provide will be maintained in all published and written data analysis resulting from the study. Data will be monitored and may be audited by the IRB while assuring confidentiality. I will ask you to be in a private room during the interview. Your answer will be entered directly on the computer soft version of the survey. Neither your name nor any other identifying information will be typed on the survey. I will assign a unique code to that survey. Therefore your participation will be entirely anonymous. The results will be shown in a group format. The soft copy of the survey completed will be stored in a password-protected computer in my personal laptop and in my private office at Hariri School of Nursing at the American University of Beirut Cairo Street, Beirut, Lebanon. I will be the only researcher who will have access to the data. All the information and data collected for the study will be kept for three years and then destroyed.

Your participation should take approximately **45-60 minutes**. Please understand your participation is **entirely on a voluntary basis and you have the right to withdraw your consent** or discontinue participation at any time without penalty. Refusal to participate or withdrawal from the study will involve no loss of benefits to which the participant is otherwise entitled nor will it affect the patient and caregiver relationship with treatment center nor with their treating physician or the quality of care they are receiving. The study carries no more than the **risk** associated with everyday life. There is a possibility to have some negative emotions upon sharing your experience with your child's care. You may take a break or stop the interview at any time as needed. If you verbalize feeling anxious and in distress, the researcher will remind you of the availability of psychological support from child's treating team with no additional charges. The main other risk is possible unintentional loss of confidentiality. I will be the only person present in the interview and I will use my earphone to maintain confidentiality of the information you share. There are no direct **benefits** to you for participating in this research study. However, your participation is a venue to express your perspectives about the care of your child. At the same time, the study may help us understand your views regarding pediatric palliative care for children with cancer in Lebanon. The data you provide will help design interventions to improve the care children and families who experience similar conditions as you have. You will receive a thank you note as a token of appreciation for your participation and you will enter a prize draw for one of four cash prizes of 150 000 LBP each. I will call you if you are the winner. A copy of this consent document will be provided to you via whatsapp.

If at any time and for any reason, you would prefer not to answer any questions, please feel free to skip those questions by just saying 'skip this question'. If at any time you would like to stop participating, please tell me. We can take a break, stop and continue at a late date, or stop altogether. You will not be penalized for deciding to stop participation at any time.

If you have any questions, you are free to ask them now. If you have questions later, you may contact me on Rima Saad phone number 03-998548 or email "rms57@mail.aub.edu". If you have questions about your rights as a participant in this research, you can contact the AUB Social and Behavioral Sciences Review Board Telephone: **01-350000, Ext: 5444/5455, Email: irb@aub.edu.lb**

Are you interested in participating in this study?

APPENDIX II

Oral Consent for Pilot Phase (Arabic)

الموافقة الشفوية على مرحلة الإختبار

معرفة المعتنين الرئيسيّن ومواقفهم وإعتقاداتهم تجاه العناية التلطيفية للأطفال المصابين بالسرطان

الباحثة الرئيسية: الدكتورة سمر نور الدين
الباحثة المشاركة: الدكتورة هدى أبو سعد هاير- ريما سعد

مرحبا. إسمي ريما سعد. أنا طالبة دكتوراه أعمل مع الدكتورة هدى أبو سعد هاير والدكتورة سمر نور الدين في كلية الحريري للتمريض في الجامعة الأمريكية في بيروت. أود أن أدعوكم للمشاركة في دراسة بحثية حول نظرة الأهل بخصوص الرعاية التلطيفية للأطفال المصابين بالسرطان. **الغرض** من الدراسة هو فحص معرفة المعتنين الرئيسيّين ومواقفهم وإعتقاداتهم تجاه الرعاية التلطيفية من أجل الكشف عن مجالات التحسين. **أنت واحد من 20 مشاركًا تم استقطابهم من خلال نشرات موزعة في في مركز العلاج أو من خلال استطلاع إلكتروني.**

قبل أن نبدأ ، أود أن أخذ بضع دقائق لشرح سبب دعوتي للمشاركة وما الذي سيجري بالمعلومات التي تقدمها. سيُطلب منك المشاركة في مقابلة عبر مكالمة فيديو واتساب. ستطرح عليك أسئلة حول معلومات عنك ، وطفلك ، وسرطان طفلك ، وآرائك حول الرعاية التلطيفية للأطفال المصابين بالسرطان. من فضلك أوقفني في أي وقت إذا كانت لديك أسئلة حول الدراسة.

أقوم بهذه الدراسة كجزء من أطروحة الدكتوراه في الجامعة الأميركية في بيروت. سأجري الدراسة على مرحلتين. تشمل المرحلة الأولى اختبارًا لقائمة الأسئلة من أجل تنقيحها قبل استخدامها في الدراسة الرئيسية. في هذه المرحلة ، سأجري مقابلات مع 20 من المعتنين الرئيسيّن بأطفال مصابين بالسرطان من ثلاثة مراكز رئيسية لعلاج أورام الأطفال في لبنان. إذا وافقت على المشاركة ، فسوف أطرح عليك قائمة الأسئلة في الاستبيان. سأطلب أيضًا ملاحظاتك وتوصياتك حول الأقسام المختلفة لتحسين قائمة الأسئلة. سأكتب إجاباتك على الأسئلة الموجودة في النسخة الإلكترونية من الاستبيان.

سأستخدم معلومات الاختبار التجريبي في دراسة أطروحتي. ممكن أيضًا أن أستخدام هذه المعلومات في المقالات التي قد يتم نشرها ، وكذلك في المحاضرات الأكاديمية. سيتم الحفاظ على خصوصيتك الفردية وسرية المعلومات التي تقدمها في جميع البيانات المنشورة والمكتوبة الناتجة عن الدراسة. . ستتم مراقبة البيانات وقد يتم تدقيقها من قبل مجلس مراجعة العلوم الاجتماعية والسلوكية مع ضمان السرية. سوف أطلب منك التواجد في غرفة خاصة أثناء المقابلة. سيتم إدخال إجابتك مباشرة على النسخة الإلكترونية من الأسئلة. لن يتم كتابة اسمك أو أي معلومات تعريفية أخرى على قائمة الأسئلة. سأخصص رمزًا فريدًا لكل استبيان مكتمل . لذلك ستكون مشاركتك مجهولة بالكامل. سيتم عرض النتائج في شكل مجموعة. سيتم تخزين النسخة الإلكترونية من الاستبيان المكتمل في جهاز كمبيوتر محمي بكلمة مرور، في جهاز الكمبيوتر المحمول الشخصي الخاص بي وفي مكتبي الخاص في مدرسة الحريري للتمريض في الجامعة الأمريكية في بيروت شارع القاهرة ، بيروت ، لبنان. سأكون الباحث الوحيد الذي سيتمكن من الوصول إلى المعلومات. سيتم الاحتفاظ بجميع المعلومات التي تم جمعها للدراسة لمدة ثلاث سنوات ثم يتم إتلافها.

تستغرق مشاركتك حوالي 45-60 دقيقة. إنّ مشاركتك طوعيّة تمامًا ولديك الحق في سحب موافقتك أو التوقف عن المشاركة في أي وقت دون عواقب. لن يؤدي رفض المشاركة أو الانسحاب من الدراسة إلى خسارة الفوائد التي يحق للمشارك الحصول عليها ولن يؤثر على علاقة المريض ومقدم الرعاية بمركز العلاج ولا مع الطبيب المعالج أو جودة الرعاية التي يتلقونها. لا تحمل الدراسة أكثر من المخاطر المرتبطة بالحياة اليومية. هناك احتمال أن تختبر بعض المشاعر السلبية عند مشاركة تجربتك مع رعاية طفلك. يمكنك أخذ استراحة أو إيقاف المقابلة في أي وقت حسب الحاجة. إذا عبّرت لفظياً عن الشعور بالقلق والضيق ، فسوف يذكرك الباحث بتوفر الدعم النفسي من فريق علاج الطفل دون تكلفة إضافية. الخطر الرئيسي الآخر هو احتمال فقدان السرية عن غير قصد. سأكون الشخص الوحيد الحاضر في المقابلة وسأستخدم سماعة الأذن الخاصة بي للحفاظ على سرية المعلومات التي تشاركها. لا توجد فوائد مباشرة لك للمشاركة في هذه الدراسة. ومع ذلك ، فإن مشاركتك هي مكان للتعبير عن وجهات نظرك حول رعاية طفلك. في الوقت نفسه ، قد تساعدنا الدراسة على فهم نظرتك للرعاية التلطيفية للأطفال المصابين بالسرطان في لبنان.

ستساعد المعلومات التي تقدمها في تصميم خطط لتحسين رعاية الأطفال والأسر الذين يعانون من ظروف مشابهة لظروفك. ستتلقى رسالة شكر كعربون تقدير لمشاركتك وستدخل في سحب على واحدة من أربع جوائز نقدية كل منها بقيمة 150000 ليرة لبنانية. سأتصل بك إذا كنت الفائز. سوف أرسل نسخة من وثيقة الموافقة هذه لك عبر الواتساب.

إذا كنت تفضل في أي وقت ولأي سبب عدم الإجابة على أي أسئلة ، فلا تتردد في تخطي هذه الأسئلة بمجرد قول "تخطي هذا السؤال". إذا كنت ترغب في أي وقت في التوقف عن المشاركة ، من فضلك قل لي. يمكننا أخذ استراحة والتوقف والاستمرار في موعد لاحق أو التوقف تمامًا. لا توجد أية عواقب على قرار إيقاف المشاركة في أي وقت.

إذا كان لديك أي أسئلة ، يمكنك طرحها الآن. إذا كانت لديك أسئلة لاحقًا ، فيمكنك الاتصال بي على رقم هاتف ريما سعد:
03-998548 أو إرسال بريد إلكتروني إلى:
"rms57@mail.aub.edu"
إذا كانت لديك أسئلة حول حقوقك كمشارك في هذا البحث ، فيمكنك الاتصال بمجلس مراجعة العلوم الاجتماعية والسلوكية في الجامعة الأمريكية في بيروت هاتف: 01-350000 ، تحويلة: 5455/5444 ، بريد إلكتروني:
irb@aub.edu.lb

هل أنت مهتم بالمشاركة في هذه الدراسة؟

APPENDIX JJ

Oral Consent for Main Study (English)

Oral Consent for Main Study
Primary Caregivers' Knowledge Attitudes and Beliefs toward Palliative Care
for Children with Cancer

Principle Investigator: Dr Samar Noureddine
Co-Investigator: Dr Huda Abu-Saad Huijer
Student Investigator: Rima Saad

Hello. My name is Rima Saad. I am a PhD student working with Dr Huijer and Dr Noureddine at the Hariri School of Nursing at the American University of Beirut. I would like to invite you to participate in a **research study** about parents' views regarding palliative care for children with cancer. The **purpose** of the study is to examine the parents' knowledge, attitudes and beliefs toward palliative care in order to uncover areas for improvement. **You are one of 110 participants recruited through direct communication with the researcher or member from the treating team, or through flyers posted in the treatment center or through electronic poll.**

Before we begin, I would like to take a few minutes to explain why I am inviting you to participate and what will be done with the information you provide. You will be asked participate in an interview via whatsapp video call. You will be asked questions on information about you, your child, your child's cancer, and your views about palliative care for children with cancer. Please stop me at any time if you have questions about the study.

I am doing this study as part of my PhD dissertation at AUB. I will be interviewing 110 primary caregivers of children with cancer from three major pediatric oncology centers in Lebanon. If you agree to participate, I will ask you the list of questions in the survey and I will type your answers to the questions on the soft copy of the survey.

I will use the information in my dissertation study. I may also use this information in articles that might be published, as well as in academic presentations. Your individual privacy and **confidentiality** of the information you provide will be maintained in all published and written data analysis resulting from the study. Data will be monitored and may be audited by the IRB while assuring confidentiality. I will ask you to be in a private room during the interview. Your answer will be entered directly on the computer soft version of the survey. Neither your name nor any other identifying information will be typed on the survey. I will assign a unique code to that survey. Therefore your participation will be entirely anonymous. The results will be shown in a group format. The soft copy of the survey completed will be stored in a password-protected computer in my personal laptop and in my private office at Hariri School of Nursing at the American University of Beirut Cairo Street, Beirut, Lebanon. I will be the only researcher who will have access to the data. All the information and data collected for the study will be kept for three years and then destroyed.

Your participation should take approximately **45-60 minutes**. Please understand your participation is **entirely on a voluntary basis and you have the right to withdraw your consent** or discontinue participation at any time without penalty. Refusal to participate or withdrawal from the study will involve no loss of benefits to which the participant is otherwise entitled nor will it affect the patient and caregiver relationship with treatment center nor with their treating physician or the quality of care they are receiving. The study carries no more than the **risk** associated with everyday life. There is a possibility to have some negative emotions upon sharing your experience with your child's care. You may take a break or stop the interview at any time as needed. If you verbalize feeling anxious and in distress, the researcher will remind you of the availability of psychological support from child's treating team with no additional charges. The main other risk is possible unintentional loss of confidentiality. I will be the only person present in the interview and I will use my earphone to maintain confidentiality of the information you share. There are no direct **benefits** to you for participating in this research study. However, your participation is a venue to express your perspectives about the care of your child. At the same time, the study may help us understand your views regarding pediatric palliative care for children with cancer in Lebanon. The data you provide will help design interventions to improve the care children and families who experience similar conditions as you have. You will receive a thank you note as a token of appreciation for your participation and you will enter a prize draw for one of four cash prizes of 150 000 LBP each. I will call you if you are the winner. A copy of this consent document will be provided to you via whatsapp.

If at any time and for any reason, you would prefer not to answer any questions, please feel free to skip those questions by just saying 'skip this question'. If at any time you would like to stop participating, please tell me. We can take a break, stop and continue at a late date, or stop altogether. You will not be penalized for deciding to stop participation at any time.

If you have any questions, you are free to ask them now. If you have questions later, you may contact me on Rima Saad phone number 03-998548 or email "rms57@mail.aub.edu". If you have questions about your rights as a participant in this research, you can contact the AUB Social and Behavioral Sciences Review Board Telephone: **01-350000, Ext: 5444/5455, Email: irb@aub.edu.lb**

Are you interested in participating in this study?

APPENDIX KK
Oral Consent for Main Study (Arabic)

<u>الموافقة الشفوية على الدراسة الرئيسيّة</u>

معرفة المعتنين الرئيسيّن ومواقفهم وإعتقاداتهم تجاه العناية التلطيفية للأطفال المصابين بالسرطان

الباحثة الرئيسية: الدكتورة سمر نور الدين
الباحثة المشاركة: الدكتورة هدى أبو سعد هاير- ريما سعد

مرحبا. إسمي ريما سعد. أنا طالبة دكتوراه أعمل مع الدكتورة هدى أبو سعد هاير والدكتورة سمر نور الدين في كلية الحريري للتمريض في الجامعة الأمريكية في بيروت. أود أن أدعوكم للمشاركة في دراسة بحثية حول نظرة الأهل بخصوص الرعاية التلطيفية للأطفال المصابين بالسرطان. الغرض من الدراسة هو فحص معرفة المعتنين الرئيسيّن ومواقفهم وإعتقاداتهم تجاه الرعاية التلطيفية من أجل الكشف عن مجالات التحسين. **أنت واحد من 110 مشاركًا تم استقطابهم من خلال التواصل المباشر مع الباحث أو عضو من الفريق المعالج ، أو من خلال أو نشرات موزعة في مركز العلاج أو من خلال استطلاع إلكتروني.**

قبل أن نبدأ ، أود أن أخذ بضع دقائق لشرح سبب دعوتي للمشاركة وما الذي سيجري بالمعلومات التي تقدمها. سيُطلب منك المشاركة في مقابلة عبر مكالمة فيديو واتساب. ستطرح عليك أسئلة حول معلومات عنك ، وطفلك ، وسرطان طفلك ، وآرائك حول الرعاية التلطيفية للأطفال المصابين بالسرطان. من فضلك أوقفني في أي وقت إذا كانت لديك أسئلة حول الدراسة.

أقوم بهذه الدراسة كجزء من أطروحة الدكتوراه في الجامعة الأميركية في بيروت. سأجري مقابلات مع 110 من المعتنين الرئيسيّن بأطفال مصابين بالسرطان من ثلاثة مراكز رئيسية لعلاج أورام الأطفال في لبنان. إذا وافقت على المشاركة ، فسوف أطرح عليك قائمة الأسئلة في الاستبيان وسأكتب إجاباتك على الأسئلة الموجودة في النسخة الإلكترونية من الاستبيان.

سأستخدم المعلومات في دراسة أطروحتي. ممكن أيضًا أن أستخدام هذه المعلومات في المقالات التي قد يتم نشرها ، وكذلك في المحاضرات الأكاديمية. سيتم الحفاظ على خصوصيتك الفردية وسرية المعلومات التي تقدمها في جميع البيانات المنشورة والمكتوبة الناتجة عن الدراسة. ستتم مراقبة البيانات وقد يتم تدقيقها من قبل مجلس مراجعة العلوم الاجتماعية والسلوكية مع ضمان السرية. سوف أطلب منك التواجد في غرفة خاصة أثناء المقابلة. سيتم إدخال إجابتك مباشرة على النسخة الإلكترونية من الأسئلة. لن يتم كتابة اسمك أو أي معلومات تعريفية أخرى على قائمة الأسئلة. سأخصص رمزًا فريدًا لكل استبيان مكتمل . لذلك ستكون مشاركتك مجهولة بالكامل. سيتم عرض النتائج في شكل مجموعة. سيتم تخزين النسخة الإلكترونية من الاستبيان المكتمل في جهاز كمبيوتر محمي بكلمة مرور، في جهاز الكمبيوتر المحمول الشخصي الخاص بي وفي مكتبي الخاص في مدرسة الحريري للتمريض في الجامعة الأمريكية في بيروت شارع القاهرة ، بيروت ، لبنان. سأكون الباحث الوحيد الذي سيتمكن من الوصول إلى المعلومات. سيتم الاحتفاظ بجميع المعلومات التي تم جمعها للدراسة لمدة ثلاث سنوات ثم يتم إتلافها.

تستغرق مشاركتك حوالي 45-60 دقيقة. إنّ مشاركتك طوعيّة تمامًا ولديك الحق في سحب موافقتك أو التوقف عن المشاركة في أي وقت دون عواقب. لن يؤدي رفض المشاركة أو الانسحاب من الدراسة إلى خسارة الفوائد التي يحق للمشارك الحصول عليها ولن يؤثر على علاقة المريض ومقدم الرعاية بمركز العلاج ولا مع الطبيب المعالج أو جودة الرعاية التي يتلقونها. لا تحمل الدراسة أكثر من المخاطر المرتبطة بالحياة اليومية. هناك احتمال أن تختبر بعض المشاعر السلبية عند مشاركة تجربتك مع رعاية طفلك. يمكنك أخذ استراحة أو إيقاف المقابلة في أي وقت حسب الحاجة. . إذا عبّرت لفظياً عن الشعور بالقلق والضيق ، فسوف يذكرك الباحث بتوفر الدعم النفسي من فريق علاج الطفل دون تكلفة إضافية. الخطر الرئيسي الآخر هو احتمال فقدان السرية عن غير قصد. سأكون الشخص الوحيد الحاضر في المقابلة وسأستخدم سماعة الأذن الخاصة بي للحفاظ على سرية المعلومات التي تشاركها. لا توجد فوائد مباشرة لك للمشاركة في هذه الدراسة. ومع ذلك ، فإن مشاركتك هي مكان للتعبير عن وجهات نظرك حول رعاية طفلك. في الوقت نفسه ، قد تساعدنا الدراسة على فهم نظرتك للرعاية التلطيفية للأطفال المصابين بالسرطان في لبنان. ستساعد المعلومات التي تقدمها في تصميم خطط لتحسين رعاية الأطفال والأسر الذين يعانون من ظروف مشابهة لظروفك. ستتلقى رسالة شكر كعربون تقدير لمشاركتك وستدخل في سحب
على واحدة من أربع جوائز نقدية كل منها بقيمة 150000 ليرة لبنانية. سأتصل بك إذا كنت الفائز. سوف أرسل نسخة من وثيقة الموافقة هذه لك عبر الواتساب.

إذا كنت تفضل في أي وقت ولأي سبب عدم الإجابة على أي أسئلة ، فلا تتردد في تخطي هذه الأسئلة بمجرد قول "تخطي هذا السؤال". إذا كنت ترغب في أي وقت في التوقف عن المشاركة ، من فضلك قل لي. يمكننا أخذ استراحة والتوقف والاستمرار في موعد لاحق أو التوقف تمامًا. لا توجد أية عواقب على قرار إيقاف المشاركة في أي وقت.

إذا كان لديك أي أسئلة ، يمكنك طرحها الآن. إذا كانت لديك أسئلة لاحقًا ، فيمكنك الاتصال بي على رقم هاتف ريما سعد:
03-998548 أو إرسال بريد إلكتروني إلى:
"rms57@mail.aub.edu"
إذا كانت لديك أسئلة حول حقوقك كمشارك في هذا البحث ، فيمكنك الاتصال بمجلس مراجعة العلوم الاجتماعية والسلوكية في الجامعة الأمريكية في بيروت هاتف: 01-350000 ، تحويلة: 5455/5444 ، بريد إلكتروني:
irb@aub.edu.lb

هل أنت مهتم بالمشاركة في هذه الدراسة؟

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