

Components and Principles of a Pediatric Palliative Care Consultation: Results of a Delphi Study

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Abstract

Background: Pediatric palliative care is a distinct specialty that requires input from pediatric and palliative medicine specialists to provide comprehensive high-quality care. Consultations undertaken early in a child's illness trajectory, when end-of-life care is not anticipated to be required, enables relationships to be established and may enhance the quality of care provided.

Objective: To define optimal components of an early pediatric palliative care consultation.

Design: Consensus of an expert group was sought in a five-round Delphi study.

Setting/Participants: Based on the literature and existing standards for specialist palliative care, components of an early pediatric palliative care consultation were derived. In rounds 2 and 3, experts from around Australia participated in online surveys to review and prioritize the components and principles. Consensus of survey items was determined by defined criteria. A flowchart was developed in the fourth round and the final round involved review and refinement of the flowchart by the expert group.

Results: Nineteen experts participated and prioritized 34 components and principles in the first survey round, and 36 statements in the second survey round. There was consensus from all participants that the first priority of a consultation was to establish rapport with the family, and examples of how to achieve this were defined. Other components of a consultation included: establishing the family's understanding of palliative care; symptom management; an emergency plan; discussion of choices for location of care, and a management plan. Components considered suitable to defer to later consultations, or appropriate to address if initiated by family members, included: spiritual or religious issues; discussion around resuscitation and life-sustaining therapies; end-of-life care; and the dying process.

Conclusion: We have provided the first published framework from expert consensus that defines the components and principles of an early pediatric palliative care consultation. This framework will provide guidance for clinical practice as well as being useful for education and research in this area.

Introduction

IN PEDIATRICS, palliative care was only formally recognized as a subspecialty in the United Kingdom in 2009.¹ Within Australia, the emergence of the specialty can be traced back to the formation of an Australian and New Zealand National Pediatric Palliative Care Reference Group formed in 2005. This multidisciplinary group has brought together services and the two pediatric hospices within Australia to meet

regularly and to share resources and innovative ideas for services. In 2014, the Royal Australasian College of Physicians (RACP) ratified a formal training pathway for pediatricians specializing in palliative medicine.²

Pediatric palliative care is by its nature, a life-affirming concept of care that has evolved to meet gaps in the care of seriously ill and dying children.³ From its outset, pediatric palliative care has shared the same philosophy of care as the adult specialty, while at the same time developing its own distinctive model. For

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example, in contrast to adult-based services that are dominated by cancer,⁴ many pediatric palliative care services care for more nonmalignant life-limiting conditions. The broad spectrum of diseases seen, often with long trajectories, means most consultations undertaken in pediatric palliative care occur early in the child's illness, not when the child is imminently dying.⁵ Furthermore, parental desire for resuscitation does not preclude involvement of a pediatric palliative care service in the care of a child with a life-threatening condition.⁶ Indeed, palliative care can also be delivered alongside curative or treatment-orientated care. These differences need to be acknowledged and inform the care provided to dying children and their families.

It is well-recognized that families caring for a child with a life-limiting illness face intense challenges, extreme suffering, and tremendous grief.⁷ As most health professionals are not experienced with the conditions and palliative care needs of a child, the patient's primary specialist team often leads care, with a pediatric palliative care service providing a supportive layer for primary and community based services or for other hospital-based teams.

Compared to the adult population, there are fewer children who require palliative care. In Australia, for every 60 adult deaths, there is just 1 death of a child.⁸ However, with advances in supportive care, the prevalence of children living with life-limiting conditions is rising. There are an estimated 32 per 10,000 children aged 0–18 years who live with a life-limiting illness; these children may also benefit from a palliative approach to their care.^{9,10} The population of children and families requiring care is therefore incrementally growing and there is a need for careful planning and management of these children, particularly in relation to how they are transitioned to adult-based services.

Assessing Clinical Consultations

Similar to findings in adult palliative care studies, involving a specialist palliative care team in the care of a child with a life-limiting condition has improved outcomes including: optimal symptom management, supporting choices in location of care, achieving goals, and minimizing regrets.^{5,11–13} These outcomes are generally achieved over time through multiple consultations between the palliative care team and the family. As a developing specialty, there is still much to be documented regarding the nature of clinical encounters in pediatric palliative care, including what occurs during a consultation. It is therefore important to understand the nature of these clinical encounters to help define the practice of pediatric palliative care.

A medical consultation has a well-established and practiced structure: history taking, physical examination, review of diagnostics, delivery of diagnosis, and initiation of treatment.¹⁴ A palliative care consultation may differ. In 2010, Temel and colleagues¹⁵ undertook a widely cited study that found that early referral to palliative care improved patient outcomes. As part of this study they identified the components of an early palliative care consultation for adult patients with lung cancer.¹⁶

The aim of this study was to define the components and principles of an early pediatric palliative care consultation (i.e., not end of life). The study was restricted to early palliative care consultations as it is acknowledged that care required at end of life is highly individual and varied.

Methods

The Delphi study method was used to obtain consensus of a group of expert clinicians. The Delphi method enables an expert opinion to be obtained, without having to physically bring together the group of experts.¹⁷ For reporting the research undertaken during this study, the COREQ guidelines for reporting qualitative research were followed.¹⁸ The study was approved by the local Human Research Ethics Committee (reference number HREC/13/QRCH/52).

The process involved rounds of online surveys, and the subsequent development and review of a framework to define the components and principles in an early pediatric palliative care consultation. The survey rounds were anonymous, included iteration to allow for change of opinion, and controlled feedback.¹⁹ Equal weighting was given to responses from all participants. Figure 1 outlines the process used for this phase of the study.

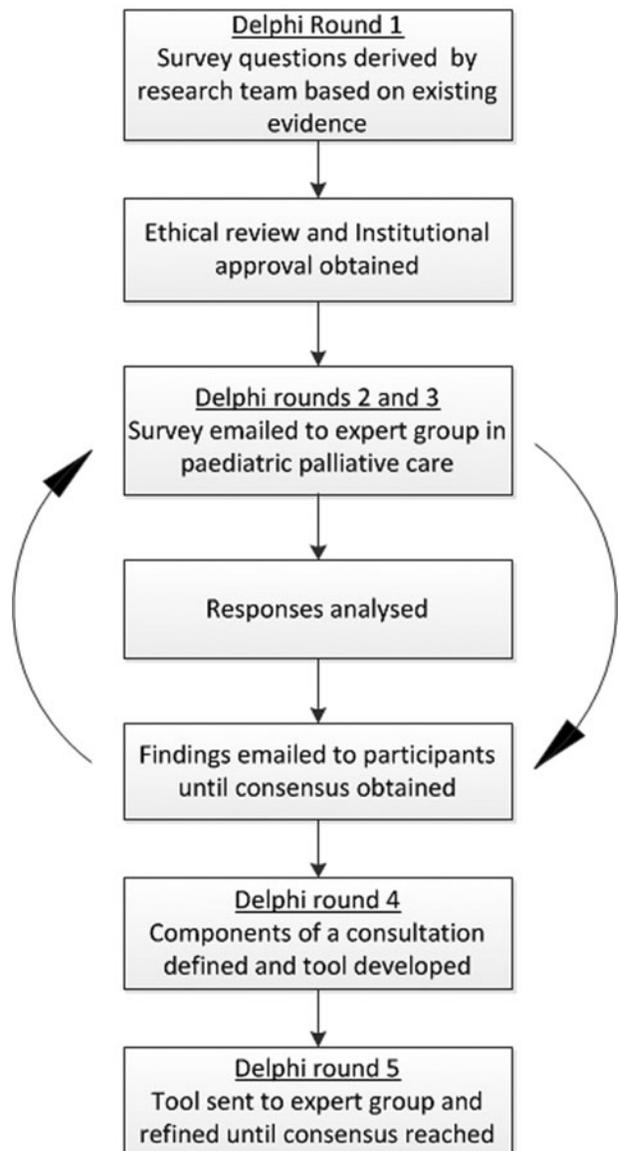


FIG. 1. Process of Delphi rounds.

Delphi round 1: Drafting of components and principles

In the first unstructured round, a core group of three experts (the authors N.B., A.H., and C.M.) derived a set of 34 possible components of a palliative care consultation from the literature including Palliative Care Australia's "Standards for providing quality palliative care for all Australians",²⁰ (which are accepted nationally as standards that enhance the quality of care for patients and their caregivers, including children),²¹ and the Core Competencies for End of Life Care developed by the United Kingdom Department of Health.²² Additional components were included based on clinical experience. Components were categorized based on patient condition, management of the patient and family, psychosocial aspects of care, and other palliative care principles such as the overarching values and knowledge required.

Delphi round 2 and 3: Evaluation of components and principles by an expert group with online survey

Recruitment and sample. Individuals who were members of the Australian and New Zealand Pediatric Palliative Care Reference Group ($n=20$) were invited to participate in the subsequent rounds. There are 8 pediatric palliative care services and 2 pediatric hospices located in Australia and New Zealand and the group comprises two interdisciplinary representatives from each of these 10 services. Most states and territories within Australia and New Zealand are represented in the group, which serves as a reference group for issues relating to palliative care for children. As well as members of this group, other expert nursing, medical and allied health professionals working with pediatric palliative care services were identified by the study author (A.H.) and invited to participate ($n=12$). Most of the experts approached to participate were physicians who had completed training specific to pediatric palliative care and who were currently working in pediatric tertiary hospitals providing palliative care. Other participants were nursing and allied health staff who worked in pediatric palliative care teams in tertiary hospitals. All experts had an extensive range of clinical experience with both with nonmalignant as well as malignant life-limiting conditions.

All correspondence occurred via e-mail. Approximately 2 weeks prior to the survey being distributed, an e-mail was sent to all potential participants providing the objectives of the study and inviting them to participate. An option to decline participation was included, and any participant who actively declined using this process was removed from future correspondence. Selection criteria required participants to be health professionals who provided clinical palliative care to pediatric patients and their families, with relevant knowledge and experience, and a willingness to participate.

The surveys. Delphi rounds 2 and 3 consisted of two surveys. The surveys were distributed via secure electronic survey and all participant responses were anonymous. Responses were analyzed, and findings collated and summarized before being disseminated to participants for verification.

In the first survey, participants were asked to rank each possible component on a 10-point scale, where 0=not important and 10=very important, for their importance in an

early pediatric palliative care consultation. There was also an option to answer with "no judgment." Scores were categorized into three groups: highly important components were those rated 9–10, components rated 7–8 were deemed moderately important, and those rated 6 or less were deemed to be less important. Percentage frequencies for each group were calculated. The survey included free text options for participants to suggest components not included in the survey that they considered relevant, or to provide explanations of responses. Participant demographic information including discipline and training in pediatric palliative care was also collected.

The second survey included components from the first survey, with the addition of newly nominated items. Participants were asked to agree or disagree with statements, which were both positively and negatively formulated, using a five-point Likert scale, effectively re-ranking components from strongly disagree (1) to strongly agree (5), with the option to include comments if desired. Very high agreement was defined as a mean score of more than 4.5, standard deviation (SD) <0.5. Moderate agreement was defined as a median score of 4–4.5, SD <1.0. Components where median scores were less than 4 were considered to be less important and discarded. Free text options were included for participants to suggest further components or principles. Each survey round was open for 3 weeks and one email reminder was sent to participants.

The fourth Delphi round involved the study authors comparing the results of the survey rounds and developing a framework to summarize the findings.

The fifth and final Delphi round involved presenting the resulting framework back to the whole reference group ($n=32$) for comments and revisions. This process of communication with participants continued until no further comments or recommendations were suggested and consensus on the framework was deemed to have been achieved.

Results

Round 2 and 3 participants

There were 19 respondents to the surveys in both Delphi round 2 and 3 (59% participation rate). Demographic details of participants are presented in Table 1. In Table 2 the results from survey 1 (of round 2) are reported as the percentage frequency for each component in groups, rated 9–10 (very important), 7–8 (important) and 6 or less (not as important). Components are ranked from most important to least important.

TABLE 1. DEMOGRAPHICS OF PARTICIPANTS ($N=19$)

| <i>Demographics</i> | <i>n (%)</i> |
|--|--------------|
| Discipline | |
| Medical physician | 9 (47%) |
| Nursing | 8 (42%) |
| Allied health | 2 (11%) |
| Gender | |
| Male | 6 (30%) |
| Female | 13 (70%) |
| Undertaken training in pediatric palliative care | |
| Yes | 19 (100%) |
| No | – |

TABLE 2. RESULTS FROM DELPHI ROUND 2 SURVEY ONE: RANK OF IMPORTANCE OF DISCUSSION OF VARIOUS POSSIBLE COMPONENTS IN AN EARLY PEDIATRIC PALLIATIVE CARE CONSULTATION (N=19)

| Rank | Component | % Rated 9–10 | % Rated 7–8 | % Rated <6 |
|------|---|-----------------|----------------|---------------|
| 1 | Establishing rapport with the family | 19 (100%) | — | — |
| 2 | The use of sensitive compassionate language | 19 (100%) | — | — |
| 3 | Establishing the parent/caregiver understanding of the illness | 18 (95%) | 1 (5%) | — |
| 4 | An explanation of what palliative care is | 18 (95%) | 1 (5%) | — |
| 5 | Psychosocial concerns of the child | 17 (90%) | 2 (10%) | — |
| 6 | Discussion of the child's current symptoms | 17 (90%) | 2 (10%) | — |
| 7 | Family coping | 16 (84%) | 3 (16%) | — |
| 8 | Establishing or clarifying goals of care | 16 (84%) | 3 (16%) | — |
| 9 | The well-being of the parent/caregiver | 15 (79%) | 4 (21%) | — |
| 10 | A management plan | 15 (70%) | 3 (16%) | 1 (5%) |
| 11 | Providing written information to parents/caregiver (e.g., pamphlets regarding services, resources) | 14 (74%) | 5 (26%) | — |
| 12 | Communication of information to other involved health care providers | 14 (74%) | 5 (26%) | — |
| 13 | How care is coordinated between providers | 14 (74%) | 4 (21%) | 1 (5%) |
| 14 | Preferred location of care | 13 (69%) | 4 (21%) | 2 (10%) |
| 15 | Child's development including school or play | 13 (69%) | 4 (21%) | 2 (10%) |
| 16 | Discussion of practical aspects (finances, equipment) | 12 (63%) | 6 (32%) | 1 (5%) |
| 17 | Review of current medications | 12 (63%) | 5 (26%) | 2 (11%) |
| 18 | The well-being of other family members (siblings, grandparents) | 11 (58%) | 8 (42%) | — |
| 19 | Spirituality or religious beliefs | 11 (58%) | 7 (38%) | 1 (4%) |
| 20 | Co-ordinating care across different settings | 11 (58%) | 7 (38%) | 1 (4%) |
| 21 | Care planning | 11 (58%) | 7 (37%) | 1 (5%) |
| 22 | Decision making regarding treatment options | 11 (58%) | 6 (32%) | 2 (10%) |
| 23 | An emergency plan | 11 (58%) | 6 (32%) | 2 (10%) |
| 24 | Discussion of anticipated symptoms | 11 (58%) | 5 (26%) | 3 (16%) |
| 25 | Undertaking a separate consultation with the patient alone, when the patient is an adolescent | 11 (58%) | 4 (21%) | 4 (21%) |
| 26 | Anticipated changes in the patient's condition | 9 (47%) | 7 (37%) | 3 (16%) |
| 27 | The presence of the child during the consultation | 6 (32%) | 10 (51%) | 3 (16%) |
| 28 | A physical examination of the patient | 6 (32%) | 6 (31%) | 7 (37%) |
| 29 | Resuscitation and provision of life sustaining measures | 4 (22%) | 10 (51%) | 5 (28%) |
| 30 | Advance directives | 3 (16%) | 12 (63%) | 4 (21%) |
| 31 | Referral to other health care providers | 2 (10%) | 14 (74%) | 3 (16%) |
| 32 | End-of-life care | 2 (10%) | 11 (57%) | 6 (33%) |
| 33 | Spiritual or religious beliefs specifically about death | 2 (10%) | 7 (38%) | 10 (52%) |
| 34 | The dying process | — | 5 (28%) | 14 (72%) |

10=very important; 1=not at all important.

Priorities in a pediatric palliative care consultation

Participants were asked their opinion regarding the optimal time for referral to pediatric palliative care; the majority of participants answered that referral at the time of, or soon after diagnosis, was preferable (Fig. 2). Other responses included "all of the above" and "no one time is optimal," but preference was soon after diagnosis. Participants also provided suggestions and comments that were incorporated into the second survey round such as the importance of memory making, discussions of fears, and establishing the goals and expectation of the referring team.

Delphi round 3: Survey 2

Participants scores from survey 2 are presented as mean values, higher values (up to 5) represent higher levels of consensus of agreement with the statements in Table 3.

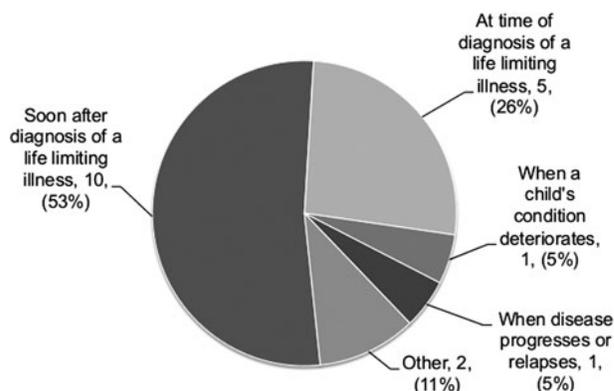


FIG. 2. Optimal time for referral.

TABLE 3. RESULTS FROM DELPHI ROUND 3, SURVEY 2: RANK OF AGREEMENT WITH STATEMENT

| <i>Statement</i> | <i>Mean score (SD)</i> |
|--|------------------------|
| It is important to judge what discussions need to occur urgently and what can wait | 5.00 (0.00) |
| Sensitive compassionate language should always be used during palliative care consultations | 4.95 (0.23) |
| A priority in early consultations is to establish rapport with the family | 4.84 (0.37) |
| It is important to establish the families understanding of palliative care | 4.63 (0.50) |
| It is important to establish or clarify the goals of care | 4.53 (0.61) |
| It is important to discuss how the family is coping | 4.37 (0.76) |
| Discussions should be directed by the family | 4.26 (0.93) |
| The focus of the consultation should be centred around the child's current issues including symptoms and psychosocial needs | 4.05 (0.78) |
| Discussion points the consultation should include: | |
| Establishing what is most important to the child and family | 4.89 (0.31) |
| The child as a person | 4.74 (0.45) |
| The caregiver and child's understanding of the illness | 4.63 (0.60) |
| Discussion of hopes and worries | 4.63 (0.60) |
| Quality of life | 4.37 (0.83) |
| Fears the child or family may have of pain and suffering | 4.37 (0.60) |
| Discussion of family strengths | 4.21 (0.54) |
| Meaning | 4.00 (0.75) |
| Memory making | 3.58 (0.84) |
| Other important components in a consultation should include: | |
| The coordination and communication of care between health care providers | 4.42 (0.60) |
| The well-being of the caregiver/parent | 4.47 (0.51) |
| A management plan for the child | 4.37 (0.60) |
| Providing written information or additional resources to families | 4.00 (0.33) |
| The following components are important, but do not need to be discussed at every consultation: | |
| Spiritual or religious beliefs | 4.21 (0.45) |
| Child's development | 4.16 (0.37) |
| Decisions regarding treatment | 4.00 (0.88) |
| An emergency plan | 4.00 (0.88) |
| Anticipated symptoms | 3.95 (0.78) |
| Care planning | 3.44 (1.48) |
| The well-being of other family members | 3.21 (1.23) |
| Review of medication | 3.16 (1.42) |
| Discussion of the following components are NOT important in an early consultation when the child is not near the end of life: | |
| Resuscitation and life-sustaining measures | 3.84 (1.07) |
| The dying process | 3.84 (1.07) |
| Advance directives | 3.74 (1.20) |
| Spiritual or religious beliefs about death | 3.56 (1.46) |
| End-of-life care | 3.53 (1.21) |
| It is not necessary for a physical exam to be performed, or the child to be present at every consultation | 3.89 (0.66) |
| Discussing preferred location of care is only important if the child is approaching end of life or the family needs respite | 2.79 (1.13) |

5 = strongly agree; 1 = strongly disagree.
SD, standard deviation.

Final rounds

A framework was developed and presented back to the original Delphi round 2 expert group ($n = 32$). Following their review and suggestions the final framework included items that were discarded in previous rounds. The framework is presented in Figure 3.

Discussion

In this study the primary aim was to understand the nature of clinical encounters and to define components or principles

of practice that are desirable in an early pediatric palliative care consultation. The Delphi method was successfully used to achieve this aim. The expert panel agreed that the resulting flowchart was an accurate reflection of the principles considered desirable in an early consultation. Consensus was based on greater than 80% of participants agreeing or strongly agreeing with statements; a Delphi study in pediatric palliative care that identified research priorities in this field used a cutoff of 66%.²³

Accurately defining clinical practice has the potential to improve quality of care by standardizing practice, and is

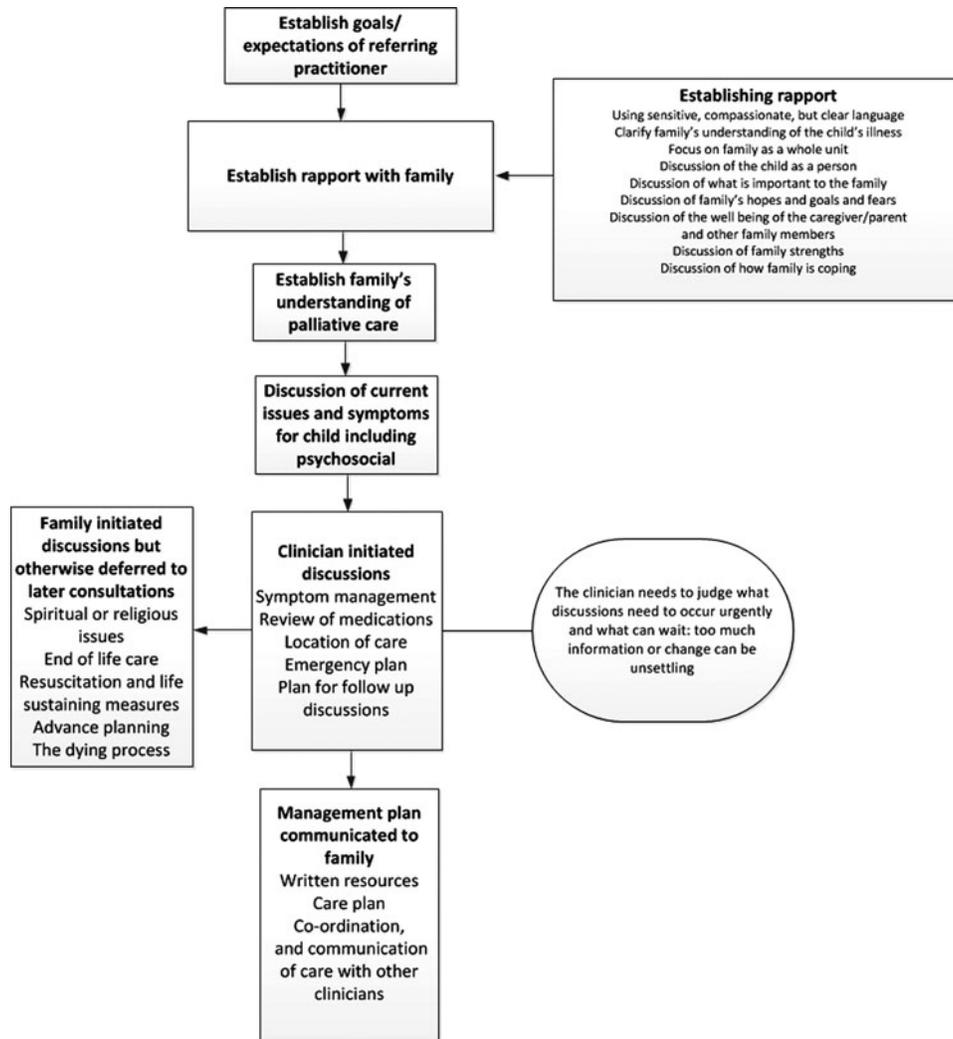


FIG. 3. Framework for components and principles of an early pediatric palliative care consultation.

useful for future research and for educating other clinicians.¹⁶ Understanding what differentiates a pediatric palliative care consultation from other health care consultations may offer improved understanding of the nature of these consultations, and the goals of palliative care, for both health care professionals and families. The flowchart has potential to be a valuable tool for health professionals, providing clarity around the goals and expectations of a consultation from the health professional perspective.

The framework may also provide a guide for documentation of clinical consultations. Poor documentation can compromise the safe delivery of quality health care; regardless of whether the failure to document is a result of the discussion not having been undertaken, or a failure to record discussions. Without accurate documentation one cannot know what has been addressed and what has not, and subsequently if interventions are consistent with family goals of care.²⁴

Inadequate documentation has been recognized as a systemic problem in palliative care with recommendations suggested by van Gunten and Weissman²⁵ for appropriate documentation. Following an established protocol for documentation may make it easier to clarify what the expectations are from referring clinicians and also what interventions have

been implemented. Documentation for consultations could include components as identified by the expert group and outlined in Figure 3:

- Reason for consultation;
- Summary/past history including family and social factors;
- Family understanding of referral and palliative care;
- Assessment of current symptoms and issues;
- Recommendations for management (medication, locations of care emergency plan, etc.), and
- Management/follow-up plan

The framework may also be useful to identify areas in curricula (such as the RACP Advanced Training Palliative Care Curriculum)² for education, or for the refinement of quality indicators in the field.

Strengths and limitations

The principles for early pediatric palliative care developed in this study were based on a national consensus of experts and to our knowledge this is the first framework to be published. This framework can be used for promoting best

practice in the provision of care for children and their families facing a life-limiting illness during the early engagement process with palliative care services. Such a framework is also useful for guiding care for all teams providing palliative care, irrespective of their location in a tertiary referral facility or a regional and remote setting with a primary care team.

There are several limitations associated with this study. First, the response rate for the survey was 59%; a response rate of over 70% is generally considered optimal for studies involving surveys.²⁶ However, the flowchart was based on the opinion of 19 experts in the field, and respondents of between 15–20 experts is considered appropriate in a Delphi study.²⁷ Additionally, all 32 experts had the opportunity to review the flowchart.

Second, there is no accepted benchmark within the published research literature to define an acceptable level of consensus. This was addressed by setting the criteria for consensus higher than other studies with a comparable purpose.^{28,29}

Third only experts from Australia and New Zealand participated in this study. It would also be worthwhile to gain the perspectives of palliative medicine specialists (who primarily care for adult patients), other pediatric specialists (nursing, medical and allied health), community services (community nursing, general practitioners) and parents themselves.

Finally, it is acknowledged that a consensus building Delphi process is subject to researcher bias; there was no formal debate between experts, and the questionnaires were developed by the research group, however there was an opportunity for participants to suggest additional items of importance through the Delphi processes.

Conclusion

Families who are caring for a child with a life-limiting condition face enormous challenges, experience extreme suffering and grief, and require the highest possible quality of care. The way this care is provided can actually assist families in their grieving process. It is important therefore to understand how this care is provided, including the components and philosophies of care that make up a medical consultation. Using the Delphi methodology, surveys with experts in pediatric palliative care were used to define these aspects of a consultation and a flowchart was developed. This flowchart offers a useful framework in the provision of evidence-based early palliative care for families and their children with a life-limiting illness. This tool may also have utility in the education of health professionals and further research in pediatric palliative care.

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All authors reviewed and approved the final manuscript and contributed to this study as follows: N.B. designed and undertook the study, analyzed data, drafted the manuscript, and participated in the design and refinement of the flowchart.

A.H. and C.M. participated in the design of the surveys, refinement of the flowchart, and revisions of the manuscript. N.A. analyzed data and contributed to the revisions of the manuscript. J.Y. contributed to the interpretation of the data, refined the flowchart and critically revised the manuscript. A.S. contributed to study design and critically revised and edited the manuscript.

Author Disclosure Statement

No competing financial interests exist.

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