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Palliative Care as a Standard of Care in Pediatric Oncology

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The study team conducted a systematic review of pediatric and adolescent palliative cancer care literature from 1995 to 2015 using four databases to inform development of a palliative care psychosocial standard. A total of 209 papers were reviewed with inclusion of 73 papers for final synthesis. Revealed topics of urgent consideration include the following: symptom assessment and intervention, direct patient report, effective communication, and shared decision-making. Standardization of palliative care assessments and interventions in pediatric oncology has the potential to foster improved quality of care across the cancer trajectory for children and adolescents with cancer and their family members. Pediatr Blood Cancer 2015;62:S829–S833. © 2015 Wiley Periodicals, Inc.

Key words: communication; family-centered care; palliative care; psychosocial support; quality of life

INTRODUCTION

The World Health Organization defines palliative care as a comprehensive care approach which "improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual."[1] A standard of early integration of palliative care for children and adolescents with cancer translates into whole-person, whole-family support regardless of anticipated disease trajectory.[2] The early integration of palliative care as a standard across sites and settings provides meaningful opportunity to care for not only the physical domains impacted by cancer, but to also attend to the full impact of illness on the patient's psychological, developmental, and spiritual wellness within the social context of each patient's family and community. The American Academy of Pediatrics advocates for an integrated, interdisciplinary approach to competent and compassionate care: "in which the components of palliative care are offered at diagnosis and continued throughout the course of illness, whether the outcome ends in cure or death."[3] The Worldwide Palliative Care Alliance recognizes the importance of integrating palliative care as a human right for children even in resource-limited health system settings,[4] requiring global collaboration for a resource-effective, evidence-based approach to best practice standards for early integration of palliative care for children and their families.

A review of the literature suggests that palliative care for pediatric cancer patients and their families varies across settings and resources and has only recently included access to services similar to those offered to adult cancer patients.[5] Empirical research for children and adolescents diagnosed with cancer reveals significant symptom and psychosocial suffering. Specifically, communication between the medical team and the patient and family; ongoing assessment of patient and family needs; developmentally informed interventions; and tangible support during times of inpatient and home care transition are target areas in which comprehensive care could be improved through a standard of palliative care.[6,7] Empirical data have found the quality of life for pediatric cancer patients and their family members can be enhanced through the prevention and alleviation of child and family suffering via the practice of compassionate and honest communication, symptom alleviation, and the psychosocial attentiveness incorporated by quality palliative care services.[5,8] This review was performed to determine whether palliative care concepts should be introduced early in the course of the diagnosis and throughout the trajectory of care.

Psychosocial Standard of Care

- Youth with cancer and their families should be introduced to palliative care concepts to reduce suffering throughout the disease process regardless of disease status.
- When necessary, youth and families should receive developmentally appropriate end of life care (which includes bereavement care after the child's death).

METHODS

This review was performed as part of the collaborative Standards for Psychosocial Care of Children with Cancer and Their Families Workgroup. For a full description of the methods used to develop

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each standard refer to the introduction in this special issue.[9] The literature search for this paper utilized four databases: PubMed, Cochrane, PsycINFO, and SCOPUS (March 1, 1995 to March 1, 2015). Search terms included "palliative care" OR "palliative" OR "hospice" OR "end of life" OR "bereavement" AND "psychosocial" OR "communication" OR "support" OR "quality of life" AND malignancy-related terms AND "child" OR "adolescent" OR "young adult" OR "family" OR "sibling" (using indexed MeSH terms). Two medical librarians independently approved the search strategies. Due to the cancer-specific nature of this recommendation, palliative care studies including patients with non-malignant diagnoses were included only if data for the cancer population were specifically summarized. The last search was run on March 30, 2015. The reference lists of all included studies were hand-searched for additional studies. GRADE Guidelines framed the approach to this standard.[10]

The study team included geographically diverse representatives from the fields of oncology, palliative care and hospice, psychology, nursing, and social work. Expert opinion from members of the SIOP Pediatric Oncology in Developing Countries Palliative Care Working Group provided the reviewer team with additional global perspective. An external team of expert pediatric oncologists and child psychologists externally reviewed the recommendation prior to final draft. External review resulted in improved awareness of standard feasibility in resource-limited settings and inclusion of 14 additional papers with psychosocial emphasis.

RESULTS

Review of data from seven mixed method, seven qualitative, 21 quantitative, and four review method papers plus 32 editorials and two consensus reports support that children and adolescents with cancer and their family members should be introduced to palliative care concepts early in the course of the diagnosis and throughout the trajectory of care. Twenty-nine of the reviewed papers specifically called for early integration of palliative care starting at diagnosis. Members of the study team previously published a paper depicting the literature review strategy and methods using the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRIMSA) reporting guidelines.[6] Due to the expanded search dates used in the current paper, an updated PRISMA flow diagram was generated (Supplemental Figure 1).

Symptom Assessment and Intervention

Comprehensive palliative care includes assessing and intervening on behalf of patients' psychological and physical symptoms. Validated questionnaire studies of bereaved parents and chart reviews of patients suggest that children and adolescents with cancer experience complex psychosocial symptoms during cancer treatment with exponentiation of these symptoms at end of life; to include symptoms of anxiety,[11–13] depression,[11,13,14] distress, worry, sadness, fear of being alone, difficulty talking about feelings, loss of independence, and loss of perspective.[15] These psychosocial symptoms often increase in the setting of disease progression and are often untreated.[16] Pain is reported as a prevalent end of life symptom in children with cancer,[8,11,15,17] a symptom reported as significantly distressing for family members to observe.[18] Over one-third of 141 bereaved parents retrospectively reported that they would have considered hastening their child's death had the child been in uncontrollable pain.[19] Bereaved parental anxiety and quality of life scales have correlated with level of child anxiety and pain at end of life,[19–22] implying early integration of palliative care as a standard of care has potential to improve long-term family wellness outcomes.

Patient Perspectives

A systematic review of empirically based end of life publications in pediatrics found that of 26 publications, only four (15.4%) included patient-reported outcomes, six (23.1%) included parent only-reported outcomes, and five (19.2%) included staff only-reported outcomes.[23] Additional research is required to solicit and document patient reports of their unique experiences to ensure appropriate interventions and care from primary stakeholders.[24] Information regarding palliative care needs should be sought directly from children and adolescents to honor the patient voice while also incorporating perspectives of family members.[25]

Compassionate and Honest Communication

Children and adolescents with cancer may wish to talk about the meaning of being ill, particularly prognosis; and care team involvement in these conversations may be important for individual children[2] and parents.[26] Recognizing that children are often aware of their imminent death, none of the 147 parents who talked with their child about death regretted having these important conversations.[27] Chart reviews investigating physician–family communication about a child or adolescent's end of life or prognostic issues rarely documented the child or adolescent's presence during these important conversations.[12,28] Notably, adolescent cancer patients and survivors describe a need for honest and respectful communication in addition to the provision of psychosocial support.[29,30] Interviews with parents of children with cancer reveal that they perceive accurate, clear, and understandable communication as beneficial.[17,31,32] Cross-sectional surveys with bereaved parents confirm that parent perceptions of clear and compassionate communication are associated with excellent care and improved psychosocial outcomes.[17,33–35] These findings underscore the importance of ongoing supportive communication, particularly as disease progresses.

Decisional Preferences

A longitudinal, multi-institutional adult cohort study revealed that patients with cancer are more likely to receive end of life care that is consistent with their preferences when they have had the opportunity to discuss their wishes regarding end of life care with a clinician.[36] Likewise, family-centered advance care planning increased patients' wishes for families to make appropriate decisions as needed, improved patients' understanding about end of life options, increased likelihood of limiting futile treatment, and increased family's ability to honor wishes of their children.[37] Adolescents with cancer described age-appropriate advance care planning as acceptable, useful, and helpful.[38,39] Effective communication among all parties from the patient and parent to the comprehensive care team (social workers, psychologists, child life specialists, and clinicians) is crucial to successfully capture the child/adolescent's end of life preferences, including the practicalities of location of death.

Relatedly, families whose primary oncologist clearly explained treatment options during their child's end of life care and who involved home-care services were more likely to plan for child's location of death.[19] Perspectives of bereaved parents reveal a need for improved and cohesive care transitions, particularly in the form and feasibility of home care and respite support services knowledgeable on pediatric and adolescent psychosocial and symptom care needs.[17,40–42] Parents were more likely to decide against resuscitation for their child with incurable cancer if an end of life discussion with their inter-disciplinary medical team occurred prior to emergent situations,[13] when both parents and providers may experience intense and conflicting emotions. The opportunity to plan location of death is associated with high quality palliative care and may suggest that communication regarding planning rather than actual location of death may be a more relevant outcome.[19,43]

DISCUSSION

Perceived cost[15,44–51] and lack of sufficient time [33,37,47,51–53] are the most frequently cited barriers to introducing palliative care concepts, thus warranting consideration of reimbursement for palliative care conversations and services. Further barriers include limited access to established support services[43] or psychosocial professionals,[11,52] thus compelling advocacy for improved palliative care education for general health providers.[8,17,54–56] Additional barriers include provider discomfort with palliative care conversations,[2,19,23,38,57] or misconceptions regarding palliative care as only beneficial when treatment is no longer effective[32,58,59] both of which may benefit from clarity in palliative care guidelines.[60]

Early integration of palliative care as a standard approach for children and adolescents diagnosed with cancer carries meaningful opportunities to improve symptom control and quality of life for patients and their families. As a minimum, symptom burden assessment with subsequent intervention and effective communication must be prioritized, as these tenets are associated with improved psychosocial outcomes for pediatric cancer patients and their families. When resources avail, tangible support for transitions between care settings (whether hospital care, ambulatory care, or home care) should support the practical needs and available resources of patients and their families. Future research should

TABLE I. Palliative Care Standard Summary of Evidence Table

Standard	Evidence summary[a]	Methodology[b]	Quality of evidence[c]	Strength of recommendation[d]
Youth with cancer and their families should be introduced to palliative care concepts to reduce suffering throughout the disease process regardless of disease status When necessary youth and families should receive developmentally appropriate end of life care [which includes bereavement care after the child's death]	Uncontrolled symptoms continue to be problematic; well-integrated palliative care has potential to improve high quality care, including decreased physical and psychological symptom burden Family centered communication, to include prioritization of the patient's voice, is critical to reducing child and family suffering Developmentally Informed advanced care planning and decision-making interventions foster honoring patient and family preferences which results in improved long-term family outcomes Tangible support during times of care transition, such as respite or home care service transitions, improves perceived cohesiveness of care	Mixed-methods, qualitative, quantitative, and literature reviews Majority cross sectional retrospective survey and in-depth interviews Limited intervention trials Replication of findings evident	Moderate quality given consistent findings from lower level evidence studies. Few cost-effective studies have been conducted. Sibling and grandparent responses are currently under-recognized as part of the larger family unit	Strong recommendation given risk-benefit ratio including significant health impact on bereaved family members and positive outcomes with earlier integration of palliative care and end of life care

[a]Based on summary of evidence table for that standard; [b]Types of studies; [c]High, moderate, low, very low; [d]Strong or weak (based on GRADE quality criteria).[7]

integrate direct patient reported preferences and prospective, longitudinal, multi-institute investigations with attentiveness to reporting cost, staffing needs, and psychosocial outcomes.

CONCLUSION

Children and adolescents living with cancer and their families should receive early, integrated access to family-centered palliative care concepts (symptom assessment and intervention; direct patient report; effective communication; and shared decision-making) to minimize symptom burden, ease suffering, effectively manage pain, and provide preventative bereavement care. The target population for palliative care includes not only patients but also those individuals identified as formative in the child's social and relational spheres, whether siblings, parents or guardians, grandparents, or other extended relatives.[15,31,40,52,61]

Current evidence for this recommendation is of moderate quality given consistent findings from lower level evidence studies (Table I). This is an overall strong recommendation given risk-benefit ratio including significant health impact on bereaved family members and positive outcomes with earlier integration of palliative care and end of life care.[2,6,51] Youth and their families should be introduced to palliative care concepts to reduce suffering and enhance well-being throughout the disease process regardless of disease status. Ongoing psychosocial assessments and appropriate interventions pertaining to palliative and end of life care are essential components of quality care for youth with cancer and their family members.

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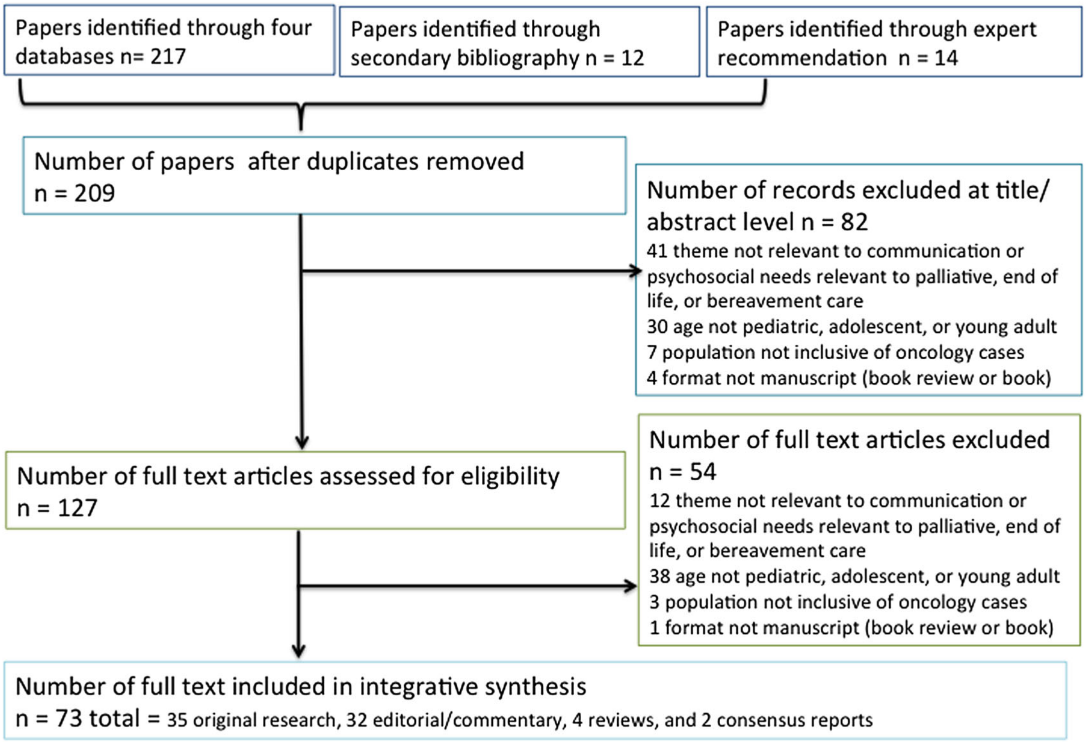

Supplemental Figure I. Preferred Reporting for systematic Reviews and Meta-Analyses (PRISMA) Flow Diagram.