

Featured AAP Section: Section on Hospice and Palliative Medicine

Integrating Palliative Care into the Ongoing Care of Children with Cancer

It Takes a Village and It Starts with the Primary Oncology Team

Justin N. Baker, MD, FAAP, FAAHPM

Chief, Division of Quality of Life and Palliative Care

Attending Physician, Quality of Life Service

Director, Hematology/Oncology Fellowship Program

Associate Member, Department of Oncology

St Jude Children's Research Hospital

Member, AAP Section on Hospice and Palliative Medicine

More than 12,000 children in the US will be diagnosed with cancer in 2015. Of these children, *2000* will die from their cancer or treatment-related issues. Two thousand is 2000 too many and we must continue to fight to find cures and save children because, as Danny Thomas once said, and we all believe, “No Child Should Die in the Dawn of Life.” Beyond these statistics, however, lies the terrible truth of why I wanted to write this piece – SUFFERING, and what to do about it. Suffering is a terrible word and a far worse condition. The amount of suffering that a patient and family must endure while pursuing cure is simply overwhelming, and too many times that pursuit still ends in increasing suffering and death. Suffering comes in many forms: pain and symptoms (some related to the treatments we inflict on these kiddos and their families in our pursuit of cure), social morbidity due to family disruption, psychological strain from having to contemplate issues of life and death at far too young an age (both the child/patient and their caregivers),

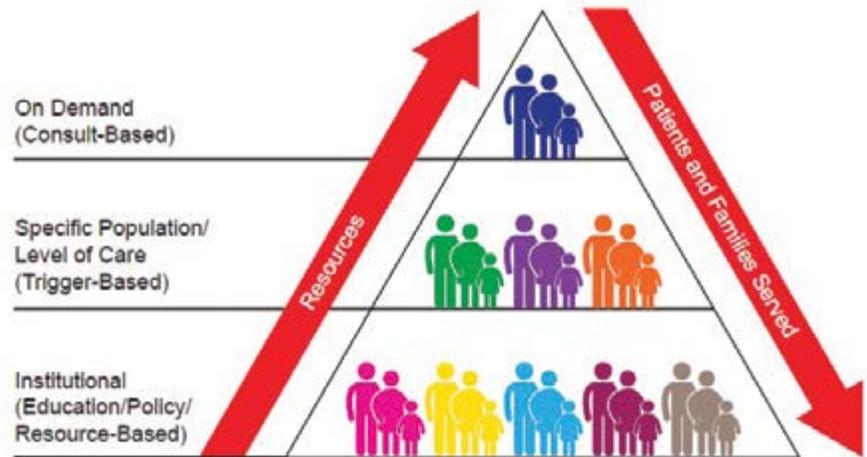
financial devastation, spiritual isolation/existential distress and, trying to maintain hope in the midst of tremendous uncertainty and innumerable other sources of suffering.

In a recent review by Waldman and Wolfe (PMID: 23337915), we were told that in treating children with cancer and their families, “palliative care is simply a novel term for the total care of a child and family, an approach that should be applied consistently and concurrently regardless of disease status.” I could not agree more! Integration of palliative care into the ongoing care of children with cancer must therefore be an urgent, upstream priority and it must start with the primary cancer team.

Integrating key pediatric palliative care (PPC) concepts can help address suffering and incorporate an emphasis on quality of life into the overall care plan from the point of diagnosis of cancer. Many oncology teams do this very well, but, it is a somewhat “silo”ed approach where the “medical team” deals with disease- and physical symptom-related issues while the “psycho-social team” deals with, well, everything else. Pediatric palliative care must be conceptualized as always being a part of the care paradigm, allowing for the transition to predominantly comfort care to occur gradually and intuitively, but also allowing for the integration of palliative care resources and expertise into the care plan at an earlier stage (preferably at the very beginning) of the illness trajectory. Indeed, by viewing palliative care as primarily oriented toward the quality of life experienced by the child and family from the start of the child’s illness, if there comes a point at which potentially curative therapy is no longer available, the continuation of attention to quality of life will not be a line ‘drawn in the sand’ between ‘curative care’ and ‘palliative care’ but will rather be a continued attention to the way the child experiences his or her day. Such a philosophy of care says to a child, ‘The first day you come to clinic with an illness we care about the quality of your life. If ever the disease progresses or relapses, we care about the quality of your life. And if the day comes when we have no more curative therapies for you, still we care about the quality of your life. This includes the last days of your life – always, we care about the quality of your life.’ Such an approach takes away the false sense that ‘palliative care’ is something new in a child’s experience. It is not.

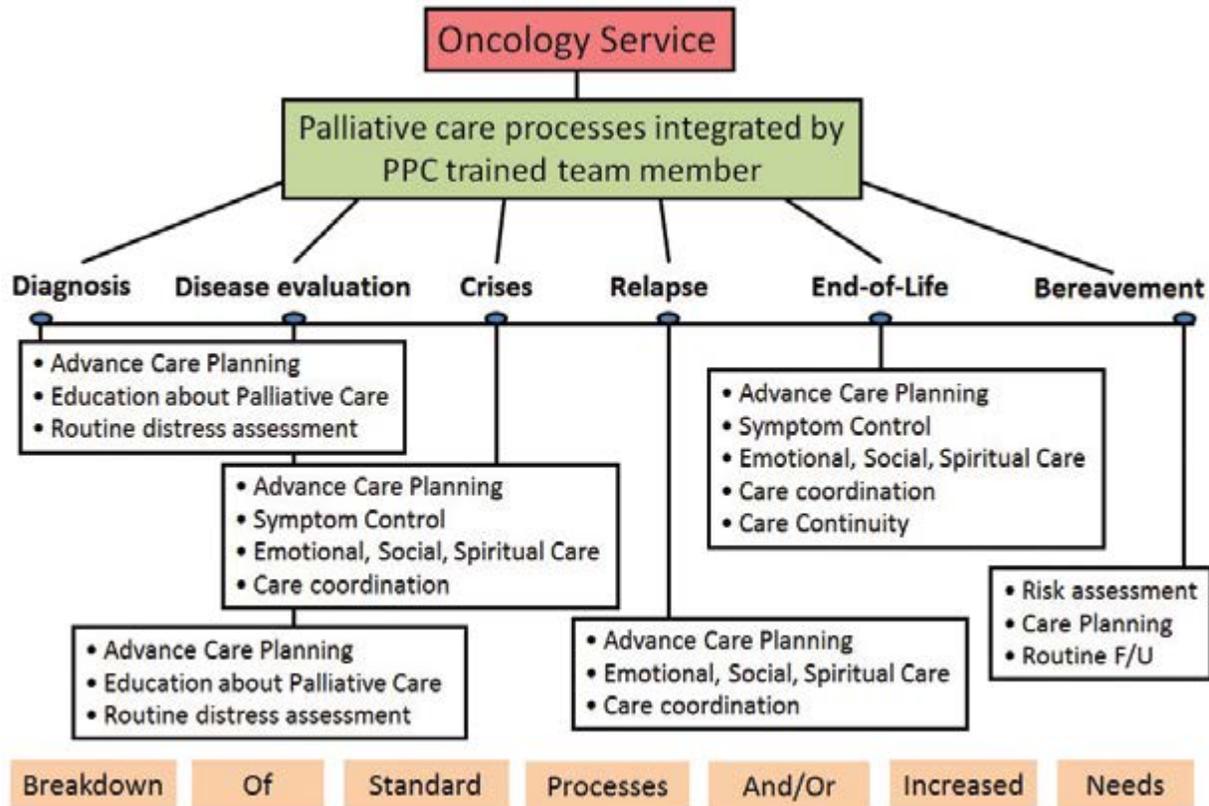
Figure 1 demonstrates that resources, education and policies need to be developed and implemented at the institutional level – for ALL children and their families. Practically speaking, at our institution this has led to the development of a policy requiring all clinical nursing staff to be trained and certified in a 2-day End-of-Life Nursing Education Consortium (ELNEC) course that our PPC team provides as well as another 8 CEU PPC course that we have developed. Many people have termed this a generalist approach toward PPC integration. Resources are obviously required in order to develop and implement these policies and educational endeavors. A robust, “face of PPC” consult team, must also be developed. This team must have exquisite consultant etiquette and a “yes”/“git er dun” approach toward partnering with the primary oncology team. A GREAT place to start is in simply asking the oncology team how the PPC team may best be of service to their patients and families as well as how they can help the primary team do their job more efficiently and effectively. The final point on integration that you may consider would be a “trigger-based” approach to integration of all or parts of the PPC team for specific “high-risk” populations. Ocenga and Friebert (through the Center to Advance Palliative Care – CAPC) have created a very helpful list of diseases to consider when creating a trigger-based intervention. You may choose to use this list or you may decide to develop a “trigger-based” approach that is more specifically tailored to meet the needs of your institution. Other ideas we have utilized include a home-based approach to palliative care assessment and intervention that is only accessible through our PPC team as well as an ICU-based point of trigger-based integration that is based on length of stay in the ICU rather than being risk or disease specific.

Figure 1.



In sum, integrating palliative care into the ongoing care of children with cancer takes a village, but it must start with the strong primary home – the oncology team. It is the careful, evidence-based, attentive response to supporting those things that make a child’s life good, a child’s days good, and a family’s experience meaningful. Articulated in this way, palliative care is something that should be welcome from the start, not a marker for the end of life. Such an approach allows clinicians to be present at all points of a child’s illness trajectory, including, in a non-threatening way, at the end of a child’s life. In order to optimize these points of integration, those of us in the PPC field must come alongside our oncology colleagues as we work hand-in-hand to address the horrific suffering of these children and their families.

Figure 2. A Model of Integrating PPC concepts into Pediatric Oncology*



Consider Consultation with Pediatric Palliative Care Team

*Modified from: [Levine D¹](#), [Lam CG²](#), [Cunningham MJ³](#), [Remke S⁴](#), [Chrastek J⁵](#), [Klick J⁶](#), [Macauley R⁷](#), [Baker JN¹](#). Best practices for pediatric palliative cancer care: a primer for clinical providers. [J Support Oncol](#). 2013 Sep;11(3):114-25