

# International Conference on Hospice & Palliative Care

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### Integrating pediatric palliative care into pediatric oncology

The trajectory of a pediatric palliative care program that has been integrated into a comprehensive cancer center is currently unknown. The purpose of this presentation is to document and assess the growth of the palliative care program over a five year time period and to examine key indicators reflecting improved quality of life for patients who have received care through the QoL Service at St. Jude Children's Research Hospital. A retrospective cohort study identified 457 patients seen at least once by the institutional palliative care service (Quality of Life Service) between January 2008 and December 2012. The number of new patient referrals to the QoL Service has steadily increased from 52 in 2008 to 127 in 2012. The average number of visits per patient by the QoL Service also increased from 5.9 in 2008 to 10.9 in 2012. The amount of time from initial consult to death has increased from 44 days in 2008 to 149 days in 2012. From 2008 to 2010, 33% of the Quality of Life Service new referrals had a primary goal of comfort and only 12% had a goal of cure. In 2011 and 2012, the percentage of new patients with a primary goal of comfort dropped to 16% and patients with an initial goal of cure increased to 28%. Additionally, there has been an increase in the number of patients dying with hospice (40% in 2008 vs. 68% in 2012) and the patients are receiving hospice earlier than in the past (mean = 25 days in 2008 vs. mean = 107 days in 2012). The percentage of patients dying with a DNR in the chart has been maintained above 80% throughout the study period, but there has been an increase in the number of days the DNR was signed before death (mean = 24 days in 2008 vs. mean = 52 days in 2012). There has also been an increase in the percentage of St. Jude patients that received "expert level" palliative care before death. This "expert level" is considered to have been achieved if the patient is enrolled on hospice and/or was evaluated and followed by the QoL Service. In the first quarter of 2008, less than 30% of all St. Jude patients that died received "expert level" palliative care. That number has now increased to 100% for the 4th quarter of 2012. The increased utilization of the QoL Service was brought about by many programmatic initiatives, including: Creation of a model for palliative care delivery within the context of a strong medical home such as pediatric oncology, increased institutional resources, many educational sessions for all levels of trainees and healthcare providers, a trigger-based End-of-Life Care Project, creation of a family advisory council and elucidation of their institutional priorities for palliative care, implementation of a home health and hospice bridging program (QoLA Kids), creation of a bereavement program, the start of a multidisciplinary "liaison" team meeting, and the creation of a HPM fellowship. Each of these initiatives will be reviewed in this presentation.

### Biography

Justin N Baker is a pediatric oncologist, palliative care physician, member of the ethics committee and Phase I and end-of-life care clinical investigator at St. Jude Children's Research Hospital. He currently serves as the Chief of the Division of Quality of Life and Palliative Care at St. Jude as well as the Medical Director of the Quality of Life Service – the St. Jude palliative care team. He also serves as the Director of the Pediatric Hematology/Oncology fellowship program. His research interests include ethical considerations surrounding enrollment in Phase I clinical trials, AYA palliative oncology care, end-of-life decision making, integrating palliative care into the ongoing care of children with cancer as well as pain and symptom control in the context of pediatric oncology care. He has participated in more than 25 studies related to pediatric palliative care and has authored numerous manuscripts and book chapters on the topics ethical decision making as well as other palliative care subjects within the context of pediatric oncology.

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