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Rescuing KR 1 and 2: Harnessing hospital and community hospice interdisciplinary care team resources to improve quality of care and quality of life for a complex patient

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Introduction: Interdisciplinary care teams are an essential part of quality care and communication in the delivery of both hospital and home based palliative care services. Optimal care coordination utilizes the collective expertise of care providers across disciplines and care settings to meet the physical, social, emotional and spiritual needs of their patients. One year ago we began the QoLA Kids (Quality of Life for all Kids) program; a home based palliative care and hospice bridge program formed as a collaborative effort of St Jude Children's Research Hospital, LeBonhuer Children's Hospital and Methodist Hospice. Biweekly interdisciplinary care team meetings bring together doctors, nurses, social workers, chaplains, child life specialists, and others, to enhance communication and quality of care for enrolled patients. The program has enabled the provision of essential care and resource utilization at a level that were previously unattainable.

Case Report: KR is a 16 year old boy with perinatal HIV, developmental delay and progressive metastatic rhabdomyosarcoma with chronic issues of pain and failure to thrive. KR has been in the custody of his maternal aunt since the death of his mother and has had issues with poverty, recurrent homelessness, school truancy, and medical neglect. The palliative care team was consulted to augment the support of hospital based services and enrolled in the newly formed QoLA Kids program. Home visits by care providers across disciplines revealed an extremely unsafe environment, narcotic diversion with untreated pain, neglect of basic care including enteral feeds, medication non-compliance, and patient anxiety and emotional distress leading to self-mutilation. Through interdisciplinary expertise and communication, the team was able to address the identified deficiencies in KR's care and improve both his safety and quality of life in ways that would have not been possible without the QoLA Kids program.

Case report Part 2: He was followed on the program for over a year during which time he and his family required intensive psychosocial and medical support. On a routine home hospice visit, he was found to be unresponsive and brought to the local emergency room at LBH. Rapid communication between the QOLA hospice nurses, palliative care teams at both hospitals, and KR's legal guardian allowed the team to clarify goals of care leading to revocation of the previously signed DNR/DNI. KR was intubated and aggressively treated for presumed reversible causes. Following acute care treatment at both hospitals, he was transferred to the Methodist hospice residence for rehabilitation and while awaiting DCS custody decision. He fully recovered from his acute illness and was recently discharged from hospice given ongoing clinical improvement and stabilization of his chaotic social situation.

Discussion: The case of KR illustrates how interdisciplinary care across care settings can dramatically improve quality of care and quality of life for complex patients.

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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