Children's Hospital of Philadelphia PolicyLab

Parental perspectives on goals of care discussions with the healthcare team for their child with cancer

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BACKGROUND: Parents of children with cancer are expected to make decisions about treatments that often have significant side effects and require a sophisticated understanding of the risks. Often these decisions are made without a clear understanding of their child's prognosis both because the prognosis is uncertain and communication about it may not be clear. The majority of parents of children with cancer had a need for more 'information about the child's illness' [1]. End-of-life literature has demonstrated that discussions about goals and families' preferences wait to occur until death is imminent [2] and that 50% of pediatric oncologists had DNR discussions with families only after they were prompted to do so by the families [3]. Outside the end-of-life period, there is little information to guide providers in knowing when and who should have these goals of care discussions (GCD) with families and the most helpful way to present information. The objective of this study was to learn about parent's experiences having GCD with their child's providers, which clinicians had those discussions with them, and whether parents want more input into who participates in GCD, when those meetings occur and how information is shared with them.

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