

for community based programs [3,4,8].

the course of a complex life-limiting illness and not for the few hours or days before end-of-life care is initiated and/or death unfortunately occurs.

As noted in the literature, one PPC program required a hospital physician's order to begin services. A general understanding exists that most reimbursement agencies require a physician's order to bill for services. Within the PPCRN, 3 of the 5 programs require a physician order to implement PPC. This finding raises the possibility that the need for a physician order may hinder the identification of potential children for PPC services. Further research is needed to determine if this requirement is a barrier in the referral process.

Within the PPCRN, only two programs specifically stated the primary care provider was involved in the palliative care referral process and held a continued multidisciplinary role in implementation of care for that child. This finding is consistent with the literature. With the medical home movement already underway, multidisciplinary collaboration among providers and services is necessary to provide access to consistent, coordinated quality health care to patients and their families. The child's primary care provider whether pediatrician or pediatric nurse practitioner must remain involved in the care of the child and holds a major role in coordination of routine, curative, and palliative care. So many children "slip through the cracks" where one physician believes and/or assumes the other physicians are handling all aspects of care. In fact, necessary services such as symptom management may be unknowingly lost. With the inception of the medical home, the multidisciplinary collaboration among providers offers guidelines and a renewed hope for increased referral and access to PPC services.

Limitations

The limitations of this qualitative survey include Master's student development of the survey questions and use of non-standardized tools. Reliability and validity of the survey was not established and self-reporting measures of the survey responses could be biased. Another limitation is the lack of relevant research available regarding PPC programs. The information collected was from a convenience sample of hospitals. Only 5 out of the 9 PPCRN programs responded to the survey therefore our findings could not be generalized. An additional limitation of this study is lack of resources available to evaluate a larger group of PPC programs.

Clinical Implications

The results of this survey offer several opportunities for improving the initiation of PPC at diagnosis. The NCP has a detailed referral process and specific guidelines that are available through the IOM, WHO, NCP and AAP for quality PPC implementation [1,2,6]. However, these policies and guidelines seem to be underutilized and/or unavailable to PPC programs. Two targeted interventions may improve the initiation of pediatric palliative care services.

First, a process and survey of 10 hospitals (group of PPC programs.)

