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Care of the Complex Chronically Ill Child by Generalist Pediatricians: Lessons Learned From Pediatric Palliative Care

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Abstract

BACKGROUND AND OBJECTIVE—Parents of children with complex chronic conditions report fragmented care, unmet medical needs, and financial strain from health care costs. The aim of this study was to identify both prevalent themes discussed during pediatric palliative care consultation of patients with complex chronic conditions cared for by pediatric generalists and variation in consultation content by age and timing of consultation in disease course.

METHODS—Forty randomly selected initial inpatient or outpatient consultation notes authored by the pediatric palliative care team at an academic, tertiary care children's hospital. Inclusion required that patients were primarily cared for by general pediatricians, pediatric hospitalists, or pediatric intensivists, instead of subspecialists. Qualitative analysis by 5 team members utilizing consensus-based findings was used to develop themes. Descriptive statistics were used to describe variations in themes across age and disease course.

RESULTS—Common themes included thorough review of patient baseline functioning, current symptoms, assessment of family's understanding of the prognosis of the patient, coordination of communication with other medical teams and outpatient health care services, consideration of caregiver resources and burdens, and offering a framework for decision-making. Variation in consult themes by age/disease course included more discussion of communication problems and symptom management when patients were at their baseline, but otherwise little variation was found.

CONCLUSIONS—Common themes covered in initial consultations correspond with documented unmet needs for chronically ill children. There was no significant variation in consultation themes by age/disease course, suggesting that generalists could broadly apply palliative care techniques to improve family-centered care.

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Keywords

general pediatrics; palliative care; comprehensive health care; complex chronic condition

There are insufficient pediatric palliative care teams to meet the needs of patients who qualify for services according to guidelines set by the American Academy of Pediatrics and Institute of Medicine,^{1,2} so generalist pediatricians (pediatric hospitalists, intensivists) frequently provide care for patients with complex chronic conditions (CCCs) without their support. These patients represent a diversity of primary disease categories,³ make up an increasing percentage of hospitalized patients, and often require complex care across their lifespan.⁴ There is considerable need to identify ways to improve the family-centered care for medically complex children cared for by generalists, because parents of children with CCC report fragmented care, unmet needs, and financial strain from out-of-pocket health care costs.^{5,6}

There has not been an in-depth qualitative analysis of palliative care consultations (PCCs) of patients most frequently cared for by pediatric generalists. In contrast to many subspecialty physicians, many general pediatric hospitalists do not provide care in the outpatient setting. Although general pediatric hospitalists may develop expertise in supporting families during hospitalization, the lack of continuity between inpatient and outpatient care of the medically complex child may result in distinct needs to be addressed during PCC. An analysis of PCC for these patients could illustrate how palliative care principles could be applied to enhance generalists' efforts to provide high-quality, family-centered care.

The primary objective of this study was to identify prevalent themes covered in pediatric PCC for patients cared for by pediatric generalists. A secondary objective was to identify variation in consultation content by age or timing of consultation in the disease course. The vivid data available from PCC notes allowed for a rich description of care challenges and resources offered during consultations.

METHODS

We analyzed 40 initial pediatric PCC notes for children with CCCs cared for at a tertiary/quaternary care academic hospital.

Study Sample

Eligible patients had an initial inpatient or outpatient PCC from 2005 to 2009 at C. S. Mott Children's Hospital at the University of Michigan performed by the Pediatric Palliative Care Team.

In an attempt to obtain information most relevant to generalist pediatricians, patients were selected if they were primarily cared for by general pediatricians, pediatric hospitalists, or pediatric intensivists. Patients generally cared for by subspecialists, for example, those with congenital cardiac disease, cystic fibrosis, or malignancy, transplant recipients, or patients requiring renal replacement therapy were excluded from the sample. Additionally, we excluded consultations primarily intended to discuss transplantation, end-of-life care when

death was imminent, or bereavement. Of the 827 PCC notes, 131 were eligible for the sample and 40 were randomly selected for this in-depth analysis.

The interdisciplinary University of Michigan Pediatric Palliative Care Team included palliative care—experienced pediatricians, nurses, a social worker, and spiritual care staff. Consultations were coauthored by several members of the team after group meetings with involved parties.

Data Analysis

Electronic medical records were used to abstract initial pediatric PCC notes. Demographic and clinical characteristics of the patients were abstracted from routine recorded data in the consultation note. Insurance status was obtained from other electronic medical record documentation. The categories for consultation timing were decided on after review of all consultation notes by 3 study team members (K.S.W., L.R.D., J.W.), and the assignment of consultation timing category was a consensus decision by these study team members after review of the consultation note. Consistent with a grounded theory approach to qualitative research, no a priori framework was used in the development of the coding scheme and organization of data into themes. Two investigators (L.R.D. and K.S.W.) read all consultation notes and identified preliminary themes. These investigators then developed a codebook based on these themes (eg, communication, home care of the child, care goals). Additional team members (P.K., T.M., J.W.) then read 5 consultations each, and, through an iterative consensus process, the research team determined that codes were clearly defined and could be consistently applied by all team members.⁷ Each consultation note was then coded by 2 team members with lead coders (L.R.D. and K.S.W.) serving as 1 of the 2 coders for each consultation. In place of a measure of intercoder reliability, we used established methods for addressing differences in coding between coders by reconciling them through discussion and consensus.^{7–9}

We used NVivo Version 8.0 (QSR International, Doncaster, Victoria, Australia) to apply codes to the transcripts and organize relevant quotes abstracted during analysis. One coder summarized each transcript with input and approval from the second coder. Summaries included key themes and text evidence for those themes. These summaries were then used for cross-case comparison and distribution of child and family characteristics among prominent themes. This study was approved by the University of Michigan Institutional Review Board.

RESULTS

Characteristics of Sample

Patients referred for PCC all possessed complex and chronic illnesses with disease processes likely to require medical care for >1 year including intermittent hospitalizations. Nearly two-thirds of the sample had a primary diagnosis of a neuromuscular disorder and one-fifth had a genetic/congenital disorder as their primary diagnosis. Associated diagnoses in approximately half of the sample included cerebral palsy and seizures. Three-quarters of the

sample had a feeding tube. Additional sociodemographic and medical characteristics are shown in Table 1.

Primary Structural Consultation Themes

Decision-Making and Care-planning—PCC often served as a forum for decision-making and to strengthen care-planning for children with CCCs. By seeking a broader picture of a patient's disease course and health status at his or her baseline, the palliative care team obtained a clearer understanding of the patient's care needs, a necessary first step in guiding the family's choices about medical care (Table 2: quotes 1 and 2). A central part of identifying the family's current goals of care included an assessment of their understanding of prognosis. If families were misinformed about their child's prognosis, the team worked to ensure a more comprehensive understanding by the family to aid in decision-making (quotes 3 and 4).

The palliative care team also assisted in coming to a decision over particular interventions. There were PCCs about increasing technologic dependence, eg, tracheostomy or gastrostomy tube placement, as well as high-risk potential curative strategies, for example, organ or bone marrow transplantation. Although we excluded consults where death appeared imminent, PCC still covered conversations around code status and end-of-life discussions, with some consults primarily intended to discuss advanced directives and family wishes for resuscitation (quote 5).

Consults around decision-making demonstrated that families understood the compromises involved in caring for children with CCCs. Families were receptive to the palliative care team's introduction of a framework for decision-making in which both the "benefits versus burdens" of medical interventions were evaluated. Families were encouraged to use this framework to better understand the trade-offs inherent with additional medical technology or life-sustaining interventions and make explicit their values and goals for their child in decision-making (quotes 6 and 7).

Because our sample included only initial PCCs, consults often focused on introducing the family to the concept of palliative care without focus on a specific decision. Consultations often discussed symptom management and the importance of continued involvement by the palliative care team and their role as coordinator of communication with other teams. The team acknowledged the importance of developing rapport and identifying families' goals before addressing a particular decision (quotes 8 and 9).

PCC also demonstrated the role the team played in clarifying care plans when the family and medical team had reached an impasse that they perceived was due to poor communication. Their recommendations provided guidance for addressing communication challenges.

Finally, PCC demonstrated the team's role in acknowledging the increasing autonomy of some adolescent patients and endeavored to help them communicate their thoughts, feelings, and goals both to their parents and the medical team (quote 10).

Symptom Management—Some consultations primarily discussed management of symptoms that were both distressing to the family and were not adequately addressed by the primary team. Common symptoms across consultations included pain, increased secretions, and constipation. Decisions to start or stop medications were also discussed within a “benefits versus burdens” framework. For example, when discussing the use of benzodiazepines for seizure control, the palliative care team highlighted the impact of these medications on the child’s alertness and elicited the family’s overall goals for the child before proceeding. In some cases, it appeared that the palliative care team focused on symptom management before addressing important upcoming decisions about their child’s care plan as a way to build rapport for more difficult conversations.

Care Coordination—The palliative care team also frequently played a mediator role and many consultations emphasized their encouragement or facilitation of ongoing discussions between parents, care providers, and ancillary staff to come to a consensus for medical care. This was particularly beneficial because the care for many of the children was complex both in the number of services required for the child’s care and in the number of interdisciplinary providers participating in that care (quotes 11 and 12). In addition to coordination of medical services for decision-making, care coordination recommendations focused on the transition from hospital to the home (quotes 13 and 14).

The Family Context

In addition to the primary themes of the consults, consultations often provided substantial information about the child within the context of an often dynamic and complex family unit. The multidimensionality of caregiver and family burden was frequently discussed (Table 3: quote 1). Caregivers experienced significant emotional distress coping with the burden of caring for a CCC child and occasionally preparing for their death (quotes 2 and 3).

Consultation notes also detailed family stress due to limited financial resources. Whereas, for some families, this stress was due to the expenses associated with the medical care of the child; for other families, limited resources were due to lack of income as 1 or more parents could not continue working in the same capacity as they had before (quotes 4–6).

The presence of people and resources, including a faith tradition, which could provide emotional, spiritual, and practical support were integral to caregiver management of stress and management of the needs of other family members (quotes 7 and 8).

Families talked about the strain that the caregiving relationship placed on the marriage relationship or relationship between unmarried parents (quotes 9 and 10). In a few cases, the burden of caring for a chronically ill child was attributed to the ending of a marriage or relationship. Caregivers’ competing demands also included personal health problems. Mental health symptoms were common, but some caregivers also had significant other physical health problems or struggled with substance use (quotes 11–13). Respite care services were discussed in some consultations as a way to manage the many stresses of caring for a chronically ill child. In addition, consultations included mention of guidance for communication among family members, and particular suggestions for increasing time spent engaging in pleasurable activities for individuals and couples.

Variation in Consultation Domains by Patient Characteristics

Of the 40 notes analyzed, spirituality was addressed in 73% of consults overall and >60% of consults regardless of time course of illness or age of the patient. Assessing parental understanding of prognosis was documented in all cases of a new diagnosis and in ~70% of notes involving acute changes in health status. Consultations that occurred at the patient's baseline state were noted to commonly address symptom management and complex communication situations either among family members or between families and the medical team. Decision-making about further medical interventions or code status were discussed less commonly in these baseline conversations. Emotional distress among family members was more commonly recorded in consultations at new diagnosis and during acute health changes compared with consultations with the timing categorized as baseline.

Variations in the content of PCC were less apparent by age group. However, there were discussions of increasing patient autonomy and social isolation of the patient and/or family for patients >12 years of age in comparison with younger children. Additionally, a focus on the "benefits versus burdens" decision-making framework was more prevalent in notes for children <2 years of age.

Coordination of care services appeared to be more frequently discussed at consultations occurring before the first discharge from the hospital or after a significant decline from baseline.

PCC and Principles of Family-Centered Care

The themes identified in our analysis can be organized according to the shared principles of family-centered care identified by Kuo et al.¹⁰ How the emergent themes of PCC in this study mapped onto principles of family-centered care and quotes embodying these values are demonstrated in Table 4.

DISCUSSION

This study offers an in-depth qualitative analysis of PCC with a rich description of discussions with families, care coordination among multiple services, and the variation of these service domains across patients of varying ages and at different points in their disease course. The relevance of these themes is underscored by the fact that they address unmet needs cited in the literature.^{5,6,11–13} The themes found in the PCC overlap with family-centered care goals of aiding families in decision-making and facilitating their movement through different aspects of the health care system, which have shown promising results for improving care.^{14–17} This thorough analysis of the documentation of these care recommendations in PCC offer new insights into how these goals can be practically realized and documented.

Taking the "Big Picture" Approach

Families with newly diagnosed chronically ill children express loneliness and helplessness because they did not have support in understanding the long-term outcomes of the diagnosis.¹¹ Although the Pediatric Palliative Care Team was often consulted to aid with

decision-making, the team also perceived the value in first assessing the patient and family's understanding of the diagnosis, care plan, and any unmet needs regardless of whether the child was newly diagnosed or the family had been caring for the child for some time. By gathering more information about the home and family life and the child's quality of life, the palliative care team identified critical areas where improvements could be made in symptom management, communication, or coordination of care services. In particular, the palliative care team appeared to serve as an essential resource to identify gaps in understanding and thereby coordinating communication.

For services provided outside the hospital, there is a varying degree of communication across different agencies (eg, between pediatric practices, medical equipment agencies, and nursing agencies).¹⁸ Attention paid by the palliative care team to communicate medical and psychosocial needs to relevant agencies outside the hospital may have benefited patients and families.

By first addressing the family's perceived needs, the palliative care team built rapport and made clear that their role was to support the family in decision-making. Also, given that many health care providers and families believe the role of palliative care is narrowly limited to end-of-life care, the process of building rapport during the initial consultation and demonstrating the beneficial services they could provide to improve quality of life for the patient independent of end-of-life decisions opened the possibility of optimizing the patient's experience both at the time of consultation and when evaluating future decisions.

Families have many goals of care for their children,¹⁹ and these occasionally come into conflict. Also, families may not explicitly state all of their goals, and so may find it challenging to articulate the reasons for their decisions both to themselves and to the care team. PCC offered families a framework for understanding their goals, analyzing conflicting goals, and coming to realistic expectations; this assistance may have been influential in decision-making. Additionally, through PCC families were reminded that many treatment decisions are optional and not mandatory, possibly leading them to critically evaluate more treatment options via a "benefits versus burdens" framework. This explicit framework for decision-making may also be useful to generalists who are often put in the role of supporting families' decisions around care proposed by subspecialists.

Although our study focused on initial consultations, it was clear that the palliative care team planned to develop ongoing relationships. In this way, the palliative care team's goals overlapped with the expectation of longitudinal outpatient care found in the medical home model.¹⁵ Unmet needs among families caring for a medically complex child demonstrate that achieving comprehensive, family-centered care in the medical home is difficult.^{5,6} Further research should evaluate how to increase the capacity of the medical home model to incorporate practical techniques of palliative care.

Caregiver Burden

Other analyses have identified the significant financial burdens on caregivers,¹³ and our qualitative work demonstrates that these burdens were both real and complexly related to psychosocial aspects of social isolation and stress placed on interpersonal relationships.

Supporting families in obtaining the needed family medical leave and serving as a resource for advocacy in their workplace has also been proven to be an unmet need for many families.²⁰

Variation Across Age Categories and Disease Course

Although there was some variation in content of PCC notes, in general, most domains were addressed consistently across the disease course and the age of the patient. Because there are not sufficient palliative care teams to offer services to families,² it may be beneficial to many chronically ill patients to have generalists also learn the skills to address family's understanding of prognosis, helping with complex communication situations, and assisting in decision-making about treatment options in patients of all ages and across disease courses. It may also be relevant for generalists to assess for signs of emotional distress among family members, particularly around the time of new chronic or life-threatening illness diagnosis and at other acute changes in disease status, particularly triggered by a hospitalization.

Limitations

This study has certain limitations. First, we evaluated PCC notes from a sample of generalist patients at 1 academic medical center, and our findings may not be generalizable to other medically complex general patients. Although patients were not screened by their *International Classification of Diseases, Ninth Revision* codes to determine if they met the complex chronic condition designation as described by Feudtner et al,²¹ our sample was similar to other samples of patients receiving palliative care meeting Feudtner's criteria.³ This increases the likelihood that conclusions from our findings may be of use to health care providers working with medically complex children. Second, we included only patients cared for by generalists. This was based on the hypothesis that consultations for these patients may differ from those of subspecialty patients and because we wanted to focus on providing guidance to generalist physicians who practice in the hospital setting. We did not perform a comparative analysis between general and subspecialty patients; thus, we cannot address whether there are differences between consultations by patient type. This merits further investigation. Third, we looked only at initial consultations. The scope of PCC was likely not captured by using only initial consultations. Third, we did not assess how the medical team used palliative care recommendations. These recommendations appear to promote improved health care quality and increased family support, but, if the primary medical team did not act on these recommendations, the potential benefits of consultation might be limited. Further research should assess facilitators and barriers to following through on palliative care recommendations.

CONCLUSIONS

Characterizing the services provided by a pediatric palliative care service can be useful in identifying skill sets that may be beneficial for pediatric generalists to obtain. We found little variation in services provided in PCC across disease course and age groups, suggesting that these skills can and should be widely offered to families of patients with chronic or life-threatening illness. Generalists could improve the care provided to their chronically ill

patients by taking a “big picture” stance and assessing the family’s understanding of prognosis, the child’s baseline functioning at home, and the family’s perceived needs. This would then allow them to assess what goals the family had for the child and offer a “benefits versus burdens” framework for further decision-making. Finally, it is important to identify and validate the struggles of caregivers caring for a chronically ill child. If possible, offering financial and psychosocial counseling services may mitigate some of the burden experienced by families. In the current model of care, the needs of many children and families managing CCCs remain unmet. Utilizing palliative care principles provides a foundation of family-centered care that may promote fewer unmet needs and greater family satisfaction with their child’s care and their role as a caregiver.

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ABBREVIATIONS

CCC	complex chronic conditions
PCC	palliative care consultation

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TABLE 1

Demographic and Clinical Characteristics of Patients receiving PCC

Characteristic	Frequency(<i>n</i> = 40)	%
Gender		
Male	26	65
Female	14	35
US insurance		
Government	24	60
Both	14	35
Private	2	5
Primary diagnoses		
Neuromuscular	24	60
Genetic/congenital	8	20
Gastrointestinal	3	8
Respiratory	2	5
Other	2	5
Renal	1	3
Associated diagnoses		
Cerebral palsy	22	55
Seizures	20	50
Minimally responsive ^a	14	47
Prematurity	8	20
Medical technology		
Feeding tubes	30	75
VP shunt	5	13
Ventilator-dependent	2	5
Tracheostomy	1	3
Home nursing ^b	7	23
Never been home	9	23
Location of Consult		
Inpatient floor	25	63
Outpatient	8	20
ICU	7	18
Code status		
Full code	36	90
Change after consult	3	8
Timing of consultation		
Acute change in status	22	55
At patient's baseline	8	20
New diagnosis	7	18
First-time home	3	8
Age at consultation, y		

Characteristic	Frequency(<i>n</i> = 40)	%
0–2	16	40
3–12	12	30
>12	12	30

VP, ventriculoperitoneal.

^a
n = 30 total patients >1 y of age.

^b
n = 31 total patients who have been home at some point in their life.

TABLE 2

Major Themes of Palliative Care Consultations

*Consultations provided the primary health care providers with a more detailed picture of the child and family's home life, which may offer insight into family's preferences for medical decision-making.

Quote 1

[The patient] is a very engaging and expressive young man. He shares that he enjoys watching TV ... playing video and board games and going outside and on outings (to the movies, out to dinner, or just to the grocery store). Child appears to have a very positive outlook on life and indicates that he rarely has a "bad day." He indicates that the "things" that bother him the most are when he has sores that are bleeding or when he wants to go somewhere and isn't able to have someone there to take him.

Quote 2

Mother shares that although she has tried many nonpharmacologic interventions to calm or soothe child, nothing has appeared to be effective. She indicates that child has many more bad days than good and suggests that child does not often have good days, but instead moments.

*Consultations provided primary health care providers with greater insight into the family's understanding of their child's condition, identified areas of communication gaps, and recommended support needed to aid the family's decision-making.

Quote 3

[Mom] envisions many more complications and increased time in the hospital with very little chance of improving this situation. She describes mixed messages from care providers regarding access for future lines should they be needed... We advise a family meeting to discuss realistic options for child's future--and what the family's wishes/goals would be if no further definitive central access can be obtained for child's TPN. Child's parents seem interested in such a discussion. Our team is willing to participate if desired.

Quote 4

Child's family members seem to have a good understanding of his past medical history and of his care requirements. The current episode of respiratory failure has taken them completely by surprise and they verbalize feeling not well informed about lung/breathing issues... This family will require ongoing support and guidance to come to consensus about the current goals of care. Providing them all with regular realistic information and updates about his status and related medical recommendations will be helpful. Our team will provide support and assistance to help promote open communication within the family with the goal of reaching consensus as soon as possible.

*The primary focus of some consultation was to work through family decisions about use of resuscitation measures.

Quote 5

After discussing the likelihood of life-threatening complications--such as infections, bleeding, end-stage liver failure--and the unlikely benefits and certain discomfort of invasive medical technologies/resuscitative efforts, the family indicated that they would prefer to Allow Natural Death (AND) and seek comfort care measures if child were to have respiratory or cardiovascular failure.

*A benefits and burdens framework was already used by some families to make medical care decisions, whereas some families were introduced to this decision-making framework during palliative care consultation.

Quote 6

[The mother said] "many of the medical decisions they have faced and are yet to face for child are not a matter of solutions but merely trade-offs." She perceives that very often they were "trading" one set of problems for another. She acknowledged understanding that decisions regarding child's care are not determining "right or wrong," but instead deciding what is best for child.

Quote 7

We have discussed that many other issues will arise in which the extent of intervention may be unclear. We specifically discussed the example of a feeding tube in the event of insufficient oral feeding. We reinforced that each new intervention is a choice, and that the family has a right to pursue or not pursue the intervention.

*Initial consultations addressed some, but not all possible issues relevant to palliative care team involvement. Management of care decisions was often deferred to allow time for rapport building.

Quote 8

We felt that, given the enormous material covered, the emotional intensity of the interview, and mother's firm hope for healing/recovery, it would be best to defer conversations about Code Status and Hospice. We will attempt to broach these additional topics as seems appropriate.

Quote 9

We would like to discuss further with her and child's father their thoughts and feelings about the balance of quality of life and aggressive medical interventions. We will plan to have another conversation at a mutually agreeable time and place.

*Consultations assessed functional status to be able to later provide recommendations for increasing autonomy.

Quote 10

Child indicates that she is able to carry perform of her own ADLs. The most prominent exception to this is toileting in which she requires assistance with reapplication of dressings...Child is dependent on others (mostly her mother and her nurse) for medication administration. When describing this dependence, she emphasizes the fear that she might forget doses rather than any physical limitation. She does admit that

she does have difficulty opening containers and that she does work with an OT (currently a male) to maintain hand function. She indicates that she has not worked with an OT on increasing her independence with toileting, but expressed interest in exploring this option with a female OT.

*Concrete recommendations for communication among health care providers promoted care coordination across the many members of the health care team.

Quote 11

Because of the importance of Drs 1 and 2 in child's care and the significant value of providing for continuity and coordination, we recommend including salient features of this consult in the discharge summary. We are also happy to discuss our thoughts and recommendations with them directly if it is deemed helpful.

Quote 12

We recommend a family conference early next week with representation from the managing medical and surgical teams. The Pediatric Palliative Care Team is also happy to participate in a family meeting if that would be helpful.

*Consultations provided recommendations for necessary care coordination to promote smoother care transitions.

Quote 13

Contacting child's PMD and getting his perspectives and buy-in for the discharge plan will be an important part of ensuring that the progress made during this hospitalization is continued. Consider this in the form of a team/family meeting.

Quote 14

While child's parents appear eager to have him transition home with them, they nonetheless expressed concern in their ability to understand his present care needs. It seems appropriate to consider transitioning child to a care environment where his parents can remain at his bedside around the clock to learn his care and increase their confidence before transitioning home.

The quotations selected for presentation in Table 2 serve as examples for the complete set of statements from which the identified themes emerged. ADL, activities of daily living; OT, occupational therapy; PMD, primary medical doctor.

TABLE 3

Family Life With a Child With a Complex Chronic Condition

*The impact of having a child with complex needs affected many aspects of family life.

Quote 1

There have also been significant negative impacts including great financial stress due to father's need to limit his work commitments; severe social isolation and emotional distress for mother who describes feeling "like she is dying inside"; and increased trouble for their oldest child who has suffered from depression.

*Having a child with complex needs contributed to both chronic and acute caregiver/family stress.

Quote 2

Mother appears concerned about the strain that the family is under and expressed some apprehension about the impact of their son returning home to live indefinitely. Specifically, mother shared some frustrations about having her marriage, her profession, and other aspects of normal adult life "put on hold" with no clear sense of things becoming easier in the future.

Quote 3

Given child's present hospitalization and most recent medical issues, child's mother articulated her fear that "this may be the beginning of the end" as she recognizes that child is getting older and thereby approaching her potential life expectancy. Child's mother was forthcoming with her thoughts and fears, and shared feelings of not being ready to "face" the conversations that lie ahead.

*Having a child with complex medical needs negatively impacted family finances, contributing to the chronic stress of caregiving.

Quote 4

Mother shares that she is limited in the time she is able to spend with her children as she has been trying to work to save enough money to be able to move out of her parents' home. She states that she was becoming close to attaining this goal; however, she needed to stop working once child's condition changed. She shares that she is not presently able to find a job that will afford her the flexibility in her schedule that child's condition requires.

Quote 5

Father works full time and carries the family health insurance which has a \$1 million lifetime limit, which is causing the family some concern due to child's ongoing medical expenses.

Quote 6

Child's parents own and operate a business that mother indicates has suffered tremendously as a result of child's ongoing needs. Child's mother used to assist in managing the business; however, since the child's birth, has devoted her time to being child's primary caregiver.

*Community and family support positively impacted families.

Quote 7

Mother and father describe significant impacts on their lives as a result of child's illness. On the positive side, they describe a feeling of cohesiveness in their immediate family that has been strengthened by their mutual efforts to support child. In addition, there has been good extended family and community support in the way of fundraising to support child's care needs.

Quote 8

Child's parents indicate that they have received much support from their parents, extended family, friends, and neighbors. They share that they have received cards from people in the community that they hardly know, and are aware that child is being prayed for at a number of local churches, both of which afford them additional comfort and support.

*Families experienced actual strain on their marriages or relationships or worried about potential relationship strain.

Quote 9

Mother shares that although in some ways child's condition has brought her and her husband together; it has also placed significant strain on their marriage. Mother indicates that she is wanting more support from her husband with the present medical decisions they are facing for child and is needing him to play a much more active role.

Quote 10

These ongoing needs are placing significant demand on her parents who are managing reasonably well at this time. However, they have concerns about the potential future impact on financial status and their marital/family relationships.

*Families experienced mental and physical health burdens that increased competing demands for their time and energy.

Quote 11

Because mother appears to be suffering from clinical depression, we suggest that she be in communication with her primary care physician to further determine the most appropriate medical management for her. We have suggested that counseling plus/minus antidepressants may be of benefit to her. Mother seemed receptive to this idea.

Quote 12

Mother indicates that she has a history of depression and suicide attempts. She indicates that child has given her purpose in her life and believes that she is managing adequately at present. Mother shares that she is currently taking a stress management course and plans to initiate individual counseling in the near future.

Quote 13

Additionally, mother shares that she has been struggling to take care of herself in light of her son's present hospitalization. She indicates that she has been receiving treatment of high blood pressure for some time and was recently taken to the ER for elevated blood pressure. She indicates that she is presently requiring further medical workup.

The quotations selected for presentation in Table 3 serve as examples for the complete set of statements from which the identified themes emerged.

TABLE 4

Principles of Family-Centered Care and the Corresponding Themes Identified in PCCs

Family-Centered Care Principle	Corresponding Themes from PCC Notes	Corresponding Subthemes	Example Quotations
Information sharing	Decision-making and care-planning	Report of baseline health status	Table 2: Quotes 1, 2 & 10
		Family understanding of prognosis	Table 2: Quotes 3 & 4
Respect and honoring differences	Decision-making and care-planning	Benefits versus burdens framework	Table 2: Quotes 6 & 7
		Faith/spirituality	Table 2: Quote 8
Partnership and collaboration	Decision-making and care-planning	Introduction of the palliative care team	Table 2: Quotes 8 & 9
		Code status/End-of life discussions	Table 2: Quote 5
		Care coordination	Table 2: Quotes 11–14
	Functional status	Good days versus bad days	Table 2: Quotes 1 & 2
		Increasing patient autonomy	Table 2: Quote 10
Negotiation	Decision-making and care-planning	Introduction of the palliative care team	Table 2: Quotes 8 & 9
		Mediating complex communication	Table 2: Quotes 3–9
Care in the context of the family and community	The family context	Caregiver burden	Table 3: Quote 1
		Emotional distress	Table 3: Quotes 2 & 3
		Financial stress	Table 3: Quotes 4–6
		Support resources	Table 3: Quotes 7 & 8
		Relational distress	Table 3: Quote 9 & 10
		Competing demands	Table 3: Quote 13
	Outpatient care	Care coordination	Table 2: Quotes 11, 13 & 14