

Relationships and Resources Supporting Children With Serious Illness and Their Parents

Jori F. Bogetz, MD,^{a,b} Anna Revette, PhD,^c Lindsay Partin, BS,^{d,e} Danielle D. DeCoursey, MD, MPH^f

ABSTRACT OBJECTIVE: Children with complex chronic conditions (CCCs) and their parents benefit from supportive serious illness care when their conditions are severe and impact their quality of life and stress. This includes not only expert medical care but also effective relationships with the clinical team. Existing data suggest that there are opportunities for improvement. This study's aim was to explore important aspects of the relationships and resources that facilitate supportive serious illness care among children with CCCs and their parents.

METHODS: We conducted semistructured interviews with adolescents and young adults (AYAs) with CCCs (aged 13–35 years), and parents of children with CCCs across 2 academic pediatric centers in the United States from December 2018 to April 2019. Transcripts were iteratively coded and analyzed by a team that included a sociologist, pediatric intensivist, and palliative care researcher by using inductive and deductive thematic analysis.

RESULTS: Seven AYAs with CCCs and 9 parents participated (16 total; 1 AYA–parent dyad). Two key categories were identified around relationships with the clinical team: trust and fostering collaboration. Three key categories related to resources are information needs, making sense of life with illness, and supportive community. Many of the key categories and themes identified by participants had both tangible and intangible components and revealed the distinct yet interconnected nature of these aspects of care.

CONCLUSIONS: Awareness and cultivation of relationship and resource support through innovative interventions and attention to those with increased needs in these areas may improve the serious illness care provided to children with CCCs and their parents.



^aDivision of Pediatric Bioethics and Palliative Care, Department of Pediatrics, University of Washington School of Medicine, Seattle, Washington; ^bSeattle Children's Research Institute, Center for Clinical and Translational Research, Seattle, Washington; ^cSurvey Qualitative Methods Core, Dana-Farber Cancer Institute, Boston, Massachusetts; ^dDivision of Medical Critical Care, Department of Pediatrics, Boston Children's Hospital, Boston, Massachusetts; ^eGeisel School of Medicine at Dartmouth, Hanover, New Hampshire; and ^fHarvard Medical School, Boston, Massachusetts

www.hospitalpediatrics.org

DOI: <https://doi.org/10.1542/hpeds.2022-006596>

Copyright © 2022 by the American Academy of Pediatrics

Address correspondence to Jori F. Bogetz, MD, Seattle Children's Research Institute, 1900 Ninth St, JMB-6, Seattle, WA 98101. E-mail: jori.bogetz@seattlechildrens.org

HOSPITAL PEDIATRICS (ISSN Numbers: Print, 2154-1663; Online, 2154-1671).

FUNDING: This work was supported by the Arthur Vining Davis Foundations (G-1805-18676; PI: DeCoursey). Funding for Dr Jori Bogetz is supported, in part, by the National Palliative Care Research Center Kornfeld Scholars Program Award and the Cambia Health Foundation. The funders/sponsors did not participate in the work.

CONFLICT OF INTEREST DISCLOSURES: The authors have indicated they have no potential conflicts of interest relevant to this article to disclose.

Dr Bogetz conceptualized, drafted, critically reviewed, and revised the manuscript; Drs Revette and DeCoursey and Ms Partin conceptualized and conducted the study and critically reviewed and revised the manuscript; and all authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

There are >500,000 children with complex chronic conditions (CCCs) living in the United States.¹ Children with CCCs are defined as children or young adults ≥ 1 month of age with a medical condition reasonably expected to last at least 12 months (unless death intervenes) and to involve either several organ systems or 1 system severely enough to require specialty pediatric care and hospitalization in a tertiary care hospital.¹ Many children and adolescents and young adults (AYAs) with CCCs live with ongoing complex medical needs that require frequent interactions within the health care system.^{2–4} When severe illness occurs that impacts quality of life and family stress, children and AYAs with CCCs and their parents deserve supportive serious illness care.^{5,6}

Meeting the needs of children and AYAs with CCCs and their families during serious illness requires not only expert medical care but also effective communication and emotional connection with the clinical team.^{7–9} This facilitates illness understanding, effective partnership, psychosocial wellness, and other resources to help these patients and families to live as well as possible.^{10–13} Yet, existing data suggest that there are opportunities to improve patient and family experience.^{14–16} These opportunities center on both the relational aspects of care that involve interprofessional clinicians and the internal and external resources that sustain children and parents across their illness trajectory. Specifically, patients with CCCs and their parents have reported not feeling heard by clinicians, having different perspectives on quality of life than their medical caregivers, and experiencing conflict during medical decision making.^{9,17,18} Additionally, patients and families have reported limited resources to bolster their psychosocial and emotional coping and resilience, navigation of the health care system, and social supports.^{16,19,20}

To better delineate the opportunities to meet these needs, the authors of this study aimed to explore aspects important to the relationships and resources that facilitate supportive serious illness care among AYAs and parents of children with CCCs.

METHODS

This study was a secondary supplementary analysis^{21,22} of data from the Pediatric Serious Illness Communication Program study, which developed a structured approach to advance care planning discussions for children/AYAs with serious illness and their parents.²³ As part of the conversation guide development, individual semistructured interviews were conducted with AYAs with CCCs and parents of children of all ages with CCCs to explore perceptions about current serious illness care, supports, and communication. We followed the consolidated criteria for reporting qualitative research guidelines to ensure methodological rigor.²⁴

Sample

This study was conducted at 2 academic tertiary pediatric centers in the northeast United States that care for CCCs into early adulthood. We employed purposive sampling based on illness type, duration of illness, and sex to maximize representation. Eligible AYAs were those with a CCC,¹ aged 13 to 35, English-speaking, and considered cognitively able to participate by their attending/primary physician. Eligible parents included English-speakers of any aged child living with a CCC. Potential AYA and parent participants were (1) self-referred after viewing study flyers in outpatient or inpatient settings throughout the pediatrics centers, (2) self-referred from posting on the Courageous Parents Network Web site (www.courageousparents.org),²⁵ which is a nonprofit organization and educational platform for families and providers that focuses on pediatric serious illness, or (3) they were referred by the palliative care service. Participants not self-referred were approached in person after attending or primary physician approval. AYA–parent dyads were permitted but not required. Adult participants, including AYAs >18 years of age and parents, indicated consent by participating in interviews. For minors, parental permission and child assent were obtained. All participants received a one-time retail gift card after

interview completion. This study was approved by the institutional review board.

Interviews

In-person or phone semistructured interviews with AYAs with CCCs and parents were conducted between December 2018 and April 2019 by a trained researcher unknown to the participants (Dr Revette, Ms Partin). Interviews were audio-recorded and professionally transcribed. Separate versions of the semistructured interview guides were developed for AYAs and parents reflecting their unique intrapersonal, interpersonal, and social contexts. To inform interview guide development, we used a literature review and interprofessional experts from palliative care and critical care as well as parents of children with CCCs who were advisors on the study. The AYA and parent interview guides are available in Supplemental Table 3.

Analysis

An interdisciplinary team consisting of a sociologist (Dr Revette), a pediatric critical care physician/clinical researcher (Dr DeCoursey), a trained research assistant (Ms Partin), and a palliative care physician/clinical researcher (Dr Bogetz) conducted thematic analysis on transcripts, incorporating both inductive and deductive dynamics.²⁶ Through an iterative process, comprehensive coding structures were developed incorporating emergent codes and prefigured codes, which were based on domains from the interview guide and existing studies regarding serious illness from pediatric oncology.^{27–30} Coding structures were then systematically applied and coded independently by 2 coders (Dr. DeCoursey and Ms. Partin). Discrepancies were identified and discussed weekly with the third coder adjudicating (Dr Revette), achieving high interrater reliability ($\kappa > .85$). Data analysis, assisted by NVivo12 (QSR International),³¹ prioritized the identification of domains, key categories, and predominant themes. Themes, with their corresponding quotes, were grouped through an iterative process by using

thematic networks analysis to identify associations.⁵²

RESULTS

Seven AYAs and 9 parents of children with CCCs participated (16 total; 1 AYA-parent dyad). An additional 3 AYAs and 1 parent were approached but declined. Two parents of children with CCCs self-referred from the Courageous Parents Network. AYA participants were a mean age of 24 years (median 25, range 17 to 32) and children of parent participants were a mean age of 18 years (median 20, range 6 to 26). The majority of AYA and parent participants were female (11, 69%) and white (14, 88%). Notably, 75% (12) of AYA

and parent participants had palliative care involvement and 57% (4) of the AYAs and 33% (3) of the parent's children died within 1 year of study participation, indicating that this was a seriously ill study population with CCCs. Table 1 reveals additional demographic information.

Two key categories were identified around relationships with the clinical team: trust and fostering collaboration. Three key categories related to internal and external resources that benefited the child and family: information needs, making sense of life with illness, and supportive community (Fig 1). Each of these categories, along with their corresponding themes, are

described in detail below and are also revealed in Table 2 with additional representative quotes.

Relationships: Trust and Fostering Collaboration

Trust was manifested through the themes of recognizing clinician expertise and following child/family expertise. AYAs described how important trust was with their clinicians and some shared feeling that their lives were literally in their clinicians' hands.

"To say that I trust in their judgment, or I trust in their abilities, I think is a big understatement. I literally put my life into their hands." [AYA 7]

Trust was felt by participants when clinicians were able to reciprocate trust and also follow the expertise of the child/AYA or parent.

"I've been doing this for years, so I kind of have a plan of my own. But I work with [doctors]. I mean, we're all a team here, and the big thing is to work with each other." [Parent 1]

According to participants, relationships were also promoted by fostering collaboration, which included themes of making the extra effort, knowing what is important to the child/parent, and feeling heard and understood.

AYAs and parents wanted to know that their clinicians were going to go the "extra step" to get things done or to care for them and/or their child.

"The doctors can take that leap and not just, 'Okay, we'll see you tomorrow on rounds, have a good day' and run out of the room—instead—be a person and really take that extra step and make that connection." [AYA 7]

Similarly, relationships with clinicians manifested through knowing the child/parent and knowing what was important to them. For example, AYAs described having clinicians they felt they could consistently go to with questions when issues arose. Parents also described the impact of clinicians who knew their child's

TABLE 1 Demographic Information

Participants	AYAs, <i>n</i> = 7	Parents, <i>n</i> = 9
Participant characteristics		
Parent age, mean (median, range)		52 (52, 28–66)
Child age, y, mean (median, range)	24 (25, 17–32)	18 (20, 6–26)
Male sex, <i>n</i> (%)	2 (29)	3 (33)
Duration of illness, y, mean (median, range)	22 (20, 12–32)	16 (18, 4–26)
Race, <i>n</i> (%)		
White	6 (86)	8 (89)
African American		1 (11)
Asian American	1 (14)	
Religion, <i>n</i> (%)		
Christian	2 (29)	6 (67)
Jewish		1 (11)
No religious preference	4 (57)	2 (22)
Disease category, <i>n</i> (%)		
Congenital and chromosomal	1 (14)	3 (33)
CNS static encephalopathy		2 (22)
CNS progressive		1 (11)
Cardiac	1 (14)	1 (11)
Oncologic	1 (14)	1 (11)
Pulmonary	3 (43)	1 (11)
Renal	1 (14)	
Palliative care involvement, <i>n</i> (%)		
Yes	5 (71)	7 (78)
Advanced directive, <i>n</i> (%)		
Yes	3 (43)	5 (56)
Insurance type, <i>n</i> (%)		
Public	5 (71)	3 (33)
Combined	1 (14)	5 (56)
AYA or parent's child died within 1 y of interview, <i>n</i> (%)		
Yes	4 (57)	3 (33)

CNS, central nervous system; —, not applicable.

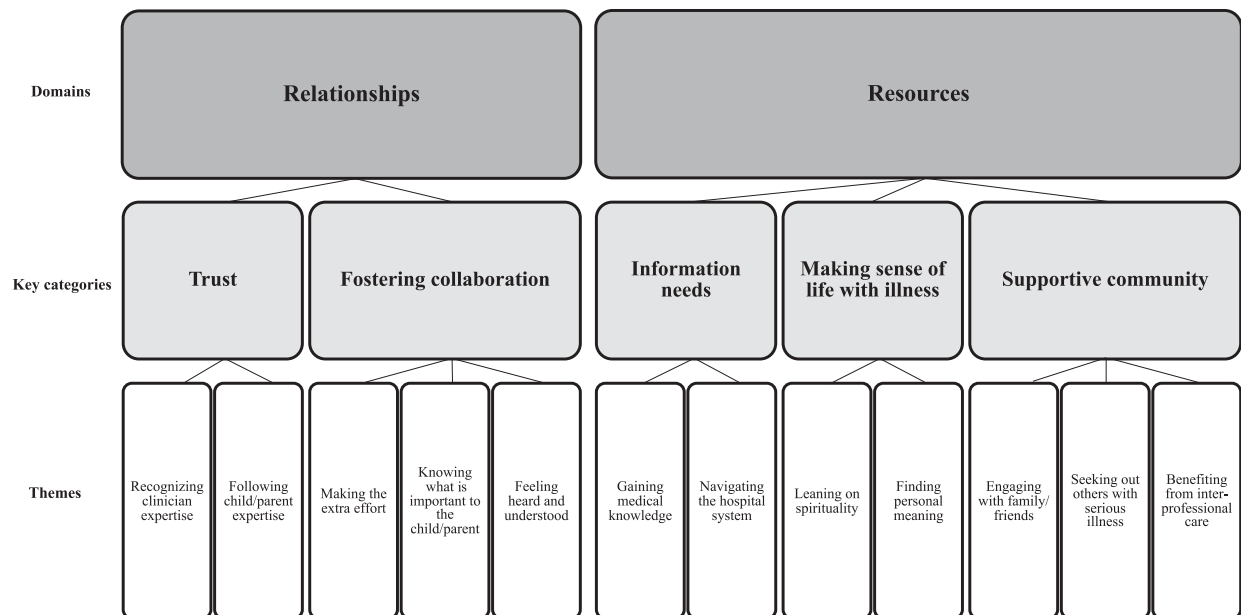


FIGURE 1 Mutually reinforcing connections among relationship and resource domains, categories, and themes.

particular needs and could help guide them through medical decisions.

“If we were to come with a new admission and [the clinicians] could say, ‘We know that you want to see [your child] sparkle, we know that you want to be sure that he’s got a good quality of life,’ that would be great—if I felt like people already knew that.” [Parent 5]

“We’ve been together for a long time [in the ICU], so they kind of have the same views I do, and they know what I want [for my child] and they try to help me do it.” [Parent 1]

Particularly in advance care planning discussions about end-of-life care, parents wanted clinicians with whom they had rapport and comfort. If participants did not feel a sense of collaboration, they disengaged.

“In my mind was, ‘Wow, I’m about to have a conversation about whether or not [my child] will live or die, and these are not the people who have been the warmest to me or made me feel most at peace and comfortable.’” [Parent 5]

Finally, participants reported that collaboration stemmed from feeling heard and understood.

“When they go that extra step to make a family feel heard and validated and appreciated, it goes a long way.” [Parent 8]

Resources: Information Needs, Making Sense of Life With Illness, and Supportive Community

For information needs, participants felt that gaining medical knowledge and an understanding of how to navigate the hospital system were essential resources that helped them cope with their or their child’s CCC.

“A lot of parents don’t have any medical background ... you’re kind of at [the medical team’s] mercy. Like when I first came in, I let them do whatever they want[ed]. I wish I knew what I know now because I probably would have done things differently.” [Parent 1]

These information needs were met over time as AYAs and parents became more well-versed in their/their child’s particular CCC and hospital care.

“I see a musician going by. How do you get to do that? ... A lot of us don’t know—I mean, you have to ask for it ... the fun

stuff that the hospital has to offer.” [Parent 6]

Participants also discussed the importance of making sense of life with illness to build their own internal resources. For some, this “sense-making” centered on leaning on their spirituality. For other participants, they described a lack of traditional forms of spiritual practice and the need for different concepts that helped with personal meaning-making. These included feeling like a good parent and/or growing personally through their parenting experience.

“I always believed in something that’s a higher power ... almost like a karma-driven thing of ‘Be a good person, promote good, give off good and in a perfect world that will come back to you.’” [AYA 7]

“We don’t have a faith in God ... I just want to feel like when we get to the end, we can say we did what we could for him, and we did good. We know we did our best by him.” [Parent 5]

Finally, resources included the supportive community that surrounded participants. This included engaging with family and friends.

TABLE 2 Exemplar Quotes From AYAs and Their Parents About the Relationships and Resources That Bolster Serious Illness Communication and Connection

Domains, Key Categories, and Subthemes	AYAs	Parents
Relationships		
Trust		
Recognizing clinician expertise	Communication is a big factor, and it's something that my family and I have recognized over the years that does not happen very well . . . because you're putting your health and you're wanting to trust these people that say my name's so-and-so, I'm with this team and we're going to get you better. [AYA 7]	One of his doctors . . . he referred me to another neurologist, and I said, why do you want me to see this guy . . . and he said because he's very comfortable with end-of-life discussions, and I think he's going to be a good asset for you. And I was so grateful for that advice, insight, and compassion . . . and [steering] me toward somebody who would feel comfortable talking with our family. [Parent 8] This one doctor said . . . "Put her on the vent, and then you can have the conversation" . . . And then as time progressed . . . make educated decisions instead of just an emotional decision. [Parent 3]
Following child/parent expertise	I felt like I was dismissed. I felt like I said something and he was just like, "yeah, okay," and for all of the pain and all of the suffering and all of the fortitude—all of those things to get to this point—I don't think that anyone deserves to be talked to like that who's dealt with such larger than life things that are just really, really hard to deal with. [AYA 7]	Parents know their kids the best . . . I think just showing that you care and then whoever they connect with would be the go-to person to talk to. [Parent 3] There's an issue for doctors of how do you know if you can trust a parent and how do you know when to listen to a parent and not? I mean, for all he knew I could have been [a] parent who was trying to do something really out of the realm of what was logical. So I get it, that he didn't know me, so why should he necessarily blindly trust what I was saying . . . I get that it's a two-way street, but nine times out of ten I think – you can respect what the parent is saying. [Parent 8]
Fostering collaboration		
Making the extra effort	I feel like [my transplant coordinator] has been there literally through every single step of my life . . . Some people you can tell that they put their whole heart into their job, and they care about their patients. [AYA 5] It's just some of them you just know that they're gonna fight for you and others not so much. [AYA 4]	There's a doctor there who . . . I've known him for 20-something years, and he used to call me at home after we were discharged to see how we were doing . . . and say, you know, it was a tough week, are you guys okay? . . . And I just always felt like that really made an impression on me . . . it's like the doctor that goes that extra step. [Parent 8]
Knowing what's important to the child/parent	I want my health but I also want a life. I want a life to be able to live and flourish with and so on, so I think that my doctors, they get that. [AYA 7] I feel like you should know and be invested in a patient rather than just a name on a piece of paper. [AYA 4]	I feel like her team does listen to her. They try to get her home as much as they can because they know her [priorities]. [Parent 2] [My son's clinicians] are almost like family . . . they know what I want . . . and they know when you're here it's difficult. [Parent 1]
Feeling heard and understood	[She's] been my nurse for a very, very long time, so I'm definitely—I feel very comfortable with her in talking about everything. [AYA 5]	I think it's a two-way street . . . I work much better with a specialist who's collaborative and who's willing to listen. [Parent 8] I would no sooner have wanted to discuss the future of my child's care with this guy because I didn't trust him in the present . . . He was doing nothing to make me feel heard and to make me feel comfortable. [Parent 8]

TABLE 2 Continued

Domains, Key Categories, and Subthemes	AYAs	Parents
Resources		
Information needs		
Gaining medical knowledge	I'm just listening to you because you're the doctor and we, as in patients, don't know anything . . . but I never realized that you can adapt and tell them that, oh, you want this and you don't want that. [AYA 6]	I didn't know anything when I first started . . . And now I know him . . . I'm [not] a medical person, but I know everything it takes to keep him going. [Parent 1]
Navigating the hospital system	It would be kind of ridiculous to have just a direct like batman signal out to your [subspecialists] and just be like you know you always have to be available to me. [AYA 5]	There's no routine when you first get here. You don't know where anything is. You don't know what you're doing. What am I going to do with my laundry? . . . Food. [But now] it's like I've lived here for a year. [Parent 1] If I can't get my [child's] doctor . . . they at least send a token somebody, but I will E-mail the doctors directly myself and say, we're here, can you come down? [Parent 8]
Making sense of life with illness		
Leaning on spirituality	I have a back-and-forth relationship with how I feel about god . . . I just like the community of people, and that's my church—[it] is the people. [AYA 5]	I think spiritually, when I know that I know, then I'm adamant . . . I'm talking about my child's life. So I believe it's definitely a divine intervention. [Parent 3] I think everybody gets closer to God when your kid is not well. [Parent 4]
Finding personal meaning	We were the initial study group for if [this drug] was going to be used . . . and it turns out that it's one of the most widely used drugs now . . . and so I feel very proud of that . . . through our struggle, something really good [came] from it. [AYA 7]	It's beautiful . . . When you have a special needs kid or a kid that's not healthy or that has challenges, you love them strictly for who they are. [Parent 4]
Supportive community		
Engaging with family/friends	For me, my family unit is extremely important. They're my rock, and they're my support network. [AYA 7] My mom and I don't talk a lot . . . we have a kind of a rocky relationship . . . [my illness] just ends up being one of those not-talked-about things. [AYA 5]	We tell our family and friends [when we are in the hospital], and then they show up for lunch, and then they feed us meals. [Parent 5]
Seeking out others with serious illness		One of the first things I do when I'm admitted is I click onto my Facebook group and I'm like, we're in trouble, we're in the hospital, who's been down this road before . . . and there will be 30 mothers who answer me within an hour. [Parent 8]
Benefiting from interprofessional care	We use some mental health organization . . . I vent to them . . . and I get that emotional support. [AYA 5] I always put a lot of faith in the social workers—they are a great liaison. [AYA 7]	[Our son's] got a really good group of personal care attendants who love him and they'll come and light up his day and light up our day. [Parent 5] I think every parent should reach out to [palliative care] because they can give you a lot of support. [Parent 1]

"I have a best friend, and ... just staying in contact with her is my emotional support." [AYA 5]

Support from other parents of children with CCCs was another aspect important to the supportive community that sustained participants.

"That was just a really important thing for me to know—that I have other people out there that are experiencing the same thing, that I can talk to and get information and suggestions [from]." [Parent 9]

Additionally, participants described benefiting from interprofessional care such as mental health professionals, child life specialists, or home nurses who sometimes felt like family to children with CCCs and/or their parents.

"Our caretakers are closer to us and [our son] and [our son's] medical situation than any of my siblings are, and even my dad ... It's not family, but they're kind of like family." [Parent 5]

DISCUSSION

This qualitative study of AYAs with CCCs and parents revealed key categories and corresponding themes within the domains of relationships and resources that support serious illness care. Trust and collaboration were considered by participants to be essential for relationships with their and/or their child's clinical team. Harnessing the necessary information, sense-making with illness, and supportive community were crucial resources. In aggregate, these aspects of care were imperative to facilitating and optimizing supportive serious illness care.

In our study, relationships centered on knowing the child and parent and the sense of collaboration and partnership felt with clinicians. When relationships did not exist, participants disengaged with clinicians which hindered communication about treatments and end-of-life care. These findings are similar to other studies among children with CCCs and their parents, in which the need to feel valued, seen, and heard as a patient and/or parent were essential for effective clinical partnerships and compassionate

communication.^{9,33,34} Similarly, resources identified by participants in this study that supported them were also aligned with other studies.^{10,35} In these studies, supports centered on knowledge acquisition for the AYA/parent and access to psychosocial resources. It also included having an illness community to draw on in times of need, both for information and for perspective, grounding, and strength as well as a way to help others.^{27,36} These aspects have been shown to be important among other seriously ill AYA/adult patient populations and their family caregivers.²⁸

What this study adds is a more nuanced understanding of the aspects of relationships and resources that support care among AYAs with CCCs and parents. Specifically, many of the key categories and themes identified by participants in our study had both tangible and intangible components. For example, for participants, trust had to do with intrapersonal aspects of feeling trusted as a person as well as interpersonal aspects such as demonstrating trusting behaviors (ie, collaboration, openness to the patient/parent perspectives). Making sense of life with illness was described similarly because participants shared that there were internal aspects such as spirituality as well as external aspects like helping others.

Additionally, many of the key categories and themes of relationships and resources revealed the distinct yet interconnected nature of these aspects of care. For example, the concepts of listening and feeling heard by clinicians were present in many of the aspects important to relationships such as aligning with the best interest of the child/parent, knowing the child/parent, and working with them toward their goals. These overlapping aspects of relationships and resources create complexity because aspects of supportive relationships and resources may influence one another in mutually reinforcing ways. These connections likely are impactful in clinical care. For example, children/parents who feel they have more resources (whether through medical knowledge or the support of family and friends) may also feel more

comfortable with advocacy for themselves/their child.³⁷ Additionally, child/parent–clinician relationships that have more trust may translate to some children/parents gaining broader access to resources and supportive services in the hospital.³⁸

Being mindful of these aspects of care can help clinicians strengthen relationships and resources for all patients/families to counteract structures that further disparities.^{39–41} Specifically, differences in access to supportive services and resources is imperative. For example, it is crucial to consider who receives extra time with clinicians or more mental health professional support because these differences can have impactful consequences in other areas of supportive care. Additionally, patients and families who feel more empowered to advocate for hospital resources may be disproportionately receiving these supports, such as music or pet therapy. There are also opportunities to consider further integration with social supports from the community and online social networks and organizations into everyday care because these may be the preferred ways that some children/families receive relational and resource supports.⁴² Innovative mechanisms to maintain community integration of family and friends, potentially using virtual platforms, may be another way to support patients and families and broaden the relationships and resources all people receive. Novel interventions and programs that are designed to share information with patients/families about hospital navigation,⁴³ engage clinicians with patient/parent expertise,⁴⁴ and promote the clinical team's knowledge of the child's/parent's goals are critical areas for further development.⁴⁵ Future work is needed to explore relationships and resources that support serious illness care more fully, to understand differences within and among different patient populations, and to develop interventions that promote these essential aspects of care.

Limitations

Our study has several limitations. Although it was conducted at 2 sites, we had a small sample size of predominantly white females, which limits transferability to more diverse child/parent populations. Additionally, all participants were English-speaking, further limiting our ability to explore the perspectives of AYAs and parents of children with CCCs who prefer a language other than English. This study was a secondary analysis of work conducted to develop a serious illness communication program and therefore aspects important to relationships and resources may have been missed. Results should therefore be considered a starting place on aspects important to patients and families within these domains. Despite this, much of the data shared by participants centered on these topics, indicating that these domains and their corresponding key categories and themes are impactful. Additionally, many AYAs and children of parent participants died within a year of the study potentially limiting information about serious illness care for CCCs earlier in the disease trajectory.

CONCLUSION

This study suggests that there are aspects of clinical relationships and internal and external resources that effectively support children with CCCs and their parents during serious illness. Cultivation of these supports through innovative interventions and attention to children/AYAs and parents who may have more needs in these areas may improve the communication and connection provided around serious illness care.

Acknowledgments

We thank the participants who generously shared their ideas and perspectives for this study.

REFERENCES

1. Feudtner C, Christakis DA, Connell FA. Pediatric deaths attributable to complex chronic conditions: a population-based study of Washington state, 1980–1997. *Pediatrics*. 2000;106(1 Pt 2):205–209
2. Berry JG, Ash AS, Cohen E, Hasan F, Feudtner C, Hall M. Contributions of children with multiple chronic conditions to pediatric hospitalizations in the United States: a retrospective cohort analysis. *Hosp Pediatr*. 2017;7(7):365–372
3. Cohen E, Berry JG, Camacho X, Anderson G, Wodchis W, Guttmann A. Patterns and costs of health care use of children with medical complexity. *Pediatrics*. 2012; 130(6):e1463–e1470
4. Simon TD, Berry J, Feudtner C, et al. Children with complex chronic conditions in inpatient hospital settings in the United States. *Pediatrics*. 2010; 126(4):647–655
5. Perrin JM, Anderson LE, Van Cleave J. The rise in chronic conditions among infants, children, and youth can be met with continued health system innovations. *Health Aff (Millwood)*. 2014; 33(12):2099–2105
6. Kelley AS. Defining “serious illness”. *J Palliat Med*. 2014;17(9):985
7. Feudtner C. Collaborative communication in pediatric palliative care: a foundation for problem-solving and decision-making. *Pediatr Clin North Am*. 2007;54(5): 583–607, ix
8. Bogetz JF, Revette A, DeCoursey DD. Clinical care strategies that support parents of children with complex chronic conditions. *Pediatr Crit Care Med*. 2021;22(7):595–602
9. Bogetz JF, Trowbridge A, Lewis H, et al. Parents are the experts: a qualitative study of the experiences of parents of children with severe neurological impairment during decision-making. *J Pain Symptom Manage*. 2021;62(6): 1117–1125
10. Boyden JY, Hill DL, Nye RT, et al. Pediatric palliative care parents’ distress, financial difficulty, and child symptoms. *J Pain Symptom Manage*. 2022;63(2):271–282
11. Coats H, Bourget E, Starks H, et al. Nurses’ reflections on benefits and challenges of implementing family-centered care in pediatric intensive care units. *Am J Crit Care*. 2018;27(1):52–58
12. Feudtner C, Schall T, Hill D. Parental personal sense of duty as a foundation of pediatric medical decision-making. *Pediatrics*. 2018;142(Suppl 3):S133–S141
13. Madrigal VN, Hill DL, Shults J, Feudtner C. Trust in physicians, anxiety and depression, and decision-making preferences among parents of children with serious illness. *J Palliat Med*. 2022;25(3):428–436
14. Basu MR, Partin L, Revette A, et al. Clinician identified barriers and strategies for advance care planning in seriously ill pediatric patients. *J Pain Symptom Manage*. 2021;62(3):e100–e111
15. Blume ED, Balkin EM, Aiyagari R, et al. Parental perspectives on suffering and quality of life at end-of-life in children with advanced heart disease: an exploratory study. *Pediatr Crit Care Med*. 2014;15(4):336–342
16. Bona K, London WB, Guo D, Abel G, Lehmann L, Wolfe J. Prevalence and impact of financial hardship among New England pediatric stem cell transplantation families. *Biol Blood Marrow Transplant*. 2015;21(2):312–318
17. Zaal-Schuller IH, Willems DL, Ewals FVPM, van Goudoever JB, de Vos MA. Considering quality of life in end-of-life decisions for severely disabled children. *Res Dev Disabil*. 2018;73:67–75
18. Nolan R, Luther B, Young P, Murphy NA. Differing perceptions regarding quality of life and inpatient treatment goals for children with severe disabilities. *Acad Pediatr*. 2014;14(6):574–580
19. Dussel V, Bona K, Heath JA, Hilden JM, Weeks JC, Wolfe J. Unmeasured costs of a child’s death: perceived financial burden, work disruptions, and economic coping strategies used by American and Australian families who lost children to cancer. *J Clin Oncol*. 2011;29(8):1007–1013
20. Cousino MK, Hazen RA. Parenting stress among caregivers of children with chronic illness: a systematic review. *J Pediatr Psychol*. 2013;38(8):809–828
21. Ruggiano N, Perry TE. Conducting secondary analysis of qualitative data:

- should we, can we, and how? *Qual Soc Work*. 2019;18(1):81–97
22. Alasuutari P, Bickman L, Brannen J, eds. *The SAGE Handbook of Social Research Methods*. Newbury Park, CA: SAGE; 2008
 23. DeCoursey DD, Partin L, Revette A, Bernacki R, Wolfe J. Development of a stakeholder driven serious illness communication program for advance care planning in children, adolescents, and young adults with serious illness. *J Pediatr*. 2021;229:247–258.e8
 24. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care*. 2007; 19(6):349–357
 25. Courageous Parents Network. Welcome. Available at: <https://courageousparentsnetwork.org/>. Accessed January 21, 2022
 26. Vaismoradi M, Turunen H, Bondas T. Content analysis and thematic analysis: implications for conducting a qualitative descriptive study. *Nurs Health Sci*. 2013;15(3):398–405
 27. Wiener L, Tager J, Mack J, Battles H, Bedoya SZ, Gerhardt CA. Helping parents prepare for their child's end of life: a retrospective survey of cancer-bereaved parents. *Pediatr Blood Cancer*. 2020; 67(2):e27993
 28. Mack JW, Ilowite M, Taddei S. Difficult relationships between parents and physicians of children with cancer: a qualitative study of parent and physician perspectives. *Cancer*. 2017;123(4): 675–681
 29. Mack JW, Wolfe J, Cook EF, Grier HE, Cleary PD, Weeks JC. Peace of mind and sense of purpose as core existential issues among parents of children with cancer. *Arch Pediatr Adolesc Med*. 2009;163(6):519–524
 30. Burkholder GJ, Cox KA, Crawford LM, Hitchcock J, eds. *Research Design and Methods: An Applied Guide for the Scholar-Practitioner*, 1st ed. Newbury Park, CA: SAGE; 2019
 31. NVIVO. Unlock insights in your data with the best qualitative data analysis software. Available at: <https://www.qsrinternational.com/nvivo-qualitative-data-analysis-software/home>. Accessed January 22, 2022
 32. Attride-Stirling J. Thematic networks: an analytic tool for qualitative research. *Qual Res*. 2001;1(3):385–405
 33. Zaal-Schuller IH, de Vos MA, Ewals FVPM, van Goudoever JB, Willems DL. End-of-life decision-making for children with severe developmental disabilities: the parental perspective. *Res Dev Disabil*. 2016; 49–50:235–246
 34. Lord S, Moore C, Beatty M, et al. Assessment of bereaved caregiver experiences of advance care planning for children with medical complexity. *JAMA Netw Open*. 2020;3(7):e2010337
 35. Thomson J, Shah SS, Simmons JM, et al. Financial and social hardships in families of children with medical complexity. *J Pediatr*. 2016;172:187–193.e1
 36. Bogetz J, Trowbridge A, Kingsley J, et al. Stuck moments and silver-linings: the spectrum of adaptation among non-bereaved and bereaved parents of adolescents and young adults with advanced cancer. *J Pain Symptom Manage*. 2021;62(4):709–719
 37. Raikes HA, Thompson RA. Efficacy and social support as predictors of parenting stress among families in poverty. *Infant Ment Health J*. 2005; 26(3):177–190
 38. Chipidza FE, Wallwork RS, Stern TA. Impact of the doctor-patient relationship. *Prim Care Companion CNS Disord*. 2015;17(5):10.4088
 39. DeGroot NP, Allen KE, Falk EE, et al. Relationship of race and ethnicity on access, timing, and disparities in pediatric palliative care for children with cancer. *Support Care Cancer*. 2022; 30(1):923–930
 40. Newacheck PW, Hung YY, Wright KK. Racial and ethnic disparities in access to care for children with special health care needs. *Ambul Pediatr*. 2002; 2(4):247–254
 41. Johnston EE, Bogetz J, Saynina O, Chamberlain LJ, Bhatia S, Sanders L. Disparities in inpatient intensity of end-of-life care for complex chronic conditions. *Pediatrics*. 2019;143(5): e20182228
 42. Househ M, Borycki E, Kushniruk A. Empowering patients through social media: the benefits and challenges. *Health Informatics J*. 2014;20(1):50–58
 43. Michelson KN, Charleston E, Aniceti DY, et al. Navigator-based intervention to support communication in the pediatric intensive care unit: a pilot study. *Am J Crit Care*. 2020;29(4):271–282
 44. Coats H, Meek PM, Schilling LM, Akard TF, Doorenbos AZ. “Connection”: the integration of a person-centered narrative intervention into the electronic health record: an implementation study. *J Palliat Med*. 2020;23(6):785–791
 45. Bogetz JF, Lewis H, Trowbridge A, Jonas D, Hauer J, Wilfond BS. From monochromatic to technicolor: parent perspectives on challenges and approaches to seeing children with severe neurological impairment holistically. *J Palliat Med*. 2022; 25(3):437–444