Parent-to-parent peer support for children and youth with special health care needs: Preliminary evaluation of a family partner program in a healthcare system

McLean D. Pollock, PhD, MSW [a],[*], David Ming, MD [b], Richard J. Chung, MD [b], Gary Maslow, MD, MPH [a],[b]

[a] Department of Psychiatry and Behavioral Sciences, Duke University School of Medicine, Durham, NC, United States of America
[b] Department of Pediatrics, Duke University School of Medicine, Durham, NC, United States of America

ABSTRACT

Purpose: Children and youth with special health care needs (CYSHCN) have complex care and coordination needs that are often managed by parents or primary caregivers. This study describes a parent-to-parent peer support pilot program for parents of CYSHCN implemented in both outpatient and inpatient settings across a large health system.

Design & methods: Retrospective data from the Family Partner Program documentation in patient health records are described. Descriptions about the encounters and types of support provided are also reviewed using qualitative descriptive analysis.

Results: Three Family Partners conducted 203 encounters with parents of 90 CYSHCN over six months. Family Partners provided both emotional and tangible support. Primary themes discussed included the persistent care, coordination and management needs related to parenting a child with complex care needs, the subsequent worry and stress about their child and family, and the need for stress management and self-care.

Conclusion: This study provides early evidence that implementation of a parent-to-parent peer support program for parents of CYSHCN in a large, academic medical center is feasible. Family Partners enhanced their healthcare team's ability to provide patient- and family-centered support for pediatric patients and their families through the provision of emotional and tangible support.

Practice implications: Family Partners, who are trained in effective use of the shared experience, the health coach model, and healthcare systems, and who are supported by a strong supervisory team, are ideally suited to support families and patients as they address their concerns and unmet needs and navigate complex health circumstances.

© 2022 Elsevier Inc. All rights reserved.

Introduction

Children and youth with special health care needs (CYSHCN) often have a multitude of service and support needs, including medical, educational, financial, social, and advocacy-related needs (Roman et al., 2020). Parents or primary home caregivers (referred to as "families") of CYSHCN often assume informal clinical responsibilities, including administering health treatments (Carter et al., 2012), monitoring and managing symptoms (Hinton & Kirk, 2017), and coordinating multiple appointments and services (Allshouse et al., 2018; Pizur-Barnekow et al., 2011), while also facing other work, family, and financial obligations (Romley et al., 2017). Additionally, caregivers must navigate multiple complex and siloed systems in order to advocate for and coordinate care and resources needed to preserve their child's health, functioning and quality of life (Golden & Nageswaran, 2012; Miller et al., 2009). The demands of managing the care of CYSHCN can result in increased parental stress (Cousino & Hazen, 2013), negative impacts on health and fatigue (Nygård & Clancy, 2018), and reduced mental and physical quality of life (Hatzmann et al., 2008; Remedios et al., 2015) and family cohesion and functioning (Quittner et al., 1998). In the face of these demands, caregivers often rely on information and support from health care providers, yet often experience negative interactions, including mistrust, lack of communication and feeling ignored within the health care system (Trollvik & Severinsson, 2004). It is of vital importance to the overall experience of care and well-being of both children and their caregivers that health care providers are able to effectively communicate and provide targeted support in the healthcare setting.

* Corresponding author at: Duke Psychiatry, DUMC, Box# 102506, Durham, NC 27 United States of America.

E-mail address: mclean.pollock@duke.edu (M.D. Pollock).

Originally designed to support families of youth with behavioral health conditions (Kelleher et al., 2008), parent-to-parent peer support (PPPS) programs offer parents of CYSHCN tangible support from another parent with current or past experience caring for a CYSHCN. Shared lived experiences as caregivers for CYSHCN (Hoagwood et al., 2010) strengthens the credibility of PPPS as a source of emotional support, tangible support, and advocacy. The PPPS model has been successfully adapted to various populations and demonstrated: reduced parental distress and enhanced coping abilities among parents of children with disabilities (Bray et al., 2017); increased parental awareness of support services (Ainbinder et al., 1998) and active planning for youth transitions into adulthood (Kingsnorth et al., 2011); and decreased isolation among parents of medically-fragile children (Nicholas & Keilty, 2013). Translating these promising research findings into busy clinical settings is a critical step that is needed before the potential benefits of PPPS can be fully realized. Given the demonstrated value of the PPPS model, active clinical healthcare settings are ideal systems in which to deploy this model to support families of CYSHCN and bring this service to a large and diverse population of CYSHCN.

In the family-centered care model family members or caregivers are valued as experts in the lives of their children. In this model the care team aims to engage family members in making decisions about the child's care and treatment, yet family members often lack the health literacy and communication skills to appropriately and sufficiently advocate for their children across systems of care (Pizur-Barnekow et al., 2011). The Family Partners program, a specific PPPS program, deploys Family Partners, who draw upon personal experiences, supplemented by health coach and health systems training, and supported by a strong supervisory team, are ideally suited to support families and patients as they address their concerns and unmet needs and navigate complex health circumstances.

This pilot study describes our experience implementing the Family Partner Program PPPS model to serve families of children, adolescents and young adults with medical complexity, chronic medical conditions, and intellectual or developmental disabilities in both outpatient and inpatient settings across a large health system. The purpose of this study was to describe the support provided and the population served through this PPPS pilot program.

Methods

Setting

We first piloted a PPPS model, the Family Partner Program, at our institution in 2014 to serve CYSHCN transitioning from pediatric to adult healthcare. The Family Partner role was created to provide a family- and patient-centered team member who can serve as a bridge between clinical expertise and the patient/parent experience. Initial funding for the Family Partner program was made available through an internal grant supported by fundraising through Duke Children's Hospital and the Department of Pediatrics. During the early stages of this program, we found that parents of CYSHCN appreciated the opportunity to speak to a supportive person with shared lived experience who partnered to enhance parental capacity to self-manage care for their CYSCHN and implement practical parental self-care strategies, such as prioritizing goals for their child's individual education plan or identifying others who can provide care for their child to provide a brief respite for the caregiver. Building on this early proof-of-concept experience, in 2018 we expanded the Family Partner Program, building a team of three Family Partners deployed to a wide range of clinical settings across our health system to serve a diverse group of CYSHCN.

This study was conducted between June and November 2018 (six months) at a large tertiary care center in the southeastern United States. The team of three Family Partners worked in three separate settings: an inpatient setting as part of a pediatric complex care program for care of children with medical complexity (Pordes et al., 2018) in a

190-bed children's hospital; a large pediatric primary care clinic with over 75,000 visits per year, and in a specialty pediatric behavioral health clinic serving children with chronic medical conditions and/or intellectual and developmental disabilities, including autism. In both inpatient and ambulatory care settings Family Partners were embedded with medical teams and interacted directly with a physician or nurse practitioner who would introduce them to the parents of CYSHCN served by the clinic. Family Partners were hired as employees of the Medical Center and were able to document their interactions with patients in the electronic health record (EHR).

Family Partner training and supervision

Family Partners are parents with current or past lived experience caring for CYHCN who are formally trained, hired, and embedded into clinical teams to serve as a bridge between clinicians and patients/parents. Similar to other peer support intervention training programs (Allicock et al., 2012; Allicock et al., 2017; Bray et al., 2017), over the course of two months, Family Partners received training that included four, half-day sessions on motivational interviewing and active listening skills from licensed clinical social workers. Ongoing training on active listening skills and resources was provided on a monthly basis after completion of the initial training and after Family Partners began working with families, which allowed Family Partners to refine their skills as they applied them in clinical settings. Regular supervision and support for each Family Partner was provided on an individual basis and as a group by a social worker, social scientist, and physician trained in pediatrics and child psychiatry; each of these supervisors devoted five hours per week to oversee the Family Partner Program. Ongoing supervision has been identified as critical to ensuring fidelity to implementation of interventions (Dorsey et al., 2013), and for peer supporters, supervision from mental health professionals can help address issues or concerns beyond the peer supporter's scope of practice (Barnett et al., 2018). The Family Partners each worked between 10 and 20 h per week and were paid on an hourly basis as health system employees. All three Family Partners were mothers of young adult children with special health care needs and identified as white, non-Hispanic/Latinx.

Approach to Family Partner intervention

After completion of training, one Family Partner was embedded into each of the three clinical settings described above. In each setting, providers and staff first identified parents of CYSHCN who could benefit from enhanced peer support from a Family Partner. Family Partners then supported parents via in-person contacts during clinical encounters or via email/phone contacts outside of clinical encounters (referred to as "supportive contacts"). Family Partners utilized their training and personal experiences to shape the content of supportive contacts with families. During these supportive contacts, Family Partners specifically provided a mix of *emotional* and *tangible support*. *Emotional support* was focused on providing empathy and encouragement through active listening, reassurance, and reflection. Through skilled use of their shared, lived experiences and active listening skills, Family Partners created a nonjudgmental environment that allowed families to discuss the complexity of caring for a CYSHCN and the wide range of emotional experiences that accompany stressors and successes. Family Partners utilized active listening and motivational interviewing skills to support families around specific areas in which *tangible support* (providing information on resources or clarifying how to obtain services, navigate various systems, or advocate for the CYSHCN's needs) was needed including educational, vocational, financial, social/recreational, and future planning. By leveraging shared lived experiences and providing valued resources, the Family Partners were able to engage parents and address needs in ways that other clinical team members were not.

Evaluation design

This was a retrospective study of data from the Family Partner Program records, including meeting minutes and notes from Family Partner training sessions, and the Electronic Health Record (EHR). Family Partners utilized an EHR standardized template to document information about types of supportive contacts provided, durations, and types of support provided. Free text descriptions about the supportive contacts and types of support provided were also documented.

EHR – Family Partner encounter note

Supportive contacts were first categorized as *emotional* or *tangible* (Dennis, 2003) and then further categorized by area of focus: educational, vocational, financial, social/recreational, and future planning (see Fig. 1 of EHR standardized template with support categorizations). These categories of tangible support were developed with the Family Partners as they reflected on their experiences as a parent of a CYSHCN, as well as prior research examining the support needs and stressors of families of CYSHCN (McConnell et al., 2016; Santelli et al., 1995; Woodgate et al., 2015). If the area of support did not fit into these categories, Family Partners designated the interaction as "other"

and provided information about the support provided. Educational support involved providing support and resource information for families' interactions with schools or educational organizations, educational advocacy efforts, obtaining/maintaining individualized education plans, and additional accommodations from early childhood through post-secondary education. Vocational content involved providing support and resource information for pre-vocational skills assessments and training through vocational rehabilitation, employment or post-secondary vocational services or accommodations. Financial content involved providing support and resource information for: health insurance, waivers, government benefits, and budgeting. Social/Recreational included providing support and resource information for extracurricular activities and programming in the community. Finally, the area of future planning involved providing support and resource information for adult living situations, legal capacity/supportive decision-making, and other areas of concerns for adolescents and young adults with special healthcare needs as they transition to older adulthood. Qualitative data for this study were extracted from the Family Partner encounter notes where Family Partners further described the area of focus, support provided, and action plans for follow up, using direct quotations from families so as to more accurately convey the families' perspectives where possible.

Figure 1. Family Partner Non-Clinical Note Template

Patient (child's) first name	[Automated from EHR]
Patient (child's) last name	[Automated from EHR]
Patient MRN	[Automated from EHR]
Parent/guardian name	[Free text]
2nd parent/guardian name	[Free text] ☐ Not applicable
Contact information:	[Free text]
Family Partner name	[Prepopulated list]
Provider name	[Free text]
Date of encounter	[Calendar]
Type of encounter	☐ In person ☐ Phone ☐ Email/in-basket message
Duration of encounter	☐ 0-14 minutes ☐ 15-29 minutes ☐ 30-44 minutes ☐ 45-60 minutes ☐ Greater than 1 hour
Meeting type	☐ Initial ☐ Follow-up
Type of support provided	☐ Tangible support ☐ Emotional support
Area of focus	☐ Educational ☐ Vocational ☐ Financial ☐ Social/Recreational ☐ Future Planning ☐ Other
Describe area of focus in more detail:	[Free text]
If follow-up meeting, please note comments by the family about support from previous meetings(s)	[Free text] ☐ Not applicable
Action Steps Taken/ Resources Given:	[Free text]
Follow-Up:	[Free text]
Additional notes (as needed):	[Free text]

Fig. 1. Family partner non-clinical note template.

Meeting minutes and training notes

In addition to information from supportive contact notes, notes of internal team and supervision meetings were reviewed to capture specific process-oriented challenges that were encountered during the implementation of this project. These challenges and the ways in which they were addressed are summarized. Parent and clinic satisfaction with the Family Partner Program was not assessed in this retrospective review that focused on the available data in the EHR.

Analysis

Descriptive statistics were used to summarize data. This descriptive data included an exploration of the type of support provided and the length of time that Family Partners spent with each patient and family within each clinical setting, and if the supportive contact was provided in person or remotely. Qualitative data were abstracted from EHR and meeting notes. The study team examined free text notes of each Family Partner supportive contact and team meeting and coded content into categories and themes using content analysis – involving a systematic method for analyzing qualitative and quantitative data by classifying data into similar and disparate concepts or categories in order to describe a phenomenon (Elo & Kyngäs, 2008; Graneheim & Lundman, 2004). The Duke Health Institutional Review Board determined this study to be exempt.

Results

Overview

Over six months (June – November 2018), three Family Partners conducted 203 supportive contacts with parents of 90 CYSHCN (mean supportive contacts per parent = 2.26; range = 1–17; see Table 1 for additional encounter information). The majority of supportive contacts

Table 1
Summary of family partner encounters.

Unique pediatric patients served, n	90
Female, n (%)	47 (52)
Age (in years), mean (range)	13 (1–24)
Race, n (%)	
American Indian/Native American	2 (2)
Asian	2 (2)
Black or African American	30 (33)
More than one race	3 (3)
White/Caucasian	51 (57)
Unknown/Not reported	2 (2)
Ethnicity, n (%)	
Latino or Hispanic	9 (10)
Not Latino or Hispanic	79 (88)
Unknown/Not reported	2 (2)
Patient/Family encounters, n	203
Encounter type, n (%)	
In-person	163 (80)
Phone	33 (16)
Email	7 (4)
Duration of encounter, n (%)	
0–14 min	53 (26)
15–29 min	71 (35)
30–44 min	44 (22)
45–60 min	26 (13)
Greater than 1 h	7 (4)
Area of focus for encounters, n (%)	
Emotional support	152 (75)
Tangible support	77 (38)
Educational	23 (30)
Vocational	7 (9)
Financial	16 (21)
Social/recreational	20 (26)
Future planning	11 (14)

were in-person (80%), while fewer were conducted by phone (16%). The majority of supportive contacts lasted 15 min or more (74%) with 39% lasting more than 30 min. 75% of supportive contacts involved emotional support, and 38% involved tangible support. The majority of supportive contacts involving tangible support also involved emotional support (61%). Content areas addressed through tangible support are described in Fig. 2 and demonstrate that areas of focus varied across clinical settings with the ambulatory settings covering a variety of content areas. In the inpatient complex care setting, tangible support was primarily categorized as "other", which includes topics such as providing resource information about self-care, building advocacy skills related to speaking with the care team, and identifying community programs for the parents.

Family Partner encounters

Common themes across all clinical settings

Narrative descriptions from the Family Partner EHR notes provided insight into the specific experiences of families receiving support. For example, areas of support included resource and information sharing regarding guardianship and legal capacity in preparation for the transition to adulthood; accessing financial assistance to attain medical equipment for the home; and adjusting to the child's diagnosis and its meaning for the family. When addressing transitioning to adulthood, one Family Partner and parent discussed identifying action steps "to build upon for independence, e.g., how to learn to take medications at appropriate times or how to do laundry." The Family Partner and parent also discussed steps the parent wanted to take to prepare for the future, such as completing the health care Power of Attorney form and determining what type of guardianship was needed for their child.

Additionally, progress notes indicated that families viewed Family Partners as trusted advocates for the family's "voice" with the healthcare team ascertaining that the family's needs were considered when determining next steps in care. Similarly, Family Partners helped caregivers find their own voice with care teams. For instance, one Family Partner helped caregivers identify what questions they wanted to ask of the care team. While the parents adopted the role of advocate, the Family Partner reported in the progress note that families expressed concerns about overstepping boundaries in this role. The Family Partner noted that the parent, "worries about being 'too much' sometimes," and the Family Partner reframed their perspective and provided reassurance for their role as advocates who "focus fully on just their child."

Finally, Family Partner notes captured the families' reporting of the impact of the intervention. Based on these notes, families commented to Family Partners that the emotional support provided was especially helpful as they managed the day-to-day aspects of parenting and caring for a CYSHCN. Family Partners listened without judgment and provided emotional support as caregivers disclosed the hardships and related stress of caring for a CYSHCN and its impact on the family and other relationships. As reported in the Family Partner progress notes, this support was especially important for caregivers as they assumed more care and management of their child and experienced isolation or anxiety-provoking situations with their child. By normalizing the experience of parenting a CYSHCN, the Family Partner also helped parents focus on self-care to help cope and mitigate the related stress. Family Partners noted that parents indicated that knowing that the Family Partner truly understood their situation and emotions based on the shared experience allowed them to disclose and explore more of their experience and ways to enhance their own emotional health and self-care options. In this sense, the Family Partner increased the quality of the care provided to patients and families.

Differences across settings

Inpatient setting – complex care

The Family Partner in the inpatient setting conducted 100 supportive contacts for 28 families and primarily provided emotional support

Fig. 2. Area of focus by clinical setting.

	Educational	Vocational	Financial	Social Recreational	Future Planning	Other
Inpatient Complex Care	4.65%	2.33%	11.63%	0.00%	0.00%	81.40%
Primary Care Clinic	26.67%	16.67%	3.33%	23.33%	16.67%	13.33%
Behavioral Health Care Clinic	29.17%	4.17%	25.00%	27.08%	12.50%	2.08%

(82%) across encounters and focused on the following themes: complexity of caring for a CYSHCN (25% of encounters), stress management (38%), financial concerns (7%), concerns about the health of the child and caregiver (13%), and the need for (parental) self-care (22%). Based on the Family Partner's EHR documentation, caregivers often noted that caring for a child with complex care needs required constant vigilance and management of multiple providers and settings and increased stress on their emotional and physical health, as well as strains on relationships and finances. Parents were often "overwhelmed and overloaded with stress". They discussed with the Family Partner their worries and stress related to "seeing [their child] code" and "staying up all night" with their children as they experienced multiple, intensive care needs. At home, parents reported that they managed multiple providers for their children, including nursing care, occupational therapy, and physical therapy. The Family Partner noted that parents reported concerns of inadequacy when their children experienced increased care needs despite their coordination efforts. When one child required placement of a jejunostomy feeding tube, the parent indicated that "converting to the J-tube feels like a step backwards [and a] failure." For this parent, the Family Partner normalized this concern and helped to reframe the intervention as a means of providing "comfort and protection" and a "step forward in quality of life." Tangible support provided by the Family Partner in the inpatient setting primarily focused on communicating caregivers' concerns directly with providers, identifying financial resources such as hospital vouchers for meals for caregivers, services and resources provided by Medicaid, and community resources for families of CYSHCN.

Ambulatory settings

Primary care. The Family Partner in the outpatient primary care setting conducted 45 supportive contacts for 32 families and provided emotional (53%) and tangible support (47%) equally across encounters. In this setting the Family Partner primarily served families of youth with intellectual and developmental disabilities (IDD), and Support focused on stress management (36%), educational needs and services (29%), managing the complexities of services and needs of CYSHCN (14%), health concerns (14%), and social supports (14%). Parents spoke with the Family Partner about the complexities of managing the needs and services for a CYSHCN and how that impacted their own lives. The Family Partner reported that one parent reported that she was unable to

continue to work outside the home due to the ongoing needs of her child, and these complexities contributed to "family tensions among siblings and one another" and resulted in the parent feeling, "very angry, frustrated, and isolated." The Family Partner also focused on educational concerns such as individualized education plans (IEPs), attending school, and transitioning to post-secondary education. Finally, the Family Partner often provided emotional support for caregivers as they discussed social support needs for both the youth and the family. The Family Partner noted that parents reported that they and their children felt isolated due to the child's condition(s), and together with the Family Partner, they made plans to identify appropriate social groups and activities. Tangible support in the outpatient primary care setting for youth with IDD centered around educational and financial concerns, including IEP resources, transportation, and Medicaid support services.

Behavioral health care. In the mental health specialty setting, the Family Partner conducted 58 supportive contacts for 30 families and primarily provided emotional support to patients and families across encounters (78%). Supportive contacts covered various areas of focus, including addressing the complexities of caring for a CYSHCN (39%), future planning or vocational concerns (26%), self-care or stress management (23%), educational concerns (19%), physical and emotional health concerns (12%), and financial concerns (10%). The Family Partner noted that caregivers identified fatigue from managing their child's care and physical and emotional health needs. This included identifying providers, as well as monitoring symptoms, activity, and nutrition logs, and how those complexities interacted with other systems, such as school and work, and relationships with family and friends. Through this, the Family Partner also helped parents articulate how to "have time for [themselves]" to focus on self-care and reduce feeling overwhelmed and stressed. Tangible support included provided information about social supports, educational resources, and financial support information, such as insurance and financial assistance programs.

Implementation process

Notes of internal team and supervision meetings tracked the progress and challenges of implementing and adapting this pilot program. As the Family Partner program was a pilot program, the Program Director maintained meeting notes to inform the continual development of the program and evaluation of the implementation of the model. The

administration of this Family Partner program in a range of settings required adjustments in an iterative fashion. Adapting the parent peer support model in the health care system underscored the need for advocates or program champions within clinical teams, continuous and clear communication across providers and Family Partners, and ongoing clinical and administrative supervision. Specific challenges identified related to both programmatic work prior to the deployment of the Family Partners as well as related to the launching of the Family Partner program within clinics. Prior to embedding Family Partners in clinical settings there were logistical challenges related to developing compliant documentation in the medical record (see Fig. 1 for Family Partner Note template), the hiring process, training, supervision, and securing funding support. In addition, healthcare team members had to learn how to best integrate the new Family Partner role within the team's workflow. Without a clear understanding of the type of support provided by the Family Partner or without institutional support in the form of Medicaid or insurance reimbursement, Family Partners had to incorporate continuous advocacy for the role and for a place within the clinic's workflow. Thus, Family Partners utilized individual and group supervision to identify ways to address or circumvent these challenges.

Specific issues arose related to initial set-up and role-clarification with clinic partners, staff identification of relevant patients, documentation strategies, planned follow-up, development and distribution of resources, and navigating the relationship between young adults and parents. Because the Family Partner role was new to the healthcare system and based on peer support and shared lived experience rather than professional guidelines and credentialing, incorporating the Family Partner as a part of the extended healthcare team required orientation and onboarding with the clinical setting before introducing the individual Family Partner. The first step was identifying at least one provider from each clinical setting who assumed the role of Family Partner champion. Champions of the Family Partner role within the individual clinic were essential to advocating for Family Partner referrals and identifying families who would benefit from this service. This role entailed utilizing a family-centric approach to pediatric patient care and valuing partnering with parents or caregivers in order to address the complex needs of CYSHCN, as well as providing care that would otherwise need to be provided by a healthcare provider who may not have the necessary content expertise or sufficient time to explore resource needs. With this understanding, the champion served as the advocate for identifying how the Family Partner could fit within their clinical setting's unique workflow, including how to refer patients/families to the Family Partner, determining how the Family Partner could communicate with families both at the clinical setting and outside of appointments, and sharing information about the patient/family between providers and the Family Partner. For this program, the Family Partner champions were physicians in the clinical setting, who often also were a Medical or Clinic Directors and who had the authority to add this new role to the healthcare team.

A key facilitator of successful implementation at the three participating clinical settings was use of a team approach. For example, staffing meetings or "huddles" to discuss caseloads and care coordination were able to incorporate the Family Partner role more efficiently and effectively than clinical settings where team huddles were not scheduled and utilized to plan for patient care. Family Partners who worked with these teams participated in team meetings and contributed additional information about the parent or family perspective. Family Partners also provided education and support to clinical staff and curated relevant resources for providers to share with families. The team-oriented communication style facilitated a better understanding across the team of how the Family Partner could serve families and contribute to other healthcare team members. In contrast, clinical settings where providers primarily functioned in silos encountered more challenges with incorporating the Family Partner role as a part of the healthcare team. Without the opportunity to discuss patients and families at a team

huddle, Family Partners found it difficult to identify opportunities to communicate and coordinate support with providers. Additionally, in the more siloed settings, providers connected fewer patients and families to the Family Partner and requested support from the Family Partner not relevant to the role, such as completing paperwork for families or submitting referrals for ancillary care. These clinical settings struggled with understanding how the Family Partner could help patients and their families, identifying families for the Family Partner to provide support, and communicating support needs and delegating responsibilities for providing that support.

An additional key facilitator of implementation was the use of team meetings. These regularly scheduled meetings helped to address challenges, develop community, and maximize the extensive collective experience and knowledge within the team about available supportive resources for patients and families. Family Partners participation in regular team meetings also instilled logistical support, information sharing, and group supervision within the program. Group supervision allowed Family Partners to share their experience and expertise with one another and to refine the intervention and its implementation based on experiences in the clinical settings. Family Partners introduced case studies to the group, and the team explored how the Family Partner could best support the family and communicate with team members about the family's and patient's needs or challenges. Team communication differences were also discussed during group supervision, and Family Partners explored strategies to improve communication within teams and advocate for families, as well as the role of the Family Partner within the team. The Family Partner cohort developed into a cohesive team as they shared resource information with one another and together strategized how to navigate challenges that their patients and families faced, as well as how to address workflow and communication hurdles in their clinical settings.

Discussion

Key findings of the study

This study describes the integration of the Family Partner Program, a parent to parent peer support model, embedded with routine and specialized care for CYSHCN within a healthcare system, including an examination of the types of services provided, key learnings from the implementation process of this pilot program, and a description of the parent peer support role within the broader context of the healthcare system. We found that Family Partners provided support and information for patients and families, taught and empowered families to utilize self-advocacy skills, and communicated patient needs and service gaps to providers. Similar to previous research (Lammers et al., 2019), Family Partners flourished when working with strong teams that communicated regularly about patients and understood and championed the peer supporter role for families. Based on Family Partner progress notes, parents often felt more comfortable sharing their experiences with a peer who "gets it", and providers who valued this role benefitted from learning more about their patients' needs and experiences through the Family Partner. When Family Partners met with families during their child's visits, families reported feeling validated and supported and were also able to attend to their own self-care needs.

Lessons learned – provider perspectives

Successful implementation of the Family Partner within the clinical setting varied based on three key facilitators of implementation: the presence of a Family Partner champion within the clinic, staff having a clear understanding of the Family Partner role, and the clinic team's communication style. As found in previous studies, barriers to implementation of in-person peer support in various clinical settings include a lack of adequate time, space and support for peer supporters to work with individuals (Shue et al., 2019), as well as negative attitudes

towards the role and role confusion within the team (Shepardson et al., 2019). Without a clear understanding of the Family Partner role within the healthcare team, integration of this role required a champion who could tailor the Family Partner role to best adapt to their clinical setting's unique workflow. As noted in another study of parent peer supporters working in a professional setting (Lammers et al., 2019), some providers were cautious about incorporating this new and unfamiliar role into the extended healthcare team. Family Partners engaged in continuous advocacy for the role and the value of providing emotional and tangible support for patients and their families. Champions of the Family Partner role within the individual clinic were also essential to advocating for Family Partner referrals and identifying families who would benefit from this service. Finally, the structure of communication between team members influenced the success of the Family Partner role within that setting. Clinical settings that utilized a team approach and held staffing meetings or "huddles" to discuss caseloads and care coordination were able to incorporate the Family Partner role more efficiently and effectively. However, clinical settings that were less team-oriented struggled with understanding how the Family Partner could help patients and their families, identifying families for the Family Partner to provide support and communicating families' support needs.

Lessons learned – family perspectives

Because Family Partners had the lived experience of educating themselves about resources, learning how to navigate complex systems, and successfully advocating for their own child and family, they held a specific type of expertise that addressed unmet care needs and that providers valued and learned to access in order to benefit their patients and families. Medical advances have resulted in a higher prevalence of children and youth with chronic medical conditions, and both health care and social assistance systems are strained to meet the related increasing care and support needs of this population (Perrin et al., 2007). At the same time, the health care system has become more financially driven so that providers have limited time to interact with patients and families and hospital stays have become shorter due to restrictive insurance coverage. This has resulted in patients and families having insufficient time to fully explore with their provider the concerns and needs of the CYSHCN during a healthcare encounter. Similarly, access to services and related coverage for children and youth with emotional health or intellectual and developmental disabilities are often limited or unavailable (Toms et al., 2015). Therefore, parents and families assume the primary responsibility of coordinating care for CYSHCN and managing their complex needs in a culture and fragmented system of care and services that relies on families but fails to support them (Allshouse et al., 2018; Carnevale et al., 2008). Consequentially, many parents also experience guilt and isolation as a result of feeling burdened by the continuous advocacy and everyday care and support needs related to parenting a CYSHCN (Ainbinder et al., 1998). Given this reliance on caregivers, who are insufficiently equipped to provide this care and care coordination, Family Partners were able to fill this gap by providing emotional support to ameliorate the related stress and reduce isolation through normalizing their experiences, as well as tangible support to connect caregivers with resources that can address the complex needs of CYSHCN. For this pilot program, Family Partners initially met with patients and families during the CYSHCN's healthcare visit. Meeting patients and families at an already scheduled appointment may have facilitated the connection between the family and Family Partner by not adding additional burden to "coordinate the coordinators" or add another meeting to an already complex schedule with various healthcare and support service providers (Levine, 2019).

Limitations

The results from this study should be understood within the context of the study's limitations. This study employed administrative data and progress notes to describe the implementation of the peer support intervention in various clinical settings within a single healthcare system. Qualitative data extracted from EHR progress notes were based on the Family Partners' perspective and recollection of the encounter. While the Family Partners summarized interactions immediately after the encounter and utilized direct quotations when feasible, the content may be biased and may not accurately and wholly characterize the families' perspectives. Additionally, the sample size was small and lacked demographic information about the caregivers. All three Family Partners identified as white women, and it is not clear if a lack of racial or ethnic alignment with all families had an impact on their ability to provide culturally responsive services (Barnett et al., 2020). Therefore, future studies employing a rigorous study design are needed to understand the impact and true benefit of this type of program on patient/family health outcomes. In addition, future research should incorporate interviews or focus groups with families who receive support from Family Partners so as to directly capture their experiences. We also acknowledge that implementing a parent peer support program within the context of the healthcare setting is initially resource intensive. Family Partners received an initial training and ongoing training and supervision at multiple levels. Additionally, faculty and staff at each clinical site required orientation and onboarding about the Family Partner role and additional support as needed to determine how to best integrate the peer support role within the site's workflow and collaborative care processes. However, findings from this pilot indicate that patients, families and providers noted benefits from working with a Family Partner, and previous research has shown a positive impact of parent peer support on child outcomes (Kutash et al., 2013; Lammers et al., 2019).

Implications for practice

While a number of studies have examined add-on peer support interventions for parents of CYSHCN through group peer support (Kingsnorth et al., 2011), remote (online or telephonically) (Akre et al., 2018; Donegan et al., 2016; January et al., 2016) or community-based settings (Dodds et al., 2018), this study adds to the extant literature by exploring the integration of an in-person parent peer support role within the healthcare setting where families frequent and are tasked with new and complex care responsibilities. One study examining the role of a parent peer supporter in a brain tumor care team also created the role to provide one-on-one emotional and informational support for families within inpatient and outpatient settings (Baron Nelson et al., 2018) and found that, similar to the Family Partner role, the parent peer supporter was in a unique position within the extended healthcare team to provide social and emotional support to families. Whereas providers primarily focused on the medical needs of the child, by integrating the peer support role for families and addressing medical and psychosocial needs, the entire care team may better equip families with the capacity to care for the child outside of the clinical setting.

Conclusions

Implementing a parent-to-parent peer support by a Family Partner for parents of CYSHCN in a large, academic medical center was attainable, and Family Partners enhanced their healthcare team's ability to provide family-centered support for pediatric patients through the provision of emotional and tangible support. Future research will evaluate impacts on clinical outcomes, provider and family partner perspectives, and parent-reported outcomes.

Financial disclosure

References

Ainbinder, J. G., Blanchard, L. W., Singer, G. H. S., Sullivan, M. E., Powers, L. K., Marquis, J. G., & Santelli, B. (1998). A qualitative study of parent to parent support for parents of children with special needs. *Journal of Pediatric Psychology, 23*(2), 99–109. https://doi.org/10.1093/jpepsy/23.2.99.

Akre, C., Polvinen, J., Ullrich, N. J., & Rich, M. (2018). Children's at home: pilot study assessing dedicated social media for parents of adolescents with neurofibromatosis type 1. *Journal of Genetic Counseling, 27*(2), 505–517. https://doi.org/10.1007/s10897-018-0213-0.

Allicock, M., Golin, C. E., Kaye, L., Grodensky, C., Blackman, L. T., & Thibodeaux, H. (2017). SafeTalk: Training peers to deliver a motivational interviewing HIV prevention program. *Health Promotion Practice, 18*(3), 410–417. https://doi.org/10.1177/1524839916663486.

Allicock, M., Kaye, L., Johnson, L. S., Carr, C., Alick, C., Gellin, M., & Campbell, M. (2012). The use of motivational interviewing to promote peer-to-peer support for cancer survivors. *Clinical Journal of Oncology Nursing, 16*(5), E156–E163. https://doi.org/10.1188/12.cjon.e156-e163.

Allshouse, C., Comeau, M., Rodgers, R., & Wells, N. (2018). Families of children with medical complexity: A view from the front lines. *Pediatrics, 141*(Supplement 3), S195–S201. https://doi.org/10.1542/peds.2017-1284D.

Barnett, M. L., Kia-Keating, M., Ruth, A., & Garcia, M. (2020). Promoting equity and resilience: Wellness navigators' role in addressing adverse childhood experiences. *Clinical Practice in Pediatric Psychology, 8*(2), 176–188. https://doi.org/10.1037/cpp0000320.

Barnett, M. L., Lau, A. S., & Miranda, J. (2018). Lay health worker involvement in evidence-based treatment delivery: A conceptual model to address disparities in Care. *Annual Review of Clinical Psychology, 14*(1), 185–208. https://doi.org/10.1146/annurev-clinpsy-050817-084825.

Baron Nelson, M., Riley, K., & Arellano, K. (2018). Adding a parent to the brain tumor team: Evaluating a peer support intervention for parents of children with brain tumors. *Journal of Pediatric Oncology Nursing, 35*(3), 218–228. https://doi.org/10.1177/1043454218762797.

Bray, L., Carter, B., Sanders, C., Blakea, L., & Keegan, K. (2017). Parent-to-parent peer support for parents of children with a disability: A mixed method study. *Patient Education and Counseling, 100*(8), 1537–1543. https://doi.org/10.1016/j.pec.2017.03.004.

Carnevale, F. A., Rehm, R. S., Kirk, S., & McKeever, P. (2008). What we know (and do not know) about raising children with complex continuing care needs. *Journal of Child Health Care, 12*(1), 4–6. https://doi.org/10.1177/1367493508088552.

Carter, B., Coad, J., Bray, L., Goodenough, T., Moore, A., Anderson, C., ... Widdas, D. (2012). Home-based Care for Special Healthcare Needs: Community Children's nursing services. *Nursing Research, 61*(4), 260–268. https://doi.org/10.1097/NNR.0b013e31825b6848.

Cousino, M. K., & Hazen, R. A. (2013). Parenting stress among caregivers of children with chronic illness: A systematic review. *Journal of Pediatric Psychology, 38*(8), 809–828. https://doi.org/10.1093/jpepsy/jst049.

Dennis, C. -L. (2003). Peer support within a health care context: A concept analysis. *International Journal of Nursing Studies, 40*(3), 321–332. https://doi.org/10.1016/S0020-7489(02)00092-5.

Dodds, R. L., Yarbrough, D. V., & Quick, N. (2018). Lessons learned: Providing peer support to culturally diverse families of children with disabilities or special health Care needs. *Social Work, 63*(3), 261–264. https://doi.org/10.1093/sw/swy019.

Donegan, A., Boyle, B., Crandall, W., Dotson, J. L., Lemont, C., Moon, T., & Kim, S. C. (2016). Connecting families: A pediatric IBD Center's development and implementation of a volunteer parent Mentor program. *Inflammatory Bowel Diseases, 22*(5), 1151–1156. https://doi.org/10.1097/MIB.0000000000000733.

Dorsey, S., Pullmann, M. D., Deblinger, E., Berliner, L., Kerns, S. E., Thompson, K., ... Garland, A. F. (2013). Improving practice in community-based settings: A randomized trial of supervision – Study protocol. *Implementation Science, 8*(1), 89. https://doi.org/10.1186/1748-5908-8-89.

Elo, S., & Kyngäs, H. (2008). The qualitative content analysis process. *Journal of Advanced Nursing, 62*(1), 107–115. https://doi.org/10.1111/j.1365-2648.2007.04569.x.

Golden, S. L., & Nageswaran, S. (2012). Caregiver voices: Coordinating care for children with complex chronic conditions. *Clinical Pediatrics, 51*(8), 723–729. https://doi.org/10.1177/0009922812445920.

Graneheim, U. H., & Lundman, B. (2004). Qualitative content analysis in nursing research: Concepts, procedures and measures to achieve trustworthiness. *Nurse Education Today, 24*(2), 105–112. https://doi.org/10.1016/j.nedt.2003.10.001.

Hatzmann, J., Heymans, H. S. A., Ferrer-i-Carbonell, A., van Praag, B. M. S., & Grootenhuis, M. A. (2008). Hidden consequences of success in pediatrics: Parental health-related quality of life—results from the care project. *Pediatrics, 122*(5), e1030–e1038. https://doi.org/10.1542/peds.2008-0582.

Hinton, D., & Kirk, S. (2017). Living with uncertainty and hope: A qualitative study exploring parents' experiences of living with childhood multiple sclerosis. *Chronic Illness, 13*(2), 88–99. https://doi.org/10.1177/1742395316664959.

Hoagwood, K. E., Cavaleri, M. A., Olin, S. S., Burns, B. J., Slaton, E., Gruttadaro, D., & Hughes, R. (2010). Family support in children's mental health: A review and synthesis. *Clinical Child and Family Psychology Review, 13*(1), 1–45. https://doi.org/10.1007/s10567-009-0060-5.

January, S. A., Duppong Hurley, K., Stevens, A. L., Kutash, K., Duchnowski, A. J., & Pereda, N. (2016). Evaluation of a community-based peer-to-peer support program for parents of at-risk youth with emotional and behavioral difficulties. *Journal of Child and Family Studies; New York, 25*(3), 836–844. https://doi.org/10.1007/s10826-015-0271-y.

Kelleher, K., Schoenwald, S., Rolls-Reutz, J., Landsverk, J., Glisson, C., & Mayberg, S. (2008). *Family Advocacy, Support and Education in Children's Mental Health: Results of a National Survey. 35(1–2).* (pp. 73–83). New York: Administration and Policy in Mental Health and Mental Health Services Research, 73–83. https://doi.org/10.1007/s10488-007-0149-4.

Kingsnorth, S., Gall, C., Beayni, S., & Rigby, P. (2011). Parents as transition experts? Qualitative findings from a pilot parent-led peer support group. *Child: Care, Health and Development, ·37*(6), 833–840. https://doi.org/10.1111/j.1365-2214.2011.01294.x.

Kutash, K., Duchnowski, A. J., Green, A. L., & Ferron, J. (2013). Effectiveness of the parent connectors program: Results from a randomized controlled trial. *School Mental Health, 5*(4), 192–208. https://doi.org/10.1007/s12310-013-9106-4.

Lammers, E. J., Zickafoose, J. S., Peterson, G. G., Blue, L., Stewart, K. A., & Kranker, K. (2019). Parent partners: Evaluation of a novel peer-support intervention for the caregivers of children hospitalized for behavioral health conditions. *Academic Pediatrics, 19*(8), 908–916. https://doi.org/10.1016/j.acap.2019.06.001.

Levine, C. (2019, June 14). A 21st century job description for family caregiving. *Health Affairs Blog.* https://www.healthaffairs.org/do/10.1377/hblog20190612.959252/full/?utm_source=newsletter&utm_medium=email&utm_content=A+21st+Century+Job+Description+for+Family+Caregiving&utm_campaign=2019.07.11_CSHCN_Network_Newsletter&.

McConnell, D., Savage, A., Breitkreuz, R., & Sobsey, D. (2016). Sustainable family care for children with disabilities. *Journal of Child and Family Studies, 25*(2), 530–544. https://doi.org/10.1007/s10826-015-0245-0.

Miller, A. R., Condin, C. J., McKellin, W. H., Shaw, N., Klassen, A. F., & Sheps, S. (2009). Continuity of care for children with complex chronic health conditions: Parents' perspectives. *BMC Health Services Research, 9*(1), 242. https://doi.org/10.1186/1472-6963-9-242.

Nicholas, D. B., & Keilty, K. (2013). *An evaluation of dyadic peer support for caregiving parents of children with chronic lung disease requiring technology assistance. Vol. 44.* (pp. 245–259). Haworth Press Inc, 245–259.

Nygård, C., & Clancy, A. (2018). Unsung heroes, flying blind—A metasynthesis of parents' experiences of caring for children with special health-care needs at home. *Journal of Clinical Nursing, 27*(15–16), 3179–3196. https://doi.org/10.1111/jocn.14512.

Perrin, J. M., Bloom, S. R., & Gortmaker, S. L. (2007). The increase of childhood chronic conditions in the United States. *JAMA, 297*(24), 2755–2759. https://doi.org/10.1001/jama.297.24.2755.

Pizur-Barnekow, K., Darragh, A., & Johnston, M. (2011). "I cried because I didn't know if I could take care of him": Toward a taxonomy of interactive and critical health literacy as portrayed by caregivers of children with special health care needs. *Journal of Health Communication, 16*(sup3), 205–221. https://doi.org/10.1080/10810730.2011.604386.

Pordes, E., Gordon, J., Sanders, L. M., & Cohen, E. (2018). Models of care delivery for children with medical complexity. *Pediatrics, 141*(Supplement_3), S212–S223. https://doi.org/10.1542/peds.2017-1284F.

Quittner, A. L., Espelage, D. L., Opipari, L. C., Carter, B., Eid, N., & Eigen, H. (1998). Role strain in couples with and without a child with a chronic illness: Associations with marital satisfaction, intimacy, and daily mood. *Health Psychology, 17*(2), 112–124. https://doi.org/10.1037/0278-6133.17.2.112.

Remedios, C., Willenberg, L., Zordan, R., Murphy, A., Hessel, G., & Philip, J. (2015). A pre-test and post-test study of the physical and psychological effects of out-of-home respite care on caregivers of children with life-threatening conditions. *Palliative Medicine, 29*(3), 223–230. https://doi.org/10.1177/0269216314560008.

Roman, S. B. M., Dworkin, P. H., Dickinson, P. R., & Rogers, S. C. M. (2020). Analysis of care coordination needs for families of children with special health care needs. *Journal of Developmental, 41*(1), 58–64. https://doi.org/10.1097/DBP.0000000000000734.

Romley, J. A., Shah, A. K., Chung, P. J., Elliott, M. N., Vestal, K. D., & Schuster, M. A. (2017). Family-provided health care for children with special health care needs. *Pediatrics, 139*(1), https://doi.org/10.1542/peds.2016-1287.

Santelli, B., Turnbull, A. P., Marquis, J. G., & Lerner, E. P. (1995). Parent to parent programs: A unique form of mutual support. *Infants & Young Children, 8*(2), 48–57.

Shepardson, R. L., Johnson, E. M., Possemato, K., Arigo, D., & Funderburk, J. S. (2019). Perceived barriers and facilitators to implementation of peer support in veterans health administration primary care-mental health integration settings. *Psychological Services, 16*(3), 433–444. https://doi.org/10.1037/ser0000242.

Shue, S. A., McGuire, A. B., & Matthias, M. S. (2019). Facilitators and barriers to implementation of a peer support intervention for patients with chronic pain: A qualitative study. *Pain Medicine, 20*(7), 1311–1321. https://doi.org/10.1093/pm/pny229.

Toms, G., Totsika, V., Hastings, R., & Healy, H. (2015). Access to services by children with intellectual disability and mental health problems: Population-based evidence from the UK. *Journal of Intellectual & Developmental Disability, 40*(3), 239–247. https://doi.org/10.3109/13668250.2015.1045460.

Trollvik, A., & Severinsson, E. (2004). Parents' experiences of asthma: Process from chaos to coping. *Nursing & Health Sciences, 6*(2), 93–99. https://doi.org/10.1111/j.1442-2018.2004.00179.x.

Woodgate, R. L., Edwards, M., Ripat, J. D., Borton, B., & Rempel, G. (2015). Intense parenting: A qualitative study detailing the experiences of parenting children with complex care needs. *BMC Pediatrics, 15*(1), 197. https://doi.org/10.1186/s12887-015-0514-5.