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Unmet Needs of Male Caregivers of Children and Youth with Special Health Care Needs

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Abstract

Objectives

The caregiving experiences and unique health needs of male caregivers of children and youth with special health care needs (CYSHCN) are not well described. This study seeks to understand potential unmet health needs and attitudes toward supportive resources from the perspective of a sample of male caregivers of CYSHCN.

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thematic analysis. The SSI explored the health needs of male caregivers, assessed attitudes toward and preferences regarding supportive resources, and garnered their advice to other caregivers regarding parenting and health care system navigation.

Results

Participants' median age is 41 years (IQR: 33, 44), and most (80%) reside full time with their CYSHCN. Most male caregivers deprioritized their own emotional, mental, and physical health needs to support the needs of their families. Many male caregivers articulated interest in seeking emotionally supportive resources (not time-intensive). They advised other male caregivers to remain involved in the medical care and wellbeing of their CYSHCN and to openly seek and receive emotional support despite the daily challenges they face.

Conclusions for Practice

Male caregivers of CYSHCN experience intense daily stress and express the need for emotionally

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What is already known on this subject? Parenting CYSHCN often requires intense engagement to maintain the health and wellbeing of their children. Positive paternal engagement strongly contributes to overall family functioning, yet the individual health needs and constraints of male caregivers of CYSHCN have been coarsely examined.

What this study adds? This work highlights unmet health needs of male caregivers of CYSHCN and the importance of improving their emotional support opportunities. Support options should be sensitive to time and location barriers while offering male caregivers spaces to give and receive support.

Introduction

National estimates indicate 19% of children have special health care needs (DRC Child/Adolescent Health, [2016](#); McPherson et al., [1998](#)). Parenting children and youth with special health care needs (CYSHCN) requires intense caregiver engagement in a panoply of roles/responsibilities to maintain child health and wellbeing (Nicholas, [2017](#); Sato et

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(Bailey-Pearce et al., [2018](#); Baldwin et al., [2018](#); Chung et al., [2012](#); Hatzmann et al., [2008](#); Heaman, [1995](#); Kerstis et al., [2018](#); Kuo et al., [2011](#); Smith & Grzywacz, [2014](#)). Children with medical complexity (CMC) represent a medically fragile subset of CYSHCN (1%) characterized by: health care service need (therapy, educational, medical), one/more chronic condition, functional limitation in bodily structure/performance of activities, and increased health care utilization. (Cohen et al., [2011](#)). These foregone parental physical and mental health needs suggest male caregivers are a specific group who could benefit from increased connection to supportive resources (Caicedo, [2014](#); Cen   et al., [2016](#); Feudtner, [2002](#); Keller & Honig, [2004](#); Kobylanskii et al., [2018](#)).

Despite the importance of positive paternal engagement in family functioning, there is a dearth of literature examining individual needs and constraints of male caregivers of CYSHCN in medical/non-medical contexts (; Baker et al., [2018](#); Tully et al., [2017](#)). Understanding unique male caregiver needs provides support opportunities for

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engage frequently with the health care system, providing family-centered care via shared decision-making is critical. (Cené et al., [2016](#); Kuo et al., [2011](#)). Thus, understanding how male caregivers of CYSHCN describe their own needs and constraints can inform clinical environments to supportively engage families. The objective of this study was to elicit perspectives of male caregivers of CYSHCN, with an emphasis on ascertaining unmet personal needs, describing parenting experiences, and identifying supportive resources.

Methods

Participants

Research Team

One female medical/public health student [AL] conducted all interviews after receiving formative training in qualitative research methods, mentor support and informing participants of study goals. The interviewer had no affiliation with practice sites, participants were not aware of any additional biases/personal characteristics. The research team consisted of six members [AL, VR, PM, ET, RT, KF]

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researcher except [RT], who was not engaged in recruitment/consenting participants.

Study Design

A convenience sample was identified and recruited from a subsample ($n = 4$) of the PA Medical Home Program (Mohanty et al., [2018](#)) primary care practices in southeastern Pennsylvania. Geographic recruitment was limited to foster in-person connection of the interviewer to participants and limit variability of practice experience as a potential confounder. Three practices were urban children's hospital-based practices and one was a suburban satellite one of the hospitals. Potential participants were identified based on chart review by practice care coordinators. Participant inclusion criteria were self-identification as a father, stepfather, foster father, or other male caregiver of a CYSHCN receiving healthcare in a one of the study practices. English and Spanish-speaking caregivers were included. Potential participants were approached in-person or by phone by [KF] who had no prior relationship to participants to explain the purpose of the study and gauge initial interest. If

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caregivers, feedback obtained, reviewed by the research team and modifications made.

Collaborators with qualitative research experience [PM, VR, RT] continued to refine the guide before usage with study participants. The finalized interview guide included thirteen open-ended questions exploring experiences of routine childcare, factors promoting resilience/success, those proving challenging for primary male caregivers, and advice to other caregivers ([“Appendix”](#)).

Semi-structured interviews (SSI) were conducted in-person or by phone between February and June, 2018. [AL] conducted all interviews in English from a comfortable, private waiting room adjacent to primary care offices. Follow up questions and probes were given based on study responses. An interpreter was available for Spanish-speaking participants, all of whom interviewed in-person. Aside from the interpreter, no one else was present besides the participant and interviewer. Support from members of the research team and a social worker were available onsite/telephonically at all

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All interviews were audio-recorded and transcribed verbatim by the interviewer. Spanish interviews were transcribed in Spanish and back translated into English by a certified interpreter. Field notes were taken during and after the interviews and discussed with the research team at regularly scheduled research team meetings. Subjects were recruited until thematic saturation was achieved. Transcripts and analyses were reviewed and discussed with the research team. Thematic results were discussed and fact checked with study participants. Written or verbal informed consent was given by all participants before their enrollment, and each received a \$25 grocery/retail store gift card upon completion of the study. This study was reviewed and approved by the Drexel University Institutional Review Board and performed in accordance with Declaration of Helsinki ethical standards and amendments. The authors followed the Consolidated Criteria for Reporting Qualitative Health Research (COREQ) criteria for reporting this research.

Analysis

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research team. Five paternal caregivers participated in codebook review and gave feedback on findings and themes generated. Qualitative analysis software [N-VIVO 12 was used (QSR International)] to produce a secondary codebook incorporating themes of the primary analysis (QSR International Pty Ltd., [2019](#)). We developed initial topical and inductive codes and definitions through open-coding of 20% of transcripts (Patton, [2005](#)). The research team engaged in collaborative discussions to revise and finalize code definitions including co-coding of three transcripts to ensure consistency in code application and assure intercoder reliability. Regular group discussion of summaries and quotes informed data reduction, synthesis, interpretation, and grounded theory where themes were generated and discussed. Consensus was achieved across research team members. Data from quantitative surveys were entered into a secure, password-protected database. Descriptive characteristics were tabulated using SAS 9.4 (Cary, NC Inc., [2019](#); QSR International Pty Ltd., [2019](#)).

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Thirty of thirty-one (97%) male caregivers approached chose to participate in the study. One participant declined enrollment due to CYSHCN hospitalization/medical complications arising at time of the study. Interview time ranged from 47 to 132 min. The CYSHCN in this study represent children meeting the definition/framework for CMC with any increased service needs, dependence of medical technology, requiring home nursing services and/or intensive care coordination. Specific diagnostic information on the sample was not included or linked to transcripts or quotes to preserve anonymity. Survey responses demonstrated 80% of male caregivers lived with their child full-time and over one quarter primarily spoke Spanish at home (28%) though only one SSI was conducted in Spanish as per caregiver comfort level and language preference. Sociodemographic characteristics of participants are shown in Table 1. All participating caregivers self-identified as trained central caregiver for the CYSHCN.

Qualitative Results

Broad themes identified within the qualitative data

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caregiving responsibilities of CYSHCN. Several respondents desired meeting personal educational goals and spending time alone with spouses/additional children. Numerous co-occurring roles described by male caregivers included acting as parent, advocate, protector, financial provider, nurse, and care coordinator.

[W]hen he gets home, I give him lunch, change him...I put him to nap from 12:30 to 2pm. At 2 pm I get them dressed...take him and other kids out...#7

.... He has all night care [g-tube/ventilator], we both work, and we have to be up with him it makes it very difficult when there's call outs [nursing] sometimes they'll come and sometimes not...#3

[I]t's very stressful...she [Mom] has him all day at home, and then I come home from work tired because I sit in front of a computer all day...then I come home, she wants to give him to me...and I'm tired from work, so I just have to make it work...#19

when I make all of those appointments I try to

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personal needs last, after the needs of their CYSHCN and co-parent.

...I. have learned....it's really important to really talk about things and not bottle things up.. #5

...[Y]ou leave in the morning, go to work, then you have a horrible day in your job, you want to come home to have a break, and then your wife had a pretty rough day with [child] that you left her in the morning with the sleeping clothes, you get back in the afternoon....and she's waiting for you to take a break... you go home to take a break and you have somebody there...expecting for you to be there for her to take a break so it continues like a constant movement mentally and physically...work and then the child at home with all the conditions...he doesn't sleep...so it was almost like 24/7 every day.#16

Most male caregivers articulated a 'need for a break' as a parent, their spouse, or family unit. Finding and maintaining quality nursing care was essential in allowing families to have a break alleviating parental physical and emotional

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tired, but I don't know if you're actually truly as physically tired as you are emotionally. Emotions make you feel physically drained. #23

Most caregivers sought time and safe spaces for reflection on experiences and feelings. However, several hinted at contrasting gender-based expectations and ascribed to perceptions of needing to 'be the strong one' in the family, assigning themselves to familial roles of tactical/logistical planning. Many indicated abilities to restrict outwardly showing emotion reinforcing critical qualities of strength and maintenance of perceived emotional calm. One participant blamed himself for his child's long-term hospital stay, explaining it as a result of 'letting their guard down'.

For me, it's just...being a dad, being 'the man of the house' you have to be kind of the strong one. Try not to show much emotion in front of the girls...especially in the beginning. #27

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Despite this internal tension, male caregivers articulated needs to improve their own emotional health/wellbeing. Expressing needs for personal privacy away from in-home care nursing/staff, they sought alone time and nurturing their spouses/co-parent relationships.

...the other day, I stood with him [child] in the house and she [wife] went to her mother's house...have a little talk with her...sometimes... we as parents need that. We need time for ourselves as well, and sometimes it's hard, because we're always with our child always at appointments. We have to work....it's really tough.#24

Parental physical/mental health care improvement was hindered by competing responsibilities and lack of residual time/energy, ultimately negatively influencing their relationships with spouses/others and overall wellbeing.

Interest in Supportive Resources

Most participants expressed an interest in support

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I would have interest...some of my constraints are...time, energy, it would have to be the right group that meets the needs of my real life, and I think that would be tough to do. I would want it to work both ways, if it's a support group I would want to be able to offer support as well as receive support for myself. #28

For those not interested in a formal support groups, many desired to give advice, share ideas/resources, build camaraderie among male caregivers of CYSHCN, participate in recreational opportunities, and obtain information about community services.

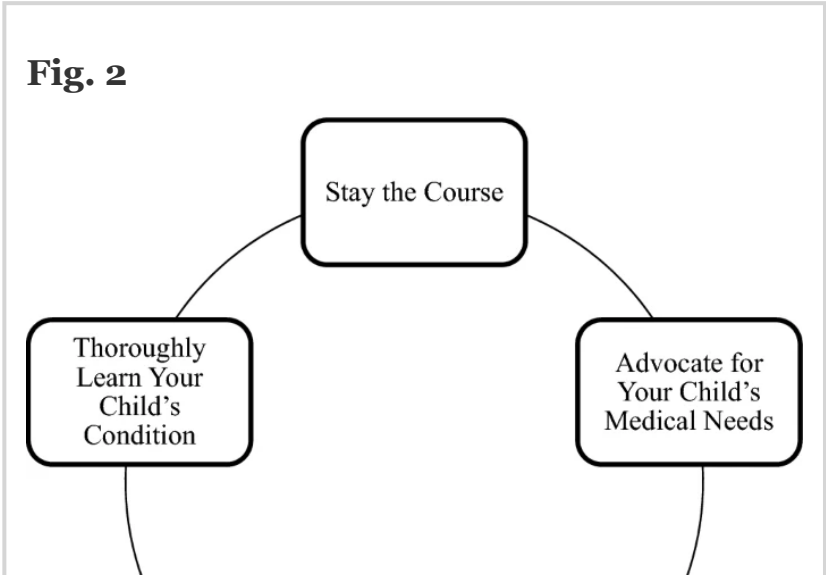
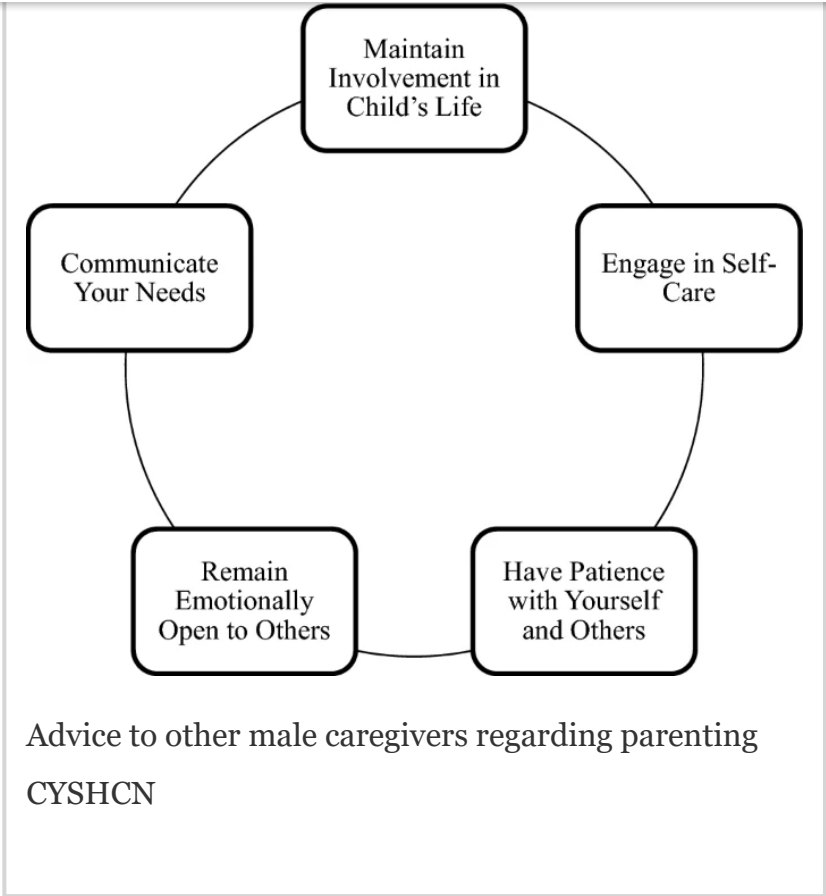
It might just be more to find some friends...it would be nice to talk to somebody who knows what you're going through. I have some friends who can empathize, but unless people are doing the same thing you are doing, they cannot relate...the next thing is time, you work a full day, come home, you want to spend time with [your child]....weekends I got [stuff] around the house I got to get to.#11

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Male caregivers were well-versed in their child's medical, social/emotional needs and logistics to support their child. They recommended other male caregivers strive for constant involvement in their child's life, commit to personal self-care, pursue emotional openness/communication with spouses/supportive individuals continuously working through challenging situations.

Stay involved and stay the course...it's going to get rough...it can get overwhelming...I know obviously us [men]...tend to deal with the task, push our emotions to the side, and sometimes we don't even deal with the emotion. Just make sure you take that time and be vulnerable if that's what you're feeling. It's ok for you to be upset, frustrated. We all know the battles we have due to our medically fragile child so, just stay the course. #21

They encouraged others to develop an attitude of patience with oneself, their child, and their atypical family situation.

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advocating for their needs within the system and become independent experts in their child's specific medical condition, treatment needs, and responses to medications/behavioral therapies. Many indicated despite initial doubts/difficulties, quickly learned care for their CYSHCN with persistent involvement aiding in the success of their child.

Everything we do is a result it...has to do with our kids, and we see the results...if I would have decided to stay in my town, I would have never seen the results I have seen. Everything that one does with love gives fruit. #29

Discussion

There is a dearth of literature focusing specifically on the unique needs of male caregivers of medically fragile CYSHCN. Prior qualitative studies underscore similar themes to this study such as consuming requirements/sacrifice of caring for CYSHCN, importance of trust of the medical system, caregiver stress burden, role of community supports, but do not delineate male caregivers'

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mental, and physical health needs and were open to receiving emotionally supportive resources providing a connection to other male caregivers of CYSHCN. Male caregivers articulated a high-stress burden resulting from caring for their CYSHCN but advised other male caregivers to remain involved. Encouraging fellow caregivers, they advised having self-compassion and preparation and proactivity on behalf of their child in medical settings, consistent with findings from prior studies (Neff & Faso, [2015](#); Rafferty & Sullivan, [2017](#)).

The sustained negative mental/physical health consequences described by parents of CYSHCN are widely documented influencing family functioning, coping ability, life satisfaction, and ability to navigate challenges (Cousino & Hazen, [2013](#); Darling et al., [2012](#); Goudie et al., [2014](#); Woodgate et al., [2015](#)). Our analysis is consistent with this research detailing the mental/physical consequences of persistent stress and hidden emotional experiences of male caregivers (Caicedo, [2014](#); Edelstein et al., [2017](#); Heaman, [1995](#); Kvarme et al., [2016](#)). As several male caregivers in our

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compatible with their lifestyles/goals. Their positive parenting attitudes were reflected in their encouraging advice to other parents of CYSHCN. Recognizing and understanding the stress and experiences of caregivers of CYSHCN reinforces needs for stronger linkages to resources for children and parents, including respite services, in-home supports and stress mitigating program opportunities. Most male caregivers saw value in support groups and resources specifically geared to male caregivers fostering opportunities to share similar lived experiences in safe spaces. Recommendations based on the themes from this study are summarized in Table 2.

Table 2 Recommendations based on themes identified

Prior studies described challenges and unmet needs of families of CYSHCN including financial burden, stress, time constraints, and service access (Jolles et al., 2018; Kuo et al., 2011). Supportive solutions considerate of lack of residual time /energy

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potential barriers such as possible caregiver adherence to a 'strong man' identity, possibly mediating his openness to receiving emotional support from others (Baldwin et al., [2018](#); Tully et al., [2017](#)). Our results suggest programs focused on problem-solving, developing strategies to maintain perceived self-control (process-driven thinking), and focus on analyzing immediate problems could be useful design considerations. Parent-led support groups/mentoring programs for parents of CYSHCN have been effective in aiding parents to develop skills, sense of power/belonging, and provide welcome sources of emotional support among sameness of experience (Ainbinder et al., [1998](#); Kingsnorth et al., [2011](#); Law et al., [2002](#); Singer et al., [1999](#)). Non-traditional formats for mentoring (social media, internet-based options) may be contextually fitting and have previously been effective (DeHoff et al., [2016](#)). Prior studies described challenges for primary care/community partners caring for CYSHCN and may consider screening for parental stress/adequate supports and engaging families in shared plans of care

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their interview in Spanish. Respondents were male caregivers of CYSHCN, however the interviewer was a young, educated, female without children and the degree of perceived dissimilarity between the respondents/interviewer may have stymied sharing. Participants were all engaged in their child's medical care, therefore this analysis does not speak to the experiences/desires of men less engaged in the care. Understanding specific experiences of male caregivers not engaged in care could yield information to better support families before a male caregiver may become estranged from their CYSHCN. The concordance of dyads of caregivers when two or more caregivers are present warrants further exploration for the impact on partnerships, marriages, and relationships between caregivers of CYSHCN and siblings. Implementors may consider non-traditional formats for establishing connection and camaraderie among male caregivers.

Conclusion

Health care systems and medical care teams should

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Data Availability

Authors have all data and study materials available for review in accordance with data procedures from IRB and human subjects protection guidelines.

Code Availability

N-VIVO 12 was used for analyses in this study. (QSR International Pty Ltd., [2019](#)).

Abbreviations

CYSHCN: Children and youth with special health care needs

CMC: Children with medical complexity

SSI: Semi-structured interviews

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All authors are responsible for the reported research and have participated in the concept and design, analysis and interpretation of data, revisions, and have approved the manuscript as submitted.

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Ethics declarations

Conflict of interests

The authors declare that they have no conflict of interests.

Ethics Approval

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Appendix

Sample Interview Guide

Tell me a little bit about your [son/daughter].

- If father has not yet shared, ask about his child's diagnosis

How has it been understanding and coping with your child's medical condition?

What is the day-to-day care of your child like?

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How do you feel included in your child's care during medical appointments, or when [he/she] is in the hospital?

- How do you feel that the doctors and medical staff listen to you and value your input?
- [If not already mentioned] are there any circumstances when you feel excluded from your child's care?

Do you coordinate any of your child's medical care?

- [If, no] Who coordinate's your child's medical care?
- [If yes] About how much time per week do you spend coordinating your child's medical care?
 - Do you share this responsibility with your child's mom? Other family member? Doctor's office?

I am going to list some services, can you let me know which ones do you already have, and which ones you don't have, but might find helpful?



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Services	Already have	Do not have	Would find helpful
Assistance with physical household changes			
Vocational counseling			
Psychological counseling			
Homemaker services			
Recreational opportunities			
Information about community services			

What keeps you strong or keeps you going? Do you have family or friends who support you when things get tough?

How does your role differ from [his/her] mother's role?

Tell me about any internet or social media tools you have used to obtain resources for your child.

- For example, Facebook, Twitter, Tumblr, Pinterest, Instagram, Yahoo or Google group, reading/writing blogs or support group

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Do you have any recommendations for your child's doctor office here [i.e. special needs] and or recommendations in general to help fathers?

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