

Original Article

Cite this article: Robinson J, Huskey D, Schalley S, Wratchford D, Hammel J, and Weaver MS (2019) Discovering dad: paternal roles, responsibilities, and support needs as defined by fathers of children with complex cardiac conditions perioperatively. *Cardiology in the Young* 29: 1143–1148.
doi: [10.1017/S1047951119001586](https://doi.org/10.1017/S1047951119001586)

Received: 22 March 2019
Accepted: 6 June 2019
First published online: 8 August 2019

Key words:

Pediatric cardiology; qualitative research; family communication; pediatric palliative

Author for correspondence:

M. S. Weaver, MD, MPH, FAAP, Division of Pediatric Palliative Care, Children's Hospital and Medical Center Omaha, 8200 Dodge Street, Omaha, NE 68114, USA.
Tel: 402 955 5432; Fax: 402 955 4184;
E-mail: meweaver@childrensomaha.org

Discovering dad: paternal roles, responsibilities, and support needs as defined by fathers of children with complex cardiac conditions perioperatively

Jacob Robinson¹, David Huskey², Sabrina Schalley³, Dale Wratchford², James Hammel⁴ and Meagham S. Weaver¹

¹Division of Pediatric Palliative Care, Department of Pediatrics, Children's Hospital and Medical Center, Omaha, NE, USA; ²Division of Spiritual Care and Ministry, Department of Pediatrics, Children's Hospital and Medical Center, Omaha, NE, USA; ³Division of Social Work, Department of Pediatrics, Children's Hospital and Medical Center, Omaha, NE, USA and ⁴Division of Cardiac Surgery, Department of Pediatrics, Children's Hospital and Medical Center, Omaha, NE, USA

Abstract

Background: Understanding perceptions of family caregivers' roles and responsibilities regarding their child with complex cardiac needs has potential to help care teams better support parents. Paternal experience has been under-explored in pediatric cardiac cohorts. **Methods:** Ten fathers of children undergoing cardiac surgery completed quantitative surveys on their knowledge needs and preferred format of communication. In face-to-face recorded interviews, they responded to open-ended questions about the definition of being a good father to a child with a complex cardiac condition, perceived paternal responsibilities, personal growth as a parent to a child with a complex heart condition, support needs, and recommendations to medical staff for paternal inclusion. Semantic content analysis was utilised. The study reports strictly followed COnsolidated criteria for REporting Qualitative research guidelines. **Results:** The fathers reported high preference for knowledge about the child's heart condition, communication about the treatment plan, and desire for inclusion in the care of their child. Paternal role was defined thematically as: providing a supportive presence, being there, offering bonded insight, serving as strong provider, and acting as an informed advocate. The fathers revealed that their responsibilities sometimes conflicted as they strove to serve as an emotional and economic stabiliser for their family, while also wanting to be foundationally present for their child perioperatively. **Conclusion:** This study provides insight into paternal experience and strategies for paternal inclusion. This summary of the self-defined experience of the fathers of pediatric cardiac patients offers constructive and specific advice for medical teams.

Understanding parental perceptions of roles and responsibilities regarding their child with complex cardiac needs has potential to help care teams better support parents during medical encounters.^{1–3} Specifically, understanding how parents of children with complex cardiac conditions strive to parent well even in the perioperative timeframe may allow cardiac care teams to foster parental sense of role cohesion and familial resiliency. The concept of “being a good parent” has been recognised as a goal of parents in critical care settings and has been thoughtfully defined by parents of children with non-cardiac diagnoses.² Children's hospitals and pediatric care settings have been recognised as having a heavy maternal focus on opportunity to improve upon paternal inclusion.^{4,5}

Paternal experiences in receiving a child's diagnosis, prognosis, and in interacting with their ill child have been found to be uniquely different from maternal experiences.^{5–9} Parental anxiety and stress in the first 24 hours after a surgery has gender predictors.¹⁰ Mothers and fathers are recognised to experience the stress of CHD differently, with fathers in the United States reporting the stress of “not being able to protect their child from congenital heart disease and the associated surgeries/pain and from difficulties balancing employment with support for their partner and care of their congenital heart disease child in the hospital.”¹¹ Fathers have been less likely to report the use of hospital-based support resources or CHD peer support as compared to mothers.¹¹ A phenomenological study of fathers of neonates with CHD needing surgery in South Korea revealed significant paternal anxiety surrounding lack of ability to personally “fix” the child's heart condition.¹² The fathers of children with congenital cardiac conditions depict high stress levels associated with balancing financial provider versus direct caregiver roles.¹³ A qualitative study of parents of children with CHDs in Spain revealed paternal need for psychosocial support due to role distress in trying to provide for their family, while also feeling the need to be physically present for their hospitalised child.¹⁴ Prior investigation into parental stress response

following cardiac surgery for an infant revealed that close to one-fifth of fathers experienced trauma symptoms consistent with a diagnosis of acute stress disorder.¹⁵

Due to low response rates (mean less than 40%) summarised in parental experience in caring children with congenital heart disorders, there has been a recent call to target fathers' inclusion to improve understanding of their unique perceptions and needs.¹⁶ Prior good parent papers did not robustly include fathers' perspective due to lower paternal response rates: $n = 5$ (8.6%),² $n = 18$ (42%),³ and $n = 60$ (30%).¹ To honor paternal voice and the unique care needs of fathers of cardiac surgical children; this study strove to understand how "being a good father to my critically ill child undergoing cardiac surgery" is defined by this cohort and how health care teams may then best support the self-defined role and resiliency strategies of fathers of critically ill children receiving cardiac care.

Materials and methods

The Institutional Review Board approved the Paternal Advice, Guidance, Education, and Support protocol. Study reports strictly followed COnsolidated criteria for REporting Qualitative research guidelines (Supplementary material 1).¹⁷

Setting and sample

This study involved voice-recorded, in-person interviews with 10 fathers of children who had undergone cardiac surgery in the past 14 days in a free-standing children hospital in the Midwestern United States with a new palliative care referral. Semi-structured interviews are appreciated as the standard approach for cognitive interviewing targeted to conceptual definitions,¹⁸ thus semi-structured interviews were conducted from November 2018 to January 2019 using an interview guide (Supplementary material 2). Eligible participants, who received new palliative care consultations, were English-speaking fathers of children who had undergone cardiac surgery in the past 14 days. Exclusion criteria included lack of verbal or cognitive capacity for interview participation as determined by the primary cardiac service line team. Screening for eligibility was based on medical record search and referrals to the study team. There were 10 eligible participants during the study timeframe. Ten potential participants were approached based on convenience sampling with $n = 10$ enrolled (100% participation rate). Study group demographics are provided in Table 1.

Procedures

After introducing the study in detail, verbal informed consent was obtained. J.R., a male interviewer, conducted all interviews in-person in a private inpatient or outpatient hospital room. Mean interview time was 20 minutes. M.S.W. completed a "content check" with each participant after each interview to allow the interviewee to verbally process his interview experience.¹⁹ Trained medical transcriptionists transcribed the interview content verbatim with a minimum of one study team member confirming accuracy. Study participants also completed a two-page, multiple-choice written survey instrument with questions on demographics and preference for information, resources, and support format as adopted from prior grandparent survey work.²¹

Data analysis

Written survey instrument analyses were descriptive and univariate in nature. The study team utilised counts for categorical

Table 1. Participant demographics.

Characteristics	n (%)	
Child's gender	Male	8 (80)
	Female	2 (20)
Child's location at the time of interview	Pediatric Intensive Care Unit	7 (70)
	Neonatal Intensive Care Unit	1 (10)
	Hospital	2 (20)
Father's ethnicity	African American	1 (10)
	Caucasian	8 (80)
	Hispanic	1 (10)
Father's home locale	Rural	5 (50)
	Sub-urban	4 (40)
	Urban	1 (10)
Does the child reside within the home?	Yes	7 (70)
	No	3 (30)
Number of other children living in the home	0	3 (30)
	1	3 (30)
	2	2 (20)
	3	2 (20)
Parental marital status	Married	7 (70)
	Engaged	2 (20)
	Single	1 (10)
Parent highest level of formal education	High school Diploma	4 (40)
	Some college	3 (30)
	College completion	3 (30)
Parent employment type	Laborer	5 (50)
	Sales/retail	2 (20)
	Stay at home father	1 (10)
	Teacher	2 (20)
Primary caregiver of child	Both	5 (50)
	Father	1 (10)
	Mother	4 (40)

variable responses. Interview data were analysed using semantic content analyses.²⁰ Every phrase spoken by the participant from each interview was entered into the qualitative software program. One member of the study team independently applied first-level codes to key phrases to capture their meaning. The interviewer created grouped classifications of phrases from the interview content to develop a code dictionary. The code dictionary contained the definition of each code and an example of use of the code. Another team member then used this grouped-specific codebook to review the content of the interview data.^{20,22} After first-level codes were applied to all interview phrases, the codes were then grouped by overlapping meaning and co-occurrence into themes. The frequency of each theme was calculated. Conceptual definition was thus developed based on the interviewed fathers' verbiage and the assessed paternal meaning.

Table 2. Knowledge content and format preference as reported by fathers.

At any point in your child's journey, to what extent do you need information about the following topics? (1 least – 4 most)	Mean/median/ range	
Your child's medical condition	4/4/4 – 4	
The possible course of your child's condition	3.9/4/3 – 4	
Survival rates for your child's condition	3.9/4/3 – 4	
The benefits or goals of medical interventions/treatments	3.9/4/3 – 4	
Possible side effects of medications/treatments	3.9/4/3 – 4	
How to interact with your child?	3.1/4/1 – 4	
How to best support yourself emotionally?	3/3/2 – 4	
How to best support your family emotionally?	3.4/4/2 – 4	
Where to get help if you are experiencing emotional difficulties?	2.7/2.5/1 – 4	
How to maximise parental employment and provision for the family?	2.9/3/1 – 4	
Information on special issues for fathers if a child reaches natural end of life	3.3/3.5/2 – 4	
How to keep (or get) yourself physically healthy?	2.3/2/1 – 4	
How to communicate with your child?	3/4/1 – 4	
How to communicate with other children in the family (your child's siblings)?	2.67/3/1 – 4	
How to communicate with your child's mother?	2.7/2.5/1 – 4	
How to talk with friends and relatives about possible problems related to your child's illness?	2.8/2.5/2 – 4	
Advice/stories from other fathers who have had similar experiences	2.9/3/1 – 4	
Spiritual care	2.1/2/1 – 4	
Would you find a booklet developed especially for fathers to be helpful as compared to a generic book for parents?	Yes	9 (90)
	No	1 (10)
Would you read a booklet developed especially for fathers of children with complex medical conditions?	Yes	10 (100)
	No	0 (0)
When seeking support, would you feel more comfortable talking to a male or female?	Male	4 (40)
	Indifferent	6 (60)
Preferred timing of receiving information	At diagnosis	5 (50)
	Later in medical care	3 (30)
	Both	2 (20)
Preferred mechanisms to receive supportive information (select all that apply)	Conversations only	3 (30)
	Conversation with paper booklet available	6 (60)
	Conversation with online information available	5 (50)
	In-person support group for couples	2 (20)
	In-person support group for fathers	1 (10)

Results

Study participants were 10 fathers of 8 males and 2 female cardiac surgical patients of mean patient age 19 months (age range from 7 months to 7 years). Heart condition was first diagnosed an average of 17 months before the interview (included gestational time). All interviews occurred within 2 weeks of a cardiac surgery. Eight children were still in the ICU at the time of their fathers' interviews and two had transition to regular hospital floor. Family residence was an average of >300 miles from the pediatric hospital.

Paternal knowledge content and format preferences

When asked to rank their preference on access to information regarding their child's care on a Likert Scale with one representing passive knowledge need and five representing proactive knowledge need: all fathers ranked their knowledge need as 5/5. Highest ranked informational priorities for fathers included: the child's medical condition to include prognostic course, survival rates, goals of intervention, and potential side effects for intervention (Table 2). Interviewed fathers consistently depicted interest in

Table 3. Paternal definition of “being a good father to my child with a complex cardiac condition.”

Themes (n = 5)	Definition	Codes, n/46 (%) participants, n/10 (%)	Exemplary quotes
Supportive presence	Providing emotional and physical support for child through comfort, encouragement, and leadership. Also, providing life guidance for child as needed	15 (32.6%) 9 (90.0%)	“Being able to console them at this point, even if it’s simple as holding so they can feel your own heartbeat.”
Being there	Making significant efforts to be present for their child in the form of physical presence within the hospital, committing to life-long presence for their child, and providing physical touch for child’s reassurance and comfort	13 (28.3%) 7 (70.0%)	“I personally feel that he knows when me or his mom is here and I think that makes a difference. He always seems to do better.” “So, to be here and be part of [the care] is . . . I think it brings us closer together forever.”
Bonded insight	Possessing a father–child bond that enables an enhanced intuition of child’s needs and wants as well as an unbreakable relationship/companionship	9 (19.6%) 3 (30.0%)	“I’ve become a parent that was deeply in tune with what it was she was saying to me.” “We’re buddies.”
Strong provider	Supplying financial and material resources for family, primarily through employment; and providing physical and emotional support for child, mother, and the rest of the family	6 (13.0%) 4 (40.0%)	“To provide as much as possible as far as financial means and everything that he’s gonna need.” “Be[ing] there to support him and his mother.”
Informed advocate	Striving to be as informed as possible on child’s condition and care. Serving as the child’s advocate, primarily by asking questions and seeking knowledge on proper medical care and attention for the child	3 (6.5%) 3 (30.0%)	“[If] something’s going on, try to not only inform the doctors helping him but try to maybe ask a lot of questions and stuff.” “Being very informed about what is going on with her. Not only, you know, before birth, post-partum, but you know, throughout her entire life.”

resources for their ability to economically and emotionally support their families higher than interest in their own personal physical, emotional, or spiritual needs ($p < 0.001$). Provision of a written booklet with conversational support was noted to be the most preferred format of information sharing. All interviewed fathers reported that they would read a supportive booklet written specifically for fathers.

Definition of paternal role and responsibilities in caring for a child with cardiac condition

In defining “being a good father,” a total of 46 codes yielded six themes central to the fathers’ definition of this important role (Table 3): providing a supportive presence, being there, offering bonded insight, serving as strong provider, and acting as an informed advocate. When asked about their responsibilities in the role of “being a good father,” 49 codes were extracted from 34 responses that corresponded to five specific themes: being a supporter for the child, involved parent, child’s advocate, committed to fatherhood, and being the fun parent. Being a supporter for the child was the most commonly identified theme for how participants defined their responsibility with 80% of fathers referencing this theme and over 40% of total interview phrases corresponding to that theme. Theme content did not differ based on paternal demographics or age of the child.

Paternal growth through pediatric cardiac diagnosis

Of the 10 interview patients, 9 made statements of personal growth occurring as a direct result of their child’s cardiac condition. A total of 34 interview statements related to personal growth: 24 phrases reflected feelings of intrapersonal growth (statements of personal insight, growth, maturity, and self-awareness) and 10 phrases reflected interpersonal growth (statements about relationship impact). Growth was further categorised as: personal growth (14 statements), emotional, or spiritual growth (11 statements), cognitive growth (5 statements),

aesthetic growth meaning the ability to appreciate beauty in new ways (4 statements).

The most repeated interview theme related to overall maturity or “growing up.” While their fathers’ experiences may have forced them into a new level of responsibility and maturity, participants were able to take pride in the fact they responded to the challenge in a positive way. As one father stated, “I’ve grown up quite a bit since he’s been here. Pretty well just growing up cause, like I said, I was, like, immature at first, but I’ve stepped up my game I guess you could say.” In addition to overall maturity, participants were able to identify how this experience has made them better fathers and brought their family closer together, revealing the intrapersonal growth resulting in inter-personal growth.

Regarding emotional and spiritual growth, participants described how they have grown in patience, compassion, and empathy, along with having increased faith. Although the specific word was not used, many of the participants described their emotional/spiritual growth as a discovery. As a result of their child’s cardiac condition and medical experiences surrounding heart care for their child, they “discovered” a level of patience, compassion, and empathy that had previously been underdeveloped. They also appeared to take pride in this discovery, often providing detailed descriptions of how this newfound awareness resulted in positive outcomes for themselves, their family, institutions, and their community. One paternal participant described discovering an entire new range and intensity of emotions as a result of his child’s heart condition diagnosed 5 months prior: “I’ve been more emotional in the last 5 months than I probably have for the last, well, I’m almost 30, so probably 20-some, well, I don’t know as a kid I guess, for at least the last 15 years.” While many participants were comfortable describing their growth in emotional terms, others preferred to identify their growth in cognitive terms. This group described their growth as a change in thinking or perspective. One participant expressed how he views the work of doctors and nurses differently with a new awareness of the sacrifices they make to take care of others. More than half of the participants described new

Table 4. Inclusive staff actions.

Communication	Specifically inquiring how each parent prefers to receive communication and how each parent approaches medical decision-making as an individual and also as a co-parent
	Lifting the role of one parent to communicate medical updates to the other parent by offering to communicate directly with each parent to include creative timing of communication or telehealth format
	Eye contact and body language inclusion of both parents in the room [fathers in the interviews reported times of feeling physically ignored in conversations].
	Considering evening rounds in addition to day rounds to foster chronologic inclusion of parents who may work different hours
	Avoiding gender assumptions in communication about roles and responsibilities within families; allow each co-parent to define their roles and responsibilities for care team
Tangibles	Establishing job corps relationships with local employers near the hospital to allow fathers who live distant to access contract work closer to the hospital, if feasible
	Maximizing resources for food security, housing, and economic care needs to lift some of the “economic provider” role for co-parents in immediate perioperative period
	Educating co-parents on medical leave employment laws and rights
	Ensuring physical space in the room conducive to paternal presence (comfortable chairs; large bed space for parents; etc)
Physiologically	Encouraging hands-on participation at the bedside for both parents to include assisting nurses with routine cares
	Checklists of parental skill sets such as dressing changes or medication administration
Socially	Support groups for fathers of children with cardiac conditions online and also in-person in the form of hobby-based or action-based gatherings (wood-working, sports)
	Inclusion of diverse gender team members to include social workers, chaplains, and physicians to foster communication
Education	When sharing written materials, considering provision of more than one information packet or booklet for co-parents to each have copies
	Writing/preparing booklets and materials specifically for fathers from other fathers of cardiac patients
	Eliciting the knowledge preferences of each parent and catering to diverse information-seeking needs within each family

academic knowledge about heart anatomy, cardiac processes, or practical knowledge. Paternal interviews captured the idea of aesthetic growth. In spite of the circumstances of extended stay in a critical care unit, one participant was able to appreciate the goodness and beauty of family life in a newfound way: “It kind of

humbles me a little bit to now realize that we do have a really cool, good family.” In the midst of challenges and difficulty, this father came to a deeper appreciation of familial relationships he previously took for granted.

Advice for other fathers of children with cardiac conditions

When asked what advice they may share with other fathers of children with complex cardiac diagnoses, 8 of the 10 fathers shared their belief that they would advise other fathers to be the foundation of the family unit. Interviewees specifically used the term “be the rock” when depicting what advice they would offer others fathers (17 phrases), emphasizing the perceived need to remain emotionally strong for the child and family. Fathers universally spoke to the importance of clear communication with doctors and nurses with the guidance to “attend rounds” stated 16 times in the interviews. Respondents recommended that other fathers seek knowledge of their child’s heart condition through reading and asking questions (15 phrases). Participants also emphasised the paternal need to find personal support (seven phrases) in order to better support the family.

Paternal inclusion in care of child with cardiac condition

Four interviewed fathers depicted that they have never felt excluded in the care of their hospitalised child. Six fathers reported that they do feel more excluded than their co-parent is included, citing that this was a reflection of their employment or absence from the hospital to care for the child’s siblings or competing responsibilities. Interestingly, actions from healthcare staff cited as most inclusive of paternal role were not actions directed towards the father himself but actions of care directed towards the father’s child. When asked about how to best include fathers of cardiac patients, seven fathers actually replied with statements of staff investment in the child’s care and staff compassion towards the child rather than replying with statements of staff actions towards themselves as fathers. Tangible forms of paternal inclusion are provided as Table 4.

Discussion

The fathers’ reflections provide important insight into the roles, responsibilities, growth, and inclusion needs of fathers of cardiac children from the paternal perspective. The quantitative and qualitative paternal responses reveal a certain altruism of perceived paternal role. Interviewed fathers ranked care for their family members higher on quantitative survey than care for self. When asked about the primary way to care for fathers of child cardiac patients, fathers replied that good care for their child is the best care of fathers.

Fathers described the challenges of parenting a child with complex cardiac condition in the hospital, as they defined their primary role as being a supportive and informed and even physically present to advocate for and comfort their child. And yet, throughout the interviews, fathers described themselves as the rock of the family unit to include economic, employment, and emotional security. The clashing reality is that the “good father” responsibilities described by the fathers were one of physical proximity to their child and a medically informed presence. And yet, the average distance from the hospital to home for these fathers was 310 miles (median 110 miles). In practicality, the majority of the interviewed fathers were balancing inclusion in their child’s day-to-day perioperative care needs with their perceived additional family stability responsibilities, which often required physical absence. Each father shared from the perspective of being placed into an unplanned

medical experience with their child and the personal challenges that arose in trying to maintain a “good father” role, while living out multiple, sometimes conflicting, responsibilities such as being at their child’s side and also maintaining family income at a geographic distance.

Limitations of this study include small sample size at a single facility. The perspective of the included fathers should not be universalised to all fathers, as family structure (whether same-gender couples or single parents or co-parents), culture, tradition, and family identity individualise the paternal experience uniquely for each father. Clinicians are wise not to generalise these findings but instead to recognise the privilege of asking parents to self-identify their sense of “good parenting” and to learn from each family ways that medical teams can best care for that family within the context of individual values and shared goals.

Recent studies have revealed that small, non-medical initiatives for fathers such as “Father of the Day” cards, paternal skin-to-skin contact for neonates, and offering the opportunity for a father to auscultate his child’s heart sounds have shown improvement in paternal subjective report of the child’s physiological patterns as well as improved parental confidence and preparedness for care of the child.^{23,24} Tangible actions such as a bead program with paternal inclusion for children with CHDs have been received by fathers as a form of inclusion.²⁵

The shared themes of proactively supporting and inclusively communicating were pervasive amongst these men and speak to the wishes medical team members should strive to meet. Ensuring that fathers of children with complex cardiac conditions have access to education and knowledge, opportunities to connect with others, and space to express their hopes and goals for their child is vital. This study revealed that many fathers of cardiac patients view themselves as their family’s foundation, and thus strengthening the foundation may be a form of strengthening the overall family. The finding that the average interview lasted only 20 minutes allows the study team to recognise a role for offering the fathers of cardiac patients the opportunity to process and reflect even in clinical and hospital interactions with medical staff.

The data provide clinic staff a clear opportunity to empower fathers, strengthen the clinic–family relationship, and increase patient satisfaction. Taking a brief moment to acknowledge the presence of fathers, helping them identify and name their growth areas, and honoring that growth will result in increased respect, accountability positive attitudes, and cardiac service line excellence.

Supplementary material. To view supplementary material for this article, please visit <https://doi.org/10.1017/S1047951119001586>

Acknowledgements. The study team wishes to thank the Hand in Hand team for review of the interviews and manuscript.

Financial Support. Transcription costs were generously supported by a University of Nebraska Department of Pediatrics Mini-Grant.

Conflicts of Interest. None.

Ethical Standards. The authors assert that all procedures contributing to this work comply with the ethical standards of the relevant national guidelines on human experimentation to include the COnsolidated criteria for REporting Qualitative research guidelines and with the Helsinki Declaration of 1975, as revised in 2008, and has been reviewed by the University of Nebraska Institutional Review Board in the form of the Paternal Advice, Guidance, Education, and Support Qualitative Study Protocol.

References

- Feudtner C, Walter JK, Faerber JA, et al. Good-parent beliefs of parents of seriously ill children. *JAMA Pediatr* 2015; 169: 39–47.
- Hinds PS, Oakes LL, Hicks J, et al. “Trying to be a good parent” as defined by interviews with parents who made phase I, terminal care, and resuscitation decisions for their children. *J Clin Oncol* 2009; 27: 5979–5985.
- October TW, Fisher KR, Feudtner C, Hinds PS. The parent perspective: “being a good parent” when making critical decisions in the PICU. *Pediatr Crit Care Med* 2014; 15: 291–298.
- Ware J, Raval H. A qualitative investigation of fathers’ experiences of looking after a child with a life-limiting illness, in process and in retrospect. *Clin Child Psychol Psychiatry* 2007; 12: 549–565.
- Nicholas DB, Beaune L, Barrera M, Blumberg J, Belletrutti M. Examining the experiences of fathers of children with a life-limiting illness. *J Soc Work End Life Palliat Care* 2016; 12: 126–144.
- Aho AL, Tarkka MT, Astedt-Kurki P, Kaunonen M. Fathers’ grief after the death of a child. *Issues Ment Health Nurs* 2006; 27: 647–663.
- Davies B, Baird J, Gudmundsdottir M. Moving family-centered care forward: bereaved fathers’ perspectives. *J Hosp Palliat Nurs* 2013; 3: 15.
- Jones JB, Neil-Urban S. Father to father: focus groups of fathers of children with cancer. *Soc Work Health Care* 2003; 37: 41–61.
- Schneider M, Steele R, Cadell S, Hemsworth D. Differences on psychosocial outcomes between male and female caregivers of children with life-limiting illnesses. *J Pediatr Nurs* 2011; 26: 186–199.
- Scrimin S, Haynes M, Altoe G, Bornstein MH, Axia G. Anxiety and stress in mothers and fathers in the 24 h after their child’s surgery. *Child Care Health Dev* 2009; 35: 227–233.
- Sood E, Karpyn A, Demianczyk AC, et al. Mothers and fathers experience stress of congenital heart disease differently: recommendations for pediatric critical care. *Pediatr Crit Care Med* 2018; 19: 626–634.
- Kim J, Cha C. Experience of fathers of neonates with congenital heart disease in South Korea. *Heart Lung* 2017; 46: 439–443.
- Woolf-King SE, Arnold E, Weiss S, Teitel D. “There’s no acknowledgement of what this does to people”: a qualitative exploration of mental health among parents of children with critical congenital heart defects. *J Clin Nurs* 2018; 27: 2785–2794.
- Paramo-Rodriguez L, Mas Pons R, Cavero-Carbonell C, Martos-Jimenez C, Zurriaga O, Barona Vilar C. An open heart: experiences of the parents of children with congenital heart disease. *Gac Sanit* 2015; 29: 445–450.
- Franich-Ray C, Bright MA, Anderson V, et al. Trauma reactions in mothers and fathers after their infant’s cardiac surgery. *J Pediatr Psychol* 2013; 38: 494–505.
- Gregory MRB, Prouhet PM, Russell CL, Pfannenstiel BR. Quality of life for parents of children with congenital heart defect: a systematic review. *J Cardiovasc Nurs* 2018; 33: 363–371.
- Weaver MS, Baker JN, Gattuso JS, Gibson DV, Sykes AD, Hinds PS. Adolescents’ preferences for treatment decisional involvement during their cancer. *Cancer* 2015; 121: 4416–4424.
- Beatty P, Willis G. Research syntheses: the practice of cognitive interviewing. *Public Opin Q* 71: 287–311.
- Mays N, Pope C. Qualitative research in health care. Assessing quality in qualitative research. *Br Med J* 2000; 320: 50–52.
- Krippendorff K. *Content Analysis: An Introduction to Its Methodology*, 3rd edn. SAGE, Thousand Oaks, 2013.
- Wakefield CE, Drew D, Ellis SJ, Doolan EL, McLoone JK, Cohn RJ. What they’re not telling you: A new scale to measure grandparents’ information needs when their grandchild has cancer. *Patient Educ Couns* 2014; 94: 351–355.
- Kuper A, Reeves S, Levinson W. An introduction to reading and appraising qualitative research. *Br Med J* 2008; 337: a288.
- Shorey S, He HG, Morelius E. Skin-to-skin contact by fathers and the impact on infant and paternal outcomes: an integrative review. *Midwifery* 2016; 40: 207–217.
- Kow S, Groot J, Puthenparampil J, et al. The impact of “mom/dad of the day” cards, newborn heart auscultation, and father skin-to-skin care on parent-newborn bonding. *Clin Pediatr (Phila)* 2019; 58: 349–353.
- Wilson V, Chando S. Parental experiences with a hospital-based bead programme for children with congenital heart disease. *J Clin Nurs* 2015; 24: 439–446.