



Parents' Perceptions of Emerging Adults With Congenital Heart Disease: An Integrative Review of Qualitative Studies

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ABSTRACT

Background: As the primary caregivers for children with congenital heart disease (CHD), parents' perceptions are important for emerging adults to achieve independence. This integrative review of qualitative studies aimed to describe parents' perceptions of emerging adults with CHD.

Method: Seven electronic databases were searched. Data extraction and quality assessment were performed. A meta-synthesis was conducted to inductively develop essential themes from five included studies.

Results: Three essential themes encompassing the parents' perspective of emerging adults with CHD were: (1) concerns about emerging adults' ability to be independent; (2) concerns about emerging adults' future; and (3) impact of disease on family. The themes depicted parents' concerns and worries about their children's ability to successfully achieve independence, especially in disease self-management and life goals.

Discussion: This review highlights parents' concerns about their emerging adult children's independence. Understanding these

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concerns allows for developing interventions to facilitate emerging adults' independence and ease parents' worries. *J Pediatr Health Care.* (2021) 35, 362–376

KEY WORDS

Congenital heart disease, parents, emerging adult, chronic disease, developmental transition

INTRODUCTION

Congenital heart disease (CHD) is the most prevalent birth defect in the United States, with approximately 2.4 million people with CHD living in the United States (Centers for Disease Control and Prevention, 2019). Advances in medical treatment and health care have changed CHD from what was once a life-threatening condition to a lifelong chronic disease (Gilboa et al., 2016). As a result, many children with CHD have reached adulthood but in doing so face tremendous challenges in achieving independence compared with their healthy counterparts (Mackie et al., 2016). Emerging adulthood is an important developmental stage for individuals aged 18–29 years to work toward independence. As the primary caregivers for children with CHD, parents' perceptions are important in assisting emerging adults to achieve independence.

Emerging adulthood is a pivotal and often unstable time to work toward independence and make decisions about future goals (Arnett, 2000; Arnett, 2015). During this developmental stage, emerging adults often move out of their family's home, enter college or the workforce, and become increasingly independent in all the aspects of life. Children with CHD who enter emerging adulthood have additional challenges to maintain health as they strive toward independent self-care of CHD.

Before emerging adulthood, parents and family members are primary caregivers who often take full charge of their children's disease management by providing daily care for CHD and navigating across multiple health care systems to ensure ongoing medical care. The importance of parents in providing care for children with CHD has led researchers to focus on the clinical needs of patients during childhood and often view the family and patient as a single unit (Wei, Roscigno, Hanson, & Swanson, 2015). However, as children with CHD survive beyond childhood and enter into emerging adulthood, they face a major transition in which they need to learn about disease management and navigation across health care systems to facilitate their health care. Parental perceptions may contribute to achieving the ultimate goals of emerging adulthood, such as independence not only in life in general but also in self-care of CHD. Since 2000, following the introduction of emerging adulthood theory (Arnett, 2000), publications on emerging adulthood have increased, specifically publications using a qualitative research approach. This change has made it possible to explore parents' perceptions of emerging adults with CHD through systematically reviewing the existing literature. The purpose of this integrative review is to evaluate evidence of peer-reviewed literature published from 2000 to 2020 to

describe and understand parents' perceptions of emerging adults with CHD.

METHODS

This integrative review of qualitative research studies was guided by the established methodology for systematic reviews and thematic synthesis of qualitative studies by Thomas and Harden (2008). Systematic identification and synthesis of qualitative studies is essential in deepening understanding of parents' perceptions of emerging adults with CHD and providing more generalizable conclusions than individual primary studies (Finfgeld-Connett, 2010; Harden et al., 2004). The reporting of this review has been guided by the Enhancing Transparency in Reporting the Synthesis of Qualitative Research framework (Tong, Flemming, McInnes, Oliver, & Craig, 2012).

Search Strategy

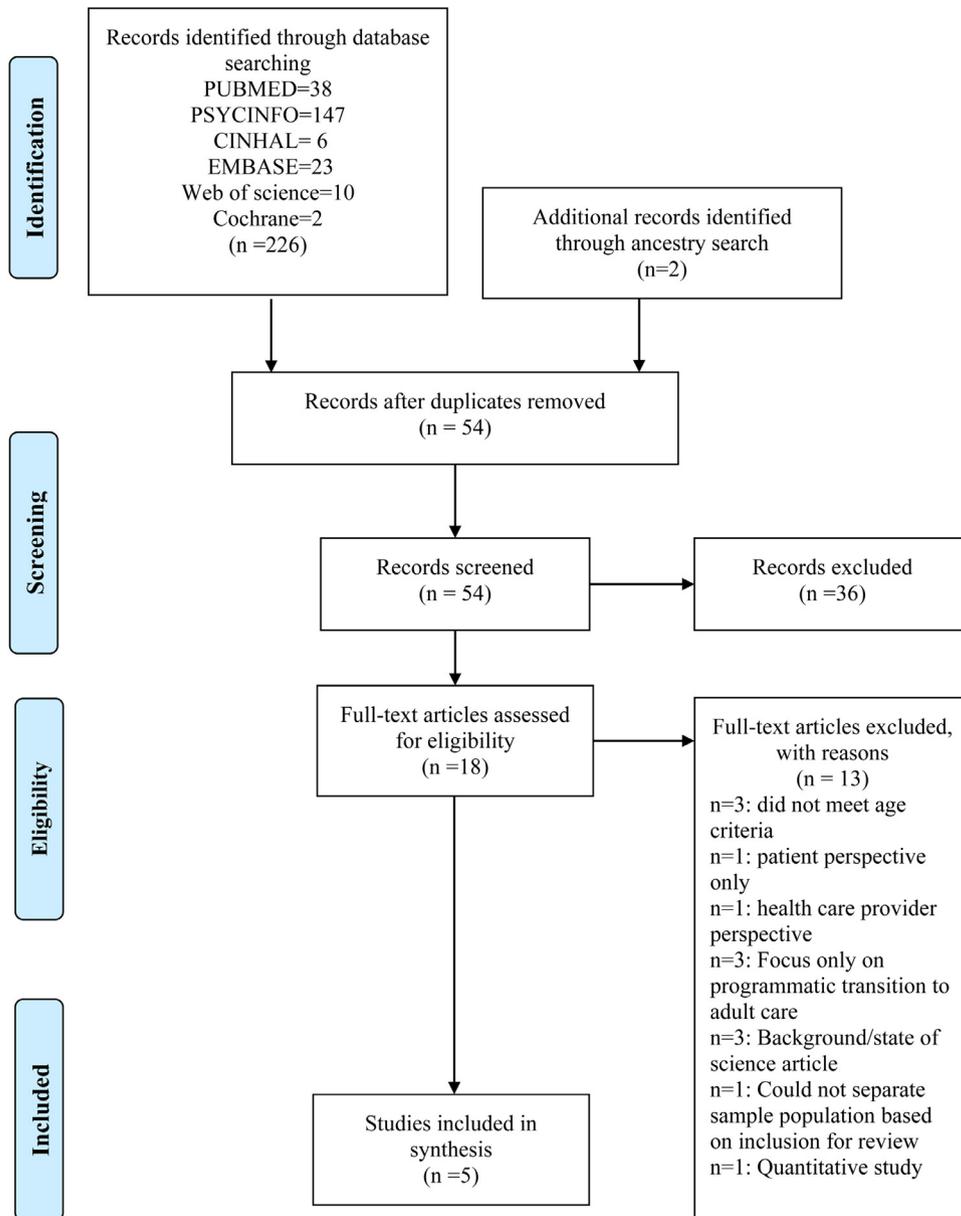
We searched the following databases: PubMed, Medline, CINAHL, Embase, PsycINFO, Web of Science, and COCHRANE from January 2000 to July 2020. The time frame of 2000 to 2020 was specified to reflect the increasing publications on emerging adults following the introduction of emerging adulthood theory introduced in 2000 (Arnett, 2000). Medical subject headings, key terms, and combinations of terms were used to search for the literature comprehensively: *emerging adult OR young adult AND congenital heart disease AND/OR (parent* OR mother OR father OR adoptive parent OR biological parent* AND/OR development AND/OR transition (not program)*. No language restrictions were applied. To ensure reliability, thoroughness, completeness, and accuracy of key searching terms, we completed the literature search with the assistance of a reference health librarian. Additional and ancestry searches of reference lists were conducted to identify further relevant studies.

After the removal of duplicates, the first author conducted the initial screen on titles and abstracts on the basis of the inclusion and excluded criteria. Articles that did not meet the inclusion criteria were excluded. For the remaining articles, full texts were obtained and assessed by two of the authors independently on the basis of inclusion and exclusion criteria. Studies that met the inclusion criteria were included. Any discrepancies were resolved via discussion among the authors (Figure).

Inclusion and Exclusion Criteria

The primary inclusion criterion was that the articles were peer-reviewed qualitative studies focusing on parents of emerging adults with CHD. A wider scope for the second inclusion criterion was selected as families of children with chronic diseases are more alike than different, thus providing a broader perspective than what could be gained from the CHD literature alone (Stein & Jessop, 1982). Studies were excluded if they solely investigated transition programs from pediatric to adult care and did not provide any relevant data on parents' perceptions of emerging

FIGURE. Preferred Reporting Items of Systematic reviews and Meta-analysis flow chart



Data from Moher, Liberati, Tetzlaff, Altman, & The PRISMA Group, 2009. (This figure appears in color online at www.jpeds.org.)

adults, case studies, and unpublished dissertations and abstracts.

Quality Assessment

An adapted quality assessment tool (Finlayson, Chen, & Fu, 2015; Fu et al., 2013; Tilley, Fu, Van Cleve, Crocilla, & Comfort, 2020) and the Critical Appraisal Skills Programme tool (Critical Appraisal Skills Programme, n.d.) were used to evaluate the quality of the included studies. For this integrative review, studies that received an affirmative score of at least 10 out of 14 were considered adequate quality (Finlayson et al., 2015; Fu et al., 2013; Tilley et al., 2020). The first two authors independently assessed the

quality of the included studies, and any discrepancies were resolved through discussions with the last author. The overall quality of the five studies was adequate (mean = 12.4, range = 11–13, standard deviation = 0.89), and all the five studies were retained for this review. Detailed information regarding the quality of studies is presented in (see Table 1).

Data Extraction

Study characteristics were extracted by the first two authors and reviewed by the last author, including author/year, study aims, country of origin, qualitative methodology, samples,

TABLE 1. Quality assessment scores of the reviewed studies

Quality assessment criteria	Total (N = 5 studies)
Explicit and soundness of literature review	5
Clear aims and objectives	5
Clear description of the setting	5
Clear description of the sample	5
Appropriate sampling procedure	5
Clear description of data collection	5
Clear description of data analysis	5
Evidence of critical reflection (qualitative study)	3
Provision of recruitment data	5
Provision of attrition data	5
Provision of psychometric properties of the measurement instruments (quantitative study)	–
Appropriate statistical analysis (quantitative study)	–
Findings reported for each outcome	5
Description of validity/reliability of results	5
Sufficient original data (qualitative study)	2
Provision of strengths and limitations of the study	5
Total score, mean (range; standard deviation)	12.4 (11–13; ± 0.89)

key findings, emerging themes, study strengths and weaknesses, and quality scores (see Table 2).

Data Synthesis

We used an iterative process of thematic analysis to synthesize the data from the included qualitative studies to develop the essential themes reflecting the range and depth of concepts and constructs across all studies to enable a rich description of parents' perceptions of emerging adults with CHD (Thomas & Harden, 2008). Quotations from participants and text from the Results, Discussions, and Conclusions sections of each study were managed in an excel file. The first two authors conducted line-by-line coding of the findings and inductively identified concepts and constructs reflecting parents' perceptions of emerging adults with CHD. Text from each study was coded into the concepts, new concepts were created as needed, and similar concepts and constructs were categorized into essential themes. Consensus on the concepts, constructs, and essential themes were accomplished through discussions among the investigators. Finally, essential themes were fashioned into a detailed description to delineate parents' perceptions of emerging adults with CHD.

RESULTS

Literature Search

The initial search yielded 228 citations. After the elimination of duplicates and nonrelevant titles and abstracts, a total of 18 full-text articles were reviewed for eligibility, with four meeting inclusion criteria. An additional article was found through ancestry searching, which met inclusion criteria

(Sparacino et al., 1997). In total, five studies from three different countries were included in this review (see Figure). Two of the five studies (Kools et al., 2002 and Sparacino et al., 1997) included only parents of CHD patients ($n=15$ parents); three of the studies included parents with CHD in a larger sample of parents with children who had diagnoses of other chronic or life-threatening illnesses but only had three parents with CHD ($n=3$ parents; Johnston et al., 2016; Peeters, Hilberink, & van Staa, 2014; Snape et al., 2019).

Synthesis

We identified three essential themes that encompass the parents' perspective of emerging adults with CHD: (1) concerns about emerging adults' ability to be independent; (2) concerns about emerging adults' future; and (3) impact of the disease on the family. The themes and subthemes are described as follows, and selected participant quotations supporting each theme are in Table 3.

Concerns About Emerging Adults' Ability to be Independent

Reliance on the family for disease and health management

Parents felt that emerging adults still relied on their family for disease and health management and were not socially or emotionally prepared for the adult world. Concerns with the child's ability to engage in self-care monitoring (consistent appraisal of signs and symptoms) were prevalent among parents as they have been managing their children's CHD since birth. The thought of independence was worrying because they feared their children would not be "prepared well enough... to see danger signals or help monitor things" (Sparacino et al., 1997, p. 191). In addition, self-care maintenance was also identified as a worry, as some parents feared that their children would not be reliable in taking their medications (Sparacino et al., 1997). Even if health care workers suggested that the parents allow their children to take more responsibility in the everyday needs of managing their health, some parents were reluctant to provide this space out of desires to protect their children's health (Peeter et al., 2014).

Parents described struggles in navigating the health care system that their emerging adult children face and felt that they still had to advocate for their children in the health care setting. Parents identified that in pediatric services, if their children needed anything, it was never an issue, but "the minute she becomes an adult, it's a problem" (Jindal-Snape et al., 2019, p. 7). Parents expressed that they knew their children "better than anyone" and considered themselves an expert in their children's condition (Jindal-Snape et al., 2019, p. 7; Kools et al., 2002). This desire to be there as an advocate for their child increased during times of medical stress, such as symptom exacerbations and hospitalization. When there were communication problems or when medical staff did not fulfill their children's request in a timely fashion, parents intervened (Jindal-Snape et al., 2019;

TABLE 2. Summary of included studies

Author, year	Study aim and country of origin	Qualitative method	Sample, gender, age, and diagnosis	Key findings	Emerging themes	Study strengths	Study weaknesses	Quality scores
Jindal-Snape et al. (2019)	Provide a clear understanding of the multiple and multidimensional life transitions experienced by young adults with life-limiting conditions and their significant others over a period Study origin: Scotland	A longitudinal study with semistructured interviews Data were analyzed with thematic analysis	<i>n</i> = 43 (total) <i>n</i> = 12 young persons (nine males/three females); range of age: 17–23 years <i>n</i> = 21 significant others (10 family members, 11 professional staff) Diagnosis: Duchenne's muscular dystrophy (<i>n</i> = 6), cerebral palsy (<i>n</i> = 2) CHD (<i>n</i> = 1), and other rare conditions (<i>n</i> = 3)	Degree/complexity of health condition impacts education and future choices Other people's beliefs and assumptions about the health status of a young adult may influence transition status more than their actual health condition (e.g., teachers) Parents and care staff perceived that young adults are not emotionally or socially prepared for independence Parents' perceived vulnerability of their child added complexity in accomplishing the normal developmental transition of moving out of the parents' home Diagnosis impacts family members' identities if they are genetic "carrier" of the condition Family members report difficulty of moving toward their own life transitions because of the health status of the young adults, which is often guilt-provoking Parents report challenges in navigating the health care system once shifting from pediatric care to adult care program	Presence of barriers that hinder education/employment for young adults with chronic health conditions Parents and siblings experience guilt when they are moving toward their own life goals Family members' mental and physical health may be impacted because of a lack of training for young adult's evolving medical needs The expectation that the children would not survive until adulthood led to prolonged dependence on parents	Longitudinal design over 6 months Inclusion of young adults that had limitations in verbal communication through the use of assistive technology	Small sample size with only one patient with CHD in the sample population An inherent limitation in sample population because of health problems resulting in some participant attrition and inability to complete the full study Did not identify factors that contribute to the parental perspective	13
Johnston et al. (2016)	Identify the nature of "relationship transitions" experienced by young adults with life-limiting illnesses Understand how these transitions inform end of life clinical needs of young adults Establish how palliative care providers respond to those needs "Relationship transitions" are defined as the adaptation between a parent-child relationship to an adult-adult relationship, and the desire for intimate relationships with partners Study origin: Scotland	Triangulated, longitudinal study with an exploratory approach Two data sources: semistructured interviews and clinical case note reviews	<i>n</i> = 43 (total) <i>n</i> = 12 young persons (nine males/three females) Range of age: 17–23 years <i>n</i> = 21 significant others (10 family members, 11 professional staff) Diagnosis: Duchenne muscular dystrophy (<i>n</i> = 6), cerebral palsy (<i>n</i> = 2), CHD (<i>n</i> = 1), and other rare conditions (<i>n</i> = 3)	Parents and care staff did not consider young adults to be socially and emotionally prepared for the adult world and perceived them as unable to be independent in decision making Lack of mutual respect between parents/care staff and young adults led to frustration among young adults. Illness may lead to overprotection from parents, resulting in young adults being ill-prepared to face potential dangers Illness is a shared experience for both the young adult and their family when close family bonds are present Parents viewed health/physical problems as having a negative impact on their child's future prospects (e.g., job and marriage). Parents and care staff make significant efforts to preserve young adults' "social" integrity by encouraging social activities Prolonged childhood and increased perceived vulnerability led to parents	Presence of prolonged childhood because of lack of adolescent developmental "norms" (i.e., gradual separation from parents) because of clinical needs Parents' and care staffs' perceived vulnerability of young adults may lead to overprotection Young adults experienced unwanted dependence on others because of their health condition, yet strove for independence, creating some tension The grief experienced because of loss of the child's or family's preillness identify young adults with life-limiting illness are more comfortable with adults and health care professionals than peers	Longitudinal approach over 12 months Providing different perspectives from patients, parents, and health care staff	Small sample size with only one patient with CHD in the sample population An inherent limitation in sample population because of health problems resulting in some participant attrition and inability to complete the full study Did not identify factors that contribute to the parental perspective Lack of evidence of critical reflection	12

(continued on next page)

TABLE 2. (Continued)

Author, year	Study aim and country of origin	Qualitative method	Sample, gender, age, and diagnosis	Key findings	Emerging themes	Study strengths	Study weaknesses	Quality scores
Kools et al. (2002)	To explore the experiences of young adults with CHD, the experiences of their families, and the perspectives of nurses who care for these patients Study origin: The United States	A grounded theory with semistructured interviews and naturalistic observations Data analyzed with dimensional analysis	<i>n</i> = 34 (total) <i>n</i> = 8 patients (four males/4 females) Age (mean, range): 28.63 years; 22–40 years <i>n</i> = 9 family members (five mothers, two fathers, one spouse, one significant other) <i>n</i> = 17 health care workers (eight pediatric nurses, nine adult unit nurses) Diagnosis: CHD	being reticent about their child's developing personal relationships Parents sometimes disagreed with their children about future ambitions because of the need to be "realistic" about the limitations of their child's illness Patients and parents expressed frustration that health care staff seemed to dismiss their experience and knowledge about their illness. Patients wanted parents to be involved in their care to help advocate for their needs but to take a secondary role in decision making Health care workers in adult units often perceived adult patients with CHD as demanding and overly dependent on their family, which disrupted normal workflow Parents played a major role in ensuring that their child's pain needs were met quickly and adequately	Young adults pursued "normality" and independence in the face of disruptions and restrictions Conflict and distrust in the competence of health care staff because of differences in expectations of care among health care workers, families, and patients Patients/families desire respect from health care workers regarding their illness-management expertise and experiences Patients' dependence on parents to advocate for their health needs, even in adulthood Adult clinicians' perception that patients with CHD did not show independent behavior, resulting in perceiving these patients as failing to achieve critical health goals Pain control is a critical issue that exemplifies how patients' and their families' perspectives contrasted greatly from that of clinicians	The sample contains only patients with CHD Highlights the different perspectives of many groups of people (nurses, families, patients) involved in the care of patients with CHD	Did not identify factors that contribute to the parental perspective	13
Sparacino et al. (1997)	To provide a better understanding of the experiences of parents of patients with CHD as their child matures through adolescence and young adulthood Study origin: The United States	A grounded theory with semistructured interviews	<i>n</i> = 8 (seven mothers, one father) Age of children (range): 13–25 years Current functional status of children: six = <i>good</i> , 1 = <i>fair</i> , and 1 = <i>poor</i> Diagnosis: CHD	On their child's diagnosis, parents had to grapple with the unfulfilled expectation of a healthy child Parents tried to treat their child as "normal" as possible, especially because their children appeared externally healthy Determining whether or not to disclose their child's diagnosis was a problem at the beginning of life, as well as during adolescence for fear of discrimination against their child or limiting their child's educational opportunities	Rapid physical, emotional, and social changes of adolescence amplified the differences between children with CHD and healthy peers Parents' struggle with attributing their child's behavior to their health problem or with just being a normal teenager Parents' worry about when or how to disclose their child's diagnosis	The sample contains only patients with CHD Focuses on the experiences of parents	Sampling did not reach saturation Few demographic/social characteristics of parents and patients	11

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TABLE 2. (Continued)

Author, year	Study aim and country of origin	Qualitative method	Sample, gender, age, and diagnosis	Key findings	Emerging themes	Study strengths	Study weaknesses	Quality scores
Peeters et al. (2014)	Gain insight into the process of achieving independence by comparing the lived experiences of young persons with a chronic condition to those of their parents Study origin: The Netherlands	Semistructured interviews covering two themes: (1) social participation and (2) participation in care The Skills for Growing Up framework was used to analyze the data	<i>n</i> = 32 (total) <i>n</i> = 16 young persons (seven males/nine females) Age (mean ± standard deviation): 18.3 ± 1.9 years <i>n</i> = 16 parents (15 mothers, one father) Diagnosis: diabetes mellitus	<p>Parents felt uncertainty about the reliability of their health care providers' predictions for their child's life because their children had already exceeded their predicted life span at birth</p> <p>Parents were unsure of whether they should encourage their children to prepare for the working world</p> <p>Parents struggled with encouraging their children to participate in physical activities because of the lack of concrete guidelines and direction from health care workers</p> <p>Parents sometimes mistook the presentation of normal adolescent risk-taking behavior for symptoms of CHD</p> <p>Parents worried about their child's reliability in taking care of their health responsibilities (e.g., taking medication)</p> <p>Parents worried that their children were not as socially integrated with their peers, instead of depending on their parents</p> <p>Families had to adapt their lifestyles to accommodate their child with CHD</p> <p>Parents expressed that siblings may have felt neglected because of the attention on their child's CHD</p> <p>Occasionally, the child's diagnosis led to the dismantling of the family structure (e.g., divorce, lack of communication/nurturing)</p> <p>Families attempted to cope with the uncertainty of their child's survival by focusing on "fixable" problems, psychotherapy and developing a life philosophy</p> <p>Parents concerned about patients' daily disease maintenance</p> <p>Patients' and parents' reports disagreed regarding independent living skills, social relationships, and self-management skills</p> <p>Patients viewed themselves as "normal," whereas parents viewed the diagnosis as having a negative impact on their child's sense of normalcy</p> <p>Patients and parents agreed on the</p>	<p>Parents' struggle with how much to push their children, given their physical disabilities and uncertainty about the future</p> <p>Parents' worry that their child would face limited occupational and social opportunities because of their diagnosis</p> <p>The negative impact of uncertainty of a child's future on the entire family</p> <p>Recognition of the importance of patients achieving independence</p> <p>Overprotection from parents may impact independence in transportation and leisure/social relationships</p> <p>Uncertainty about the future because of the</p>	<p>Deep understanding of patients' and parents' perspectives on the impact of the disease on the patient's life and achieving independence</p>	<p>Only one patient with the diagnosis of CHD in this sample</p> <p>The sample included those with and without physical limitations; therefore, unable to decipher how this factor in particular impacts lived experience compared with having a</p>	13

(continued on next page)

TABLE 2. (Continued)

Author, year	Study aim and country of origin	Qualitative method	Sample, gender, age, and diagnosis	Key findings	Emerging themes	Study strengths	Study weaknesses	Quality scores
			(n = 2), spina bifida (n = 6), CHD (n = 1), cystic fibrosis (n = 3), juvenile idiopathic arthritis (n = 3), and sickle cell disease (n = 1)	<p>importance of independence as a logical step to adulthood; however, parents were wary of providing the space for independence</p> <p>Parents reported concern about the chronic condition limiting study/work opportunities</p> <p>Patients viewed difficulties in social relationships as not related to diagnosis, whereas parents felt the diagnosis contributed to increased limitations</p> <p>Patients and parents defined self-management of condition similarly (arranging hospital visits, showing up for consultations, talking with caregivers, making decisions, responsibility in keeping these decisions)</p> <p>Parental support for medical self-management was convenient for some patients so they could focus on other things</p>	<p>diagnosis (e.g., fertility)</p> <p>Parents' protective attitude toward self-management of the condition may impact independence</p> <p>Discordance between patients and parents regarding how to achieve independence</p> <p>Parent identification of need for patient's learning of self-management of condition and challenge this poses from the parents' perspective</p>		<p>chronic condition diagnosis in general</p> <p>Did not identify factors that contribute to the parental perspective</p>	

Note. CHD, congenital heart disease.

TABLE 3. Synthesized themes and representative quotes

Subthemes	Quotations	Articles
<p>Theme 1: concerns about emerging adults' ability to be independent</p> <p>Reliance on the family for disease and health management</p>	<p><i>Self-care monitoring (i.e., routine appraisal of signs and symptoms)</i></p> <p>"If she was a normal child without a heart problem, I would say she was healthy. . . but she's not a healthy child, if you are considering the fact that she has a serious heart problem. . . .you have to remind yourself sometimes that you need to look below the surface as to what's going on with her because of her physical health—mother (Sparacino et al., 1997)</p> <p>"I worry. . . whether she she's going to be prepared well enough down the road to face a lot of things on her own when we're not there to see danger signals or help monitor things"—mother (Sparacino et al., 1997)</p> <p><i>Self-care management (i.e., recognizing and responding to symptoms when they occur)</i></p> <p>"I guess he did everything that everyone else did. Last time I guess his mother thought he was dying because he was seeing things and everything. We rushed him to the hospital and come to find out he ate some mushrooms or something"—father (Sparacino et al., 1997)</p> <p>"Self-management is like when your children go to school by bike for the first time on their own"—parent (Peeters et al., 2014)</p> <p><i>Self-care maintenance (i.e., adhering daily medication or other treatment regimen)</i></p> <p>"What I worry about most is [his] smoking, because I feel it is the only thing I can change"—mother (Sparacino et al., 1997)</p> <p>"Last year she had her first treadmill, and she did beautifully on that, and she really pushed herself. . . I would have never pushed her that hard"—mother (Sparacino et al., 1997)</p> <p>"They said [in the hospital]: 'You don't have to tell anything to [your son], let him think for himself, let him take his medication on his own, let him spray on his own, let him think what to do.' But that doesn't work for [my son]!"—parent (Peeters et al., 2014)</p> <p>"I've been wrought with uncertainty in regard to how much of what she is doing is related to her heart problem or related to just being a normal teenager"—mother (Sparacino et al., 1997)</p> <p><i>health care system navigation.</i></p> <p>"Children's Services were great. . . anything [my daughter] needed as a child, there wasn't a huge fight about it. . . the minute she becomes an adult it's a problem"—parent (Jindal-Snape et al., 2019)</p> <p>". . . I'm just worried that if she needs something, they can't get to it as fast as I think they should, and maybe they don't need to get to her as fast as they should, and only I think they should because I'm her mother. . . if I weren't here, I would worry that she's not being cared for as well as I think she should be after having come from ICU only one day"—parent (Kools et al., 2002)</p>	<p>Jindal-Snape et al. Kools et al. Peeters et al. Sparacino et al.</p>
<p>Lack of social and emotional maturity</p>	<p>"Of course we talk about boyfriends. . . sometimes, but she is. . . absolutely not ready for that"—parent (Peeters et al., 2014)</p>	<p>Jindal-Snape et al. Johnston et al. Peeters et al. Sparacino et al.</p>
<p>Perception of normality</p>	<p>"Often, . . . when others are around, she feels a bit ashamed [about her disease], shy to acknowledge that she's different from others."—parent (Peeters et al., 2014)</p> <p>"He's just a normal child. So, we always try to be normal with him; [or] You have to let yourself forget about the heart problem in order to go on through life; [and] Live normally. Let your family continue on as normal as possible, because the rest of the world is not going to give one hoot that this kid's got this defect, so don't let him use it as an excuse."—parent (Sparacino et al., 1997)</p> <p>"He just has not got the capacity to play full-court basketball or running. Otherwise he has no restrictions. He's on absolutely no medications and he leads a pretty much normal life."—mother (Sparacino et al., 1997)</p> <p>"He was playing on the playground and he was doing just fine. The surgeries were well out of the way and over with, and some kid knocked him down and knocked the wind out of him. And the principal called</p>	<p>Peeters et al. Sparacino et al.</p>

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TABLE 3. (Continued)

Subthemes	Quotations	Articles
Social integration	<p>the ambulance and the paramedics and the fire department, and the whole nine yards. . . And I got there, and the paramedics were going to take him away, and I said, "To hell you are." I said, "There's nothing wrong with him." And they said, "Oh, but his heart, his heart." I said, "I have told you repeatedly, there's nothing wrong with him. He's completely normal, and he's just got the wind knocked out of him like any other kid."—mother (Sparacino et al., 1997)</p> <p>"[My son's] afraid to grow up. He's sort of safer to kind of sit around here and not taking risks, and not going out."—mother (Sparacino et al., 1997)</p> <p>"I've been wrought with uncertainty in regard to how much of what she's doing is related to her heart problem or related to just being a normal teenager. . . It's an ongoing struggle, and it's been more difficult lately than I think it was all those other years."—mother (Sparacino et al., 1997)</p> <p>"I think he worries about fitting in with other boys his own age. . . he can't really find very many kids who like the same stuff he does. . . [but] as he gets older, that will change."—mother (Sparacino et al., 1997)</p>	<p>Jindal-Snape et al. Johnston et al. Peeters et al. Sparacino et al.</p>
Overprotection	<p>"We're just happy [young adult's] got the computer and the Internet so [young adult] can communicate with other people, bar looking at us 24/7!"—father (Johnston et al., 2016)</p> <p>"[Young adult] still very childlike because [young adult] been wrapped in cotton wool and not been out there exposed to life's elements."—mother (Johnston et al., 2016)</p> <p>(My Son) would like to go out—into town on his own. Well, I don't want to hear about that, because I really do not support that!"—parent (Peeters et al., 2014)</p>	<p>Jindal-Snape et al. Johnston et al. Peeters et al.</p>
The tension between desired independence and necessary dependence	<p>"We don't think he's ready to live independently, because, for one thing, he will be fully isolated then and secondly he needs help. . . in his daily living activities, otherwise he just forgets it."—parent (Peeters et al., 2014)</p> <p>"[She] is not independent at all, no. . . I think this has to do with her disease because she has no notion of how to do things."—parent (Peeters et al., 2014)</p> <p>"She is more dependent. . . on us, and she absolutely doesn't like that, [but] that's how it is"—parent (Peeters et al., 2014)</p> <p>"[My son] would like to go out—into town on his own. Well, I don't want to hear about that, because I really do not support that!"—parent (Peeters et al., 2014)</p>	<p>Jindal-Snape et al. Johnston et al. Peeters et al.</p>
Theme 2: concerns about emerging adults' future Uncertainty in disease prognosis	<p>"Oh traumatic. . . when they said that it would be unlikely she would be a teenager. . . and she was ten, so you're saying 'God that's only two or three years to go,' . . . traumatic, and it took us a while to get over it"—grandparent (Jindal-Snape et al., 2019)</p> <p>"So often the confusion sets in—do I, should I, even be thinking in term of goals? Or do you just stop and focus on the fact that she's healthy right now and be thankful for that and not worry about goals?"—mother (Sparacino et al., 1997)</p>	<p>Jindal-Snape et al. Johnston et al. Sparacino et al.</p>
Concerns about education and employment	<p>"We were told then that it was terminal and that they didn't give [young adult] any much more hope than 18 years. . . So obviously it, it sort of blew us, we really, we all fell to pieces."—mother (Johnston et al., 2016)</p> <p>"When they get to this age there's nothing for them. . . there's nothing, there's no job prospects, there's no future prospects, there's no, like marriage, there's none, there's none of that in front of them."—Johnston et al. (2016)</p> <p>"I hope he will not have problems when applying for a job later, because that's what you hear sometimes. All right, he has a chronic disease and often employers don't know exactly what it is. When you are disabled, they don't want you anymore, because you are a burden."—</p>	<p>Jindal-Snape et al. Johnston et al. Sparacino et al. Peeters et al.</p>

(continued on next page)

TABLE 3. (Continued)

Subthemes	Quotations	Articles
Problems with moving out of the home and transportation	<p>parent (Peeters et al., 2014)</p> <p>“We’ve told the teachers, and we’ve had problems. We changed schools because we had some problems with the teachers focusing on her heart”—mother (Sparacino et al., 1997)</p> <p>“I wanted to know if they didn’t hire him because he looked weird, because besides looking blue, he has glossy [sic] eyes, and they might have thought he was doing drugs.”—mother (Sparacino et al., 1997)</p> <p>“Susan wanted to move into a flat with her boyfriend. . . she’s been dating since school. . . he’s also wheelchair bound. . . I was so against it. . .”—mother (Jindal-Snape et al., 2019)</p> <p>“[My daughter] has plans to live independently, but I think she is not ready yet.”—parent (Peeters et al., 2014)</p>	Jindal-Snape et al. Johnston et al. Peeters et al.
Fertility concerns/future for family planning	<p>“If [my daughter] wants to have children, I think [she] has to overcome a number of obstacles.”—parent (Peeters et al., 2014)</p>	Peeters et al.
Theme 3: impact of diagnosis and disease on parents/family Sense of suffering	<p>“I think he’s [patient’s sibling] probably suffered more than anyone. . . ‘cause he doesn’t have your normal childhood”—mother (Jindal-Snape et al., 2019)</p> <p>“At one point I was thinking, well why should I be out partying and enjoying myself, when he’s stuck in the house and he can’t do nothing”—sister (Jindal-Snape et al., 2019)</p> <p>“mum wasn’t particularly easy in the whole process. . . she was pushing people away. . . if they wanted to be there and part o’ her life as much as I did then they would have fought for it”—sister (Jindal-Snape et al., 2019)</p> <p>“Our whole family was just really destroyed by this whole thing, and it was a number of years before, in my case, I sort of got my mental faculties back”—mother (Sparacino et al., 1997)</p> <p>“The only indication I had that they were neglected was when the oldest sister needed something and she says, ‘I can’t help it if I’m not sick’. . . I think that might have been the effect on the other kids. They weren’t getting attention.”—mother (Sparacino et al., 1997)</p> <p>“The marriage wasn’t too good at this point. . . you don’t even think about yourself or anything else around you. . . it was wearing on us.”—father (Sparacino et al., 1997)</p>	Jindal-Snape et al. Sparacino et al.
Trauma to and exhaustion of parents as caregivers	<p>“I had ten months o’ going back and forward and being told I was neurotic and, a first-time mother and you know he was just a lazy baby. . . it was quite traumatic. . .”—mother (Jindal-Snape et al., 2019)</p> <p>“I was grief-stricken, whatever, I was too tired, it was like my crap life, that’s it, it’s like, you know, there was times when I just didn’t want to be here.”—mother (Johnson et al., 2016)</p> <p>“(Hospice) was one of the best things that’s ever happened. . . definitely, em, that was a lifesaver, that definitely saved our lives.”—mother (Johnston et al., 2016)</p> <p>“He has also not been able to get comfortable at night. This has a big impact on my ability to sleep, and my feelings of tiredness. It’s stressful—mental stress. . . he had written on his Facebook page ‘I hate my life’. . . lots of emotional responses, and people contacted me with their concerns. I had to deal with all that.”—parent (Jindal-Snape et al., 2019)</p>	Jindal-Snape et al. Johnston et al.

Kools et al., 2002). Parents felt that their presence ensured that their children were getting the best care possible: one parent remarked, “if I weren’t here, I would worry that she’s not being cared for as well as I think she should be” (Kools et al., 2002, p. 123). Especially in these times of acute distress, patients relied on their parents to “take over if you see that I [the patient] am having too much trouble on my own” (Kools et al., 2002, p. 120). Therefore, emerging adult

patients with CHD were often still reliant on their parents for health management, and parents felt that they needed to continue to be involved in protecting their children’s health and ensuring the quality of medical care.

Lack of social or emotional maturity

Another consequence of overprotection was that parents worried that their emerging adult children were not socially

or emotionally mature enough for relationships in the adult world. For example, parents expressed that their children were “absolutely not ready” (Peeters et al., 2014, p. 37) for romantic relationships, in part because they had been sheltered for much of their life and had little experience (Jindal-Snape et al., 2019; Peeters et al., 2014). Another danger of overprotection was that it led to emerging adults being overly naive when navigating the adult world, such as providing personal details to strangers online (Johnson et al., 2016).

Perception of normality

Parents worried about how their children with CHD would be viewed by others in society. Some parents felt that their children seemed outwardly different from other children and then became “ashamed [about her disease], shy to acknowledge that she’s different from others” (Peeters et al., 2014, p. 36). Another parent described worries about her child’s physical appearance that made him look thinner and weaker than other males his age and made him “feel uncomfortable running around in shorts and a T-shirt” (Sparacino et al., 1997, p. 189).

By contrast, some parents viewed their children as normal compared to other children their age. Especially because the effects of CHD are not always visually obvious, many parents acknowledged that their emerging adults appeared normal to the outside world. Although one parent admitted that her son “just has not got the capacity” to participate in some physical activities fully, she insisted that “he’s on absolutely no medications and he leads a pretty much normal life” (Sparacino et al., 1997, p. 189). For some parents, treating their children as normally as possible was a mechanism to train their children to deal with people outside of the family because people were “not going to give one hoot that this kid’s got this defect, so don’t let him use it as an excuse” (Sparacino et al., 1997, p. 189). However, in other cases, emerging adults with CHD felt that their disease did cause others to view them differently. In one case, the patient’s peers found out “that she had a hole in her heart,” causing the patient to “feel bad, that she was different. . . And she got pretty upset. . . and then she began to think less of [her classmates]” (Sparacino et al., 1997, p. 191). Therefore, parents expressed worry about how others’ perceptions of their child might affect their child’s self-image. However, some parents insisted on treating their children normally and assuming others would view their child as normal to foster self-efficacy.

Social integration

Parents expressed disparate views of how well their children were able to integrate into their peer groups. Some parents felt their children “worried about fitting in with other boys his own age” or “afraid to grow up” (Sparacino et al., 1997, p. 191). In these cases, often the emerging adults’ social life revolved around their caretakers, such as their parents or health care workers, perhaps because they felt “safer to kind of sit around here and not taking risks and not [go] out”

(Jindal-Snape et al., 2019; Sparacino et al., 1997, p. 191). Parents felt that technology such as the internet was able to reduce the barriers faced by their children in interacting with peers and expand their social circle outside of their caretakers (Johnston et al., 2016).

Other parents found it became difficult to discern whether certain incidents were a result of CHD disease or risk-taking behaviors that are typical of this age group as their children grew into emerging adulthood. For example, one parent mistook the effect of recreational drug use as a problem with his son’s heart, which caused his realization that his son “was doing what everybody else was doing” (Sparacino et al., 1997, p. 191). Although this behavior may indicate social integration, it can cause parents to be “wrought with uncertainty” about this “ongoing struggle” to discern whether an incident might be cause for concern about their children’s health (Sparacino et al., 1997, p. 191).

Overprotection

Because of the uncertainty of survival during adulthood for some children with CHD, parents often viewed their children as vulnerable. This perceived vulnerability caused parents to feel the “need to nurture, protect, and wrap,” preventing their children from achieving a sense of self and identity (Jindal-Snape et al., 2019, p. 6). As a result, parents often viewed emerging adult children as “childlike” because they had not been “exposed to life’s elements” (Johnston et al., 2016, p. 8). This sense of overprotecting their children also caused parents to limit their children’s experiences in emerging adulthood. For example, one parent reported that they “really do not support” their child going out on his own (Peeters et al., 2014, p. 37).

Tension between the desire for independence and necessary dependence

Parents and emerging adults with CHD often had conflicts regarding their emerging adult children’s readiness for independence. This clash was even more complicated because, often, the emerging adult children were still reliant on their families for medical or lifestyle needs. However, the dependence on their parents often became the source of resentment for emerging adults, who “absolutely did not like that” (Peeters et al., 2014, p. 38). For example, although emerging adults desired intimate, romantic relationships, their parents dismissed them as unprepared for this (Jindal-Snape et al., 2019). Parents were worried over the emerging adults’ capability to live independent lives, emphasizing that their children’s disease required their “help. . . in his daily living activities, otherwise he just forgets it” because their children often had “no notion of how to do things” (Peeters et al., 2014, p. 37).

Concerns About Emerging Adults’ Future

Uncertainty in disease prognosis

Because advances in medicine and health care have transformed CHD into a lifelong chronic illness, any potential of

or delivery of a terminal prognosis caused family members to initially feel a sense of helplessness and deep loss at the time of diagnosis. Family members described receiving the news that their children would likely die before adulthood as “traumatic” and caused parents to “[fall] to pieces” (Jindal-Snape et al., 2019; Johnston et al., 2016, p. 9). This sense of uncertainty permeated through daily life, causing parents to worry each day whether “you’re going to wake up and find if he’s alive or not. It was terror” (Sparacino et al., 1997, p. 190).

These feelings of uncertainty affected both parents’ treatment toward their children and caused them to be cautious of setting goals for their children’s future. One parent described feeling afraid to get attached and connect with her newborn son following his diagnosis of CHD because she was constantly afraid that she would suddenly lose him (Sparacino et al., 1997). As their children grew into emerging adults, the uncertainty of their survival continued to affect parents’ ability to set goals for their children’s future. Although emerging adulthood is often characterized by trying to narrow down and consolidate an individual’s goals in life, parents wondered if they should “even be thinking in terms of goals? Or do you just stop and focus on the fact that she’s healthy right now and be thankful for that” (Sparacino et al., 1997, p. 190). Even though their children had already survived past their expected lifetime, the expectation of an early death still cast a shadow on parents’ expectations of their children and made them reluctant to establish long-term goals.

Concerns about education or employment

The major issue that parents struggled with regard to their children’s future was their prospects of education or employment. Parents often felt helpless that “there’s nothing for them. . . no job prospects, there’s no future prospects” as their children reached adulthood (Johnston et al., 2016, p. 9). In some cases, emerging adult patients and parents struggled to decide if normal educational transitions, such as entering university, would be possible for them because “there was a great deal unknown about longevity” (Jindal-Snape et al., 2019, p. 9).

This concern was fueled by the fear that their children’s diagnosis might cause them to experience stigma. For example, parents often found that teachers and school officials would treat their child differently because of their health condition, often limiting their experiences compared with their peers (Sparacino et al., 1997). This fear extended to employment concerns, with many parents worried that their children’s disease would cause employers not to hire them because “you are a burden” (Peeters et al., 2014, p. 37). In other cases, parents worried that potential employers might mistake the visible manifestations of CHD, such as blue-tinged skin and glossy eyes, as potential drug use, leading to them not hiring their children (Sparacino et al., 1997). Therefore, parents felt that having CHD made it more difficult for their children to have equal opportunities as their peers for

educational and professional life transitions because of stigma and the physical manifestations of their disease.

Issues with moving out of the home and transportation

One significant step of development in emerging adulthood is moving out of the family home because it is an important step toward independence. Many parents were “so against” their children moving out because they felt they were “not ready yet” (Johnston et al., 2016; Peeters et al., 2014, p. 36). This reluctance to support their child from moving out was tied to parents’ concerns that their children were not responsible enough to take care of their health on their own or simply unable to take care of themselves because they had been overprotected (Johnston et al., 2016; Sparacino et al., 1997).

In addition, many emerging adult patients found themselves still highly reliant on their parents for transportation, which reduced their ability to plan social events independently and be fully independent in their health management (Jindal-Snape et al., 2019; Peeters et al., 2014). Even though emerging adults expressed that they were not satisfied with this dependence on their parents for transportation, parents saw this problem as just “how it is” even though their child “absolutely doesn’t like that” and felt that they could do much more than you think when it comes to organizing things” (Peeters et al., 2014, p. 38).

Fertility and family planning concerns

One concern that parents had was whether the emerging adult would be able to have children and a family. This important step in personal life transitions was shrouded in uncertainty. Some parents saw marriage as unlikely for their children (Johnston et al., 2016). With regard to having children, one parent acknowledged that her daughter would have to “overcome a number of obstacles” because of her health condition (Peeters et al., 2014, p. 37). Therefore, family planning and fertility was a concern for both parents and emerging adult patients.

Impact on Parents and Family

Sense of suffering

The diagnosis of CHD had a large impact on parents, but also other family members and the family unit as a whole. In this sense, the CHD diagnosis was a shared experience among the whole family because they were “in it together” (Johnston et al., 2016, p. 8). In particular, parents felt that siblings were affected and “suffered more than anyone. . . ‘cause he doesn’t have your normal childhood” (Jindal-Snape et al., 2019, p. 9). One parent felt that the siblings felt neglected and that they were not getting attention (Sparacino et al., 1997). Siblings also felt a sense of guilt because of their ability to experience normal events of emerging adulthood like “partying and enjoying [themselves],” whereas the emerging adult patients could not (Jindal-Snape et al., 2019, p. 9).

The diagnosis of CHD had a significant effect on the family unit as a whole. On a practical level, parents had to ensure that family activities and food could accommodate the needs of the CHD patients, such as choosing activities with less physical demands and a lower sodium diet (Sparacino et al., 1997). For some parents, going through the stress of taking care of their children, “if anything, it brought us closer together” (Sparacino et al., 1997, p. 192). However, the diagnosis sometimes had an even more negative impact on the family unit. Parents became emotionally closed off, requiring siblings to fight to be a part of their life (Jindal-Snape et al., 2019). In some cases, marriages became less stable as parents began to focus on only their children with CHD, rather than “think[ing] about yourself or anything else around you. . . it was wearing on us” (Sparacino et al., 1997, p. 192). The uncertainty of prognosis also contributed to family dynamics because “waiting for this kid to die” led to parents staying together, despite marital problems (Sparacino et al., 1997, p. 192). Therefore, the CHD diagnosis not only affected the patient but also created a shared experience among the entire family.

Trauma to and exhaustion of parents as caregivers

The initial diagnosis caused many families to feel a sense of trauma because CHD was considered a terminal illness (Jindal-Snape et al., 2019; Johnston et al., 2016; Sparacino et al., 1997). Parents described feeling “grief-stricken” over their children’s diagnosis, and some even described suicidal thoughts: one parent said at some points, she “just didn’t want to be here” in her “crap life” (Johnston et al., 2016, p. 9). As their children grew into emerging adulthood, the stress and psychological weight of the diagnosis increased on the children; however, it was also a shared experience for parents. For example, when emerging adult patients shared their emotional stress online, writing “I hate my life,” parents had to not only support their children but also had to “deal with” other people contacting the parents with concerns about their children’s well-being (Jindal-Snape et al., 2019, p. 9). One major concern for parents was that they felt extremely fatigued. As taking care of their children’s needs had “a big impact on my [the parent’s] ability to sleep and my [the parent’s] feelings of tiredness” (Jindal-Snape et al., 2019, p. 9). Feelings of grief also caused parents to feel exhaustion (Johnston et al., 2016). Caregiving was an ongoing struggle for parents, causing intense emotions, such as sorrow, trauma, and worry.

DISCUSSION

This integrative review of five qualitative studies from 2000 to 2020 described the perspective of parents of emerging adults with CHD. The overall small number of parents of CHD patients in the studies found in this integrative review highlights the paucity of research in understanding the perspective of parents of CHD patients. This thematic synthesis identified that parents had concerns about their children’s ability to be independent, concerns about their children’s

future, and recognized the impact of the disease on themselves and the family unit, resulting in stress and exhaustion. This review identified that the parents’ major concern was their emerging adult children’s ability to engage independently in self-care of CHD. Parents described four major types of self-care behaviors that they worried about whether their children would be able to accomplish: self-care maintenance (i.e., adhering daily medication regime), monitoring (i.e., routine appraisal of signs and symptoms), and management (i.e., recognizing and responding to symptoms when they occur), as well as health care system navigation. Although in this review, we chose to focus on the parents’ perception, all the studies included the perspective of the emerging adults, showing a consistent contrast between the perception of emerging adults from that of the parents. Although parents specified the disease management behaviors that they worried about if their emerging adult children were able to perform independently, emerging adults usually only expressed a desire for increasing their independence. They seldomly identified what self-care behaviors that they were able to perform independently and what behaviors needed their parents’ help.

It should be noted that only one quantitative study (Helm et al., 2018) was yielded from the literature search, and no studies were focused solely on emerging adults with CHD. Thus, it remains largely unknown if emerging adults with CHD share the same concerns as their parents in their ability to independently engage in self-care of CHD through these four types of self-care behaviors. It is important to understand the perspective of emerging adults with CHD regarding their ability to perform independent self-care of CHD so that targeted interventions can be designed to support emerging adults through the transition to independence in self-care of CHD.

This review also identified parents’ concern about the uncertainty of their emerging adult children’s future and opportunities regarding employment, education, family planning, relationships, and residential living status. Parents’ uncertainty about their children’s future is rooted deeply in the lived experience of raising a child with a potentially poor prognosis. Even when their children have grown into emerging adulthood, many parents continue worrying if their children would still be alive in a few years, leading to parents’ inability to foresee future options and make plans for their children. Such parental perception may impact emerging adults’ development of independence during this important developmental milestone. Perhaps, ongoing disclosure of disease prognosis and multidisciplinary support for individualized care planning for emerging adults with CHD’s future may ease the overall parental concerns and worries. Given parents’ concerns are multifaceted, including employment, education, family planning, relationships, and residential living status, support for parents and emerging adults may need to include multidisciplinary team members, such as social worker, career consultant, developmental psychologist, and relationship/marriage advisor.

Strengths and Limitations of the Review

The synthesis of the available qualitative studies identified important essential themes that individual primary studies were not able to identify to provide, such as a deeper understanding of parents' perceptions of emerging adults with CHD. The focus on emerging adults with CHD is an emerging area; thus, there is limited data specific to the focus of this integrative review. As families of children with chronic diseases are more alike than different, and to provide a broader perspective than what could be gained from the CHD literature alone, we chose to include studies whose samples included multiple diagnoses of pediatric, chronic, lifelong conditions (Stein & Jessop, 1982). This decision may be viewed as the limitation of the review.

Conclusions

This synthesis of qualitative studies revealed a detailed and vivid description of parent's perception of emerging adults with CHD, specifically their concerns about emerging adults' ability to independently engage in self-care of CHD and concerns about emerging adult's future; all these concerns and worries generate a tremendous impact on parents and families. Understanding parents' concerns regarding emerging adults' independence in CHD management is essential in developing interventions to optimize emerging adults' self-care and consequently empower parents to facilitate the independence of their emerging adult children. Furthermore, enhancing emerging adults' ability to engage independently in self-care of CHD may also lead to better social and emotional integration and a sense of normalcy for the emerging adult with CHD, while also reducing parents' concerns and worries. Clinical interventions focusing on a shared disease management model that fosters self-care throughout childhood to emerging adulthood may simultaneously support parents to foster emerging adults' independence and lead to better outcomes for emerging adults with CHD and parents.

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