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Care of Children and Young Families With Cardiopulmonary Disorders

Families of children with congenital heart disease: A literature review

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ABSTRACT

In 2000 and 2002, the National Heart, Lung, and Blood Institute launched two initiatives to encourage treatment innovations and research on children with heart disease and their families. Since then, no systematic reviews have examined the evidence regarding the impacts of having a child with congenital heart disease (CHD) on families. This review synthesized key findings regarding families of children with CHD, critiqued research methods, described what has been done, and provided recommendations for future inquiry. Databases searched included PubMed, CINAHL, Family & Society Studies Worldwide, Women's Studies International, and PsycINFO. The literature search followed the PRISMA guidelines. As a result, ninety-four articles were reviewed. Four major themes were derived: parents' psychological health, family life, parenting challenges, and family-focused interventions. In conclusion, while they found parents having psychological symptoms, researchers did not explore parents' appraisals of what led to their symptoms. Research is needed to explore parents' experiences and expectations.

Introduction

Congenital heart disease (CHD) is the most prevalent birth defect and a leading cause of children's deaths in the United States (US).[1] About 40,000 children are born with CHD each year in the US, with an incidence rate of 8–10 per 1000 live births.[1,2] Congenital heart disease is among the birth defects that lead to the longest hospital stays, highest mortality rates, and greatest average hospital charges in children.[3–5]

In 2000 and 2002, the National Heart, Lung, and Blood Institute launched two major funding initiatives to encourage treatment innovations and research for children with heart disease and their families.[6] No literature reviews, however, have synthesized the research done on families of these children since then. This paper, therefore, reviewed the published research on families of children with CHD from 2000 to 2014, synthesized key concepts, critiqued research methods, noted what still needs to be done, and provided future research directions.

Methods

The literature search was conducted in accordance with the Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA).[7] Search strategies were developed by the first and third authors and a university medical research librarian. Databases searched included PubMed, CINAHL, Family & Society Studies Worldwide, Women's Studies International, and PsycINFO. Search terms used to capture the experiences of families of children with CHD included "congenital heart disease", "mother", "father", "caregiver", "family", "infant", "child*" for child or children, and "parent*" for "parents", "parenting", or "parental". These terms were entered in different combinations to ensure an exhaustive search.

To be included, articles should be research-based, focus on families' experiences, and published between January 2000 and December 2014. The year of 2000 was when the National Heart, Lung, and Blood Institute launched its first major initiative to encourage treatment innovations and research on children with heart disease,[6] and 2014 was the time of the search. Studies were excluded if they focused only on children with CHD. Because the review was designed to synthesize current information on families

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of children with CHD, no studies were excluded based on a priori decisions about methodological quality.

Articles were searched using key words and phrases and selected based on the inclusion criteria. After the key words and phrases were entered into the databases, articles were screened by their titles and abstracts. Potential articles were then read in full to decide their eligibility. Articles that met the inclusion criteria were imported into Refworks, where duplicates were identified. Subsequently, a reference list search was done to identify other possible articles.[8]

Data analysis was done following Miles and Huberman's constant comparative analysis method.[9] All the articles selected were uploaded into ATLAS ti for Windows to aid the analytic process.[10] To begin, a list of the content to be extracted was developed, which included study purposes, conceptual frameworks, designs, and key concepts that focused on families of children with CHD. Each article was read several times with memos being done while the content was being extracted. The memos and the extracted content helped us compare findings across studies and find themes. To illustrate, an example of the analytic process was described. While reading the articles, we found that parental stress was a prominent phenomenon, which was noted in our memos. Then “stress” was coded to capture the relevant findings about that topic. Finally, initial codes, such as “stress,” “depression,” and “anxiety,” comprised a broader theme about parents' psychological health.

Results

Ninety-four articles met the inclusion criteria (66 quantitative and 28 qualitative). The PRISMA flow chart[7] (Fig. 1) displays the stages of the literature search. Four major themes were inductively derived: parents' psychological health, family life, parenting challenges, and family-focused interventions.

Parents' psychological health

Parents' psychological health was defined as parents' emotional responses to their child's CHD, such as stress, depression, and anxiety. Among the supporting articles listed in Table 1, 18 of the 24 (75%) articles reported that these parents of children with CHD reported greater stress, depression, and anxiety than the general population. Parents reported emotional ups and downs from the moment they were informed of their child's CHD.[12,35] Upon receiving the diagnosis, they felt shock and disbelief[14] and significant stress, whether the diagnosis was made in the prenatal or postnatal period.[11] When children were hospitalized, parents also reported significant stress.[16,18,36] Franck,[16] for example, surveyed 211 parents whose children were admitted for CHD interventions and found that parents' stress remained high throughout the hospital stay. Similarly, Lawoko and Soares[22] compared parents of children with CHD to parents of children with unspecified diseases or healthy children, and found that parents of children with CHD reported significantly higher levels of anxiety, depression, and stress than the reference groups.

The other 6 of the 24 (25%) articles, however, reported that parents of children with CHD did not have higher levels of stress than parents of children without CHD or the general population. Fischer et al[15] and Vrijmoet-Wiersma et al,[32] for example, found no significant differences in anxiety levels between parents of children with and without CHD, and other investigators found that parents of children with CHD reported significantly lower levels of psychological distress than the general population.[26,29,31] Hearps et al,[17] who studied parents of infants who had heart surgery within 4 weeks after birth, found that 60% of the parents rated their risk to have psychosocial issues as low, 36% of the parents rated at the reference levels, and only 2.6% of the parents rated their risk to have psychosocial issues at a clinically high level.

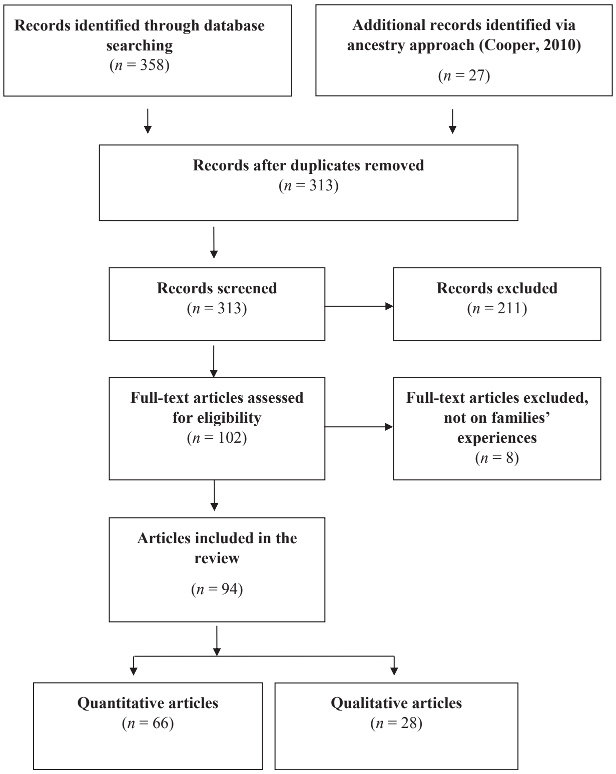

Fig. 1. PRISMA[7] flow chart of search, inclusion and exclusion screening, and accepted studies of the review on families of children with CHD.

One explanation for the inconsistency of the findings across studies may be the lack of consensus on how and what to measure in regard to parents' psychological symptoms. Investigators used many different scales to measure parents' stress, anxiety, and depression, including the Parenting Stress Index,[37] the Brief Symptom Inventory,[38] the Spielberger State Trait Anxiety Inventory,[39] the General Health Questionnaire,[40,41] the Symptom Check List-Revised,[42] the Hopelessness Scale,[43] and the Parent Stressor Scale: Infant Hospitalization.[44]

These scales measure the psychological responses from different perspectives. For instance, the Parenting Stress Index focuses on parents' stress related to parenting, e.g., “I find myself giving up more of my life to meet my child's needs than I ever expected.”[30(p165)] The Parent Stressor Scale: Infant Hospitalization[44] focuses on parents' stress related to the behaviors and appearance of the hospitalized infant, hospital-related parental role interruption, and the scenes and noise of the hospital environment. The General Health Questionnaire[40,41] assesses parents' psychological distress, including somatic symptoms, anxiety, social dysfunction, and depression. The use of different measurements of parents' psychological symptoms made it difficult to compare studies and may explain the inconsistencies in findings on the presence, absence, and magnitude of psychological symptoms among parents whose child had CHD.

Family life

This theme was derived from studies that focused on the impact of the child's CHD on various aspects of family life, such as family