



The role of spirituality in the well-being of families with children with congenital heart disease: scoping review

Sophia Livas de Moraes Almeida^{1^}, Luana Izabela Azevedo de Carvalho^{2^}, Edward Araujo Júnior^{3,4^}, Jonas Byk^{1^}, Luciane Alves da Rocha Amorim^{1^}

¹Postgraduate Program in Health Sciences, Medical School, Federal University of Amazonas (UFAM), Manaus, Brazil; ²Department of Medicine, Medical School, Amazonas State University (UEA), Manaus, Brazil; ³Department of Obstetrics, Paulista School of Medicine, Federal University of São Paulo (EPM-UNIFESP), São Paulo, Brazil; ⁴Discipline of Woman Health, Municipal University of São Caetano do Sul (USCS), São Caetano do Sul, Brazil

Contributions: (I) Conception and design: LA da Rocha Amorim; (II) Administrative support: J Byk; (III) Provision of study materials or patients: SL de Moraes Almeida; (IV) Collection and assembly of data: LIA de Carvalho; (V) Data analysis and interpretation: E Araujo Júnior; (VI) Manuscript writing: All authors; (VII) Final approval of manuscript: All authors.

Correspondence to: Edward Araujo Júnior, PhD. Department of Obstetrics, Paulista School of Medicine, Federal University of São Paulo (EPM-UNIFESP), Rua Belchior de Azevedo, 156 apto. 111 Torre Vitoria, Vila Leopoldina, São Paulo 05089-030, Brazil; Discipline of Woman Health, Municipal University of São Caetano do Sul (USCS), São Caetano do Sul, Brazil. Email: araujojred@terra.com.br.

Background: Congenital heart disease (CHD) is the leading cause of death from malformations in infants and has a significant psychological impact on families. This scoping review explored the role of spirituality in supporting families of children with CHD. It also sought to identify gaps in the existing literature and suggest directions for future research.

Methods: A synthesis review was conducted following the framework of Arksey and O'Malley, incorporating the principles of the Joanna Briggs Institute. We systematically searched four databases—Medline, Embase, Lilacs, and Scielo—selecting studies based on inclusion criteria focused on spirituality in families of children with CHD. Articles without full text, book chapters, lectures, conference abstracts, review articles, and editorials were excluded. We analyzed the year of publication, study location, objectives, methodology, participants of the study, and main results.

Results: A total of 17 studies were included in the review, most of which were conducted in the past 10 years. The studies were conducted in various regions of the world, including Japan, the USA, China, Iran, Sweden, and Brazil, and they examined different religious traditions, including Christianity, Islam, Buddhism, and non-denominational spiritual practices. Twelve qualitative studies, three descriptive studies, one cross-sectional study, and one case report were included. The articles were categorized based on several themes: the influence of spirituality on mental and emotional well-being, cultural and religious diversity, integration of spirituality into health care, and its assistance in decision-making.

Conclusions: Spirituality plays a crucial role in addressing the emotional and psychological challenges of CHD. There is a need for structured models of spiritual counseling and more research in diverse cultural and socioeconomic contexts. Identifying these gaps can help guide future studies to enhance our understanding and improve the support provided to these families, thereby promoting more holistic and patient-centered healthcare.

Keywords: Congenital heart disease (CHD); children; spirituality; scoping review

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[^] ORCID: Sophia Livas de Moraes Almeida, 0009-0007-5412-1325; Luana Izabela Azevedo de Carvalho, 0000-0002-5118-6509; Edward Araujo Júnior, 0000-0002-6145-2532; Jonas Byk, 0000-0001-5854-4316; Luciane Alves da Rocha Amorim, 0000-0003-3990-865X.

Introduction

Congenital heart disease (CHD) is the most common congenital anomaly and the leading cause of death due to malformations in the first year of life (1). Significant technological advancements have led to a deeper understanding of fetal cardiology in recent years, resulting in increasingly earlier diagnoses (1,2). The stress experienced by family members who receive this diagnosis stems from the uncertainty about the child's health prospects. Consequently, there is a critical need for comprehensive counseling for these families, starting from the moment of diagnosis, which should address medical, psychological, and social aspects (3,4).

Highlight box

Key findings

- Emotional support: spirituality provides crucial emotional and psychological support to families of children with congenital heart disease (CHD), helping them manage stress, anxiety, and grief.
- Cultural and religious influence: diverse cultural and religious beliefs significantly influence families' coping mechanisms and decision-making processes, highlighting the need for tailored support.
- Integration into healthcare: incorporating spiritual care into healthcare enhances families' overall well-being, promoting better communication and compassionate care.
- Recommendations: (I) develop and implement structured spiritual counseling models within healthcare settings to support families of children with CHD; (II) train healthcare professionals in spiritual competencies to address spiritual issues sensitively and effectively, ensuring holistic patient care; (III) conduct further studies in diverse cultural and socioeconomic contexts to explore the global applicability of spiritual support practices.

What is known and what is new?

- This scoping review is among the first to systematically synthesize literature on the role of spirituality for families with a diagnosis of CHD, offering a comprehensive understanding of its impact. Including studies from various regions and religious traditions, this review provides a global perspective on spirituality in managing CHD, highlighting both universal and culturally specific aspects.

What is the implication, and what should change now?

- Spiritual support can significantly improve the emotional and psychological well-being of family members, leading to better overall health outcomes. Integrating spiritual care into healthcare can foster more holistic, patient-centered approaches, addressing physical, emotional, and spiritual needs. Insights from this review can inform healthcare policies, encouraging the inclusion of spiritual care in standard treatment protocols for families dealing with CHD.

Family members often undergo a grief reaction characterized by stages such as shock, denial, anger (including questioning the diagnosis), guilt, and sadness. During this process, they may also experience a desire or "bargaining" for a miraculous resolution of the heart disease (3,5). The diagnosis of CHD has a significant psychological impact on parents, with studies suggesting that between 25% and 50% of parents of children with severe CHD report symptoms of anxiety or depression (6). Regardless of the type of CHD and the child's age, families face considerable stress in caring for their children, leading to emotional, financial, and familial strain (6).

Spirituality has become increasingly crucial in mental health as a source of resilience and comfort during challenging times (7). Therefore, spiritual care is an essential aspect of healthcare that should be provided without discrimination or religious imposition (8).

The purpose of this scoping review was to synthesize existing literature on the role of spirituality in the well-being of family members of children with CHD and to identify gaps in current research and pave the way for future studies. We present this article in accordance with the PRISMA-ScR reporting checklist (available at <https://tp.amegroups.com/article/view/10.21037/tp-24-134/rc>).

Methods

We followed the principles outlined by Arksey and O'Malley (9) and recommended by the Joanna Briggs Institute.

This method consisted of five steps: identifying the research question, finding relevant studies, selecting studies, mapping data, and presenting results. Since this was a review, the ethics committee's approval was unnecessary.

Research question identification

The research question was: "Is there existing literature on the role of spirituality on the well-being of family members of children with CHD?"

Identification of relevant trials

Four databases were used: Medline, Embase, Lilacs, and Scielo, during January and March 2024. The search strategy was developed with the descriptors used were: "congenital heart disease" and "spirituality" (Table 1). All identified studies were transferred to the Rayyan system for analysis in an organized and secure manner. The

Table 1 Descriptors used in each database

Database (portal)	Search	Filter	Items found	Search date
Medline	("spirituality"[MeSH Terms] OR "spirituality"[All Fields]) AND ("heart defects, congenital"[MeSH Terms] OR "congenital heart defects"[All Fields])	Humans	8	March 18, 2024
Embase	('congenital heart malformation'/exp OR 'congenital heart malformation') AND 'religion'/exp	Humans	62	March 18, 2024
Lilacs	(mh:("Espiritualidade")) AND (mh: "Cardiopatias Congênitas" OR (cardiopatías congénitas) OR (heart defects, congenital) OR (malformação cardiovascular) OR (defeitos cardiovasculares congênitos) OR (anormalidades cardíacas) OR mh:c14.240.400* OR mh:c14.280.400* OR mh:c16.131.240.400*)	Descriptor do assunto	1	March 18, 2024
Scielo	(Cardiopatias Congênitas) OR (Cardiopatías Congénitas) OR (Heart Defects, Congenital) AND (religiosity)	No filter	1	March 18, 2024

protocol for this scoping review was registered with the Open Science Framework (<https://doi.org/10.17605/OSF.IO/73SDG>).

Selection of studies

Inclusion criteria were: studies addressing how different forms of spirituality, such as religion, personal beliefs, or spiritual practices, can influence emotional well-being, quality of life, or coping with illness; papers in any language qualitative or quantitative studies. The studies were selection until 2024. Articles without full text, book chapters, lectures, conference abstracts, review articles, and editorials were excluded.

The screening process began with the removal of duplicate articles. Two reviewers (master's student in health sciences) worked together to assess the titles and abstracts of all publications based on the eligibility criteria. After this first screening, the full texts of the selected studies were thoroughly reviewed. The disagreements were resolved through a third reviewer (fetal and pediatric cardiologist). Additionally, cross-referencing and an active search for relevant articles were conducted.

Data mapping

The following variables were collected from the included studies: author details, year of publication, study location, objectives, methodology, participants of the study, and main results. The development of an Excel data extraction form was an organized practice to collect relevant information from the studies.

Presentation of findings

The results of this scoping review were presented in narrative and tables. The main findings of the studies were presented in tables according to the main themes addressed. This thematic approach was divided into the following segments: influence of spirituality on mental and emotional well-being; cultural and religious differences; incorporating spirituality into health care; and supporting decision-making.

Results

The scoping review included a total of 17 studies that address the topic of spirituality in the context of CHD. The studies analyzed provided a comprehensive view of the role of spirituality in the well-being of family members of children with CHD.

The initial search of the four databases Medline (n=8), Embase (n=62), Lilacs (n=1) and Scielo (n=1) yielded a total of 72 articles. After removal of 2 duplicate articles and evaluation of titles and abstracts, 59 articles were excluded. Cross-referencing analysis was performed, and at the end of the screening process, 17 articles remained for in-depth review. This final number represents the studies considered eligible for inclusion in the review (*Figure 1*).

Table 2 provides a detailed overview of the 17 eligible articles, including author details, year of publication, study location, objectives, methodology, participants of the study, and main results.

The majority of studies have been conducted in the past 10 years, indicating a growing interest in understanding the interaction between spirituality and family members coping

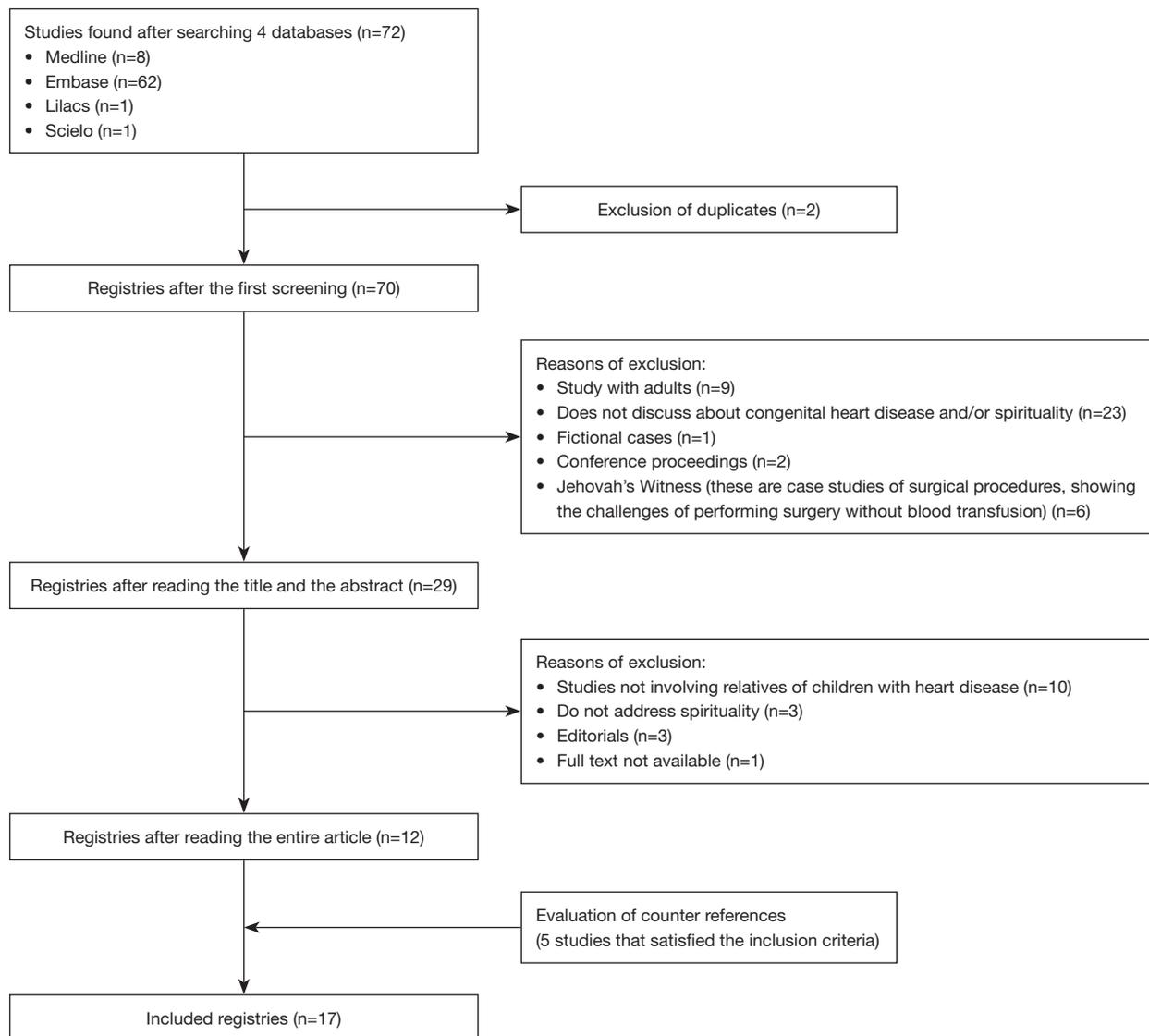


Figure 1 Study's flowchart.

with CHD (6,10,11,13,14,16,18-23). The first study in this scoping review is a 1999 case report that highlights the role of spirituality in a family that has a 3-month-old child with CHD (8). It emphasizes the dilemma between the family's spiritual beliefs and the health professionals' intentions regarding the child's treatment. This study illustrated how spiritual beliefs influence decision-making and interactions between families and medical teams.

The studies were conducted in various regions around the world, including USA (7,8,12-15,19,20,23), China (18,22), Iran (6), Sweden (17), and Brazil (10,16). However, additional studies are required in other low-income countries to

enhance our understanding of cultural and socioeconomic factors. This will provide a more comprehensive global perspective on the role of spirituality in the context of CHD.

Considering the methodology, we recorded 12 qualitative studies (6,10-12,14,16-21,23), 3 descriptive (7,15,22), 1 cross-sectional (13), and 1 case report (8) (*Table 2*). The studies typically employ a qualitative methodology, utilizing semi-structured interviews and content analysis to delve into the experiences and perceptions of family members.

Participants mainly included parents (mothers and fathers) of children with CHD; most were studies of complex CHD conditions requiring multiple surgeries

Table 2 Main results of the included studies

References	Objective	Methodology	Participants/health team	Main results relation with spirituality
Clayton and Kodish (8), USA, 1999	To discuss a case report of a 3-month-old infant with CHD whose parents declined corrective surgical treatment	Case report	1 participant; cardiology, family physician, pediatric, social worker	The text discusses the challenges physicians face when dealing with family members who object to medical treatment for their children based on religious beliefs. It highlights efforts to convince guardians of the importance of the treatment and the involvement of the guardianship council in making a judicial decision
Desai <i>et al.</i> (7), USA, 2002	To describe the staff of patient and family support services within children's healthcare of Atlanta	Descriptive	No participants; pediatrics, social worker, chaplain	It emphasizes collaboration among child life specialists, social workers, and chaplains to address the developmental, psychosocial, and spiritual needs of patients and their families. The chaplain plays a central role in providing spiritual support that is tailored to the family's beliefs and offers interventions that promote understanding, hope, and comfort. This support helps families cope with the child's illness by providing a sense of meaning and connection during difficult times, and significantly reduces the stress and anxiety associated with hospitalization and medical procedures
Salgado <i>et al.</i> (10), Brazil, 2011	To explore the experiences and coping mechanisms of families with children undergoing cardiac surgery	Qualitative	6 participants	It identifies that religiosity, and a strong social support network were critical in helping mothers maintain adaptive behaviors. The constant presence of the mother during all stages of treatment minimized the distress caused by hospitalization. The study highlights the ambivalence of feelings such as fear of death, guilt, and helplessness, and emphasizes the significant role of spiritual support in providing a foundation for coping with adversity
Gitsels-van der Wal <i>et al.</i> (11), The Netherlands, 2014	The study aimed to explore the influence of religious beliefs on the decision-making process regarding antenatal screening among pregnant Muslim women of Turkish origin	Qualitative	10 participants	The study found that religious convictions significantly impacted their decisions, with most women rejecting the option of pregnancy termination in case the of fetal anomalies. Despite Islamic jurisprudence allowing pregnancy termination under certain conditions, the women were largely unaware of these allowances, leading to decisions heavily influenced by personal beliefs. The findings highlight the need for health care providers to understand and consider the religious context of their patients when counseling
Harvey <i>et al.</i> (12), USA, 2013	To explore the lived and recalled experiences of mothers of infants with moderate to severe CHD who were diagnosed post-natally and needed heart surgery prior to their first birthday	Qualitative	7 participants	Many mothers found that spirituality played a key role in providing them with meaning and spiritual connection during their experience. They reported that their faith and spiritual connection gave them strength and coping mechanisms during the stressful and challenging times of their baby's heart surgery. Having a spiritual connection helped these mothers to make sense of the situation and to face difficult circumstances with greater resilience
Sira <i>et al.</i> (13), USA, 2014	The study aimed to examine the coping strategies used by mothers of children with CHD, with a focus on the roles of spirituality and Internet use in their coping mechanisms	Cross-sectional	175 participants	The study found that parents most often used understanding the medical situation and communicating with other parents as coping strategies, while they least often used self-esteem and psychological stability. The study also found that greater reliance on spirituality was associated with effective family integration and optimism, while frequent use of the Internet was associated with better understanding of the medical situation and improved communication. These findings underscore the importance of integrating spiritual support and providing reliable Internet resources to enhance coping strategies for mothers coping with their children's CHD
Holston <i>et al.</i> (14), USA, 2015	To explore the critical role of relationships and faith in providing comfort to families experiencing neonatal loss, mainly due to CHD like hypoplastic left heart syndrome	Qualitative	Interviews with healthcare professionals, including nurses, chaplains, and social workers, who provided emotional, spiritual, and practical support to bereaved families	It found that faith and prayer are important sources of comfort for families, and that compassionate care from healthcare providers plays a critical role in helping families cope with their loss. The study highlights the need for an integrated support system that includes health care professionals, extended family, friends, and clergy to help families through their grief
Wei <i>et al.</i> (15), USA, 2016	To describe parents' experiences when their child with CHD underwent heart surgery	Descriptive	13 participants	The study highlights the emotional challenges faced by parents and identifies critical times such as diagnosis, surgery, and the stay in the pediatric intensive care unit. It highlights the importance of spirituality in providing comfort, strength, and hope to help parents cope with the stress and find meaning during their child's medical journey
Barreto <i>et al.</i> (16), Brazil, 2016	To understand the experiences of parents of children with CHD, focusing on their feelings, obstacles, and expectations	Qualitative	11 participants	The study identified some key themes: parents felt unprepared and desperate, experienced intense anxiety and fear, and faced significant barriers such as financial instability and lack of support, but found spirituality to be a critical coping mechanism. Spirituality provided faith and hope, helping parents manage stress and maintain a positive outlook during their child's illness
Carlsson <i>et al.</i> (17), Sweden, 2016	To explore experiences and preferences of care following a prenatal diagnosis of congenital heart disease among Swedish immigrants	Qualitative	9 participants	The study identified some main themes: the importance of trustworthy information, the challenges of language barriers, the impact of psychosocial situations, the value of peer support, and the influence of religious beliefs on decision-making. The study concluded that healthcare professionals need to provide clear, trustworthy information, consider language and cultural barriers, offer psychosocial support, and respect religious beliefs to better support immigrant families facing a prenatal diagnosis of CHD
Nakazuru <i>et al.</i> (18), China, 2017	To examine the stress and coping strategies of mothers of babies who required surgery for CHD, identifying the factors that influenced these strategies	Qualitative	11 participants	The study highlighted that religion and spirituality played a key role in mothers' coping. Mothers often turned to faith and trust in God as a way to cope with the stress and uncertainty associated with their children's condition and treatment. Spirituality provided a sense of hope and strength that helped them face emotional and psychological challenges during the process of preparing for surgery and during the long waiting period
Golfenshtein <i>et al.</i> (19), USA, 2017	To identify factors influencing maternal coping and to understand how these mothers managed stress throughout the diagnosis, waiting period, surgery, and postoperative phases	Qualitative	11 participants	Many mothers reported relying on religious beliefs and practices, such as praying and trusting in God's will, to cope with the stress associated with their child's condition and surgery. This spiritual reliance provided them with comfort, hope, and a sense of control during a very uncertain and stressful time. Mothers often turned to spirituality as a means of finding strength and keep emotional stability, illustrating its crucial role in their overall coping mechanisms

Table 2 (continued)

Table 2 (continued)

References	Objective	Methodology	Participants/health team	Main results relation with spirituality
Sood <i>et al.</i> (20), USA, 2018	To understand the emotional states, stressors, and supports of parents caring for a child with CHD, focusing on similarities and differences between mothers and fathers	Qualitative	34 participants	The study found that both mothers and fathers relied on spiritual beliefs as an important coping mechanism. Many parents reported that their faith gave them emotional support and comfort during the crucial periods of diagnosis and surgery. Spirituality helped them make sense of their experiences and provided a sense of hope and resilience that was critical to their psychological well-being
Dalir <i>et al.</i> (6), Iran, 2020	To explore coping strategies used by families of children with CHD in the face of caregiving stress	Qualitative	40 participants	According to the results, efforts to keep well-being emerged as a major theme, which included five categories: spirituality in caregiving, acceptance and adjustment, optimism and hope, self-control and patience, and management of psychological needs. The findings underscore the importance of spiritual beliefs as a valuable coping mechanism that helps families find comfort and resilience amidst the difficulties of caring for children with CHD
Ladak <i>et al.</i> (21), Pakistan, 2020	To explore the influence of individual, socio-cultural and environmental factors that influence parents' health-related decision-making and the perceived health related quality of life of children and adolescents for children or adolescents after CHD surgery in Pakistan	Qualitative	38 participants	The study found that religion and faith in God were important coping mechanisms for parents at the sociocultural level. These spiritual beliefs provided comfort and helped parents cope with the stress and emotional challenges associated with their child's illness. Faith played a critical role in helping parents cope with unrealistic expectations of surgical outcomes and the ongoing care demands of their children
Liu <i>et al.</i> (22), China, 2021	To evaluate the association between positive and negative religious coping methods and psychological distress and quality of life among parents of infants with CHD	Descriptive	115 parents	The study revealed that using positive religious coping methods was connected to lower levels of depression and higher quality of life, particularly in terms of vitality, social functioning, and mental health. On the other hand, negative religious coping was linked to higher levels of depression and lower mental health. These findings indicate that encouraging positive religious coping can enhance the well-being and quality of life for parents of infants with CHD. This highlights the importance of integrating spiritual support into family care
Delaney <i>et al.</i> (23), USA, 2022	To understand how parents decide on treatment options—termination, palliative care, or surgery—for their fetus or neonate diagnosed with a severe CHD	Qualitative	56 parents	Many parents consider spirituality and religious beliefs as key factors in their decision not to terminate pregnancies. Sisters provide support and perspective, assisting parents in forming their values when making such choices. Faith provides emotional comfort and strength, helping them cope with stress and emotional challenges while deciding on treatment for their children with CHD

CHD, congenital heart disease.

Table 3 Thematic approach about different segments

Thematic approach	Included studies
Impact of spirituality on mental and emotional health	Desai <i>et al.</i> (7); Harvey <i>et al.</i> (12); Sira <i>et al.</i> (13); Wei <i>et al.</i> (15); Golfenshtein <i>et al.</i> (19); Ladak <i>et al.</i> (21); Liu <i>et al.</i> (22)
Cultural and religious differences	Dalir <i>et al.</i> (6); Salgado <i>et al.</i> (10); Gitsels-van der Wal <i>et al.</i> (11); Nakazuru <i>et al.</i> (18); Ladak <i>et al.</i> (21); Delaney <i>et al.</i> (23)
Integration of spirituality in healthcare	Desai <i>et al.</i> (7); Sira <i>et al.</i> (13); Holston <i>et al.</i> (14); Wei <i>et al.</i> (15); Carlsson <i>et al.</i> (17); Liu <i>et al.</i> (22)
Assistance in decision-making	Clayton and Kodish (8); Gitsels-van der Wal <i>et al.</i> (11); Wei <i>et al.</i> (15); Barreto <i>et al.</i> (16); Sood <i>et al.</i> (20); Liu <i>et al.</i> (22); Delaney <i>et al.</i> (23)

and long-term care. The studies explored various religious traditions, including Christianity, Islam, Buddhism, and non-denominational spiritual practices (6,8,10,18,19,21). They highlighted the influence of different belief systems on family members' coping strategies and emotional well-being. This diversity in culture and religion enriches our comprehension of the role of spirituality in caring for children with CHD.

In the scoping review, 17 studies showed that spirituality plays a crucial role as a coping strategy for parents and families of children with CHD. Spirituality provides significant emotional support (7,10,12,14-16,18,20-23), aiding parents in making difficult decisions such as terminating a pregnancy (11,23) and treating illness (8). Furthermore, spirituality has been found to reduce stress, depression, and grief, while also offering understanding, hope, and comfort (7,10,12,14-16,18,20-23). The studies also emphasized that spirituality improved relationships between medical staff and family members (13), leading to more effective communication and compassionate, holistic care.

Observing the primary findings of the 17 studies, we identified similarities in certain topics, allowing us to categorize the approach of these articles included in our scoping review into four themes: the impact of spirituality on mental and emotional well-being; cultural and religious diversities; integration of spirituality into healthcare; and its assistance in decision making. In *Table 3*, we have reorganized the articles included based on their main results regarding the role of spirituality in family members of children with CHD.

Discussion

This scoping review compiled existing literature on the impact of spirituality on the well-being of family members of children with CHD. We identified 17 studies,

highlighting the paucity of literature on this topic. Recognition of the lack of research in this area emphasizes the need for more studies on spirituality in healthcare related to CHD. Furthermore, the dissemination of knowledge already generated by these studies can help us better understand the role of spirituality in this context.

The emotions of parents of children diagnosed with CHD do not develop in a linear fashion (15). This review highlights that families of children with CHD use a variety of coping strategies, including spirituality, acceptance, optimism, patience, and management of psychological needs, based on their beliefs, attitudes, skills, and available resources in the face of caregiving stress (3). Dissemination of the knowledge generated by these studies can contribute to a better understanding of diagnosis, treatment, follow-up, and other aspects related to CHD in this specific context.

According to the thematic approach we used in the results, we will proceed with our discussion.

Impact of spirituality on mental and emotional health

Research has shown that spirituality is a vital source of mental and emotional strength for family members of children with CHD (7,10,12,14-16,18,20-23). The studies reviewed highlight that faith and spiritual practices provide a strong emotional foundation, helping parents cope with the stress and anxiety associated with CHD diagnosis and treatment. Strong spiritual beliefs enable parents to find meaning and purpose in adversity, offering hope and resilience during challenging times (10).

The study by Desai *et al.* (7) emphasized the collaboration between chaplains and healthcare providers in offering spiritual support tailored to the family's beliefs (7). This supports significantly reduced stress and anxiety, providing families with understanding, hope, and comfort during

hospitalization and medical procedures. Similarly, the research by Sira *et al.* (13) demonstrated that parents who relied on spiritual coping strategies reported higher levels of family integration and optimism (13). This suggests that spirituality not only aids in emotional stability but also fosters a cohesive family environment, which is crucial for managing the long-term challenges of CHD.

Furthermore, the study by Wei *et al.* (15) described the profound emotional challenges faced by parents during their child's heart surgery and stay in the pediatric intensive care unit (PICU) (15,23). The findings revealed that spirituality provided essential comfort, strength, and hope, helping parents find meaning during their child's medical journey. This aligns with the research by Liu *et al.* (22), which found that positive religious coping methods were associated with lower levels of depression and higher quality of life among parents of infants with CHD (22).

These studies collectively highlight the significant role of spirituality in mitigating adverse emotional outcomes and promoting psychological well-being.

Cultural and religious differences

Including diverse religious and spiritual practices in the reviewed studies underscores the importance of understanding spirituality in a multicultural and multi-faith context (8,11,17,23).

The findings from Gitsels-van der Wal *et al.* (11) highlight how Islamic beliefs significantly affect decision-making processes among pregnant Muslim women, particularly in the context of antenatal screening and pregnancy termination decisions. This study illustrates the need for healthcare providers to be culturally sensitive and knowledgeable about the religious beliefs of their patients to provide appropriate counseling and support (11,17).

The study by Nakazuru *et al.* (18) in Japan not only sheds light on the role of Buddhism in helping mothers cope with the stress and uncertainty of their child's CHD surgery but also provides practical insights for healthcare providers (18). The reliance on Buddhist practices and the sense of spiritual peace and resilience it provides illustrate the profound impact of spirituality on mental and emotional well-being. This highlights the necessity for healthcare systems to incorporate spiritual care tailored to specific cultural and religious contexts, ensuring that support is relevant and meaningful to the families receiving it.

Ladak *et al.* (21) further emphasizes the critical role of Islam in the lives of parents in Pakistan, particularly

in managing unrealistic expectations and the emotional challenges of CHD. The study shows that trust in God and religious coping mechanisms are integral to how these parents navigate the healthcare system and the difficult decisions they face. This underscores the broader need for healthcare providers to respect and integrate spiritual beliefs into the care plans of families from diverse religious backgrounds, facilitating a holistic approach to medical care that encompasses physical, emotional, and spiritual health.

These findings collectively highlight the diverse ways in which spirituality, shaped by various religious beliefs, supports families dealing with CHD. They call for a more inclusive approach in healthcare that respects and incorporates the spiritual dimensions of patient care, recognizing the significant role that religion and spirituality play in coping with severe health conditions. Future research should explore these diverse contexts to understand how best to support the spiritual needs of families from distinct cultural and religious backgrounds.

Integrating spirituality into healthcare

The integration of spirituality into healthcare practices has been shown to significantly enhance the care experience for families of children with CHD. The studies included in this scoping review highlight the importance of a collaborative approach between healthcare providers and spiritual support services in addressing the holistic needs of families.

Desai *et al.* emphasized the critical role of chaplains and child life specialists in providing spiritual care tailored to the family's beliefs (7). This collaboration helps reduce stress and anxiety by offering emotional support and easing understanding, hope, and comfort during hospitalization and medical procedures. The presence of chaplains as part of the healthcare team ensures that families receive personalized spiritual support, which is crucial in helping them cope with the challenges associated with CHD.

The study by Holston further underscores the importance of an integrated support system that includes healthcare professionals, extended family, friends, and clergy (14). This comprehensive approach helps families navigate the emotional and psychological challenges of CHD, providing a network of support that addresses their spiritual needs alongside medical care. Healthcare providers who acknowledge and incorporate spiritual care into their practice can build stronger, more empathetic relationships with families, enhancing trust and communication.

Moreover, the research by Wei *et al.* (15) revealed that

parents deeply appreciate the involvement of healthcare providers in spiritual discussions. This engagement not only helps them feel supported and understood, but also fosters a sense of partnership and collaboration between families and the healthcare team. By engaging in conversations about spirituality, healthcare professionals can better understand the values and beliefs of the families they serve, leading to more tailored and compassionate care. This approach not only supports the emotional well-being of parents but also fosters a sense of partnership and collaboration between families and the healthcare team.

Liu *et al.* (22) found that positive religious coping methods, supported by the healthcare team, were associated with better psychological outcomes for parents. When healthcare providers actively support the spiritual practices of families, it can enhance the overall quality of life and mental health of parents, helping them to navigate the complexities of CHD with greater resilience and hope.

Integrating spirituality into healthcare also involves practical measures, such as providing dedicated spaces for prayer and meditation within healthcare facilities. These spaces are not just physical areas but also symbols of our commitment to the spiritual well-being of families. They offer families a refuge for peace and spiritual support, contributing to their overall well-being during hospital stays. Additionally, training healthcare professionals in spiritual competencies can equip them with the skills to address spiritual issues sensitively and effectively, enhancing the holistic care provided to families.

Overall, the integration of spirituality into healthcare is a powerful tool for the well-being of families dealing with CHD. By empowering healthcare providers to integrate spiritual care into their medical practice, we can offer more comprehensive, compassionate, and patient-centered care. This collaborative approach not only supports the emotional and psychological health of families but also strengthens the therapeutic alliance between healthcare providers and families, ultimately leading to better health outcomes for children with CHD (8). Future research should continue to explore strategies for effectively integrating spirituality into healthcare to further enhance the support provided to these families.

Support for decision-making

Spirituality plays a crucial role in the decision-making process for parents and families of children with CHD. The reviewed studies indicate that faith provides a moral

and ethical framework that guides parents' choices, helping them find clarity and confidence in their decisions.

Research by Gitsels-van der Wal *et al.* (11) illustrates that religious convictions significantly impact decisions around antenatal screening and potential pregnancy termination. Parents often rely on their faith for guidance, which offers reassurance and a sense of direction during difficult times (11). This underscores the importance of healthcare providers being aware of and sensitive to the spiritual beliefs that influence their patients' decisions.

Delaney *et al.* (23) examined how parents choose treatment options for their children with CHD, revealing that spirituality and religious beliefs are critical in determining whether to pursue aggressive treatments, palliative care, or consider termination. Spirituality provides hope and resilience, helping parents make decisions aligned with their values, thus easing the emotional burden of these choices.

Wei *et al.* (15) found that spirituality is essential during critical periods such as diagnosis and surgery. Parents who lean on their faith report feeling more confident and less anxious about their decisions, which helps them manage the stress and uncertainty of medical treatments.

Liu *et al.* (22) noted that positive religious coping methods correlate with lower depression levels and higher quality of life among parents of infants with CHD. When parents incorporate spirituality into their decision-making, it enhances their emotional well-being. This suggests that healthcare providers should encourage positive spiritual practices as part of their support.

Additionally, the case study "Baby Aaron and the elders" highlighted the complex interplay between spiritual beliefs and medical decision-making within an Amish community (8). The parents' refusal of life-saving surgery for their child based on religious grounds illustrates the profound impact of spirituality on their decisions. This case underscores the necessity for healthcare professionals to engage respectfully with families' spiritual beliefs and to seek collaborative solutions that honor these values while addressing medical needs.

During critical moments, such as initial diagnosis or urgent surgery, spirituality acts as a comforting and guiding force. Trusting in a higher power or seeking counsel through religious practices can provide a sense of control and purpose, offering comfort and relief from the stress and uncertainty of decision-making. This is particularly significant when medical options are complex, and the consequences of decisions are profound.

Furthermore, spiritual support can facilitate communication

between families and medical teams, helping align expectations and ensure that decisions reflect medical needs and patients' spiritual beliefs. Healthcare professionals who recognize and respect the role of spirituality in parents' decisions can offer more empathetic and personalized care. This enhances the care experience and strengthens trust and collaboration between healthcare providers and families.

This scoping review has provided a comprehensive understanding of CHD and the role that spirituality plays in the lives of parents in terms of coping and challenges faced by families, highlighting the complexity of the scenario and the need for further research on the topic.

Contributions to new research

To better support families of children with CHD, future research should focus on several key areas. Firstly, it is essential to develop and evaluate structured spiritual counseling models. Research should aim to create counseling frameworks that systematically integrate spiritual support into healthcare and assess their effectiveness in improving the emotional and psychological well-being of family members and patient care quality and satisfaction. Secondly, it is necessary to explore the impact of spirituality across diverse cultural and socioeconomic contexts. Comparative studies between developed and developing countries can shed light on cultural variations and the applicability of spiritual support practices in various settings, enriching our approach to global healthcare.

It is essential to conduct longitudinal studies to check how parents' spiritual beliefs evolve and the ongoing impact on their emotional well-being. This will help us understand how spirituality affects resilience and adaptation during different stages of treatment and recovery for their children. Additionally, we should explore practical ways to incorporate spiritual support into clinical protocols. This involves training healthcare professionals in spiritual competencies and developing guidelines for integrating spiritual practices into daily care. Evaluating the impact of these integrations on care quality, communication between healthcare providers and families, and overall patient experience will be vital in creating a more holistic and patient-centered healthcare approach.

Strengths and limitations

The review included a wide range of studies from different cultural and socioeconomic contexts, providing an extensive

overview of the role of spirituality in the care of children with CHD. This breadth allows for a more complete understanding of how spirituality can influence family members' emotional and psychological well-being in various settings. Additionally, the review identified gaps in the existing literature, such as the lack of structured spiritual counseling models and the need for more studies in developing countries. These insights are valuable for guiding future research and interventions, helping to direct resources and efforts towards areas that could have the most significant impact.

The limitations of the study were: due to the nature of scoping reviews, this study did not assess the quality of included studies, which might affect the depth of conclusions that can be drawn; the focus on published literature might have missed relevant unpublished or non-peer-reviewed studies, limiting the scope of findings. Furthermore, despite the diversity of studies included, certain demographic groups may still be underrepresented, such as fathers (compared to mothers) and families from lower socioeconomic backgrounds or minority religious groups. This underrepresentation can lead to an incomplete view of the experiences and needs of these specific groups, limiting the universal applicability of the findings.

Conclusions

This scoping review has underscored the role of spirituality in the well-being of families of children with CHD. The reviewed studies suggest that spirituality provides mental and emotional support, aid in decision making, and offers benefits when integrated into the healthcare team. However, significant gaps were also identified, such as the need for structured spiritual counseling models and more research in diverse cultural and socioeconomic contexts.

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Footnote

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