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COMMENTARY

Spirituality in Congenital Heart Disease Counseling: Toward a Practical, Evidence-Informed Framework for Family-Centered Care

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ABSTRACT: The diagnosis of congenital heart disease (CHD) brings profound uncertainty and emotional distress to families, yet the spiritual dimension of this experience is often overlooked in routine counseling. Based on a narrative review of the literature and our group's prior scoping work, this commentary proposes a practical, ethically grounded framework for integrating spiritual awareness into fetal and pediatric CHD counseling. We distinguish spirituality from related constructs, religiosity, coping, resilience, and cultural values, and discuss both its potential benefits (e.g., fostering resilience, supporting decision-making) and risks (e.g., spiritual distress, fatalism, conflict with medical recommendations). Practical guidance is offered on when and how to address spiritual concerns, who may initiate the conversation, documentation practices, and referral thresholds for chaplaincy, psychology, social work, or palliative care. Feasibility constraints, including time limitations, clinician training, workforce availability, and telemedicine, are acknowledged. Future research should evaluate whether spiritually sensitive counseling measurably improves parental anxiety, decisional conflict, satisfaction, coping, and trust. Spirituality should not be assumed to be universally beneficial or inherently religious; some families are secular and prefer purely practical discussions. When handled flexibly and ethically, spiritual awareness can complement—but not replace—medical precision in family-centered CHD care.

KEYWORDS: Congenital heart disease; fetal cardiology; spirituality; family-centered care; counseling

1 Introduction

The diagnosis of congenital heart disease (CHD), whether identified prenatally or postnatally, represents a significant disruption in the anticipated course of parenthood. Families across diverse populations and healthcare systems frequently characterize this experience as one marked by shock, fear, and profound uncertainty [1,2]. Although medical advances have substantially improved diagnostic accuracy and survival rates, the emotional and existential burden associated with a CHD diagnosis has remained largely constant [3,4]. Parents are confronted with complex medical information as well as challenging questions regarding suffering, hope, and their child's future [1,5,6].

This commentary addresses a specific gap: although qualitative literature repeatedly identifies spirituality as influential in how families interpret a CHD diagnosis, this evidence remains fragmented and has rarely been translated into structured, actionable counseling guidance. Prior discussions, including work from

our own group, have remained largely conceptual, describing spirituality as relevant without specifying who should address it, when, how concerns should be documented, or when referral is warranted. The purpose of this article is, therefore, to move from principle to practice: we propose an evidence-informed, ethically grounded framework that clarifies the conceptual boundaries of spirituality, acknowledges its risks alongside its potential benefits, and offers concrete, time-feasible strategies for fetal and pediatric CHD counseling. This commentary is explicitly framed as a perspective and proposed framework, not as a systematic review or as a claim that spirituality is a universally beneficial or required component of care.

2 Approach to the Literature

This commentary is an evidence-informed perspective and proposed conceptual–practical framework, not a systematic review. It is based on a narrative, targeted review of literature concerning CHD counseling, prenatal diagnosis, parental coping and decision-making, pediatric palliative care, spirituality and religiosity in health care, and ethical communication, supplemented by literature on telemedicine and artificial intelligence (AI) in CHD. Sources were identified through targeted database searches and through our group's own empirical and scoping work, including two prior scoping reviews addressing family counseling and spirituality in CHD [7,8] and a multidisciplinary counseling editorial [9]. No formal meta-analysis, risk-of-bias assessment, or systematic evidence grading (e.g., GRADE) was performed. Accordingly, this commentary should be read as a synthesis intended to inform clinical reasoning, ethical practice, and future research priorities, rather than as a definitive evidence base.

3 Clarifying Spirituality: Conceptual Boundaries

Spirituality refers to the ways individuals and families seek meaning, express hope, interpret suffering, and act on deeply held values; it may or may not be religious [1,10]. Used loosely, however, the term risks becoming so broad that almost any parental response could be labeled "spiritual." We therefore distinguish it from related constructs that are sometimes used interchangeably in the literature.

3.1 Spirituality Versus Religion/Religiosity

Religion refers to organized systems of belief, practice, and community; spirituality is broader and may be entirely secular, expressed through philosophy, family tradition, nature, art, or a sense of responsibility toward others [11].

3.2 Spirituality Versus Coping

Coping describes the general strategies people use to manage stress. Spiritual or religious coping is one subtype, and it is not uniformly protective: positive religious coping (e.g., trust, meaning-making) has been associated with lower depression scores among parents of infants with CHD, whereas negative religious coping (e.g., feeling punished or abandoned) has been associated with higher depression scores and poorer mental-health-related quality of life in the same population [12].

3.3 Spirituality Versus Psychological Resilience

Resilience is the capacity to adapt to adversity; spirituality may be one resource contributing to resilience, but the two are not synonymous because resilient parents are not necessarily spiritual, and spiritual parents are not necessarily resilient.

3.4 Spirituality Versus Cultural Values

Culture shapes how spirituality is expressed (e.g., through family harmony, collective responsibility, or community ties rather than overtly religious language), but cultural values and spirituality are conceptually distinct [2,13].

3.5 Spirituality Versus Social Support

Social support is relational and structural; spirituality is meaning-oriented. The two frequently co-occur, for example, through faith communities, but are separable constructs that should be assessed differently.

Critically, spirituality should not be assumed to be religious, nor should it be imposed. Some families are secular, reject spiritual or religious framing altogether, and prefer purely practical, biomedical discussions. This preference should be respected without judgment or further probing, and is addressed explicitly in the practical guidance below.

4 Advances in Medical Insights

Over recent decades, fetal and pediatric cardiology have advanced through earlier diagnosis, refined surgical techniques, and improved perioperative care; more recently, artificial intelligence, automated image analysis, and predictive algorithms have further increased diagnostic precision and risk stratification [14,15]. These developments have helped transform many forms of CHD from often fatal conditions into chronic and frequently manageable conditions [4,16]. However, technological sophistication does not interpret suffering, contextualize uncertainty, or accompany existential distress; effective parental counseling remains an essential element that can be overshadowed by medical progress [17].

Telemedicine in fetal and pediatric cardiology illustrates the same tension. Remote consultations can expand access to expert care, which is particularly relevant in resource-limited or geographically dispersed settings [3,4]. Whether telemedicine helps or hinders relational and spiritual dialogue depends on implementation: reduced nonverbal cues and time pressure can narrow opportunities for deeper conversation, while structured follow-up calls and written materials can extend them [18,19]. Technology should be understood as a tool that can support but cannot substitute for relational counseling.

5 Parental Experience

Qualitative literature on parental experience after a CHD diagnosis consistently describes families drawing on spiritual beliefs and value systems to manage distress and uncertainty, and associates spirituality with resilience and emotional adaptation during extended decision-making [1,17,18,20]. Counseling that allows space for emotional and spiritual expression may also support the grieving process that frequently accompanies the loss of the anticipated, healthy child, and may help sustain the parent–child bond, particularly for families continuing a pregnancy and preparing to care for a child with complex medical needs [5,21].

This evidence should not be read as showing that spirituality is universally beneficial. The broader literature on serious pediatric illness describes spiritual distress, religious struggle, guilt, and fatalistic interpretations of diagnosis. In the one quantitative study identified in this area, negative religious coping (e.g., feeling abandoned or punished) was independently associated with higher depressive symptom scores and lower mental-health-related quality of life among parents of infants with CHD, in contrast to the protective association observed for positive religious coping [12]. Beliefs can also contribute to refusal or delay of recommended care, or to conflict between parental convictions and medical recommendations. Clinicians themselves are not immune to this dynamic: provider beliefs have been shown to vary and to

influence how fetal cardiac counseling is delivered, underscoring the risk of unintentional imposition or boundary violation when spiritual or religious framing is not handled with neutrality [22,23].

6 Ethical Considerations

Ethical practice requires a clear distinction between acknowledging spiritual concerns and promoting specific beliefs. Healthcare professionals should respect diversity, maintain neutrality, and remain sensitive to each family's cultural and spiritual background, creating a safe environment in which families can choose whether to share their values without feeling compelled to do so [22,23]. The role of healthcare professionals is not to provide answers to spiritual questions, but to recognize when such questions are present and respond with openness and respect.

This neutrality is most tested when parental beliefs conflict with medical recommendations, for example, in decisions about pregnancy management, the timing or extent of intervention, palliative or comfort-focused care, or the informed consent process itself, when beliefs shape how risks and benefits are weighed. In these situations, an ethically sound response involves exploring the values underlying the family's position without abandoning the medical recommendation, seeking a time-limited and respectful dialogue rather than confrontation, and involving ethics consultation, palliative care, or spiritual care services when an impasse persists. Discussions and their resolution should be documented, and families' informed refusals should be respected within legal and ethical limits, provided that consent is genuinely informed. Throughout, clinicians must guard against imposing their own beliefs, religious or secular, while avoiding dismissal of a family's framework simply because it conflicts with the recommended course of care.

7 Practical Integration into CHD Counseling

Translating these principles into time-limited clinical practice requires explicit guidance on when, by whom, and how spiritual concerns should be addressed; such structure is consistent with broader moves toward standardized and family-responsive fetal cardiology counseling [24].

7.1 When

Spirituality need not, and often should not, be raised at the first encounter. Natural opportunities arise during ongoing counseling visits, particularly before major decisions (intervention, mode of delivery, transition to palliative or comfort-focused care) and when families themselves introduce value-laden or existential language (e.g., "why did this happen," expressions of fatalism or hope).

7.2 Who May Initiate

Any team member who notices these cues may open the conversation with a brief, neutral question. The treating cardiologist or maternal–fetal medicine specialist often introduces the topic briefly; nurses, genetic or fetal counselors sustain it through ongoing rapport; psychologists and social workers explore coping and decisional support in greater depth; and chaplains or trained spiritual care providers lead deeper existential or spiritual exploration when needed.

7.3 Documentation

A brief, structured note (e.g., "spiritual/values preferences discussed; referral offered/accepted/declined") is sufficient and respects privacy; detailed theological documentation is neither necessary nor appropriate.

7.4 Referral Thresholds

Referral to chaplaincy, psychology, social work, or palliative care is warranted when families explicitly request it, when spiritual distress is expressed, when fatalistic or guilt-laden beliefs appear to be influencing decisions, or when beliefs are associated with refusal or delay of recommended care.

7.5 Secular Families

The option should be offered neutrally and without assumption, for example: "Some families find it helpful to talk about the values or beliefs guiding their decisions; would that be useful, or would you prefer we focus on the medical and practical aspects?" A preference to decline should be respected without further probing.

7.6 Time-Limited Consultations

Rather than a separate visit, a single screening question can be embedded within an existing psychosocial intake or counseling encounter. Structured frameworks such as Faith and Belief, Importance, Community and Address in Care (FICA) [25] and Sources of Hope, Organized religion, Personal spirituality and practices, and Effects on medical care and end-of-life decisions (HOPE) [26] were developed for general palliative and primary care and, when applied to CHD counseling, should be adapted and used as brief conversational entry points rather than full theological assessments. Illustrative, non-imposing clinician questions include: "What gives you strength as you face this diagnosis?"; "Are there values, beliefs, or traditions you would like us to understand as we plan care?"; "Would you like support from someone from your faith, spiritual, or community network?"; and "Are there beliefs or concerns that may affect how you are thinking about treatment decisions?" Table 1 summarizes how these elements can be organized across stages of care. It is intended as an illustrative, preliminary organizing aid and should not be interpreted as a validated pathway or practice guideline.

Table 1: Practical approaches for integrating spiritual awareness into congenital heart disease counseling.

Stage of Care	Who May Initiate	Suggested Prompt/Action	Documentation	Referral Threshold
Initial diagnosis disclosure (prenatal or postnatal)	Cardiologist/maternal–fetal medicine specialist	"What gives you strength as you face this diagnosis?" (offered once, optionally)	Note whether family welcomes or declines further discussion	Overt distress or explicit request → same-visit social work or chaplaincy referral if available
Follow-up counseling visit	Nurse, genetic or fetal counselor	"Are there values, beliefs, or traditions you'd like us to understand as we plan care?"	Brief note on values relevant to care planning	Beliefs may affect treatment decisions → multidisciplinary discussion
Pre-intervention/decision-making visit	Physician with psychologist/social worker	"Are there beliefs or concerns that may affect how you are thinking about treatment decisions?"	Document decisional concerns and resolution plan	Persistent conflict with recommendation → ethics consultation
Palliative or end-of-life discussion	Palliative care team, chaplain	"Would you like support from someone from your faith, spiritual, or community network?"	Document referral offered/accepted	Spiritual distress or existential suffering → offer chaplaincy or spiritual care support when available
Secular or non-responsive families	Any team member	"Some families find it helpful to talk about values or beliefs; would that be useful, or we should focus on medical and practical aspects?"	Document preference; do not re-probe	None, unless distress later emerges
Telemedicine consultation	Treating physician	Same screening question, with extra pause for response; offer follow-up call with counselor or chaplain if needed	Note modality and whether topic was addressed	Low connection quality/time pressure → schedule dedicated follow-up

8 Feasibility and Implementation

Several real-world constraints limit how consistently this framework can be applied. Time pressure in busy clinics, clinician discomfort, and limited training in spiritual communication are common barriers; provider beliefs and comfort with the topic vary substantially and shape what is actually discussed with families [22]. Trained spiritual care professionals are often unavailable, particularly in low-resource settings, and telemedicine introduces additional constraints, including reduced nonverbal cues and compressed visit time. Pragmatic responses include brief, optional screening questions embedded in existing workflows rather than separate spiritual assessments; clear, team-based referral pathways that do not depend on any single clinician having specialized training; and institutional protocols that define roles and documentation expectations in advance. Where dedicated spiritual care services are not available, structured collaboration with community or religious leaders identified by the family, when desired by the family, may serve a similar function.

Consequently, any clinical implications drawn from this framework should remain cautious. The current evidence base is dominated by narrative synthesis, qualitative observations, and a small number of quantitative CHD-specific studies; implementation should therefore be adapted locally and prospectively evaluated before the framework is treated as a standard of care.

In Fig. 1, we present a conceptual framework intended to organize discussion; it is not an empirically validated model, nor the product of a formal consensus process. It illustrates four domains relevant to family-centered CHD counseling: (1) the emotional impact of diagnosis, reflecting shock, grief, and uncertainty; (2) technological advances, reflecting improvements in diagnostic precision, risk stratification, and access (including AI-assisted tools and telemedicine); (3) structured counseling, reflecting the team-based communication practices through which information and support are delivered; and (4) the spiritual dimension, reflecting the search for meaning, hope, and connection described above. These domains are proposed to interact rather than operate independently: for example, technological precision shapes the information delivered within structured counseling, which in turn can create space for emotional and spiritual dialogue; the spiritual dimension, reciprocally, shapes how families interpret technologically derived information and emotionally process the diagnosis. These relationships are proposed to guide clinical attention and future research and should not be interpreted as established causal pathways.

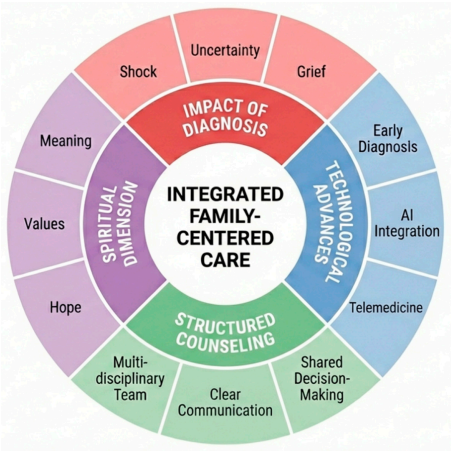

Figure 1: Conceptual framework illustrating four interacting domains relevant to family-centered counseling in congenital heart disease: emotional impact of diagnosis, technological advances, structured counseling, and the spiritual dimension. Arrows indicate proposed bidirectional influence rather than established causal pathways.

9 Future Research

Future studies should evaluate whether spiritually sensitive counseling measurably affects parental anxiety, decisional conflict (e.g., using the Decisional Conflict Scale), satisfaction with counseling, coping, quality of life, preparedness for surgery or palliative care, adherence to follow-up, and parent–clinician trust. Evidence directly linking spirituality to hard clinical outcomes in CHD remains limited: to our knowledge, only a small number of quantitative studies exist, restricted largely to single-center, cross-sectional samples [12]. Rigorous studies using validated instruments, ideally with longitudinal and multicenter designs, are needed before clinical recommendations that go beyond the general, ethically grounded practices proposed here can be made with confidence. Validation studies should specifically examine the feasibility, acceptability, and outcome sensitivity of the prompts, documentation steps, and referral thresholds outlined in Table 1 across prenatal, postnatal, low-resource, and telemedicine settings.

10 Conclusions

Comprehensive care for children with CHD extends beyond surgical success and technological precision. Families carry the diagnosis not only as a medical fact but as an emotional and existential experience, shaped by personal values, relationships, and—for many, though not all—spiritual perspectives. We have proposed a practical framework that invites clinicians to acknowledge this dimension without imposing beliefs, while remaining alert to its risks and to the reality that some families prefer purely practical discussions. This framework is not a mandate, but an invitation: to listen more attentively, to ask with humility, and to respond with flexibility. Whether this approach translates into measurable improvements in parental anxiety, decision-making, or trust remains an open question. Future research, preferably multicenter and longitudinal, is needed to test these outcomes across diverse clinical and cultural settings. Until then, we offer this perspective as a step toward care that is not only technically excellent but also genuinely family-centered.

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