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Guarding Fragile Hearts: Lived Experiences of Parents Caring for Children with Congenital Heart Defects Post- Hospital-Based Palliative Care in Tagum City

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Abstract:
This study aimed to explore the lived experiences of parents caring for children with congenital heart defects post-hospital-based palliative care in Tagum City, with particular focus on the emotional, physical, financial, and caregiving challenges encountered in providing care at home. A descriptive phenomenological approach was employed to understand the depth and significance of parents' caregiving experiences. The findings revealed three emergent themes: Emotional Toll, Anchors of Resilience, and Transformative Caregiving. Parents described fear, anticipatory grief, emotional exhaustion, physical demands, and financial difficulties while managing their children's healthcare needs and daily caregiving responsibilities. Despite these challenges, parents demonstrated resilience through family support, spiritual faith, hope, and positive coping strategies. Their experiences also revealed how parents developed caregiving skills, reorganized family responsibilities, and sought financial assistance and community resources to sustain care at home. The findings highlighted the importance of strengthening nursing practice through caregiver education, psychosocial support, comprehensive discharge planning, and family-centered care. Clear instructions on medication administration, symptom monitoring, and prescribed caregiving activities may improve parental preparedness and confidence in providing care. Furthermore, collaboration among healthcare professionals, social workers, and community providers may help families access available services and maintain continuity of care. The study underscores the need for accessible and sustained support systems to address the interconnected emotional, physical, social, social, and financial challenges experienced by parents caring for children with CHDs following hospital-based palliative care. These measures may improve caregiver preparedness, family well-being, and pediatric palliative care services.

Keywords- Congenital Heart Defects, Parental Caregiving, Post-Hospital-Based Palliative Care, Descriptive Phenomenology, Tagum City, Philippines

INTRODUCTION

Caring for a child with congenital heart defects after hospital-based palliative care is a complex and transformative experience for parents, characterized by increased caregiving responsibilities, emotional strain, and ongoing uncertainty. Congenital heart defects, which affect approximately 1 in 100 live births, are serious structural conditions that may lead to life-threatening complications if not promptly managed

(Singh, 2025; Martínez, 2025). Due to financial constraints, many families rely on palliative care rather than definitive surgical interventions, necessitating a transition from hospital-based support to home caregiving (Lopez, 2025).

Globally, in countries such as the United States, Canada, and the United Kingdom, comprehensive palliative care services provide medical, psychological, and social support to parents of children with congenital heart defects (Harrison et al., 2023). Despite these resources, parents still face significant emotional challenges, including grief and anxiety, due to uncertainty about their child's future (Feldman et al., 2023). In Europe, particularly in the Netherlands and Germany, pediatric palliative care is more integrated into healthcare systems and offers continuous support. The emotional burden remains high even with specialized services, with many parents needing additional psychological support (Muller et al., 2022).

In the Philippines, congenital heart defects are a significant pediatric health concern, affecting approximately 1 in 100 live births (De Guzman & Villanueva, 2022). Although advances in medical technology and surgical interventions have improved survival rates, many children with complex congenital heart defects eventually require palliative care when curative treatments are no longer effective (Torres & Cruz, 2022). Access to palliative care services is largely concentrated in major urban centers, such as Metro Manila and Cebu City, leaving families in rural and remote areas with limited options for ongoing support and specialized care (Llanes & Santos, 2023).

Locally, in the Davao Region, congenital heart defects remain a significant pediatric health concern, with many children requiring surgical interventions to improve survival and quality of life (Lopez & Gonzales, 2023). Parents of children undergoing surgery often experience emotional and psychological stress due to uncertainty about operative outcomes and complications (Reyes & Cruz, 2022). The financial burden of hospital stays and post-operative care, including palliative and follow-up care, further strains families (Garcia & Santos, 2021).

This study addressed the research gap by exploring the lived experiences of parents caring for children with congenital heart defects (CHDs) post-hospital-based palliative care in the Davao Region (Santos, 2025). Previous studies primarily focused on the medical management of CHDs, with limited attention to the emotional, psychological, and financial challenges experienced by parents during post-hospital care in regional settings (Lopez et al., 2023). The study also highlighted the importance of family-centered care and hospital support programs in helping parents cope with these challenges and continue providing appropriate care for their children (Cruz, 2024).

PURPOSE OF THE STUDY.

This descriptive phenomenological study explored and understood the lived experiences of parents caring for their children after hospital-based palliative care. Specifically, the study sought to understand better how parents navigated the multifaceted challenges, emotional responses, coping mechanisms, and personal transformations that arose during the post-palliative care period.

The participants were parents of children diagnosed with congenital heart defects who had undergone hospital-based palliative care interventions. The study adopted a descriptive phenomenological approach guided by the framework of John W. Creswell and J. David Creswell (2023), which emphasized systematically exploring participants lived experiences to uncover the essence, meaning, and structure of the phenomenon under investigation.

RESEARCH QUESTIONS

This study aimed to explore the lived experiences, coping mechanisms, and insights of parents who cared for children with congenital heart defects following hospital-based palliative care.

To fully understand the study, it sought to answer the following research questions:

1. What are the lived experiences of parents caring for children with congenital heart defects continuing palliative care at home?
2. How do these parents cope with these experiences?
3. What insights can these parents share to help other primary care providers like them?

IMPORTANCE OF THE STUDY

This study provided valuable insights into the lived experiences of parents caring for children with congenital heart defects after transitioning to palliative care. By exploring these parents' experiences, the study aimed to educate healthcare professionals on the importance of adopting a positive, supportive approach to addressing these families' unique needs. The findings highlighted the emotional, psychological, financial, and caregiving burdens that parents faced, thereby contributing to a deeper understanding of their experiences and informing more effective interventions.

Primarily, this study's findings benefited parents of children with congenital heart defects by offering insights into the challenges they faced, emphasizing the importance of emotional and psychological support, and recognizing the financial and caregiving burdens. The study empowered parents to engage more actively in their child's care, develop effective coping strategies, improve communication with healthcare providers, and ultimately enhance their quality of life and autonomy.

Second, the findings offered healthcare providers insights into the emotional, financial, and caregiving challenges parents face. With this knowledge, healthcare professionals could tailor care strategies, provide more personalized support, and address key concerns, ultimately improving patient outcomes, enhancing care quality, and fostering stronger relationships with families.

Thirdly, for palliative care center administration, the results provided insights into parents' knowledge and perceptions of palliative care and its impact on their child's health, identified barriers to accessing care, and suggested strategies to improve family engagement and program awareness. The findings guided the development of effective communication and support systems, enhancing healthcare delivery, patient satisfaction, and program effectiveness, especially in resource-limited settings.

Lastly, future researchers could use the information gathered in this study as a reference for further research on the lived experiences of parents caring for children with congenital heart defects in palliative care. The findings provided insights into the challenges, coping strategies, and support needs of parents navigating palliative care, offering a foundation for future studies aimed at improving patient outcomes and the quality of care provided

RESEARCH METHODOLOGY

Research Design

This study employed a qualitative, descriptive-phenomenological research design to understand the lived experiences of parents caring for children with congenital heart defects following hospital-based palliative care. This approach was ideal for capturing parents' subjective experiences, beliefs, attitudes, emotions, and coping mechanisms, particularly in managing their child's care after palliative interventions. The primary data collection method was in-depth interviews, which allowed participants to provide rich,

detailed responses through open-ended questions that were analyzed thematically (Creswell & Poth, 2023).

The research design involved conducting individual interviews with parents to explore their caregiving experiences, emotional responses, and coping strategies following their children's palliative care. This qualitative approach allowed an in-depth understanding of the parents' emotional, social, and psychological experiences that may not be fully captured through quantitative methods (Finlay, 2023). The findings provided insights into parents' challenges and support needs, which may inform the development of appropriate programs and interventions for families in similar situations (Smith, 2024).

Participants

The study used purposive sampling, a non-probability sampling method commonly used in qualitative research to identify and select information-rich participants with direct experience of the phenomenon under study (Etikan et al., 2022; Fetters et al., 2023). This approach involved selecting individuals who were knowledgeable about or had personally experienced the phenomenon of interest. Data were gathered through in-depth interviews with parents of children diagnosed with congenital heart defects who had experienced hospital-based palliative care.

Parents whose children had undergone successful operations and were no longer in a palliative care situation were not included in the study. Conversely, parents whose children had already passed away, those who had not experienced post-hospital-based palliative care, and those who had provided home care for less than three (3) months were excluded from the study. The sampling process also considered the participants' willingness to participate and their ability to communicate their experiences and perspectives openly.

Because of the sensitive and deeply personal nature of the topic, focus group discussions (FGDs) were not used. Instead, in-depth interviews were conducted to provide participants with a safe, private environment to openly share their lived experiences, emotional challenges, coping strategies, and caregiving responsibilities. The selected participants provided valuable insights into the realities of caring for children with congenital heart defects following hospital-based palliative care. This participant selection process ensured the collection of meaningful, relevant data needed to address the research questions and achieve the study objectives.

Data Sources

Data for this qualitative research were gathered from multiple sources, including written documents, field notes, and observational insights (Creswell & Poth, 2023). Utilizing a phenomenological approach, the primary data were obtained through in-depth interviews with parents who were caring for children diagnosed with congenital heart defects following hospital-based palliative care. Participants were selected based on established inclusion criteria, ensuring they had direct, meaningful experiences relevant to the study's focus.Due to the emotional and logistical complexities faced by families in palliative care situations, focus group discussions were deemed impractical. Therefore, in-depth interviews (IDIs) served as the principal method of data collection. Secondary data sources, including relevant literature and informal observations made throughout the research process, complemented the primary data and helped contextualize the participants' narratives.

A semi-structured interview guide was developed to facilitate open-ended yet focused conversations, allowing participants to share their lived experiences in depth and authenticity. The number of participants was determined by data saturation. Interviews were conducted either face-to-face or via a secure online platform, depending on the participants' availability and preference. All interviews were recorded using a

cellphone recorder to ensure accurate transcription and analysis. This approach enabled the researcher to capture a rich, nuanced understanding of the realities faced by parents caring for children with congenital heart defects after palliative care (Creswell & Poth, 2023).

Data Collection Procedure

The researcher used a researcher-made interview guide as the study's research instrument. The major questions of the study, along with sub-questions, were formulated using a guide questionnaire, which was reviewed by the thesis adviser for approval. This process helped refine the questions to ensure they were clear and conducive to obtaining specific responses from participants, while also improving their form and style. The thesis adviser reviewed the final guide questionnaire before it was validated by three research specialists or validators. These specialists used a validator form provided before the interview guide was distributed or used (Brown, 2023).

The primary source of data for this study was parents of children with congenital heart defects who had received palliative care. Data were gathered from the participants' responses to the questions posed during in-depth interviews (IDI). These questions were specified in the interview guide and were aligned with the study's purpose. The researcher recorded participants' responses during interviews using a cellphone to ensure accurate documentation (Smith & Patel, 2023).

This research provided rich and detailed descriptions of the lived experiences of parents caring for children with congenital heart defects after transitioning to palliative care, offering insights that allowed readers to assess the transferability of the findings to other settings (Johnson, 2023). The researcher included verbatim quotes of the participants' experiences to illustrate the findings. At the start of the study, the researcher provided participants with a brief introduction to the study. According to Thompson and Harris (2024), this approach significantly enhanced the participants' understanding of the research process.

The researcher obtained an approved letter signed by the Program Chair of the Graduate School under the Master of Arts in Nursing program at Davao Doctors College. Before the interviews began, the researcher provided the participants with a brief overview of the study and obtained informed consent using an informed consent form (ICF) (Williams, 2023).

In this study, participants were interviewed face-to-face using in-depth interviews. The study was conducted with parents of children with congenital heart defects following hospital-based palliative care in Tagum City. Because of the emotional and logistical complexities families face in palliative care, focus group discussions were not feasible. Interviews were conducted individually, giving each participant enough time to share their experiences fully. Each interview lasted between 30 minutes and 1 hour. To ensure participant confidentiality, interviews took place in a safe, comfortable location that provided a predictable, non-threatening environment. All information gathered was analyzed, and themes and sub-themes were developed based on the data (Roberts & Reed, 2023)

Research Reflexivity

In this study, reflexivity referred to the researcher's ongoing critical evaluation of personal biases, preconceptions, and how these might have influenced each stage of the research process. The researcher consistently questioned initial impressions and interpretations, linking these reflections to participants' specific experiences and circumstances (Mills et al., 2023).

As a healthcare professional familiar with pediatric care and palliative support, the researcher brought a unique perspective to the study. This professional background allowed the researcher to appreciate both the challenges and positive experiences faced by parents caring for children with congenital heart defects after transitioning to palliative care. Reflexivity enabled the researcher to identify potential areas for

improvement in family-centered care and palliative services, offering insights that could enhance support for both children and their families.

Reflexivity also deepened the researcher's understanding of parents' coping strategies, emotional responses, and caregiving practices. The researcher continuously reflected on how personal beliefs or experiences might have affected data collection, interpretation, and analysis, ensuring that participants' perspectives remained central to the study.

Through this process, the researcher enhanced the validity and credibility of the findings, ensuring the study accurately represented parents' lived experiences. Reflexivity also allowed the researcher to acknowledge the limitations and potential biases inherent in the research process. Ultimately, this approach strengthened the study's contribution to understanding the experiences of parents caring for children with congenital heart defects following palliative care and provided valuable insights for healthcare professionals, policymakers, and palliative care programs in the Filipino context (Kumar et al., 2023; Rivera et al., 2023).

Ethical Considerations

In conducting this study, the researcher obtained agreement and approval from the Head of the Master's Program in Nursing at Davao Doctors College and sought permission from the relevant institution or hospital to access participants. Several ethical issues were considered in this process.

Social Value. The study aimed to explore the lived experiences of parents caring for children with congenital heart defects following hospital-based palliative care. The primary purpose was to understand how these parents coped with the emotional, physical, and psychological challenges of caregiving in the context of palliative care. The findings were shared with healthcare providers, policymakers, and other stakeholders to enhance support for families in similar situations and to inform palliative care practices in the region (Bowlby & King, 2023). In addition, this study limited the use of Artificial Intelligence (AI) tools to assisting with language refinement, grammar correction, and the structural organization of research writing (Shenton, 2024). AI tools also helped the researcher organize themes and improve the clarity of interview guides; however, they were not used to interpret data or generate final findings (Forero et al., 2023).

Risks and Benefits. The research involved personal reflections and sensitive topics, which could have caused emotional distress for some participants. However, the study ensured that all information was used solely for research purposes. Potential benefits included raising awareness of the challenges parents faced and advocating for improved care and resources. The findings could have helped develop intervention programs or support systems aimed at alleviating the struggles these parents faced (Creswell & Poth, 2023).

Voluntary Participation. Participation in this study was entirely voluntary. Participants could refuse to participate or withdraw at any time without consequence. If participants decided to withdraw, all information they had provided was excluded from the study (Rubin & Rubin, 2023).

Privacy and Confidentiality. The researcher ensured that all personal data collected were handled in compliance with the Data Privacy Act of 2012. Participants were assured of anonymity, and the researcher did not disclose identifying information in any published results. All collected data were kept confidential, and access was restricted to the researcher. If any findings were published, participants' identities were not revealed. The researcher securely disposed of raw data after the study concluded. Participants were also given the option to receive a copy of the results upon request.

Data Analysis

This study utilized Colaizzi's descriptive phenomenological method to analyze the interview data and explore the lived experiences of parents caring for children with congenital heart defects following hospital-based palliative care. The method provided a systematic process for identifying, interpreting, and describing the essential meanings of the participants' experiences.

First, the researcher familiarized themselves with the data by reading and rereading the interview transcripts several times to gain a comprehensive understanding of the participants' narratives. During this stage, the researcher immersed themselves in the participants' accounts while staying aware of experiences relevant to the research questions.

Second, the researcher identified and extracted significant statements from the transcripts. Statements that directly described the participants' experiences, emotions, challenges, coping strategies, caregiving practices, and sources of support were selected. The researcher retained these statements in their original context to preserve the meaning of the participants' responses.

Third, meanings were formulated from the significant statements. The researcher carefully examined each significant statement and interpreted its underlying meaning in relation to the phenomenon being studied. The formulated meanings remained closely grounded in the participants' actual experiences and were reviewed to avoid interpretations that were not supported by the data.

Fourth, the formulated meanings were organized into theme clusters. Meanings that reflected similar or related experiences were grouped to identify patterns across the participants' narratives. The researcher reviewed and compared these clusters with the original transcripts to ensure they accurately represented participants' experiences.

Fifth, the researcher developed an exhaustive description of the phenomenon. The researcher integrated the identified theme clusters into a comprehensive description of the lived experiences of parents caring for children with congenital heart defects following hospital-based palliative care. The description included the emotional, physical, social, financial, spiritual, and caregiving dimensions reflected in the participants' narratives.

Sixth, the fundamental structure of the phenomenon was identified. The researcher synthesized the exhaustive description to determine the essential meaning and central structure of the parents' lived experiences. This synthesis represented the core of the phenomenon based on the common experiences shared by the participants.

Seventh, the researcher validated the findings through member checking. The researcher returned the findings or interpretations to the participants to determine whether these accurately reflected their experiences. Participants were allowed to clarify, confirm, or correct interpretations as needed. Any relevant clarification was incorporated into the final analysis.

Throughout the analysis, the researcher maintained fidelity to the participants' original narratives and continuously reviewed the transcripts, significant statements, formulated meanings, and theme clusters to ensure the final findings remained grounded in participants' lived experiences.

IV. RESULTS AND DISCUSSION

This chapter presents the findings of the study based on ten in-depth interviews with parents caring for children with congenital heart defects post-hospital-based palliative care in Tagum City. Participants were selected based on the established inclusion criteria to ensure their experiences were directly relevant to the phenomenon under investigation.

The interview data were systematically analyzed to identify significant statements and emerging themes related to the parents' lived experiences, caregiving challenges, coping strategies, responsibilities, and sources of support. Participant codes were used to ensure confidentiality and protect the identities of the participants and their children.

Ethical principles were observed throughout the research process. Participants provided informed consent and were informed of their right to decline participation or withdraw from the study without penalty. Interviews were conducted in a private, safe environment, and audio recording was undertaken only with participants' permission. All collected data were securely stored and managed in accordance with institutional policies on confidentiality and data privacy.

Overall, the findings demonstrate that parents experienced substantial emotional, physical, financial, and caregiving challenges in providing palliative care at home. The findings further emphasize the need for accessible healthcare services, financial assistance, emotional support, and continuous guidance for families caring for children with CHDs at home.

Profile of the Participants

The study involved ten (10) participants who were parents or primary caregivers of children diagnosed with congenital heart defects and who had experienced hospital-based palliative care. The participants were purposively selected based on the established inclusion criteria and had direct experiences relevant to the study.

To ensure anonymity and confidentiality, participant codes were assigned and identifying information was excluded from the presentation of findings. Table 1 presents the demographic and relevant caregiving profiles of the ten participants included in the study.

Table 1. Participant's Profile

Code Name	Age	Sex	Civil Status	Study Group
P1	36	F	M	IDI
P2	45	F	M	IDI
P3	40	M	M	IDI
P4	38	F	M	IDI
P5	38	M	M	IDI
P6	33	F	M	IDI
P7	28	F	S	IDI
P8	35	F	M	IDI
P9	29	F	M	IDI
P10	40	F	M	IDI

The ten participants in this study were interviewed using a guided questionnaire designed to explore three central research questions: (1) What are the lived experiences of parents caring for children with congenital heart defects continuing palliative care at home? (2) How do these parents cope with their experiences? Furthermore, (3) What insights can these parents share to help other primary caregivers in similar situations?

Following the in-depth interviews (IDIs), the audio recordings were transcribed and translated, when necessary, to represent participants' responses accurately. The data were analyzed using Colaizzi's descriptive phenomenological method to understand the lived experiences of parents caring for children with congenital heart defects following hospital-based palliative care. The researcher repeatedly reviewed the transcripts, identified significant statements, and formulated meanings that captured the essence of the participants' experiences.

The researcher compared and organized the formulated meanings into clusters based on similarities and recurring patterns. Thematic analysis was then applied to identify common experiences related to caregiving responsibilities, emotional challenges, coping strategies, sources of support, and the continuation of palliative care at home. Through an inductive process, codes and cluster themes were developed, leading to the emergence of major themes aligned with the three research questions.

The analysis resulted in three emergent themes. The first theme focused on the lived experiences of parents caring for children with congenital heart defects after hospital-based palliative care. The second theme explored parents' coping experiences and strategies in managing the emotional, physical, social, and practical demands of home-based caregiving. The third theme highlighted the insights and lessons parents gained, which may guide and support other caregivers in similar circumstances.

These findings are consistent with Puriani et al. (2023), who emphasized parental uncertainty and the need for adequate healthcare support, and Nogueira and Ribeiro (2023), who highlighted the importance of coping strategies, family support, continuous learning, and professional assistance. Similarly, Fields et al. (2023) underscored the value of understanding parents' experiences to improve the quality of pediatric palliative care.

Table 2 presents the study's thematic map, showing the significant statements, formulated meanings, cluster themes, and emergent themes derived from the interview data.

Table 2. Examples of Significant Statements and Related Formulated Meanings

Significant Statements	Formulated Meanings
"As a parent, it is difficult to see my child experiencing pain and struggling with the condition. Sometimes I feel worried and helpless, but I still try my best to stay strong because my child needs me. (Participant 1, Transcript 1, Line 1-3)	Experiencing emotional distress and helplessness but remaining strong and committed to caring for their child out of love and parental responsibility.
My faith in God, prayer, and the support of my family gives me the strength to keep caring for my child despite the hardships. (Participant, Transcript 4, Line 16-17)	Drawing strength from faith in God, prayer, and family support to overcome caregiving challenges and continue caring for the child.

Instead of panicking every time her condition flares up, I lean on what the healthcare team taught us and keep a positive mindset that we can manage whatever comes. (Participant 5, Transcript 9, Line 139-140)	Maintaining a positive outlook by managing anxiety and applying healthcare professionals' guidance when the child's condition worsens.

Formulated meanings were derived from the significant statements shared by participants regarding their lived experiences as parents caring for children with congenital heart defects post hospital-based palliative care in Tagum City. These significant statements and their corresponding meanings were grouped into cluster themes. To preserve the authenticity and credibility of the participants' narratives, the researcher compared the formulated meanings with the original statements to ensure that the interpretations accurately reflected their experiences.

Each formulated meaning was coded according to its corresponding theme cluster. The researcher grouped similar meanings based on shared experiences, concerns, and coping strategies expressed by the participants. The data were carefully examined to identify statements relevant to the study objectives. These statements were organized into clusters, which were then synthesized into broader emergent themes. Table 3 presents examples of formulated meanings and their associated theme clusters derived from the participants' significant statements.

Table 3. Examples of Formulated Meanings with their Associated Theme Clusters

The emergent themes were developed from the identified cluster themes and represented parents' common experiences. The major emergent themes focused on Lived Experiences in Home-Based Care, Coping and Resilience, and Insights and Support for Other Caregivers.

Formulated Meanings	Cluster Themes	Emergent themes
Experience fear, sadness, and uncertainty over their child's survival and possible loss. Parents endure physical and emotional exhaustion while facing financial hardship and sacrificing personal and work responsibilities to meet their child's caregiving needs. Adapt to home-based palliative care while managing uncertainty and developing caregiving confidence.	Experiencing fear and anticipatory grief Bearing Caregiver Exhaustion and Financial Strain Navigating Home Care Challenges	Emotional Toll
Maintain hope, faith, and determination while facing uncertainty, cherishing each moment with their child despite ongoing challenges. Parents draw strength from family support, healthcare guidance, and spiritual	Maintaining Positivity Amid Uncertainty Family-Centered Supportive Therapy and Spiritual Surrender . Embracing Acceptance and Emotional Adaptation	Anchors of Resilience

faith to cope with caregiving challenges and sustain hope. Gradually accept their child's condition, manage emotional distress, and adapt to the realities of palliative care while continuing to provide love and support.		
Adapt to caregiving responsibilities by developing practical skills, following medical instructions, and organizing daily routines to meet their child's needs. Parents restructure daily routines, family roles, and personal priorities to meet their child's ongoing caregiving needs. They seek financial assistance and community resources to cover medical expenses and ensure continued care for their children despite limited resources.	Adapting to Caregiving Responsibilities Reorganizing Daily Life Around the Child's Care Needs Mobilizing Financial and Community Resources	Transformative Caregiving

The comprehensive data revealed the lived experiences of parents caring for children with congenital heart defects post-hospital-based palliative care in Tagum City. The data were systematically analyzed through transcription, coding, identification of significant statements, formulation of meanings, clustering of related themes, and synthesis of the findings. The participants' narratives were organized and presented through a thematic map, as shown in Figure 2, illustrating the relationships among the formulated meanings, cluster themes, and emergent themes

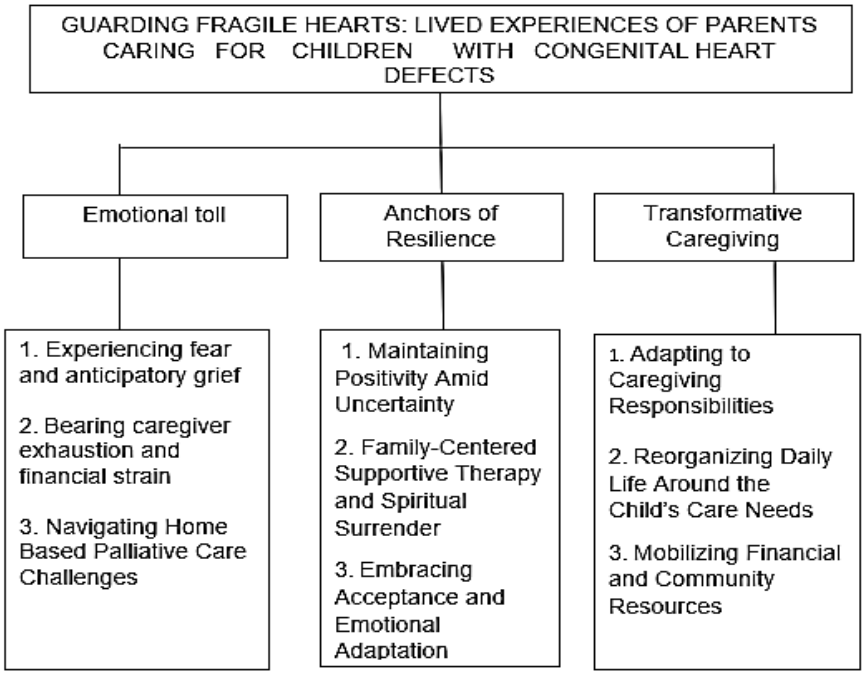


Figure 2: Thematic Map

The thematic map illustrates the lived experiences of parents caring for children with congenital heart disease (CHD) following hospital-based palliative care in Tagum City, highlighting three emergent themes: Emotional Toll, Anchors of Resilience, and Transformative Caregiving. The first emergent theme, Emotional Toll, encompasses experiencing fear and anticipatory grief, bearing caregiver exhaustion and financial strain, and navigating home care challenges. Parents experience emotional distress, uncertainty about their child's survival, financial difficulties, and exhaustion while adjusting to the responsibilities of providing care at home. These experiences highlight the psychological and emotional challenges faced by parents of children with CHD (Dandy et al., 2024).

The second emergent theme, Anchors of Resilience, includes maintaining positivity amid uncertainty, family-centered supportive therapy and spiritual surrender, and embracing acceptance and emotional adaptation. Despite their struggles, parents draw strength from prayer, faith in God, family support, hope, and guidance from healthcare providers. These resources help them manage emotional distress, gradually accept their circumstances, and continue providing love and care for their children. These findings reflect the importance of spiritual coping, family and social support, and emotional regulation among Filipino mothers caring for children with CHD (Felipe-Dimog et al., 2025).

The third emergent theme, Transformative Caregiving, comprises adapting to caregiving responsibilities, reorganizing daily life around the child's care needs, and mobilizing financial and community resources. Parents develop caregiving skills, adjust their routines and family roles, and seek financial assistance to meet their children's medical needs.

Overall, the three emergent themes demonstrate how parents experience emotional hardships, draw upon resilience resources, and adapt to the demands of home-based palliative care. These findings emphasize the importance of parent partnership, psychosocial support, caregiver education, and access to healthcare resources in promoting family well-being (Kogon et al., 2023).

Emergent Theme 1: Emotional Toll

The first emergent theme, Emotional Toll, reflects the fear, uncertainty, and emotional distress experienced by parents caring for children with congenital heart disease (CHD) under palliative care. It comprises three cluster themes: Experiencing Fear and Anticipatory Grief, Bearing Caregiver Exhaustion and Financial Strain, and Navigating Home Care Challenges. Parents struggle with the possibility of losing their child while managing the demands of continuous caregiving.

Experiencing Fear and Anticipatory Grief highlights parents' sadness and helplessness, while Bearing Caregiver Exhaustion and Financial Strain reflects physical fatigue, reduced employment opportunities, and difficulties affording medical needs. These challenges are consistent with Cole et al. (2024), who discussed the impact of caregiving stress on parental well-being, and Zhang et al. (2023), who identified financial burdens and family challenges among families of children with CHD.

In addition, Navigating Home Care Challenges describes parents' anxiety about managing their child's condition without immediate medical assistance. Learning to administer medications, monitor symptoms, and respond to health changes adds to their responsibilities. Overall, these findings emphasize the need for psychosocial support, caregiver education, and accessible healthcare resources to help parents manage the emotional, physical, and financial burdens of home-based palliative care.

Cluster Theme 1.1: Experiencing Fear and Anticipatory Grief

This cluster theme reflects the emotional struggles of parents caring for children with congenital heart disease under palliative care. It highlights their fear of losing their child, sadness, helplessness, and

uncertainty about the child's survival. Parents find it difficult to witness their child's suffering while facing the limitations of available treatment and the possibility of loss.

The following verbatim statements express these experiences:

> As a parent, it is difficult to see my child experiencing pain and struggling with the condition. Sometimes I feel worried and helpless
> (P1, Transcript 1, L 2-3)

It is tiring and exhausting, but I just keep fighting and carrying on.
(P5, Transcript 1, L 118)

> I feel physically, mentally, and emotionally exhausted because of our situation. (P6, Transcript 4, L 151)
>
> Sometimes I cry because the situation is too difficult, but I still find the strength to continue. (P7, Transcript 4, L176-177)
>
> As a parent, you want to save your child, but there are situations that are beyond your control. I felt helpless. (P9, Transcript 4, L226-227)

These statements reveal that fear and anticipatory grief are deeply embedded in the experiences of parents caring for children with congenital heart disease under palliative care. Parents struggle between hoping for their child's survival and accepting the limitations of treatment, often experiencing helplessness and emotional exhaustion. Despite these challenges, they continue to find the strength to care for their children. This finding is supported by Hill et al. (2024), who discussed the emotional challenges and uncertainty experienced by parents caring for children with life-limiting conditions.

Cluster Theme 1.2 Bearing Caregiver Exhaustion and Financial Strain

This cluster theme reflects how parents experience physical, mental, and emotional exhaustion while managing the financial demands of caring for children with congenital heart disease under palliative care. It highlights the sacrifices parents make to sustain their child's care despite limited resources, ongoing stress, and the challenges of meeting their child's needs.

The following verbatim statements express these experiences:

> Sometimes we struggle financially because we still need money for medicines and other needs. (Participant 4, Transcript 2 Line 97-98)
>
> My life has also changed financially because I cannot work regularly anymore. Sometimes we struggle to buy medicines and other things my child needs. (Participant 8, Transcript 2 Line195-196)
>
> It's not easy to live in this world having a CHD child who was in palliative care since we don't have enough money for surgery.
> (Participant 10, Transcript 4 Line 254-255)

These statements reveal that financial difficulties contribute to the emotional and physical exhaustion of parents caring for children with congenital heart disease under palliative care. Limited income, medication costs, and the inability to afford surgery make caregiving more challenging. This finding is supported by Zhang et al. (2023), who discussed the financial and emotional challenges experienced by families of children with congenital heart disease. This cluster theme highlights the sacrifices parents make to sustain their child's care despite financial constraints.

Cluster Theme 1.3: Navigating Home Care Challenges

This cluster theme reflects how parents manage the challenges of providing home-based palliative care for children with congenital heart disease. It describes their efforts to monitor their child's condition,

administer medications, and respond to unexpected changes despite fear, uncertainty, and limited access to immediate medical assistance.

The participants expressed this cluster through these statements:

> I was happy when we were able to go home, but I realized that it was more difficult because there were no nurses or doctors to help us
> (Participant 2, Transcript 3 Line 38-39)
> Every day, caring for my child with CHD is difficult and exhausting. I need to constantly watch over my child, give medicines, provide food, and observe their condition (Participant 4, Transcript 1 Line 93-94)
> I learned to understand my child's needs better. I became more attentive to her breathing, feeding, medicines, and other changes in her condition.
> (Participant 5, Transcript 9 Line 133-134)

These statements highlight the challenges parents face in providing home-based palliative care for children with congenital heart disease, particularly in monitoring symptoms, administering medications, and managing unexpected changes without immediate medical assistance. These responsibilities contribute to emotional distress and caregiving burden, emphasizing the importance of caregiver education and healthcare support. As Gerard et al. (2023) note, these challenges underscore the responsibilities and emotional demands of caregiving; however, this reference should be verified for direct relevance to parental home care.

Emergent Theme 2: Anchors of Resilience

This emergent theme reflects how parents of children with congenital heart disease in palliative care develop resilience while navigating the emotional and practical challenges of caring for their child at home. It highlights how maintaining hope, receiving family support, relying on spiritual beliefs, and gradually accepting their child's condition help parents cope with uncertainty and emotional distress. This theme matters because it shows how resilience strengthens through positive thinking, supportive relationships, and faith amid the challenges of pediatric palliative care (Felipe-Dimog et al., 2025).

The cluster theme Maintaining Positivity Amid Uncertainty highlights parents' determination to remain hopeful despite fears about their child's condition and future. Family-Centered Supportive Therapy and Spiritual Surrender emphasizes the role of family encouragement, shared caregiving, prayer, and faith in helping parents endure difficult circumstances. Meanwhile, Embracing Acceptance and Emotional Adaptation illustrates how parents gradually acknowledge their situation and develop coping strategies to continue providing care. Together, these cluster themes reveal how hope, family support, and spirituality serve as essential sources of strength in sustaining parental resilience throughout the palliative care journey (Tumulak et al., 2025)

Cluster Theme 2.1 Maintaining Positivity Amid Uncertainty

This cluster theme reflects how parents of children with congenital heart disease in palliative care strive to remain hopeful despite fears, emotional distress, and uncertainty about their child's future. It highlights their determination to maintain a positive outlook, manage stressful situations, and continue providing care despite financial difficulties and the unpredictable nature of their child's condition. This experience demonstrates how optimism and perseverance serve as important coping strategies that strengthen parental resilience throughout the palliative care journey. The participants expressed this cluster through these statements:

> Having a positive mindset and refusing to give up help me face every challenge in caring for my child. (Participant 1 Transcript 7 Line 16-17)
>
> I learned what the healthcare team taught us and keep a positive mindset that we can manage whatever comes (Participant 5 Transcript 9 Line 139-140)
>
> I learned that being patient and positive helps me continue caring for my child even when I feel tired. (Participant 9 Transcript 8 Line 238-239)

The participants' narratives reveal that maintaining a positive mindset and persevering through challenges are essential coping strategies in caring for children with congenital heart disease under palliative care. Their determination to remain hopeful, practice patience, and follow healthcare providers' guidance reflects their efforts to manage uncertainty and caregiving exhaustion. These findings highlight how optimism and perseverance strengthen parental resilience, enabling parents to continue providing care despite emotional and physical challenges. This is consistent with Lin et al. (2024), who emphasized the importance of positive psychological well-being in the experiences of parents caring for children with congenital heart disease.

Cluster Theme 2.2. Family-Centered Supportive Therapy and Spiritual Surrender

This cluster theme reflects how parents draw emotional strength from family support, prayer, and faith in God while caring for children with congenital heart defects under palliative care. Family encouragement and shared caregiving responsibilities help parents manage emotional distress and caregiving demands, while spiritual surrender provides hope, comfort, and strength amid uncertainty. These experiences emphasize the importance of familial connectedness and spiritual beliefs in strengthening parental resilience and sustaining their commitment to their child's care (Chang et al., 2024).

The participants expressed this cluster through these statements:

> My faith in God, prayer, and the support of my family gives me the strength to keep caring for my child despite the hardships.
>
> (Participant 1 Transcript 6 Line 14-15)
>
> I talk to my family about my worries because their support helps me feel better. (Participant 4 Transcript 8 Line 109-110)
>
> Prayer, deep faith in God, and my commitment to working hard give me the courage to care for my child. (Participant 10 Transcript 6 Line 261-262)

The participants' narratives reveal that family support, prayer, and faith in God serve as essential sources of emotional strength in caring for children with congenital heart defects under palliative care. Sharing worries with family members provides comfort, while spiritual beliefs help parents maintain hope and courage amid uncertainty. These experiences emphasize how familial connectedness and spirituality strengthen parental resilience and support continued caregiving despite emotional challenges; Miquel et al. (2024) explored the role of spirituality, religious beliefs, and relationships in helping parents cope with caring for children receiving palliative care.

Cluster Theme 2.3 Embracing Acceptance and Emotional Adaptation

This cluster theme reflects how parents gradually accept their child's diagnosis and adjust emotionally to the realities of providing palliative care. Parents experience sadness, fear, helplessness, and uncertainty regarding their child's condition and survival, yet they learn to manage these emotions through patience, positive coping strategies, and focusing on their child's immediate needs. These findings emphasize the importance of psychological adjustment and acceptance in sustaining parental well-being while caring for

a child with a life-limiting condition (Engel et al., 2023). The participants expressed this cluster through the following statements:

> I felt like my world stopped, but I slowly learned to accept the situation and become stronger for my child. (Participant 1 Transcript 5 Line 12-13)
>
> At first, I did not understand what I was feeling, but now I am slowly learning to accept our reality. (Participant 3 Transcript 3 Line 65-66)
>
> The hardest part is accepting my child's condition while continuing to hope and do everything I can to make her comfortable (Participant 4 Transcript 4 Line 101-102)

Emergent Theme 3: Transformative Caregiving

The third emergent theme highlights how parents caring for children with congenital heart defects post hospital-based palliative care gradually develop greater acceptance, emotional strength, adaptability, and confidence as they navigate the challenges of caregiving. Through these experiences, parents cultivate resilience and develop new perspectives that strengthen their commitment to their child's well-being despite uncertainty, financial limitations, and ongoing caregiving demands. This emergent theme is further explained through three cluster themes: Adapting to Caregiving Responsibilities, Reorganizing Daily Life Around the Child's Care Needs, and Mobilizing Financial and Community Resources. Together, these cluster themes illustrate how parents acquire practical caregiving skills, restructure their daily lives, and seek external assistance to sustain their child's care at home (Alfraheed et al., 2026).

Cluster Theme 3.1 Adapting to Caregiving Responsibilities

The theme describes how parents gradually learn to assume caregiving responsibilities after hospital-based palliative care. As they transition from a hospital setting to home-based palliative care, parents become more familiar with administering medications, monitoring their child's breathing and physical condition, managing feeding and bathing, and recognizing changes that may require medical attention.

The participants expressed this cluster through these statements:

> I needed to understand every detail from operating the oxygen equipment at the bedside to preparing their medications correctly.

(Participant 1 Transcript 9 Line 26-27)

> I made sure to master every detail of her medication routine and learned to recognize the exact physical signs. (Participant 3 Transcript 9 Line 85-86)
>
> The things I learned from the nurses are very useful at home.
> (Participant 6 Transcript 9 Line 162)

These statements reveal that parents gradually develop the knowledge, practical skills, and confidence necessary to provide appropriate care for their children at home. Learning to operate oxygen equipment, administer medications correctly, and recognize changes in the child's physical condition helps parents become more prepared to manage their child's healthcare needs after hospital discharge. Guidance from healthcare professionals and adequate discharge preparation are essential in helping parents manage complex caregiving responsibilities and ensure a safer transition from hospital to home (Thacker et al., 2025).

Cluster Theme 3.2 Reorganizing Daily Life Around the Child's Care Needs

This theme highlights how parents adjust their daily routines, family roles, and personal priorities to accommodate their child's ongoing medical and caregiving needs. Parents may sacrifice personal time, modify work schedules, and share responsibilities with family members to ensure consistent care for their child. These adjustments demonstrate how caring for a child with CHD requires families to reorganize

their everyday lives while balancing caregiving demands and personal responsibilities (Voss et al., 2025). The following verbatim has been expressed:

> My daily routine has really changed. Things are different now compared to before. Since my child was diagnosed with CHD and placed under palliative care, my child has become my priority. (Participant 1 Transcript 2 Line 4-6)
>
> My life has changed because I can no longer work regularly. Most of my time is spent caring for my child (Participant 4 Transcript 2 Line 96-97)
>
> My life became more tiring because I must wake up early, give my child her medicines, feed her, and monitor her condition (Participant 7 Transcript 2 Line 170-171)

These accounts show how parents gradually reorganize their daily lives to prioritize the care and comfort of their children with congenital heart defects receiving home-based palliative care. Parents adjust their routines, modify employment arrangements, and redistribute family responsibilities to accommodate medication schedules, feeding, and continuous monitoring. These changes demonstrate how caring for a child with CHD affects not only the parents' daily activities but also the functioning and priorities of the entire family. This highlights the importance of family support, flexibility, and resilience in helping parents manage the ongoing demands of caregiving while maintaining their commitment to their child's well-being (Nemes et al., 2025)

Cluster Theme 3.3: Mobilizing Financial and Community Resources

This theme describes how parents actively seek financial assistance and community support to address the costs of caring for children with congenital heart defects receiving home-based palliative care. Facing limited financial resources and expenses for medications, medical supplies, and possible surgical procedures, parents explore government assistance programs, charitable organizations, and community resources to meet their child's healthcare needs. The following verbatim has been expressed:

> Even when the situation is difficult, keep fighting and ask for help because people and programs are willing to help.

(P2 Transcript 10 Line 56-57)

> Do not be shy to approach government programs, organizations, and support groups that help children with heart conditions. (P5 Transcript 10 Line 135-136)
>
> Parents, you should not hesitate to ask for help from government agencies, charitable organizations, and community groups because some programs provide free surgery, medicines, and financial assistance. (Participant 8 Transcript 10 Line 215-217)

These statements show that parents continue to fight despite financial difficulties by seeking help from government programs, charitable organizations, and community groups. The researcher understood that asking for assistance takes courage, especially when parents worry about their children's health and treatment. Their experiences show that financial support can help ease their burdens and give them hope in providing the care their children need (Delaney et al., 2024).

This cluster theme reflects parents' determination to find ways to support their children despite limited financial resources. The researcher realized that parents' willingness to approach healthcare providers and support organizations shows their love, hope, and commitment to their children. Their experiences emphasize the importance of accessible assistance and supportive communities in helping families face the challenges of caring for children with heart conditions (Moro et al., 2025).

Moreover, the participants' statements reveal that caring for a child with a heart condition involves not only emotional and financial struggles but also the courage to seek help. The researcher recognized that

behind every effort to find assistance is a parent who wants to give their child a better chance at life. Despite their difficulties, parents continue to persevere and explore available resources, demonstrating that seeking help is an important part of caring for their children. These experiences highlight the value of financial assistance and social support in helping parents continue their caregiving journey (Nadarajah et al., 2024).

Conclusion and Recommendation

The study concludes that parents caring for children with congenital heart defects (CHDs) following hospital-based palliative care experience emotional, physical, financial, and caregiving challenges. Despite these difficulties, parents demonstrate resilience through family support, spiritual faith, hope, and positive coping strategies. Their experiences emphasize the importance of caregiver education, psychosocial support, family-centered nursing care, and continuous healthcare services to strengthen parental preparedness and improve family well-being. It is recommended that future researchers explore similar experiences in other healthcare settings and rural communities, include the perspectives of healthcare professionals and other family members, and utilize quantitative, mixed-methods, and longitudinal approaches to further understand caregiver burden, resilience, and support needs. Future studies may also evaluate the effectiveness of caregiver education, psychosocial interventions, discharge planning, and family-centered palliative care to develop more effective healthcare services and support programs for families caring for children with CHDs.

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