

# Experiences and well-being strategies of caregivers of children with congenital heart disease

Vivências e estratégias de bem-estar de cuidadores de crianças com cardiopatia congênita

Experiencias y estrategias de bienestar de cuidadores de niños con cardiopatía congénita

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## Abstract

**Objective:** To understand caregivers' perceptions and experiences regarding congenital heart disease and the well-being strategies adopted during the children's illness process.

**Methods:** A qualitative, descriptive, and exploratory study was conducted with 24 caregivers of children with congenital heart disease at a public hospital in Santa Catarina, Brazil. Data were collected through a semi-structured questionnaire, including sociodemographic and clinical information, and analyzed using Minayo's Thematic Analysis.

**Results:** Four topics emerged: (1) Initial impact with the diagnosis: difficulties and overcoming them; (2) Challenges in self-care; (3) Breaking with preconceived notions and changes in plans and goals; (4) Well-being strategies.

**Conclusion:** Caregivers experience intense emotional impact and overload, but seek balance through love for their child, family support, spirituality, and self-care. Clear guidance, religiosity, leisure activities, and self-care were identified as strategies that support caregivers' well-being.

## Resumo

**Objetivo:** Compreender a percepção e vivência dos cuidadores sobre a cardiopatia congênita e as estratégias de bem-estar adotadas no processo de adoecimento da criança.

**Métodos:** Estudo qualitativo, descritivo e exploratório, realizado com 24 cuidadores de crianças com cardiopatia congênita em um hospital público de Santa Catarina. Os dados foram coletados por meio de questionário semiestruturado, incluindo informações sociodemográficas e clínicas, e analisados com base na Análise Temática de Minayo.

**Resultados:** Emergiram quatro temas: (1) Impacto inicial com o diagnóstico: dificuldades e superações; (2) Desafios no autocuidado; (3) Quebra do imaginário e mudanças nos planos e metas; (4) Estratégias de bem-estar.

**Conclusão:** Os cuidadores vivenciam intenso impacto emocional e sobrecarga, mas buscam equilíbrio por meio do amor ao filho, do apoio familiar, da espiritualidade e do autocuidado. Orientações claras, religiosidade, lazer e autocuidado foram identificados como estratégias que favorecem o bem-estar.

## Resumen

**Objetivo:** Comprender la percepción y experiencia de los cuidadores sobre la cardiopatía congénita y las estrategias de bienestar adoptadas durante el proceso de enfermedad del niño.

**Métodos:** Estudio cualitativo, descriptivo y exploratorio con 24 cuidadores de niños con cardiopatía congénita en un hospital público de Santa Catarina, Brasil. Los datos se recolectaron mediante un cuestionario semiestructurado, con información sociodemográfica y clínica, y se analizaron usando el Análisis Temático de Minayo.

**Resultados:** Surgieron cuatro temas: (1) Impacto inicial con el diagnóstico: dificultades y superación de las mismas; (2) Desafíos en el autocuidado; (3) Ruptura con nociones preconcebidas y cambios en planes y metas; (4) Estrategias de bienestar.

**Conclusión:** Los cuidadores experimentan un intenso impacto emocional y sobrecarga, pero buscan el equilibrio a través del amor por su hijo, el apoyo familiar, la espiritualidad y el autocuidado. La orientación clara, el autocuidado, el ocio y la religiosidad favorecen el bienestar.

## Keywords

Congenital heart disease; Caregivers; Pediatric Nursing; Pediatrics

## Descritores

Cardiopatias congênita; Cuidadores; Enfermagem pediátrica; Pediatria

## Descriptores

Cardiopatia congénita; Cuidadores; Enfermería Pediátrica; Pediatria

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## Data availability:

The study data are available in this article.

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## Introduction

Congenital heart disease is a structural and/or functional malformation of the heart, with an incidence in Brazil of 9.4 per 1,000 live births, corresponding to 30% of congenital malformations.<sup>(1)</sup> Advances in health technologies have allowed for early diagnosis, reducing complications and mortality, and increasing patient survival. The increase in life expectancy of children brings new challenges to caregivers, who face difficulties in coping with the situation.<sup>(2)</sup>

Congenital heart disease diagnosis is emotionally impactful for caregivers, bringing feelings of pain, distress, uncertainty, doubt, loss, and lack of control.<sup>(3)</sup> The presence of this malformation changes the family organization, affecting caregivers' personal and professional lives. The family needs to adapt to the new circumstances and adopt a new lifestyle.<sup>(4,5)</sup> In addition, the demands associated with congenital heart disease can negatively impact caregivers' well-being.<sup>(2)</sup>

A study<sup>(6)</sup> indicated that obtaining clear information about heart disease brings a feeling of relief. Other studies have shown that activities such as religious practices, integrative health practices, family support and self-care are related to maintaining well-being.<sup>(6,7,8,9)</sup>

In this context, nurses, by establishing direct contact with children and their caregivers, play an important role in the care of children with congenital heart disease. This proximity facilitates the identification of the family's needs and allows for guidance on specific care. Nursing professionals can contribute to quality care, promoting the physical, emotional, and psychological well-being of both the child and their family.<sup>(4)</sup>

A scoping review that sought to identify research priorities in pediatrics highlights concerns about communication between the child, family, and healthcare professionals, in order to meet these individuals' needs.<sup>(10)</sup>

This perspective aligns with the concept of advocacy in health, which can occur at different levels: individual, with actions directed at a specific audience; community, with an impact on the collective landscape; organizational, promoting administrative changes; and governmental, contributing to the formulation of legislation and public policies.<sup>(11)</sup> Healthcare professionals' work in this field is vital for the

advancement of contemporary care. The Society of Pediatric Nurses highlights advocacy as an essential competency of nurses working in the care of neonates, children and adolescents, reinforcing the profession's ethical and social commitment. In this context, the study of family life with a child with heart disease also constitutes an advocacy practice, giving voice to families' experiences and needs, supporting clinical, educational, and political actions in accordance with reality.<sup>(12)</sup>

In this way, investigations conducted in developing countries such as Brazil can enrich the global debate by revealing unique coping strategies, support networks, and care practices in resource-limited contexts. Furthermore, by valuing caregivers' perspective, this type of study strengthens the international body of knowledge on pediatric and family care in situations of chronic illness.

Thus, this study aimed to understand caregivers' experiences in relation to congenital heart disease and the well-being strategies adopted during the child's illness process.

## Methods

This is a qualitative, descriptive study, whose report followed the COnsolidated criteria for REporting Qualitative research guidelines.<sup>(13)</sup> Data collection took place between June and July 2024 at a public pediatric hospital in northern Santa Catarina, focused on the cardiology sector. This hospital was founded in 2008 and has 106 qualified beds.

The sample was a convenience sample. Twenty-four caregivers of children with congenital heart disease participated in the study. Those included were caregivers with a congenital heart disease diagnosis older than six months, hospitalized in the cardiology unit during the data collection phase, who were the child's primary caregiver, and aged 18 years or older. Caregivers with cognitive limitations that hindered verbal expression were excluded from the study. There were no dropouts during the research.

Invitations to participate in the research were made personally by the researcher, an undergraduate student in nursing, under the guidance of PhD-level nursing professors from the program and after train-

ing to conduct the interviews. The interviewer worked as a nursing technician at the research site and also completed a six-month supervised internship during data collection. The supervisor had experience in research and practice in pediatric nursing. A bond was established between the researcher and participants during the supervised internship months, allowing participants to learn about the study's objectives and the researcher's interest in the topic, stemming from her prior experience with the subject.

The interviews were conducted in a private room with chairs, ensuring privacy and freedom from interference. Data were collected using a semi-structured interview with guiding questions. Sociodemographic and clinical data were gathered to characterize participants. The interviews were audio-recorded, transcribed in full, and stored on a Google Drive storage platform. The interviews were concluded when data saturation was identified, as no new elements emerged from participants' statements.<sup>(14)</sup>

The data were analyzed following the stages proposed by Minayo for thematic analysis, which includes the following stages: data collection; literal transcription; contextualization; material organization into an analytical instrument; and identification of contextual units, core meanings, and topics.<sup>(15,16)</sup>

Coding was created through detailed reading and interpretation of discourses, resulting in four thematic categories. The decision was made not to use a coding tree or software. The analysis stage involved exhaustive and manual reading of the interviews, as well as transcription of the questions and answers into a table for better visualization. Afterwards, the data were grouped based on the questions and answers in tables for better visualization. Similar meanings were grouped into similar topics, forming core meanings, which gave rise to four categories. There was no feedback of results to participants.

The study was authorized by the *Hospital Regional Hans Dieter Schmidt/SES/SC* Research Ethics Committee (Opinion 6.868.385 and Certificate of Presentation for Ethical Consideration 80067124.4.0000.5363). All participants signed the Informed Consent Form. Anonymity was preserved through the use of fictitious names, in this case, flower names, in accordance with Resolution 466/12 of the Brazilian National Health Council.

## Results

The sample consisted of 24 caregivers of children with congenital heart disease hospitalized in the cardiology department of a hospital in northern Santa Catarina. Ten (41.6%) participants reside in the municipality, while 14 (58.4%) live in cities that have the municipality as a cardiology referral center. Caregivers' ages ranged from 21 to 63 years, with a mean of 36 years. Regarding gender, two (8%) of the caregivers are male, and 22 (92%) are female. Concerning occupation, five (20.8%) dedicate themselves exclusively to childcare and housework, and 19 (78.2%) are in the formal job market. Children's ages ranged from 6 months to 11 years, with an average age of approximately 3 years; 15 (58.3%) were younger than 2 years; and nine (37.9%) were older than 2 years. Furthermore, 11 (45.8%) children were male, and 13 (54.2%) were female.

Based on the analysis of participants' statements, four categories emerged: 1) Initial impact with the diagnosis: difficulties and overcoming them; (2) Challenges in self-care; (3) Breakdown of preconceived notions and changes in plans and goals; (4) Well-being strategies.

### Initial impact with the diagnosis: difficulties and overcoming them

Through participants' statements, it became evident that the discovery of heart disease generates emotional difficulties from the moment of diagnosis, reflecting in feelings such as fear and anxiety in the face of the unknown.

*"Horrible. It feels like I was punched in the face without even being hit". (Bromeliad)*

*In addition to the above, the statements revealed that access to clear information about heart disease stands out as a potential benefit, contributing to alleviating the emotional difficulties faced by caregivers.*

*"We didn't know much about heart disease, so we didn't have much information. Until we found out what it really was, what needed to be done, whether it was serious or not, a lot of worry arose". (Princess Flower)*

*"But seeking knowledge about his illness was a crucial point. But the most important thing was trusting the professionals who are taking care of him, and people*

*give us a lot of confidence. So, we feel more at ease because of that". (Cyclamen)*

*"And also, nowadays I understand more. So, I end up being calmer. Because I know more... so, nowadays, I'm much calmer compared to the beginning". (Tulip)*

## Challenges in self-care

Among the challenges caregivers reported, they cited prioritizing childcare to the detriment of their own needs, including hygiene, sleep, and leisure.

*"When you have children, you already shift a bit to the reality of taking better care of the child, but because of the heart condition, you end up putting that aside more... we had several plans... we end up neglecting ourselves because of this". (Cyclamen)*

*"I think taking care of myself right now, I'm not very focused on. I'm more worried about taking care of João right now". (Trumpet Tree)*

## Breakdown of preconceived notions and changes in plans and goals

The statements also highlight the shattering of the idealized, imaginary child, changing the family's short, medium, and long-term plans.

*"Because you plan one thing for your child, but then you have to recalculate the route, medications, depending on their development, whether they will develop or not, whether I'll put them in a more reserved school, one that doesn't have much commotion, there's all that". (Violet)*

*"For leisure, we want to, but we don't go out because we're afraid he'll catch the flu or some respiratory problem that could worsen his heart condition. We don't go out". (Allamanda)*

## Well-being strategies

The statements indicate that, despite the challenges, participants find motivation to maintain their physi-

cal and mental well-being for themselves, their families, and especially for a child with heart disease. Caregivers emphasize the importance of their support networks, mainly composed of family members, highlighting the help of parents, in-laws, siblings, friends, as well as therapists and teachers, who offer emotional and practical support.

*"She. She is my fuel. I need to be okay because she needs me so much and I need her so much. She is my everything". (Princess Earring)*

*"I have a lot of support. I have my family, I have therapists, teachers. Family is extremely important". (Hibiscus)*

*"I have a support network in my entire family, parents, in-laws, siblings, friends... when we are here, they are always asking me. They take him, go out to distract him... and always encouraging us. Saying that everything will be alright, supporting us". (Azalea)*

Daily tasks and financial assistance are also cited as support offered by family members, highlighting the essential role of the family in the care and well-being of children and caregivers, being considered the main support network.

*"My support network is quite strong, it comes from my family, who take care of the other child so I can be with her". (Daisy)*

There is also recognition of the need to balance their various responsibilities, with the help of their partners and children's parents, to cope with the circumstances.

*"And to take care of her, I manage. I'm a homemaker, a mother, a businesswoman, a woman... I have a house, a shop, and I even help my husband bake bread, but he helps me take care of her". (Princess Earring)*

Caregivers of children with heart disease utilize various forms of emotional support to cope with the situation. They seek solace and energy through spirituality, such as prayer, attending church, listening to meditations, and practices like reflexology, Reiki, apometry, and positivity. These statements highlight the value of emotional and spiritual support methods

in managing stress associated with caring for a child with a serious condition.

*“Going to church, I try to find more ways to give myself strength and help myself... to give myself strength, balance”. (Pansy)*

*“The only thing I’m doing, that’s recharging my batteries, is listening to Catholic preaching... it makes me have positive thoughts. That she will be healed... that this little heart will get better”. (Violet)*

*“But I meditate, I pray, I do Reiki, apometry, so I apply myself and I do a lot of therapy, experiences with nature”. (Orchid)*

Other strategies mentioned relate to caregivers’ individual time, including activities without the child present, such as self-care practices like washing hair and doing nails, physical activities like weight training, Zumba, and Muay Thai, and leisure activities like going out with friends, watching movies, walking the dog, listening to music, and taking keyboard lessons.

*“I take some time to do my nails, wash my hair, take a shower, eat calmly. Maybe watch a movie, to try to relax. I like working, being in agriculture, in the countryside”. (Princess Flower)*

*“I try to distract myself a lot. We have a group of friends that we’re always with... going for walks, having fun. There’s also time just for me and my husband”. (Azalea)*

*“So, one of the things I do is work out. It’s an hour and a half where I don’t think about anything. That’s what I do for myself”. (Princess Earring)*

Participants also reported seeking professional treatment, mentioning therapy with psychologists and psychiatric consultations.

*“It’s about going to see a psychologist, a psychiatrist, I have everything. I’m going to see them, because otherwise we all start to go a little crazy”. (Heliconia)*

## Discussion

A congenital heart disease diagnosis generates emotional difficulties, such as pain, uncertainty, doubt,

stress, fear, and anxiety, due to its rarity and complexity, impacting caregivers’ well-being.<sup>(3,4)</sup> This impact is reflected in participants’ statements, which express a feeling of pessimism, fear, and uncertainty regarding the diagnosis, revealing the shock and emotional disorganization that mark the beginning of the care journey. This moment of rupture, as the literature points out, represents the transition from caring for an idealized imaginary child to caring for a child with a chronic illness, requiring emotional reorganization and a redefinition of expectations.<sup>(3,5,6)</sup>

This study showed that access to clear and concise information alleviates the emotional difficulties faced, in line with previously published studies.<sup>(6,17)</sup> The results showed that participants reported greater tranquility and confidence after receiving information and clarifications about heart disease and its treatment from healthcare professionals, reinforcing evidence that knowledge is essential in coping with the disease, as it contributes to reducing caregiver anxiety.<sup>(4,6)</sup> Furthermore, these studies indicate that effective communication between the health team and the family fosters a bond of trust, demonstrating that caregivers value healthcare professionals’ empathy and compassion.<sup>(4,6)</sup> This aspect further reinforces the importance of listening and communication as instruments at the individual level of advocacy in nursing.<sup>(11,12)</sup>

Following the initial shock of diagnosis, caregivers reported facing significant changes in their routine due to the specific needs of a child with heart disease, such as medication administration, fragile immunity, and restrictions on social activities, which persist throughout children’s development. Similarly, a study with Dutch families highlights the need to consider heart disease when planning activities due to a child’s specific needs, such as medication use, intolerance to physical exertion, and the need to be near hospital facilities.<sup>(5)</sup> This set of daily changes highlights the overlap between technical care and emotional care, creating a daily routine permeated by the tension between control and affection, a common characteristic of families living with chronic childhood illnesses.

The research showed that caregivers face changing expectations in their lifestyles, often reassessing priorities in their careers and personal lives, prioritizing jobs with alternative hours, working from home, and changes in family planning. Analogously to the

aforementioned study, in which caregivers began to value jobs with flexible hours or working from home, the concern with obtaining a good health plan and defining the number of children reflects a trend of reorganizing professional and family life to reconcile the caregiving demands.<sup>(3,18)</sup> This re-signification demonstrates the adaptive capacity of families, transforming initial distress into new ways of existing and living with a child's condition.

The changes in routine caused by heart disease reported by caregivers impose a physical and mental burden that goes beyond the common difficulties associated with the arrival of a new family member. This data is consistent with research carried out in Brazil with caregivers of children with heart disease which revealed that they also presented a moderate level of burden, reinforcing the fact that caring for children with congenital heart disease contributes to this burden on caregivers and emphasizing that continuous care contributes to physical and emotional exhaustion.<sup>(13)</sup> However, it is observed that, even in the face of this burden, caregivers mobilize coping and self-care strategies that act as resilience mechanisms.

As strategies for maintaining well-being, the family emerged as a source of inspiration to overcome the challenges imposed by heart disease, with particular emphasis on the love directed towards the child with heart disease. The results are consistent with the findings of a study carried out in 2022, which demonstrated that the unconditional love of parents for their children encourages reflection on the priorities of parenthood and expectations, motivating caregivers to face the challenges and adapt their routine according to a child's condition.<sup>(6)</sup> The affective bond therefore appears as a central element in the routine reconstruction.

Sharing care and family support was reported as the main support network and an important tool for maintaining emotional balance. Similarly, a study conducted in the United Kingdom showed that family support, especially from spouses, was essential in helping to balance reactions during crises.<sup>(6)</sup> This data reinforces the importance of support networks in reducing overload, promoting a sense of belonging and emotional security, and maintaining hope.

Regarding emotional balance, spirituality and faith were considered a form of support for caregivers, who reported seeking hope and strength. Interna-

tional research supports this perspective, highlighting that positive spiritual activities are associated with improved perception of health and coping capacity in the face of chronic disease.<sup>(7,8,19)</sup> Thus, faith functions as a symbolic and emotional resource, offering meaning to the experience of distress and promoting psychic balance, and can be used as a functional and positive tool by healthcare professionals to promote well-being.

In addition to spirituality, the practice of physical activities was mentioned as a self-care and well-being strategy, aiming to provide caregivers with time for themselves and bringing balance between the demands of childcare and their own personal well-being.<sup>(9,19)</sup>

Furthermore, the practice of physical activity has been identified as a strategy for managing well-being, as cited in a study that pointed to improvements in the health and psychological well-being of caregivers of adults, associating the regular practice of physical exercise with a reduction in stress, anxiety, and depression, contributing to the strengthening of emotional resilience in the face of the difficulties of caregiving.<sup>(20)</sup> In this regard, self-care emerges as a practice of resistance, allowing caregivers to remain present and healthy to fulfill their caregiving role.

The transversality among categories shows that coping with congenital heart disease is a dynamic and interconnected process: the initial impact of the diagnosis, the challenges in self-care, the shattering of expectations and goals, and well-being strategies do not follow linearly, but are intertwined in the trajectory of family adaptation. Distress, the reorganization of routines, and the recovery of internal and social resources make up a continuous cycle of vulnerability and strengthening. This interpretation reinforces that caring for a child with heart disease involves the subjective reconstruction of the family, which seeks meaning, balance, and hope.

In this context, family support and spirituality emerge as essential sources of emotional support. In addition, self-care practices, leisure, and physical activities contribute to the well-being of caregivers of children with congenital heart disease.

Understanding these experiences and coping strategies supports nurses' decision-making in caring for this specific population. Strategies such as including guidance on self-care and well-being activities during outpatient consultations, or the creation of

support groups among caregivers in primary care, can contribute to emotional strengthening and reduced burden. Thus, the study reinforces the nurse's role as an advocate, promoting family-centered care, supporting caregiver autonomy, and working towards the formulation of more humane practices integrated into the life context of these families.

As a limitation, this study collected information at a single point in time during hospitalization, without tracking whether caregivers' perceptions evolved over time as they adapted to their lived reality.

It is recommended that future studies explore in greater depth the strategies for maintaining well-being for caregivers of children with heart disease, aiming to develop effective approaches to support these caregivers.

## Conclusion

This study revealed that a congenital heart disease diagnosis generates feelings of fear and anxiety, negatively affecting caregivers' well-being and emotional balance. The initial impact of diagnosis creates emotional difficulties and shatters the image of a perfect child, creating a new reality of arduous and exhausting care that also leads to changes in plans and goals for the future due to different routines, family planning, the search for medical assistance, and specific care for the child, such as medication, fragile immunity, and hospitalizations.

In this context, caregivers face challenges in their self-care, prioritizing the care of children over themselves. To balance these demands, caregivers seek well-being strategies such as family support, spirituality, self-care practices, leisure, and access to clear information.

## Contributions

Marcelino CF, Almeida CS, Marcelino CF, Almeida CS, and Rocha PFA declare that they contributed to study conception. Marcelino CF, Almeida CS, and Rocha PFA declare that they contributed to data collection. Marcelino CF, Almeida CS, and Rocha PFA declare that they contributed to data analysis and interpreta-

tion. Marcelino CF, Almeida CS, and Rocha PFA declare that they contributed to the discussion of results. Marcelino CF, Almeida CS, Rocha PF, Aires LC, Cruz YC, and Januario EM declare that they contributed to manuscript drafting and/or critical revision. Marcelino CF, Almeida CS, Rocha PFA, Aires LC, Cruz YC, and Januario EM declare that they approved the final version to be published.

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