



Original Article

The Quality of Life and Perceived Level of Stress among Mothers of Children with Congenital Heart Disease, in Sri Lanka

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Abstract

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Introduction: Congenital Heart Disease (CHD) is the most common among all congenital defects, with Asia reporting the highest prevalence. The experience of having a child with CHD can induce stress levels and significantly compromise the quality of life (QOL) of the parents.

Objective: To determine the quality of life and perceived level of stress among mothers of children with congenital heart diseases, in Sri Lanka.

Methodology: A descriptive cross-sectional study was conducted among randomly selected 75 mothers who sought treatment for a child with CHD at the cardiology clinic of Lady Ridgeway Hospital for Children, Sri Lanka. The QOL was measured using the Brief Version of the World Health Organization Quality of Life (WHOQOL-BREF) scale, while the level of stress was measured using the Perceived Stress Scale (PSS). Data were analysed using both descriptive and inferential statistics via IBM SPSS version 25. Ethical approval was obtained from the Ethics Review Committee of KIU (KIU/ERC/19/42).

Results: Among the participants, most of the mothers were Sinhalese (n=64, 85%) and Buddhists (n=55, 73%). Nearly half of the respondents (n=39, 52%) had education up to senior secondary level (G.C.E. O/L). Most of the participants were married (n=66, 88%) and unemployed (n=43, 57%). Only 29% (n=22) reported their QOL was at a good level, and 41% (n=31) were neither satisfied nor dissatisfied with their general health. Also, 67% of them (n=50) experienced moderate perceived stress. Further, the physical health domain (p≤0.001), psychological domain (p=0.004), social relationship domain (p≤0.001) and environment domain (p=0.001) of QOL were significantly associated with perceived stress levels.

Conclusion: Most mothers of children with CHD exhibited poor QOL and experienced high levels of perceived stress. Perceived stress demonstrates a significant association with physical, psychological, social relationships, and environmental QOL domains. In that context, interventions aimed at enhancing QOL and mitigating stress levels should be implemented for mothers of children with CHD.

Keywords: Children, Congenital heart diseases, Mothers, Perceived stress, Quality of life

Introduction

Congenital heart diseases (CHD) are among the most common types of birth defects, contributing to almost one-third of all major congenital abnormalities. There has been a substantial increase in the birth prevalence of children with CHD, particularly in Asia, reporting the highest CHD birth prevalence reaching 9.3 per 1,000 live births (Van et al., 2011) and more than 250,000 deaths have occurred due to CHD globally in 2017 (Kassebaum et al., 2020). According to the reports by Wickramasinghe et al. (2001), over 3,000 children are born with CHD in Sri Lanka each year. Consequently, the birth of a child with CHD poses a distressing experience for many parents. In such circumstances, both fathers and mothers respond differently, while showing varying levels of anxiety. However, it is often observed that mothers are more profoundly affected by their child's illnesses than fathers (Yildiz, Celebioglu & Olgun, 2009). As a result, mothers may experience both physical and mental challenges (Farzad, 2018). It is believed that mothers of children with CHD have a poor quality of life (QOL) in comparison to mothers of children with other illnesses (Sileshi & Tefera, 2017). For instance, a study by Uzark and Jones (2003) found that approximately 1 in 5 parents, particularly mothers of children with CHD, expressed clinically significant levels of stress.

The QOL can be defined as the multidimensional concept that encompasses various aspects of an individual's well-being and overall satisfaction with life, such as physical, psychological, social, and environmental components. In this interpretation, physical health pertains to the condition of the body, psychological health encompasses mental and emotional well-being, social health involves relationships and community ties, whilst environmental well-being involves harmony between individuals and their surroundings (Martinez et al., 2012).

According to the definition provided by the World Health Organization (WHO, 1997), QOL is the perception of an individual's position

in life within the culture and value systems of their surroundings. These mainly include goals, expectations, and standards. Not surprisingly, the QOL of parents of children with CHD is influenced by various factors, primarily including the clinical status of the child, psychological status, social support (Arafa et al., 2008), educational level, marital status, number of children, income, and type of heart disease (Warnakulasooriya & Kasturiaratchi, 2020).

The responsibility of caring for a child with CHD significantly affects the mother's QOL and stress level. This provides insights on QOL and stress experienced by parents which can be utilised to improve the well-being of parents with such children. The gap in the literature in the context of Sri Lanka underscores the need for the study. Therefore, the purpose of the study is to determine the QOL and perceived level of stress among mothers of children with CHD at Lady Ridgeway Hospital, Sri Lanka.

Methodology

A descriptive cross-sectional study was conducted among 75 mothers of children with CHD who attended the cardiology clinic in Lady Ridgeway Hospital (LRH), Colombo, Sri Lanka, from August 2019 to November 2019. Ethical approval was obtained from both Ethics Review Committees (ERC) of KIU (KIU/ERC/19/42) and LRH, Sri Lanka. Study participants were interviewed by trained investigators using an interviewer-administered questionnaire. The questionnaire was pre-tested with 10 mothers of children with CHD who attended the cardiology clinic in LRH. Based on the feedback received, the pre-tested questionnaire was modified. Pregnant mothers and mothers with critically ill children were excluded from the study. The socio-demographic characteristics evaluated in the questionnaire included age, race, religion, education, marital status, and economic status.

QOL was assessed using the World Health Organization Quality of Life Brief Version (WHOQOL-BREF). The WHOQOL-BREF

is a shorter version of the original instrument, designed for use in large research studies or clinical trials. It comprises 26 items that measure broad domains including physical health, psychological health, social relationships, and environment (WHO, 1996). A validated version of WHOQOL-BREF for the Sri Lankan context was used in this study (Cronbach's alpha > 0.7 for all domains) (Kumarapeli, Seneviratne & Wijeyaratne, 2006). The QOL scores were rated on a 0-100 scale, with scores equal to or less than 45 considered low, scores between 46-65 considered moderate, and scores above 65 indicating high QOL. The 1st two questions addressed the participants' perceived overall QOL and general health.

Perceived Stress Scale (PSS) is a valid and reliable instrument (Berardi et al., 2021) to assess the level of stress (Chan & La Greca, 2020). Scores ranging from 0-13, 14-26, and 27- 40 were respectively considered as low, moderate, and high perceived stress (Cohen et al., 1983). Data analysis was performed using appropriate descriptive and inferential statistics. The association between perceived stress and levels of the four domains of QOL was evaluated using the chi-square test. Statistical significance was at p-value < 0.05. Data were analysed using IBM Statistical Package for Social Science (SPSS 25) version 25.

Results

Demographic characteristics of the participants

The majority of the mothers were Sinhala (n=64, 85%) and Buddhists (n=55, 73%). Nearly, half (n=39, 52%) of the respondents were educated up to senior secondary level (G.C.E. O/L). A significant proportion of the participants were married (n=66, 88%) and the majority were unemployed (n=43, 57%) (Table 1).

Table 1: Demographic characteristics of the participants

| Characteristics | Frequency | Percentage % |
|------------------------|-----------|--------------|
| Age | | |
| 19 ≤ | 1 | 1.3 |
| 20 – 29 | 8 | 10.7 |
| 30 – 34 | 27 | 36.0 |
| 35 – 39 | 21 | 28.0 |
| 40 ≥ | 18 | 24.0 |
| Religion | | |
| Buddhist | 55 | 73.3 |
| Catholic | 12 | 16.0 |
| Hindu | 8 | 10.7 |
| Race | | |
| Sinhala | 64 | 85.7 |
| Tamil | 11 | 14.3 |
| Marital Status | | |
| Married | 66 | 88.0 |
| Unmarried | 9 | 12.0 |
| Education Level | | |
| Up to O/L | 39 | 52.0 |
| Up to A/L | 30 | 40.0 |
| Diploma | 4 | 5.3 |
| Degree | 1 | 1.3 |
| Postgraduate | 1 | 1.3 |
| Working Status | | |
| Unemployed | 43 | 57.3 |
| Self-employed | 10 | 13.3 |
| Privet sector employee | 12 | 16.0 |
| Government employee | 10 | 13.3 |
| Health Problems | | |
| Yes | 11 | 14.7 |
| No | 64 | 85.3 |

The quality of life of the participants.

Out of all the participants, only 29% of the mothers (n=22) reported that their QOL was good. Additionally, less than half of the mothers (n=35, 47%) expressed satisfaction with their overall health. Table 2 displays the perceived overall QOL and general health of the mothers of children with CHD.

Domains of quality of life of the participants

Approximately, half of the mothers had good physical health (n=41, 55%) and social relationships (n=32, 43%). Only 32% (n=24) of mothers of children with CHD reported good psychological health, and 28% (n=21) reported good environmental health (Table 2).

Table 2: QOL and general health

| Characteristics | Frequency | Percentage (%) |
|------------------------------------|-----------|----------------|
| Perceived Overall QOL | | |
| Very poor | 3 | 4.0 |
| Poor | 20 | 26.7 |
| Neither poor nor good | 30 | 40.0 |
| Good | 17 | 22.7 |
| Very good | 5 | 6.6 |
| Perceived General Health | | |
| Very dissatisfied | 1 | 1.3 |
| Dissatisfied | 8 | 10.7 |
| Neither satisfied nor dissatisfied | 31 | 41.3 |
| Satisfied | 27 | 36.0 |
| Very satisfied | 8 | 10.7 |
| Physical health domain | | |
| Poor | 12 | 16.0 |
| Average | 22 | 29.3 |
| Good | 41 | 54.7 |
| Psychological health domain | | |
| Poor | 23 | 30.7 |
| Average | 28 | 37.3 |
| Good | 24 | 32.0 |
| Social relationships domain | | |
| Poor | 15 | 20.0 |
| Average | 28 | 37.3 |
| Good | 32 | 42.7 |
| Environment domain | | |
| Poor | 27 | 36.0 |
| Average | 27 | 36.0 |
| Good | 21 | 28.0 |

Level of stress of mothers of children with CHD

Level of stress of mothers of children with CHD

The findings revealed that 67% (n=50) of the mothers of children with CHD experienced moderate perceived stress. Figure 1 shows the distribution of stress levels among these mothers.

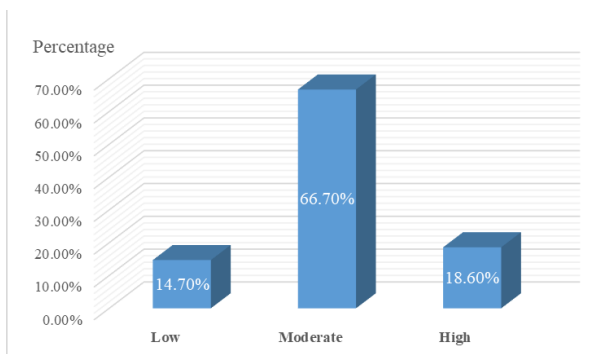


Figure 1: Level of stress of mothers of children with CHD

A significant association was observed between stress levels and QOL among mothers of children with CHD in the physical health domain ($p \leq 0.001$), psychological domain ($p = 0.004$), social relationship domain ($p \leq 0.001$), and environmental domain ($p = 0.004$).

Discussion

Mothers of children with CHD in this study exhibited poor QOL and experienced high levels of perceived stress. A significant portion of the participants did not indicate an overall satisfactory level of QOL, aligning with findings from studies in both developed countries like Switzerland (Ehrler et al., 2023) and developing countries like Africa (Sileshi & Tefera, 2017a) and Iran (Sanayeh et al., 2021). This indicates that caring for a child with CHD has a distinct impact on parental well-being, likely due to emotional stress stemming from concerns about their child's health, frequent hospital visits, surgeries, and fear of the future. The responsibilities associated with caregiving, particularly for a child with complex medical requirements, can result in both physical and emotional exhaustion.

Consistent with the findings of this study, a report from Egypt by Arafa et al. (2008) revealed a notable decline in QOL among parents of children diagnosed with CHD compared to those with minor illnesses (Arafa et al., 2008). Similarly, Swedish parents of children with CHD reported lower QOL in comparison to parents of children with other diseases (Lawoko & Soares, 2003).

The preliminary finding of this study highlights a significant association between the participants' stress levels and various sub-domains of QOL: physical, psychological, social, and environmental. Confirming the findings of our study Parsaei et al. (2020) reported that stress affects different aspects of an individual's quality of life. For instance, Hachenberger et al. (2023) mentioned the correlation between stress and physical health issues such as cardiovascular problems, weakened immune systems, and gastrointestinal disorders, which can impact QOL. Stress is also closely linked to, mental health, potentially leading to conditions like anxiety and depression, which significantly impact an individual's ability to function and maintain relationships (Ribeiro et al., 2018).

Further, stress can lead to social withdrawal and a decreased ability to cope with social situations, negatively impacting an individual's social support network, crucial for overall QOL (Schneiderman et al., 2005).

A study conducted in Sweden revealed that mothers, in comparison to fathers, reported lower QOL scores across social, physical, and psychological aspects (Lawoko & Soares, 2003) when caring for children with heart diseases. This evidence highlights the fact that mothers bear a higher burden of responsibilities and caregiving tasks for sick children, contributing to lower health well-being. However, research suggests that the psychological stress and diminished QOL of mothers may persist long after the child has received corrective treatment (Ehrler et al., 2023). Given these circumstances, increasing awareness about disease management and treatment options among these mothers could

potentially reduce stress and promote well-being and healthcare professionals also play a crucial role in providing comprehensive and supportive care for the entire family, especially mothers, both before and after their child undergoes treatment for CHD.

Conclusion

The current study highlights that the mothers of children with CHD experience strain on their psychological, social, and environmental well-being, although physical health remains relatively unaffected. These four aspects of QOL are linked with perceived stress levels. Additionally, providing access to support networks and resources can bolster mothers' resilience and coping strategies, fostering a sense of community and shared experiences that can alleviate stress and promote overall well-being.

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