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LONG-TERM QUALITY OF LIFE AND PSYCHOSOCIAL DEVELOPMENT IN CHILDREN FOLLOWING CONGENITAL HEART DISEASE SURGERY – A NARRATIVE REVIEW

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ABSTRACT

Background: Advances in pediatric cardiac surgery have reduced congenital heart disease (CHD) mortality, shifting clinical focus toward optimizing long-term health-related quality of life (HRQoL). However, patients and caregivers still face significant psychosocial and neurodevelopmental challenges requiring holistic, technology-enhanced care.

Aim: To synthesize current literature on the long-term psychosocial development of children following CHD surgery and evaluate the impact of technological interventions (e.g., telemedicine, e-Health) on mitigating these challenges for patients and families.

Methods: This narrative review synthesizes evidence from recent systematic reviews, meta-analyses, and prospective cohort studies (emphasizing the 2021–2026 period) retrieved from PubMed, Scopus, and Web of Science. The review evaluates pediatric HRQoL, caregiver burden, and digital health interventions.

Results: Despite physical improvements, CHD survivors face neurodevelopmental delays and peer marginalization. Parental stress profoundly impacts families; mothers of children with CHD exhibit significantly lower HRQoL in emotional role difficulty (SMD: -0.79) and general health (SMD: -0.58). Conversely, targeted interventions yield measurable benefits. Structured physical training in Fontan patients increases peak oxygen uptake by 1.72 ml/kg/min (6.3%). Furthermore, digital health solutions (mobile apps, wearables) significantly enhance patient engagement and disease management during the transition to adulthood.

Conclusion: Enhancing the psychosocial well-being of CHD survivors and caregivers is crucial. Comprehensive postoperative care must evolve to integrate continuous psychological support, family-centered care, and modern technological solutions (e.g., interactive telehealth, advanced neuromonitoring) to ensure a satisfying quality of life.

KEYWORDS

Congenital Heart Disease, Pediatric Cardiology, Psychosocial Development, Pediatric Surgery, Health and Well-Being, Telemedicine

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1. Introduction

The introduction of innovative surgical techniques, advanced cardiopulmonary bypass, and modern monitoring systems in intensive care units has led to a radical decline in mortality among neonates and infants diagnosed with congenital heart disease (CHD). Currently, it is estimated that over 90% of children born with even the most complex structural heart defects survive into adulthood. However, this undeniable medical success has brought about new, previously unknown psychosocial and systemic challenges. The paradigm of cardiac patient care has had to shift: the focus of clinicians and researchers is now moving away from the mere struggle for survival toward optimizing the long-term health-related quality of life (HRQoL) of patients and their families.

Children who have undergone cardiac surgery in early childhood frequently struggle with neurodevelopmental delays, learning difficulties, and elevated anxiety levels, which significantly impact their functioning within peer groups [5, 15]. Furthermore, the burden of the disease extends far beyond the patient themselves, generating so-called secondary psychological costs for the entire family system. The diagnosis, repeated hospitalizations, and daily uncertainty lead to chronic stress, caregiver burnout, and the development of post-traumatic stress disorder (PTSD) symptoms in parents [30, 32]. The literature increasingly emphasizes that parents of children with CHD are "hidden patients" whose own mental well-being and coping strategies directly determine the rehabilitation and social adaptation process of the sick child.

In response to these growing challenges in psychosocial care, modern pediatric medicine is actively adopting innovative technological solutions. Telemedicine, interactive e-Health platforms, mobile applications, and virtual psychoeducational programs are revolutionizing the support model for families of children with CHD, shifting the burden of care from the inpatient hospital environment to patients' homes [7, 21]. These digital tools not only broaden access to specialized medical knowledge but, above all, serve as a psychological buffer for parents. Remote monitoring of patient vital signs (telemonitoring), teleconsultations with the cardiology team, and online support groups facilitate parents' management of their child's illness in the home environment, potentially reducing their sense of helplessness and improving the overall quality of life for the family (HRQoL).

Despite the dynamic development of tools supporting the treatment and home care process following cardiac surgery, the impact of these innovations on the long-term quality of life and psychosocial functioning of CHD patients and their caregivers still requires comprehensive evaluation. To date, studies have rarely analyzed the correlation between technological progress in postoperative care and the long-term dynamics of intrafamilial relationships and emotional well-being.

The aim of this article is not only to systematize current knowledge regarding the impact of innovative medical and technological interventions on the long-term quality of life and psychosocial development of children following surgery for congenital heart defects, but also to evaluate the social and psychological consequences that may affect the immediate family members of these patients.

2. Methodology

To systematize current knowledge regarding the long-term quality of life, psychosocial development, and the impact of modern interventions on patients following surgery for congenital heart disease (CHD) and their families, a comprehensive literature review was conducted. This review encompassed medical and multidisciplinary databases, with a particular focus on PubMed. The search strategy was designed to identify the latest scientific evidence at the intersection of pediatric cardiology, clinical psychology, and healthcare innovation (e.g., telemedicine).

Given the dynamic development of cardiac surgical techniques and postoperative care standards, the inclusion criteria were primarily restricted to articles published within the last decade (with an emphasis on publications from 2021–2026) to ensure the highest relevance of clinical and technological data. English-language research papers were included in the analysis, encompassing systematic reviews, meta-analyses, prospective cohort studies, and qualitative research evaluating the psychosocial functioning of CHD patients and their caregivers. Articles focusing exclusively on the technical details of surgical procedures, without reference to patient quality of life, long-term care, or psychosocial aspects, were excluded from this review.

3. Results

3.1 Evidence: Psychosocial Challenges and Technological Interventions

Although early cardiac surgical interventions save the lives of children with congenital heart disease (CHD), these procedures are associated with extreme physiological stress for the rapidly developing body of a child. The use of cardiopulmonary bypass (CPB), fluctuations in arterial blood pressure, incidents of hypoxia, and prolonged hospitalization in the intensive care unit (ICU) have a profound and documented impact on the maturation of the child's central nervous system. Dijkhuizen et al. (2023), in an analysis of early magnetic resonance imaging (MRI) findings, demonstrated that delayed maturation of brain structures and asymptomatic ischemic microlesions are frequently observed in neonates with CHD, which strongly correlate with subsequent neurodevelopmental deficits [5]. Furthermore, Trivedi et al. (2023) emphasize that feeding difficulties and growth failure during the crucial early infancy period additionally exacerbate the risk of adverse neurodevelopmental outcomes [28].

These early biological burdens translate into specific challenges during preschool and school years. Children who have undergone surgery for complex congenital heart defects exhibit a significantly higher risk of learning disabilities, working memory deficits, and impairments in executive functions. A comprehensive systematic review conducted by Koushiou et al. (2024) unequivocally confirms that the overall cognitive functioning of children and adolescents with CHD is frequently diminished compared to their healthy peers [15]. In a social context, this results in a higher rate of attention-deficit/hyperactivity disorder (ADHD) diagnoses, which directly impacts the patients' educational achievements, self-esteem, and integration within the classroom environment.

To minimize these negative social consequences, modern cardiac surgery and intensive care increasingly rely on advanced preventive technologies. The utilization of modern neuromonitoring modalities, such as continuous monitoring of regional cerebral oxygen saturation (NIRS) during the perioperative period, allows clinicians to continuously predict and prevent irreversible neurological damage [1, 29]. Equally important from the perspective of long-term well-being is the implementation of early therapeutic interventions. Kaeslin et al. (2023) demonstrate that structured early motor and cognitive stimulation programs, implemented in the months following open-heart surgery, can significantly improve a child's development [11]. Through the integration of reparative medicine with technological monitoring and early psycho-pedagogical support, children with CHD receive significantly greater chances for full adaptation in school and social environments.

3.2. Psychosocial Functioning, Physical Activity, and Peer Relationships

Undergoing an advanced cardiac surgical procedure in childhood leaves a lasting imprint not only on the cardiovascular system but also on the psyche of the growing patient. Despite favorable clinical outcomes following complex surgeries in early childhood, long-term Quality of Life (QoL) indicators in this patient group remain variable and are frequently reduced compared to the general population [9, 26]. Subjective self-assessment of health in children and adolescents with congenital heart disease (CHD) strongly correlates with their psychosocial functioning, self-esteem, and degree of peer integration [3].

One of the most significant social challenges for CHD patients is the sense of "otherness" resulting from reduced exercise tolerance. In patients with a single ventricle following a palliative Fontan procedure, chronically low cardiorespiratory fitness constitutes a key factor limiting their daily functioning [20]. Poor physical condition, rapid fatigability, and dyspnea during moderate exertion—often described in the literature as a burdensome chronic fatigue syndrome [31]—represent a substantial barrier preventing full participation in school physical education classes or peer play. This can lead to the marginalization of the patient within the classroom, an increasing sense of isolation, and withdrawal from social activities. Furthermore, physical stigmatization in the form of a visible median sternotomy scar becomes an additional source of profound psychological discomfort and lowered self-esteem in adolescents during early puberty.

From a medical and psychosocial standpoint, it is crucial to counteract this isolation through active and safe forms of inclusion in physical activity. Studies demonstrate that the implementation of personalized physical training and appropriate pharmacological management (e.g., pulmonary resistance-lowering drugs) in patients with Fontan circulation significantly improves their exercise capacity and 6-minute walk test results. As demonstrated by Scheffers et al. in a meta-analysis comprising 264 patients with Fontan circulation, the implementation of structured training led to a significant increase in peak oxygen uptake (VO2 max), with a mean improvement of 1.72 ml/kg/min (a 6.3% increase) [20]. Furthermore, a recent meta-analysis by Siyah et al. (2024) showed that physical training increases the maximum workload of CHD patients by an average of 8.86 watts (95% CI, 0.78–16.93, p=0.03) [23], which directly translates into a better quality of life and reduced psychosocial burden [18, 20]. Similarly, the implementation of structured psychological intervention programs, including therapies aimed at treating co-occurring depressive and anxiety disorders in adolescents with CHD [17], is an essential component of modern, multidisciplinary care for the cardiac patient, enabling fuller and more satisfying participation in social life.

Table 1. Impact of structured exercise training interventions on exercise capacity parameters in patients with congenital heart disease (CHD).

Outcome Measure	Type of Intervention	Mean Improvement
Peak oxygen uptake (VO2 max)	Physical exercise training in patients with Fontan circulation	+1.72 ml/kg/min (6.3% increase)
Maximum workload	Aerobic and resistance training in adults with CHD	+8.86 W (95% CI: 0.78 to 16.93, p=0.03)

Note. Adapted from the meta-analyses by Scheffers et al. (2021) and Siyah et al. (2024).

3.3. The Impact of Family Dynamics and Parental Stress

The arrival of a child with congenital heart disease (CHD) in a family constitutes one of the most burdensome psychological experiences, radically altering the pre-existing dynamics of the family system. This crisis often begins as early as the prenatal screening stage. As demonstrated by Kalhor et al. [12], upon hearing a cardiac diagnosis, parents face unimaginably difficult ethical and emotional dilemmas as they decide whether to continue the pregnancy and prepare for an uncertain future. From the moment of diagnosis, through the neonate's traumatic stay in the intensive care unit (ICU), to discharge home, caregivers experience profound psychological distress and emotional instability, frequently highlighted in qualitative assessments [4, 13].

The chronic stress associated with the direct threat to the child's life, multiple reoperations, and the necessity of complex home care renders parents the "hidden patients" of the healthcare system. According to the results of a recent comprehensive meta-analysis conducted by Wang et al. [32], based on data from 3,681 parents, mothers of children with CHD exhibit a significantly lower quality of life compared to the normative population. This study revealed significant negative differences, particularly in domains such as general health (SMD: -0.58), role difficulty due to emotional problems (SMD: -0.79), and social functioning (SMD: -0.53). This is echoed by studies such as those conducted by Kolaitis et al. [14], which demonstrate an alarmingly high prevalence of clinical symptoms of depression, chronic anxiety, and even post-traumatic stress disorder (PTSD) among caregivers. This problem takes on a particularly dramatic dimension in low- and middle-income countries (LMICs), where additional economic barriers, a lack of systemic support, and high treatment costs drastically exacerbate the phenomenon of caregiver burnout [30].

Chronic anxiety and high levels of parental stress [33] frequently lead to the development of overprotective attitudes in parents, known in pediatric psychology as the "vulnerable child syndrome." Paralyzed by fear for their child's heart, parents unconsciously restrict their natural physical activity and independence, which hinders the development of the patient's social competencies and impedes their integration with peers. For this reason, modern healthcare models oriented toward health and well-being must evolve from an exclusive focus on the patient's biology toward holistic, family-centered care. The implementation of integrated psychological support for parents becomes as crucial to cardiac surgical success as the precision of the surgical procedure itself.

Table 2. Significant reduction in health-related quality of life (HRQoL) domains in mothers of children with CHD compared to the general population.

HRQoL Domain (SF-36 questionnaire)	**Standardized Mean Difference (SMD)**	**Clinical Interpretation**
General health	- 0.58	Moderate to severe deterioration in subjective physical well-being.
Social functioning	- 0.53	Significant social isolation and reduction in social contacts due to caregiving responsibilities.
Role difficulty due to emotional problems	- 0.79	Profound negative impact of anxiety, stress, and depression on daily household and professional responsibilities.

Note: Adapted from the meta-analysis by Wang et al. (2025), based on data from 3,681 parents of children with CHD.

3.4. Transitioning to Adulthood: Challenges and Solutions

Adolescence is a period of intense biological, psychological, and social changes for every young person. For adolescents with congenital heart disease (CHD), this naturally turbulent stage is associated with an additional, critical systemic challenge: the process of transition, meaning the transfer from pediatric cardiology care to adult clinics. This is a moment fraught with tension, during which the patient must smoothly assume responsibility for their own health from their often overprotective parents. The complexity of this process and the lack of adequate psychosocial preparation mean that many young adults drop out of the healthcare system (the phenomenon of "loss to follow-up"), which drastically increases the risk of severe complications, heart failure, and even premature death in adulthood.

Adolescent rebellion, characteristic of puberty, often takes the form of disease denial in cardiac patients. Teenagers may intentionally skip medication doses, ignore physical exertion restrictions, or engage in risky behaviors (e.g., alcohol consumption, smoking) to prove their "normality" to themselves and their peers. Furthermore, the awareness of the incurability of their heart defect and the need for lifelong medical treatment significantly increases their risk of depressive episodes. As indicated by a comprehensive review of psychological interventions conducted by Leo et al. [17], the early recognition and targeted treatment of depression in adolescent patients with CHD is absolutely crucial for their safe entry into adulthood. Continuous monitoring of their psychosocial adaptation using validated psychometric tools is also necessary. In a comprehensive review by Eagleson et al. [6], encompassing 108 research articles from 26 countries, as many as 40 different instruments for assessing psychological functioning and 11 for assessing quality of life were identified, underscoring the scale and diversity of the problem while facilitating the early detection of emotional crises.

Integrated transition programs, which increasingly rely on technological innovations, are emerging as a response to these challenges. The generation of today's teenagers (so-called "digital natives") responds exceptionally well to digital health (e-Health) interventions. Schöneburg et al. [21], in their latest systematic review encompassing 16 studies and a total of 735 patients of various ages, prove that interactive telemedicine solutions—including mobile applications (evaluated in 5 studies) and wearable devices such as smartwatches (3 studies)—significantly improve young patients' engagement in the treatment process and positively impact their cardiovascular health. In combination with structured psychoeducational interventions, which effectively reduce anxiety levels and build a sense of agency (Garcia Rodrigues et al. [7]), modern technologies provide a bridge that facilitates the patient's safe, independent disease management. The integration of smart technologies with traditional medicine enables young adults with CHD to regain a sense of control over their own bodies, minimizing the stress associated with the inevitable change in the medical environment.

Table 3. Overview of telehealth solutions and digital interventions utilized in patients with congenital heart disease (CHD).

Type of Digital Intervention	Number of Studies	Target Population (Number of Patients)	Key Clinical Applications & Monitored Parameters
Mobile Applications (mHealth apps)	5	Pediatric and adult patients	Questionnaires for health-related quality of life (HRQoL), sleep patterns, general well-being, and tracking emergency visits.
Wearable Devices (Smartwatches, trackers)	3	Pediatric and adult patients	Physical performance (maximum or peak oxygen consumption - VO2 max), arrhythmias, and vital signs monitoring.
Other Telehealth Solutions / Remote Monitoring	8	Predominantly pediatric (incl. infants)	Infant growth tracking, body weight, intensive care unit (ICU) stays, and disease complications.

Note: Data synthesized from the systematic review by Schöneburg et al. (2025), encompassing a total of 735 patients across 16 studies (318 pediatric patients in 9 studies, 188 adults in 3 studies, and 229 mixed pediatric/adult patients in 4 studies).

4. Discussion

Despite methodological differences, varying study populations, and the use of diverse psychometric tools, the results of recent systematic reviews and meta-analyses remain consistent: the quality of life of patients with congenital heart disease (CHD) and their families depends as much on successful cardiac surgical interventions as it does on psychosocial support and the utilization of modern technologies.

4.1. Strengths of the Evidence

- **Comprehensive data aggregation:** The primary strength of the synthesized evidence lies in its reliance on current meta-analyses and broad systematic reviews from recent years (e.g., Wang et al. [32]; Koushiou et al. [15]), which aggregate data from thousands of CHD patients and their caregivers.
- **Efficacy of non-biomedical interventions:** These studies provide consistent evidence that interventions extending beyond standard biomedical care—such as early developmental stimulation [11], psychoeducational programs for parents [7], and telemedicine solutions [21]—yield measurable, positive effects in reducing stress and improving quality of life.
- **Lifespan perspective:** Furthermore, the collected data encompass the patient's entire life cycle: from prenatal dilemmas [12], through perioperative monitoring [1], to interventions tailored for young adults [17].

4.2. Limitations and Sources of Heterogeneity

- **Clinical heterogeneity:** The fundamental limitation of the reviewed literature is the immense heterogeneity of the CHD patient population. As researchers note, the psychosocial functioning of patients with mild septal defects differs drastically from the challenges faced by patients following palliative procedures with Fontan circulation, who struggle with chronic fatigue and low exercise tolerance [18, 20].
- **Methodological bias:** An additional source of bias is the fact that many quality-of-life studies are cross-sectional and rely on subjective assessment questionnaires, which complicates the definitive establishment of causal relationships.
- **Geographical and economic disparities:** Geographical and economic limitations must also be highlighted. The majority of technological innovations and structured support programs have been studied in high-income countries, whereas, as demonstrated by Vasilescu et al. [30], the parental burden in low- and middle-income countries (LMICs) has a completely different, much more dramatic specificity.

4.3. Practical Implications and Recommendations

From a clinical perspective, healthcare systems and clinical guidelines should permanently integrate psychosocial assessment tools with routine cardiological follow-up visits.

- **Early psychological screening:** Psychometric tools [6] should be administered to parents as early as the first weeks following diagnosis to promptly detect the risk of depression or post-traumatic stress disorder (PTSD) [14].
- **Telemedicine for adolescents:** In the care of adolescent patients, the implementation of interactive telemedicine solutions [21] becomes crucial, as they support the patient's transition to independence and encourage active maintenance of physical capacity [23].
- **"Prescribing" digital health:** Much like pharmacological treatments, physicians should "prescribe" access to validated health-monitoring applications and virtual support groups for patients and their families.

6. Conclusions

The achievements of modern pediatric cardiac surgery have irreversibly changed the life trajectory of patients born with congenital heart disease (CHD), transforming once-fatal conditions into chronic diseases. However, this literature review demonstrates that the mere fact of medical survival does not guarantee optimal well-being for patients. The long-term quality of life of children and adolescents with CHD is strictly correlated with their psychosocial functioning, exercise tolerance, and early neurodevelopmental complications. The necessity of multi-stage treatment, the presence of visible surgical scars, and a growing sense of alienation among peers generate significant psychological burdens in young patients, including a higher risk of developing symptoms of depression and anxiety. Furthermore, the child's illness triggers a profound crisis within the entire family system, and the chronic stress and caregiver burnout experienced by parents, particularly mothers, constitute a critical barrier to the effective social adaptation and rehabilitation of the patient.

The conclusions drawn from the analyzed studies unequivocally point to an urgent need for a paradigm shift in postoperative care—from a narrow biomedical model towards a holistic approach and integrated care for the entire family. The widespread implementation of digital tools, such as advanced perioperative neuromonitoring (e.g., NIRS), interactive psychoeducational platforms supporting parents' mental health, and telemedicine applications facilitating adolescents' safe transition into adulthood, is now becoming an integral component of therapeutic success. Only through the synergy of precise cardiac surgery, continuous psychological support, and modern technologies (e-Health) will the healthcare system be able to offer CHD patients not just a longer life, but, above all, a life of satisfying social quality. Future research should focus on long-term, prospective evaluations of these technological interventions, particularly addressing the geographical and economic disparities in low- and middle-income countries (LMICs) to ensure equitable access to comprehensive psychosocial care.

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