Cardiology in the Young

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Psychosocial impact of inherited arrhythmia syndromes on anxiety in paediatric patients and their families

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Original Article

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Abstract

Background: Inherited cardiac arrhythmias are life-threatening conditions associated with a high risk of sudden cardiac death. These diseases impose a substantial psychological burden. Parents experience heightened anxiety due to uncertainty, medical interventions, and risk of adverse events. However, limited research has examined anxiety levels in affected individuals and their families. *Objective:* This study aimed to assess anxiety levels in children and adolescents diagnosed with inherited cardiac arrhythmias, specifically Long QT Syndrome and Catecholaminergic Polymorphic Ventricular Tachycardia, and to identify factors influencing anxiety in both patients and parents. *Methods:* A prospective, survey-based cohort study was conducted between June 2023 and June 2024, including 53 patients (0–18 years) diagnosed with inherited arrhythmias. Anxiety was assessed using the State-Trait Anxiety Inventory. Demographic and clinical variables, including disease type, invasive procedures, family history of sudden cardiac death, and parental education, were analysed. *Results:* Mothers exhibited the highest anxiety (STAI-T: 46.6 ± 10.6) while fathers had the lowest (37.3 ± 7.0). Catecholaminergic polymorphic ventricular tachycardia patients reported significantly higher anxiety (49.2 ± 7.7) than long QT syndrome patients (38.0 ± 7.0, $p < 0.01$). Children undergoing invasive procedures, particularly sympathetic denervation, had elevated anxiety (45.1 ± 8.2 vs. 36.5 ± 6.4, $p < 0.05$). Mothers of male children and those with a family history of sudden cardiac death had significantly higher anxiety ($p < 0.01$). *Conclusion:* Inherited arrhythmias significantly impact psychological well-being, with mothers experiencing the highest anxiety levels. Disease severity, invasive procedures, and family history of sudden cardiac death contribute to increased anxiety, emphasising the need for psychological support in managing these conditions.

Introduction

Inherited cardiac arrhythmias are life-threatening conditions that are closely associated with sudden cardiac death.[1] The increased need for invasive procedures and continuous medical treatment in children, combined with parents' sense of loss of control over their child's condition, may lead to elevated long-term family stress levels and affect family cohesion due to societal attitudes. Many parents experience significant distress when their child is first diagnosed, feeling helpless and fearful, which can result in excessive protectiveness and attachment, ultimately restricting the child's activities. This situation lowers the quality of life for both the child and their family.[2] Understanding the psychological impact of these diagnoses is crucial, as it can inform interventions that support both parents and children in coping with the challenges posed by inherited cardiac arrhythmias.

Studies assessing anxiety levels in patients diagnosed with channelopathies and their parents are limited. Due to their genetic nature and the risk of sudden cardiac death, these diseases represent a major source of anxiety for patients and their families.[3] Various studies have identified factors associated with anxiety levels in patients with channelopathies and their parents, including the unpredictable course of the disease, fear of sudden death, a family history of sudden death, and the presence of an implantable cardioverter-defibrillator. In addition, factors such as diagnosis at a young age, clinical uncertainty, high rates of implantable cardioverter-defibrillator therapy, and a family history of the disease have been associated with high anxiety levels.[4] Furthermore, patients following sudden cardiac death demonstrated significantly elevated levels of anxiety that negatively affect both physical and psychological recovery, ultimately reducing the overall quality of life.[5] These findings underscore the importance of addressing mental health concerns in this patient population, as effective psychological support may play a crucial role in improving both emotional well-being and treatment outcomes.

The aim of this study was to evaluate levels of anxiety in patients with inherited arrhythmias, which carry a high risk of mortality and adverse events, on affected children, adolescents, and their families, and to identify the factors contributing to this impact. Accordingly, the study seeks to develop management plans that can effectively address the needs of patients in the future.

Methods

Study design and ethical approval

This study was a survey-based, prospective cohort study conducted over a one-year period from June 2023 to June 2024. Patient recruitment was performed during outpatient clinic visits. Patients diagnosed with Long QT Syndrome or Catecholaminergic Polymorphic Ventricular Tachycardia who met the inclusion criteria were identified and invited to participate in the study. No financial compensation or incentives were provided for participation. After obtaining informed consent from the participants and their families, a face-to-face interview was conducted, and the specified assessment scales were administered. All questionnaires were administered face-to-face by a paediatrician, who at the time was not involved in the clinical care of the participants. This approach was selected to minimise potential authority bias. Participants and their caregivers were informed that participation was voluntary, responses would remain strictly confidential, and data would not affect their current or future medical care. Efforts were made to create a comfortable and non-judgemental setting to reduce the risk of social desirability bias during the assessment process. Ethical approval was obtained from the Local Ethics Committee (Approval Number: GO 23/613).

Inclusion and exclusion criteria

Patients previously diagnosed with a channelopathy and under follow-up, aged 0–18 years, without confirmed intellectual disability or concurrent psychiatric disorder were included in the study. For children aged 0–10 years, the anxiety scale was administered to parents, while for those aged 10–18 years, it was applied to both the patients and their parents.

Assessment tools and data collection

Disease information data form

A researcher-developed form was used to collect disease information, including demographic and clinical data. Medical records from the local automation system were reviewed to complete this form. This form inquired about the patient's age, gender, diagnosis, age at initial diagnosis, symptoms that led to diagnosis (asymptomatic, syncope, previous arrest, palpitations), history of recent events (syncope, intracardiac defibrillator implantation, history of implantable cardioverter-defibrillator therapy, history of arrest), presence of family members diagnosed with channelopathy, family history of sudden death and arrest, medical treatment, parental educational level (illiterate, primary-middle-high school graduate, or university graduate), consanguinity between parents, genetic test results, and history of invasive procedures (sympathectomy, implantable cardioverter-defibrillator implantation).

STAI anxiety scale

The State-Trait Anxiety Inventory adult version was used to assess anxiety levels. This scale consists of two separate self-report inventories that measure: State anxiety (STAI-S), temporary anxiety levels at a specific moment and trait anxiety (STAI-T), general anxiety levels over time. The state-trait anxiety inventory has demonstrated high reliability and validity. The STAI-T subscale consists of 20 statements assessing general anxiety levels, while the STAI-S subscale contains 20 statements evaluating anxiety at a given time. Each item is rated on a 4-point scale (not at all, somewhat, moderately, very much).[6] The total state-trait anxiety inventory score ranges from 20 to 80, categorised as follows; No or low anxiety (20–37), moderate anxiety (38–44), high anxiety (45–80).[7] The original state-trait anxiety inventory scale was first validated by Spielberger et al.[6] and later adapted into Turkish by Öner and Le Compte, with its reliability tested in various Turkish youth and adult populations.[8] Although the state-trait anxiety inventory-Children is typically recommended for younger populations, the adult version was selected to ensure consistency across the full age range. Prior to the study, the adult state-trait anxiety inventory was piloted in a small subset of participants aged 10–12 years, confirming the comprehensibility of the items for this group. Instructions were delivered with additional clarification as needed to support understanding.

Statistical analysis

A power analysis was performed prior to the study using data from Kobayashi et al. (2018),[9] which assessed anxiety in parents of children undergoing cardiac catheterisation. The primary outcome of the current study was the evaluation of state and trait anxiety levels (State-trait anxiety inventory scores) in patients with channelopathies and their parents. Based on a two-sided t-test comparing the sample mean to normative data, with an effect size of 0.5, alpha level of 0.05, and power of 0.90, the required sample size was calculated to be 44 patients. A total of 53 patients were ultimately included in the study.

Statistical analyses were performed using IBM® SPSS software, version 27.0. Descriptive analyses were performed. Categorical variables were presented as frequencies and percentages, and continuous variables were expressed as mean ± standard deviation or median (minimum–maximum), depending on their distribution. The normality of continuous variables was assessed using visual methods (histograms and probability plots) and analytical tests (Kolmogorov-Smirnov/Shapiro-Wilk tests). Categorical variables were compared using the Chi-square (χ^2) test or Fisher's exact test, as appropriate. Two independent groups were compared using Student's t-test (for normally distributed variables) or Mann-Whitney U test (for non-normally distributed variables). Three independent groups were compared using one-way ANOVA (for normally distributed data). Spearman's correlation test was used to assess relationships between at least one non-normally distributed continuous variable. A p-value <0.05 was considered statistically significant.

Results

Study population

A total of 93 individuals were approached for participation in the study; however, data were collected from 53 participants, as 40 individuals were excluded for the reasons outlined in Figure 1. The median age of these participants was 11 years, with an age range of 1 to 17 years. Among them, 56.6% were female, and 60.4% had parental consanguinity. The majority were diagnosed with long QT syndrome (84.9%), while 15.1% had catecholaminergic

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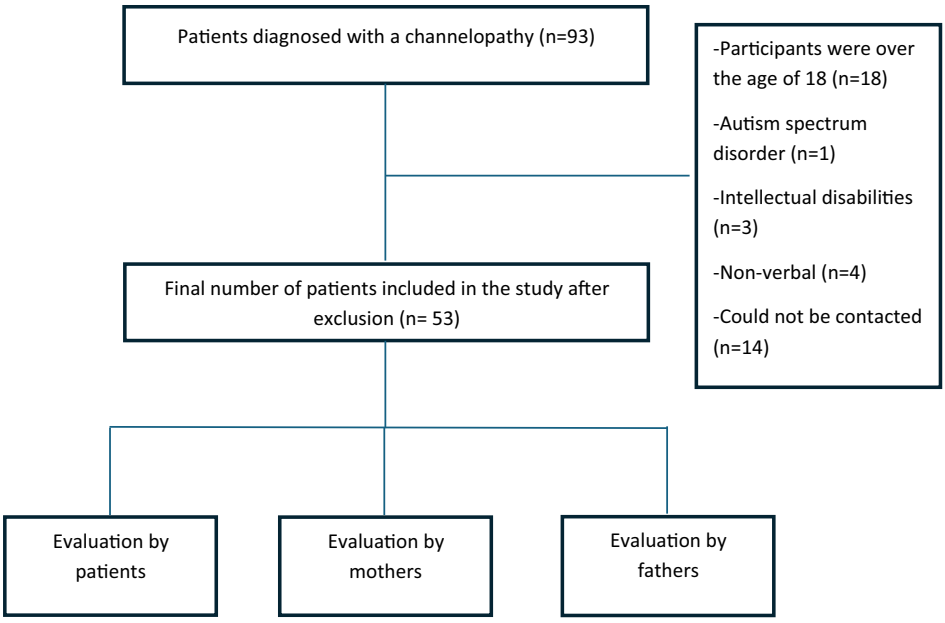

Figure 1. Flow chart of participants included in the study.

polymorphic ventricular tachycardia. The median age at diagnosis was 60 months (range: 0.1–192). A family history of channelopathy was present in 56.6%, and 67.9% had a family history of sudden death. Diagnosis was made in 47.2% of cases incidentally, while 41.5% presented with syncope, 9.4% with cardiac arrest, and 1.9% with palpitations. Invasive procedures were applied to 39.6% of the participants, including implantable cardioverter-defibrillator implantation (22.6%) and sympathectomy (24.5%). Among implantable cardioverter-defibrillator recipients, 6/12 (50.0%) received implantable cardioverter-defibrillator therapy. A history of cardiac arrest was noted in 11.3%. Regarding parental education, 38.3% of mothers and 57.7% of fathers were high school graduates, while university graduation rates were 8.5% for mothers and 11.5% for fathers. All patients included in the study were recommended medical treatment; however, three patients were considered non-adherent to the treatment.

STAI anxiety scale scores

The mean scores and standard deviations for state and trait anxiety are presented in Figure 2. As shown in the table, mothers exhibited the highest anxiety levels, while fathers had the lowest scores. Patients' anxiety levels were intermediate between the two parental groups.

Further categorisation of anxiety levels showed that a greater proportion of mothers had high trait anxiety (59.6%) compared to fathers (19.2%). The patient group exhibited moderate anxiety levels relative to their parents. Overall, mothers reported the highest trait anxiety, while fathers predominantly had low state and trait anxiety (Figure 3).

Parental education level and effect on STAI anxiety scale

The study revealed that among the participating parents, the most common level of education was high school graduation, although the proportion of those with a primary school education also holds significant weight. No statistically significant difference was identified in state anxiety scores based on mothers' educational levels ($p = 0.137$). However, a significant difference was observed in STAI-T ($p < 0.001$), with higher anxiety levels detected among mothers with primary or secondary education.

Effect of diagnosis on patients' STAI scores

The STAI-S score was found to be significantly lower in children diagnosed with long QT syndrome compared to those diagnosed with catecholaminergic polymorphic ventricular tachycardia (32 ± 5.2 vs. 38.5 ± 4.6; $p = 0.009$). Similarly, the STAI-T score was also lower in children with a long QT syndrome diagnosis than in those with catecholaminergic polymorphic ventricular tachycardia (38 ± 7 vs. 49.2 ± 7.7; $p = 0.002$).

Effect of invasive procedures on patients' STAI scores

The mean STAI-S and STAI-T scores were significantly higher in children with a history of invasive procedures compared to those without any interventions with a mean score of 35.9 ± 4.7 vs. 31.4 ± 5.6 ($p = 0.028$), and 45.1 ± 8.2 vs. 36.5 ± 6.4 ($p = 0.003$), respectively. The presence of implantable cardioverter-defibrillator implantation did not result in a statistically significant difference in either state ($p = 0.332$) or trait scores ($p = 0.141$). However, both scale scores were significantly higher in children who had undergone sympathectomy compared to those who had not ($p = 0.027$ and $p = 0.012$).

Effect of ICD therapy on patients' STAI scores

Evaluation of children's state-trait anxiety inventory test results revealed that the mean STAI-S score was 36.8 and the mean STAI -T score was 45.6 in patients who had received implantable cardioverter-defibrillator therapy. In contrast, these scores were measured as 32.6 and 39.12, respectively, in the group that had not received implantable cardioverter-defibrillator therapy. Statistical analysis revealed no significant difference between groups for STAI-S and STAI-T scores ($p > 0.05$).

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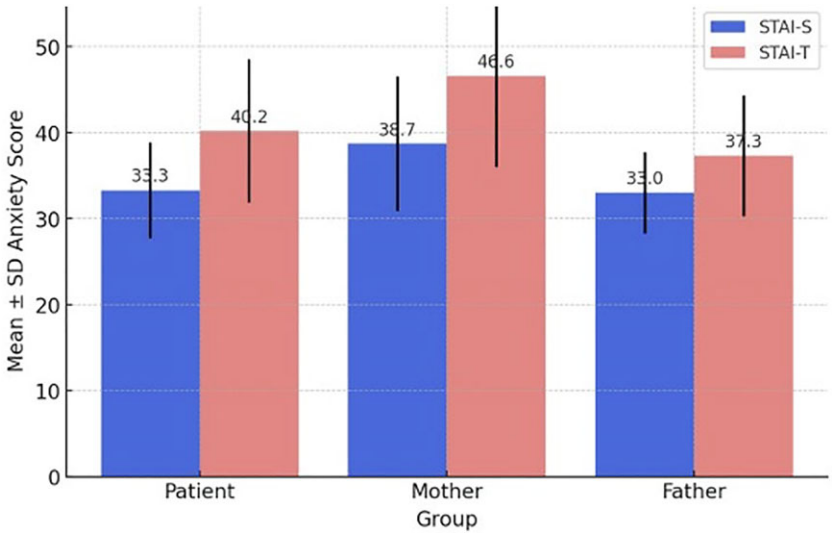

Figure 2. State and Trait Anxiety Scores by Group. Mean ± standard deviation (SD) scores on the State-Trait Anxiety Inventory (STAI) for each participant group. The STAI-State (STAI-S) scores are shown in blue, and the STAI-Trait (STAI-T) scores in red. Anxiety levels were assessed in three groups: patients with inherited arrhythmias ($n = 30$), mothers ($n = 47$), and fathers ($n = 26$).

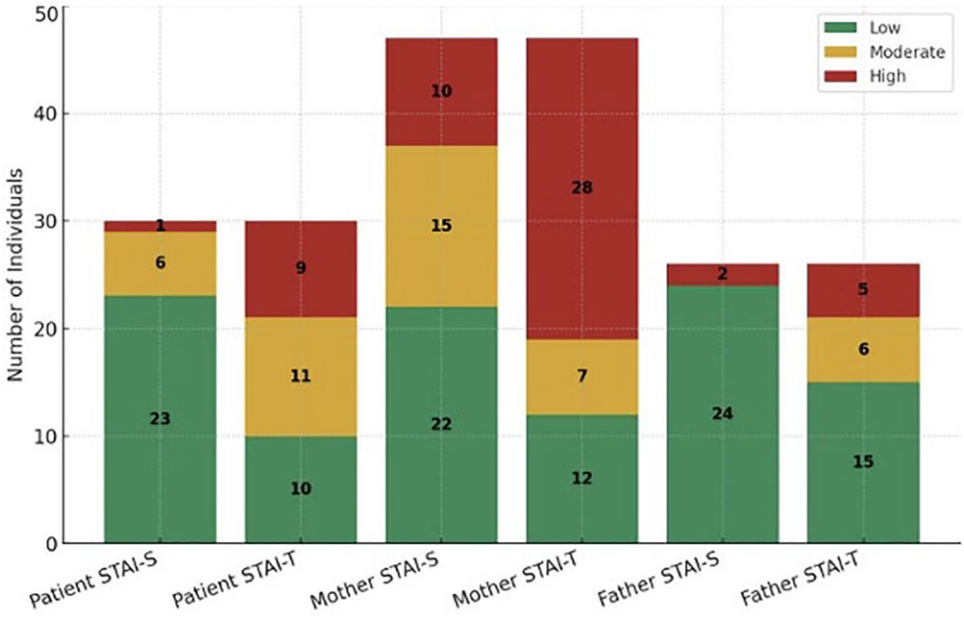

Figure 3. Distribution of State and Trait Anxiety Levels Among Patients and Parents. Distribution of anxiety levels by group, categorised according to State-Trait Anxiety Inventory (STAI) scores. The bar chart presents the number of individuals classified as having low (green), moderate (yellow), or high (red) anxiety levels across three participant groups: patients, mothers, and fathers. Each group is shown separately for state anxiety (STAI-S) and trait anxiety (STAI-T).

Factors affecting the STAI scores of parents

Statistical analyses identified two significant factors influencing mothers' scores on the state-trait anxiety inventory tests: having a male child and having a family history of sudden death. Mothers of male children had a significantly higher mean STAI-S score (42.2 ± 7.7) compared to mothers of female children (36.2 ± 7) ($p = 0.008$). Similarly, the mean STAI-T score was significantly higher in mothers of male children (51 ± 11.2) than in those of female children (43.4 ± 9.1) ($p = 0.014$). While the presence of a family history of sudden death did not result in a significant difference in STAI-S scores ($p = 0.203$), mothers with such a history had significantly higher STAI-T scores compared to those without (50.3 ± 9.1 vs. 39.6 ± 9.9; $p < 0.001$).

Although high state-trait anxiety inventory test scores were not observed among fathers overall, those with children diagnosed with catecholaminergic polymorphic ventricular tachycardia exhibited higher scores than those without such a diagnosis. Furthermore, analysis of the relationship between fathers' anxiety levels and various factors revealed that fathers of children diagnosed with long QT syndrome had significantly lower STAI-T compared to those of children diagnosed with catecholaminergic polymorphic ventricular tachycardia. (36.3 ± 6.8 vs. 45 ± 0; $p = 0.039$)

Discussion

Inherited arrhythmias, due to their potential to cause life-threatening events, lead to depression and anxiety both in patients and their family members. Throughout the course of the disease, patients not only bear the burden of anxiety related to the

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possibility of a life-threatening event but also face significant psychological stress caused by invasive procedures such as implantable cardioverter-defibrillator implantation and sympathetic denervation. In addition, the treatments received during the follow-up period after implantable cardioverter-defibrillator implantation and complications related to implantable cardioverter-defibrillator, as seen in all chronic diseases, contribute to a substantial psychological burden, manifesting as depression and anxiety.[10,11]

The condition of children with chronic illnesses directly affects their primary caregivers. However, among caregivers, mothers are more significantly impacted in terms of both anxiety and depression.[12] When the participating patients and their parents were assessed using the state-trait anxiety inventory, it was observed that mothers exhibited the highest levels of anxiety among caregivers. Furthermore, the anxiety levels of mothers were found to be even higher than those of the patients themselves. This phenomenon can be attributed to two key factors: first, the traditional role of mothers as the primary caregivers for their children, and second, the limited level of knowledge and comprehension that children have regarding their illness. It should be noted that a child's emotional function is associated with supportive care needs among parents,[13] and the emotional well-being of mothers caring for chronically ill children can significantly impact the psychological well-being of the children themselves. This reciprocal relationship may create a vicious cycle, which can be mitigated through appropriate support provided to caregivers, particularly mothers.

The clinical course of inherited arrhythmias varies significantly among patients. Some individuals remain asymptomatic for extended periods, with sudden cardiac death as their first manifestation. This leads to some patients being diagnosed only after experiencing a life-threatening event. In contrast, other patients are diagnosed through ECG screening during sports participation or through family screenings following the identification of an affected relative. Research has demonstrated that the diagnostic process itself is associated with a significant psychological impact.[3]

Among these conditions, patients diagnosed with catecholaminergic polymorphic ventricular tachycardia exhibit the most severe clinical presentations. Compared to long QT syndrome, catecholaminergic polymorphic ventricular tachycardia is associated with a higher incidence of cardiac events, with cardiac arrest or sudden death frequently occurring within the first two decades of life.[1] In this study, the patients diagnosed with catecholaminergic polymorphic ventricular tachycardia represented a smaller proportion of cases, due to low incidence compared to long QT syndrome. Nevertheless, the high scores observed in catecholaminergic polymorphic ventricular tachycardia patients and parents align with expectations given the severity of the disease course.

Although medical therapy and lifestyle modifications form the cornerstone of treatment for inherited arrhythmias, numerous invasive procedures are often required throughout the disease course. Among these, implantable cardioverter-defibrillator implantation is a primary intervention, frequently necessitating reintervention, especially in paediatric patients, due to complications. Additionally, concerns related to implantable cardioverter-defibrillator therapy represent a significant psychological burden. Several studies have assessed the impact of implantable cardioverter-defibrillator implantation and its associated treatments on both adult and paediatric patients using various methodologies.[14,15] In this study, while invasive procedures emerged as a key factor contributing to increased anxiety levels, implantable cardioverter-defibrillator implantation itself did not significantly elevate anxiety levels in patients. However, among the subgroup of children who received implantable cardioverter-defibrillator therapy, anxiety scores were higher compared to those who had not experienced such an event. This finding suggests that children may only become fully aware of the impact of implantable cardioverter-defibrillator therapy after undergoing treatment. Inappropriate implantable cardioverter-defibrillator therapy not only has detrimental effects on the myocardium and the potential to trigger electrical storms in inherited arrhythmias but is also associated with increased anxiety, as observed in this study. Therefore, these psychological effects should be considered in implantable cardioverter-defibrillator programming and management strategies.

Sympathetic denervation has become an increasingly preferred treatment option, particularly for patients with implantable cardioverter-defibrillators who experience recurrent appropriate implantable cardioverter-defibrillator therapies or for high-risk patients who are non-adherent to medical therapy prior to implantable cardioverter-defibrillator implantation.[16,17] In our facility, the procedure is performed laparoscopically and compared to surgical implantable cardioverter-defibrillator implantation, it is a less invasive intervention. However, the observed high STAI-T scores are likely not only due to the procedure itself but rather due to the high-risk characteristics of the patient group requiring the intervention, such as the necessity for implantable cardioverter-defibrillator therapy or a diagnosis of catecholaminergic polymorphic ventricular tachycardia.

For parents, managing the disease necessitates adapting to the constant threat of sudden death in their child. However, studies indicate that parents often struggle to fully acclimate to this reality and experience persistent anxiety regarding the potential onset of symptoms.[18] Given that these arrhythmias frequently follow an autosomal dominant inheritance pattern, a history of sudden death may already exist within the family prior to the child's diagnosis. Witnessing such an event, particularly within the immediate family, constitutes a profoundly distressing experience. As a result, both this study and the broader literature have established a strong association between parental psychological distress, including depression and anxiety, and the burden of the disease.[3,19]

The higher anxiety scores observed in parents of male children may be attributed to two primary factors. First, within Turkish society, male children are often regarded with greater cultural and familial significance. Second, male children, by nature, tend to exhibit higher levels of physical activity and engage more frequently in risk-prone behaviours, which may contribute to increased parental concern.[20]

This study has several limitations that should be acknowledged. First, the sample size was relatively small, particularly for subgroups such as catecholaminergic polymorphic ventricular tachycardia patients and fathers, which may limit the generalisability of the findings. Second, anxiety levels were assessed using the adult version of state-trait anxiety inventory, a widely used tool for measuring anxiety; however, self-reported measures may be subject to bias, such as social desirability or response tendencies. In addition, while the measure was piloted for age-appropriateness and found to be comprehensible, it may still present challenges related to language complexity and developmental variability in this younger subgroup. In children under 10 years of age, anxiety was assessed solely through parental report, which may not fully reflect the child's internal emotional state. This reliance on proxy reporting may have introduced bias or underestimation of

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subjective anxiety, particularly in younger participants unable to articulate their feelings. While anxiety was the primary psychological construct assessed in this study, other potentially relevant factors—such as socioeconomic status, parental occupation, cultural background, and comorbid psychiatric conditions (e.g. depression)—were not evaluated. These variables may influence or interact with anxiety symptoms and should be considered in future studies to provide a more comprehensive understanding of the psychological burden in this population. Additionally, the cross-sectional nature of the study precludes conclusions about causality or changes in anxiety over time. Future studies with larger, more diverse cohorts and longitudinal designs would be valuable in further exploring the psychological impact of inherited arrhythmias and identifying effective interventions.

Conclusion

The findings of this study highlight several important areas for future research and clinical practice. Inherited arrhythmias pose a substantial psychological burden on both patients and their families due to the unpredictable and potentially life-threatening nature of the disease. Patients often experience chronic anxiety—not only related to the risk of sudden cardiac death but also due to the necessity of invasive procedures. This psychological impact extends to caregivers, particularly mothers, who, in our study, demonstrated even higher levels of anxiety than the patients themselves.

A key contributor to this anxiety is the uncertainty experienced during the diagnostic process or following diagnosis. Although genetic testing may partially mitigate the uncertainty encountered during the diagnostic period, our findings also support the importance of early diagnosis through family screening, which may help reduce the need for emergency interventions and thereby alleviate anxiety. It is inherently impossible to fully eliminate the unpredictability of potential arrhythmic events that may arise after diagnosis due to the nature of the disease itself. Additionally, the implementation of comprehensive education programmes for patients and caregivers—covering disease course, treatment options, and emergency preparedness—may empower families and reduce psychological distress. Having a predefined action plan in the event of life-threatening situations, such as ensuring that family members and caregivers receive resuscitation training, providing access to an automated external defibrillator, and fostering awareness that immediate intervention is possible in case of a sudden event at the patient's location, is a factor that can contribute to reducing anxiety levels. Physicians caring for individuals with inherited arrhythmias should remain aware of the significant emotional toll these conditions impose and incorporate psychological assessment and support into standard care. Moreover, managing such rare and complex diseases in specialised centres with experienced multidisciplinary teams is essential. Establishing an organised support system around the patient and their family—including access to psychosocial care, resuscitation training, and emergency action planning—is critical for improving both psychological well-being and clinical outcomes. Future studies should evaluate the effectiveness of these interventions in reducing anxiety and preventing adverse events.

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Declaration of Generative AI and AI-assisted technologies in the writing process. There is no usage of generative AI and AI-assisted technologies in writing.

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