# Distress levels in Turkish parents of children with congenital heart disease

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## KEY WORDS

Congenital heart disease, distress, mothers, fathers, parents

## ABSTRACT

**Objective**

The purpose of this research was to determine the distress levels of parents of children with congenital heart disease and identify factors that influenced the levels of distress.

**Design**

The research used a cross-sectional, descriptive study design.

**Setting**

The setting was a Paediatric Cardiology Outpatient Clinic at a university hospital in Erzurum, Turkey.

**Subject**

The subjects for the research were 262 parents (130 fathers and 132 mothers) of 147 children with congenital heart disease.

**Main outcome measure**

The Symptom Check List (SCL- 90-R), developed by Derogatis (1997) was used to measure parents' distress.

**Results**

Mothers had higher scores than fathers on all distress dimensions (somatisation 1.17 ± 0.43; anxiety 1.78 ± 0.52; depression 1.54 ± 0.50 - $p<0.001$). Additionally, the intensity of distress for both mothers and fathers increased with the severity of the child's disease.

**Conclusion**

Parents were seriously affected by the illness of their children. Parents (especially mothers) of children with congenital heart disease should receive psychological and emotional support from health professionals for distress stemming from parenting a child with special needs.

## INTRODUCTION

Congenital heart disease (CHD) can be defined as constructive (anatomic) dysfunction of heart or large blood vessels that exist at the time of birth. CHD is one of the most commonly found congenital anomalies (Çavuşoğlu 2004; Neyzi and Ertuğrul 2002; Görak et al 1996). Congenital heart disease occurs in approximately 1% of live births (Uzark and Jones 2003; Lawoko and Soares 2002). Advances in medical and surgical management of CHD have improved survival rates and resulted in a steady increase in the number of children with CHD (Uzark and Jones 2003; Lawoko and Soares 2002; Mörelius et al 2002).

The birth of a baby is a major life cycle event and it is a source of great expectation and hope for parents. When a child is born with CHD, families must adjust to the fact that the child's disease is life-threatening, has the potential to cause permanent handicap and will dramatically affect familial daily routines (Çavuşoğlu 2004; Lawoko and Soares 2002). After learning of the diagnosis, parents are initially shocked and then tend to experience intense stress and anxiety. When concomitant anger is repressed long term, parents may develop stress-related diseases and depression (Çavuşoğlu 2004; Kobya 1997; Çavuşoğlu 1992). Various studies have demonstrated that families of children with CHD experience psychological and physical problems (Uzark and Jones 2003; Lawoko and Soares 2002; DeMaso and Campis 1991).

Studies related to CHD have shown that families suffer from chronic disappointment accompanied by increased stress that has the capacity to negatively impact on familial and marital dynamics and relationships due to physical and psychological stress, depression, feelings of guilt, and socioeconomic hardship (Ireys and Silver 1996; McCubbin 1989; Kazak 1986; Dunst and Trivette 1986; Lipsky 1985).

Response to treatment and successful outcomes of treatment may be diminished if families are left alone and unsupported, allowing potential psychological problems caused by the presence of chronic disease in a family member to develop (Baysal 1996).

One of the main nursing interventions in clinical settings (outpatient/inpatient) is to support the parents of children with CHD, such as educating, caring for and providing guidance regarding the disease, developing plans for care, being a representative of the health care team and acting as advisor to families (Bayramova and Karadakovan 2004). For a nurse to provide satisfactory support for parents suffering from psychological problems, family members must be encouraged to express their grief and to face and define their stress, suffering and other psychological, emotional or physical problems. Nurses should assess parenting distress at each health care visit to provide appropriate support and guidance. Appropriate planning and interventions can then be provided to parents who are in need of professional support (Çavuşoğlu 2004). Through support and skilled counselling, nurses may significantly influence parenting behaviour and psychosocial outcomes for children with CHD.

Knowledge of the degree of parental distress will promote more efficient nursing interventions for parents of children with CHD. The aim of this study was to determine levels of distress in parents of children with CHD and identify factors that influenced the levels of distress. Based on that knowledge, nurses will be able to plan for appropriate nursing intervention for parents.

## METHODS

### Setting and Sample

The study was conducted with 262 parents (132 mothers and 130 fathers) of 147 children with CHD who were seen at the Paediatric Cardiology Outpatient Clinic in the Department of Paediatric Diseases and Health Care at a university hospital, in Erzurum, Turkey between December 2004 and April 2005.

Study participants were the parents of children under 12 years old, who had a diagnosis of CHD for at least three months and who did not have any other congenital or acquired disease. The study was conducted during routine clinic visits in which mothers and/or fathers accompanied their children.

Before collection of the data, children were classified according to the child's cardiac diagnosis. In order to asses the degree of medical severity more accurately Cardiologist's Perception of Medical Severity Scale (CSEV) (DeMaso et al 1991) was rated by a paediatric cardiologist for all children. Classifications for this scale are as follows:

- Group 1: Mild disorder - lesion requires no operative intervention, only long term follow up
- Group 2: Moderate disorder - child is asymptomatic, but has had or will require operation, easy repair.
- Group 3: Marked disorder – child quite symptomatic has had or will require difficult repair.
- Group 4: Severe disorder – uncorrectable cardiac lesion or only complex palliative repair possible.

**Data Collection Instruments**

Questionnaire: The questionnaire was composed of 11 close-ended questions, based on previously published literature (Lawoko and Soares 2002; Tak and McCubbin 2002; Kobya 1997), designed to determine factors affecting the parents' level of somatisation, anxiety and depression and also to gather demographic information about the child with CHD.

The Symptom Check List (SCL-90-R): The SCL-90-R was developed by Derogatis (1997) and its reliability and validity was evaluated by Dağ (1991) for a Turkish population. Cronbach alpha internal consistency was 0.90 and test-retest reliability coefficients ranged between 0.65 and 0.87 in the Turkish version (Dağ 1991). In current research coefficient alphas were determined as 0.81 for anxiety, 0.84 for somatisation, and 0.90 for depression. The items in this instrument are psychopathological descriptors based on an individual's self-evaluation. These expressions are evaluated utilising a 5 point Likert scale. High scores demonstrate higher degrees of psychopathology (Lawoko and Soares 2002; Öner 1997; Savaşır and Şahin 1997; Kılıç 1997; Dağ 1991). The SCL-90-R is composed of 90 items divided into nine symptom dimensions (subscales). Three subscales were used in the current study: somatisation (12 questions), anxiety (10 questions) and depression (13 questions). A Global Severity Index (GSI) was also calculated based on the average of individual scores for somatisation, anxiety and depression.

The questionnaire and SCL-90-R were administered during a face to face interview with parents. The interview with parents took place immediately following their child's examination in the paediatric cardiology outpatient clinic. Each interview lasted 15 to 20 minutes.

**Ethics**

Ethical permissions were received from participating institutions prior to the study being conducted. Additionally, informed written consent was obtained from all participants.

**Data Analysis**

SPSS descriptive statistics, independent sample t test, ANOVAs, and Cronbach alpha coefficient were used in the evaluation of the data.

## RESULTS

### Demographic characteristics

Of the children with CHD, 51.7% were female, 57.8% were aged between 3 months and 6 years and 36.1% were in group 1of the CSEV (table 1).

**Table 1: Demographic characteristics of children with CHD**

| Characteristics | n=147 | % |
|---|---|---|
| Gender | | |
| Female | 76 | 51.7 |
| Male | 71 | 48.3 |
| Age | | |
| 3 months- years | 85 | 57.8 |
| 7-2 years | 62 | 42.2 |
| Medical severity | | |
| Group 1 | 53 | 36.1 |
| Group 2 | 47 | 32.0 |
| Group 3 | 35 | 23.8 |
| Group 4 | 12 | 8.1 |

Parents demographic characteristics are outlined in table 2: 44.7% of mothers were between the ages of 20 and 29; 52.3% were literate and graduates of primary school; 97.7% were married; 97.0% were not employed; and 53.0% stated they did not have any economic problems. Of fathers, 59.2% were between the ages of 30 and 39; 40.0% were graduates of secondary or high schools; 100% were married and employed; and 58.5% stated they did not have any financial problems (table 2).

**Table 2: Demographic characteristics of parent participants**

| Characteristics | Mothers | | Fathers | |
|---|---|---|---|---|
| | n=130 | % (100) | n=132 | % (100) |
| Age | | | | |
| 20–29 | 59 | 44.7 | 17 | 13.1 |
| 30–39 | 56 | 42.4 | 77 | 59.2 |
| 40 or more | 17 | 12.9 | 36 | 27.7 |
| Education Level | | | | |
| Not literate | 27 | 20.5 | - | - |
| Primary | 69 | 52.3 | 50 | 38.5 |
| Secondary-High | 36 | 27.2 | 52 | 40.0 |
| University | - | - | 28 | 21.5 |
| Marital Status | | | | |
| Married | 129 | 97.7 | 130 | 100.0 |
| Other | 3 | 2.3 | - | - |
| Current employment status | | | | |
| Employed | 128 | 97.0 | - | - |
| Unemployed | 4 | 3.0 | 130 | 100.0 |
| Financial Difficulties | | | | |
| Yes | 62 | 47.0 | 54 | 41.5 |
| No | 70 | 53.0 | 76 | 58.5 |

### Average Distress Scores

Mothers' average scores were: somatisation (1.17±0.43); anxiety (1.78±0.52); depression (1.54±0.50); and Global Severity Index (GSI) (1.48±0.43) which were statistically significantly higher (p<0.001, table3) than those of fathers in the study.

**Table 3: Comparison of parents' GSI, somatisation, anxiety and depression scores**

| | Mothers X±SD | Fathers X±SD | T | p |
|---|---|---|---|---|
| GSI | 1.48±0.43 | 0.82±0.35 | t=13.575 | p<0.001 |
| Somatisation | 1.17±0.43 | 0.60±0.33 | t=12.065 | p<0.001 |
| Anxiety | 1.78±0.52 | 1.21±0.40 | t=9.816 | p<0.001 |
| Depression | 1.54±0.50 | 0.74±0.44 | t=13.658 | p<0.001 |

### Parents' average distress scores according to children's descriptive characteristics

For those parents with young children (between 3 months and 6 years of age), mothers' average scores for somatisation, anxiety, depression and GSI were: 1.18±0.44, 1.86±0.49, 1.63±0.50, and 1.54±0.43 respectively; all of these scores were higher than those of fathers. The difference between somatisation and GSI scores analysed according to age was not statistically significant (p>0.05), however the difference between anxiety (p<0.05) and depression (p<0.01) scores was significant (table 4). Mothers' average scores for somatisation, anxiety, depression and GSI were higher for those with ill daughters rather than sons, however the difference between the groups was not statistically significant (p>0.05) (Table 4). Parents whose children's were in Group 4 of the CSEV classification had higher average scores for somatisation (1.44±0.48); anxiety (2.10±0.57); depression (1.94±0.62); and GSI (1.81±0.50). The difference between the groups in terms of somatisation and anxiety was not significant (p>0.05); however the difference between the groups in terms of depression and GSI scores (p<0.01, p<0.05, respectively) was significant.

The average score for somatisation for fathers of young children (between 3 months and 6 years of age) was 0.63±0.32; for anxiety 1.29±0.41; for depression 0.79±0.44; and for GSI 0.88±0.35. The difference in somatisation scores between the different age groups was not statistically significant (p>0.05), while the difference between anxiety, depression and GSI scores was significant (p<0.01). Fathers with ill daughters had higher average scores for somatisation (0.64±0.37); anxiety (1.23±0.45); depression (0.74±0.46); and GSI (0.84±0.39), however the difference between the groups was not statistically significant (p>0.05, table 4).

When analysed according to CSEV classification, the average score for fathers of Group 4 children for somatisation was 0.76±0.44; anxiety 1.45±0.60; depression 0.93±0.51; and GSI 1.02±0.49. The difference between the groups in terms of depression and GSI score was not statistically significant (p>0.05), however the difference between the groups for somatisation and anxiety scores was statistically significant (p<0.05, table 4).

**Parents' average distress scores according to gender, age, educational and financial status**

Mothers in the 20 to 29 age group demonstrated higher depression scores than those of the other groups, however the difference between the depression scores according to age groups was not statistically significant (p>0.05, table 5).

Literate mothers who graduated from primary school had higher scores with regard to somatisation (1.23±0.43); anxiety (1.89±0.51); depression (1.62±0.50); and GSI (1.56±0.42) than the mothers in other groups. The difference between the literacy levels in relation to somatisation, depression and GSI was not significant (p>0.05); however the difference for anxiety, was statistically significant (p<0.05).

**Table 4: Comparison of parents' SCL subcale scores according to children's chracteristics**

| Characteristics | Mothers | | | | Fathers | | | |
|---|---|---|---|---|---|---|---|---|
| | Somatisation | Anxiety | Depression | GSI | Somatisation | Anxiety | Depression | GSI |
| Gender | | | | | | | | |
| Girls | 1.18±0.38 | 1.83±0.48 | 1.54±0.44 | 1.50±0.37 | 0.64±0.37 | 1.23±0.45 | 0.74±0.46 | 0.84±0.39 |
| Boys | 1.16±0.47 | 1.73±0.55 | 1.54±0.56 | 1.46±0.49 | 0.55±0.27 | 1.20±0.36 | 0.73±0.43 | 0.80±0.31 |
| Statistics and significance | t=0.210 | t=1.108 | t=0.070 | t=0.478 | t=1.600 | t=0.394 | t=0.109 | t=0.552 |
| | p>0.05 | p>0.05 | p>0.05 | p>0.05 | p>0.05 | p> 0.05 | p>0.05 | p>0.05 |
| Age | | | | | | | | |
| 0-6 | 1.18±0.44 | 1.86±0.49 | 1.63±0.50 | 1.54±0.43 | 0.63±0.32 | 1.29±0.41 | 0.79±0.44 | 0.88±0.35 |
| 7-12 | 1.15±0.40 | 1.66±0.54 | 1.41±0.48 | 1.39±0.42 | 0.55±0.33 | 1.10±0.36 | 0.65±0.44 | 0.73±0.33 |
| Statistics and significance | t=0.321 | t=2.103 | t=2.473 | t=1.891 | t=1.461 | t=2.586 | t=2.586 | t=2.383 |
| | p>0.05 | p<0.05 | p<0.01 | p>0.05 | p>0.05 | p<0.01 | p<0.01 | p<0.01 |
| Severity of child's illness | | | | | | | | |
| 1 | 1.06±0.40 | 1.70±0.45 | 1.38±0.43 | 1.36±0.37 | 0.54±0.35 | 1.16±0.41 | 0.71±0.53 | 0.78±0.37 |
| 2 | 1.17±0.42 | 1.73±0.56 | 1.49±0.44 | 1.45±0.42 | 0.58±0.30 | 1.12±0.37 | 0.67±0.35 | 0.75±0.31 |
| 3 | 1.23±0.42 | 1.85±0.51 | 1.70±0.51 | 1.58±0.44 | 0.66±0.28 | 1.36±0.31 | 0.80±0.36 | 0.91±0.29 |
| 4 | 1.44±0.48 | 2.10±0.57 | 1.94±0.62 | 1.81±0.50 | 0.76±0.44 | 1.45±0.60 | 0.93±0.51 | 1.02±0.49 |
| Statistics and significance | KW 7.164 | KW 6.384 | KW 13.989 | KW 9.617 | KW 7.847 | KW 10.554 | KW 4.014 | KW 7.233 |
| | df: 3 | df: 3 | df: 3 | df: 3 | df: 3 | df: 3 | df: 3 | df: 3 |
| | p>0.05 | p>0.05 | p<0.01 | p<0.05 | p<0.05 | p<0.05 | p>0.05 | p>0.05 |

Average scores for somatisation, depression, anxiety and GSI of mothers citing financial problems were higher than those citing no such difficulties. The difference between the groups for financial difficulties, was statistically significant for somatisation (p<0.05); depression (p<0.01); and GSI (p<0.05); but not for anxiety (p>0.05, table 5).

Fathers' average somatisation score (0.80±0-41); average anxiety score (1.48±0.55); average depression score (0.97±0.53); and average GSI score (1.06±0.47) were observed to be highest in the 20 to 29 age group. The difference between the groups was statistically significant (p<0.05).

**Table 5: Comparison of parents' SCL subscale scores according to their individual characteristics**

| Characteristics | Mothers |  |  |  | Fathers |  |  |  |
|---|---|---|---|---|---|---|---|---|
|  | Somatisation | Anxiety | Depression | GSI | Somatisation | Anxiety | Depression | GSI |
| Age |  |  |  |  |  |  |  |  |
| 20–29 | 1.19±0.45 | 1.83±0.51 | 1.66±0.53 | 1.55±0.46 | 0.80±0.41 | 1.48±0.55 | 0.97±0.53 | 1.06±0.47 |
| 30–39 | 1.15±0.44 | 1.79±0.51 | 1.48±0.47 | 1.45±0.41 | 0.58±0.30 | 1.17±0.37 | 0.72±0.44 | 0.79±0.33 |
| 40 or more | 1.16±0.29 | 1.57±0.55 | 1.35±0.42 | 1.35±0.39 | 0.54±0.30 | 1.17±0.34 | 0.65±0.36 | 0.76±0.28 |
| Statistics and significance | F:0.175<br>p>0.05 | F:1.779<br>p>0.05 | F:2.042<br>p>0.05 | F:1.643<br>p>0.05 | F:4.00<br>p<0.05 | F:4.31<br>p<0.05 | F:3.02<br>p<0.05 | F:4.75<br>p <0.05 |
| Education Level |  |  |  |  |  |  |  |  |
| Not literate |  |  |  |  |  |  |  |  |
| Primary | 1.13±0.36 | 1.60±0.51 | 1.52±0.47 | 1.41±0.41 | 0.55±0.28 | 1.18±0.39 | 0.72±0.38 | 0.79±0.32 |
| Secondary | 1.23±0.43 | 1.89±0.51 | 1.62±0.50 | 1.56±0.42 | 0.64±0.36 | 1.27±0.40 | 0.77±0.48 | 0.87±0.35 |
| University | 1.07±0.45 | 1.71±0.51 | 1.42±0.50 | 1.38±0.43 | 0.61±0.33 | 1.16±0.42 | 0.70±0.47 | 0.78±0.39 |
| Statistics and significance | F:1.816<br>p>0.05 | F:3.763<br>p<0.05 | F:1.910<br>p>0.05 | F:2.649<br>p>0.05 | F:0.914<br>p >0.05 | F:0.965<br>p>0.05 | F:0.262<br>p>0.05 | F:0.804<br>p>0.05 |
| Financial Difficulties |  |  |  |  |  |  |  |  |
| Yes | 1.27±0.43 | 1.84±0.51 | 1.68±0.48 | 1.58±0.43 | 0.54±0.29 | 1.16±0.36 | 0.73±0.40 | 0.78±0.33 |
| No | 1.08±0.41 | 1.73±0.52 | 1.42±0.49 | 1.39±0.41 | 0.63±0.35 | 1.25±0.43 | 0.74±0.47 | 0.85±0.36 |
| Statistics and significance | t=2.543<br>p<0.05 | t=1.252<br>p>0.05 | t=3.048<br>p<0.01 | t=2.612<br>p<0.05 | t= -1.513<br>p>0.05 | t= -1.313<br>p>0.05 | t= -0.032<br>p>0.05 | t= -1.077<br>p>0.05 |

Average GSI scores of fathers having secondary education were higher than those in other groups. The difference between GSI scores in relation to educational background was not statistically significant (p>0.05).

Average scores taken from all sub-dimensions of SCL-90-R for fathers citing financial problems were higher than those of fathers claiming no financial difficulties. The difference between the GSI scores relating to financial problems was not statistically significant (p>0.05, table 5).

## DISCUSSION

The study that validated and assessed the reliability of the SCL-90-R in Turkish populations found the average GSI score to be 1.06 and suggested that a GSI score of at least 1.00 was indicative of distress (Dağ 1991). The current results indicated an average for mothers of 1.48 ± 0.43 and for fathers 0.82 ± 0.35. Since the GSI average scores of parents was found to be above the limitation for mothers and very close to it for fathers, it is thought these parents were seriously affected by the illness of their children. Previous studies on this subject also found parents of children with CHD (from many different cultures) have various psychological problems (Ashkani et al 2004; Krulik et al 1999; Cohen 1999; Cohn 1996; Rona et al 1998; Patterson and Garwick 1994; Rao et al 1992; Goldberg et al 1990).

Scores for mothers included in this study were found to be higher than those of fathers on all distress dimensions (somatisation, anxiety, depression, and GSI). Previously published studies comparing the distress levels of mothers and fathers have found similar results to the current study, namely mothers of children with CHD have a higher average GSI score than fathers (Lawoko and Soares 2002; Goldberg et al 1990; Emery 1989). The results of several studies indicate mothers experience psychological stress and feelings of guilt and sadness more often than fathers (Carey et al 2002; Katz 2002; Knafl and Zoeller 2000; Davis et al 1998; Gardner et al 1996).

We may conclude that mothers are more affected by their children's disease than fathers, possibly because mothers are more actively engaged in their children's care than fathers, more often in communication with their children and spend much more time with their children. Data on parental caring of chronically ill children including CHD indicate mothers are highly involved in care tasks and such involvement may lead to strain (Lawoko and Soares 2002; Jessop et al 1988).

We found no statistically significant difference in mothers' and fathers' distress levels when analysed according to their child's demographic characteristics. Although mothers and fathers had higher average distress scores for chronically ill daughters as compared to sons, the difference was not statistically significant. However a previously published study (Tak and McCubbin 2002), found the gender of the child had a significant effect on fathers' stress levels.

This study found that parents of children with more severe disease, such as in Group 4 of the CSEV, have higher distress scores, which is similar to a previously published study (Lawoko and Soares 2002). Some studies of parents of children with chronic disease (Yavaş et al 1994; Goldberg et al 1991) reported parents' moods varied according to the gravity of their child's diseases. DeMaso and Campis (1991) found mothers were influenced by the seriousness of their child's diseases and, as the severity of the disease increased, they suffered from higher level of stress, weakness and feelings of being incapable. However Mörelius and colleagues (2002) found the severity of the child's CHD is of no distinct importance to the degree of parental stress.

Among parents included in the study, those aged between 20 and 29 were found to have higher levels of distress than parents in other age groups. Interestingly, previous studies found that older parents showed more symptoms of distress (Lawoko and Soares 2002). The difference between current and previous results may be due to the fact the studies were carried out in different cultures.

This study also found parents' educational level did not have a significant effect on the level of distress. This suggests parent's education level was not a determinant of distress for this research group.

The levels of somatisation, depression and GSI scores of the mothers who said they were experiencing financial problems were higher than those of the mothers reporting no such difficulty. This is similar to other studies in which parents' financial state did influence levels of psychological stress (Lawoko and Soares 2002; McCubbin 1989; Dunst and Trivette 1986). Askhani et al (2004) also reported parents living at lower socioeconomic levels have more severe and numerous symptoms of depression due to the difficulty in meeting the expensive and long-term requirements of such disease in addition to coping with other ramifications of the disease.

A limitation of this study was that it was based on parents' subjective assessment of their own situation.

## CONCLUSION

The study found that parents of children with congenital heart disease experience varying levels of distress, with mothers experiencing distress more intensely than fathers. The significance of the study is that parents, especially mothers, who have a child with CHD are in need of psychological and emotional support. An increase in the severity of the child's disease increases the intensity of distress for both mothers and fathers. Distressed parents will experience difficulty in helping each other and other people and provide support for them. Therefore, as observed in this study, it is necessary for parents who have children with congenital heart disease to obtain enough support from health professionals so they can remain effective caregivers and family members.

Nursing interventions to meet parent's needs are important to reduce or prevent parental distress. These interventions may include support, counselling, listening, and accurate information about the current situation and expectations. Through support and skilled counselling, nurses may significantly influence parenting behaviour and psychosocial outcomes for them.

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