# PSYCHOLOGICAL FUNCTIONING OF PARENTS OF CHILDREN WITH CONGENITAL HEART DISEASE: REVIEW OF LITERATURE

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#### Abstract

Advancement in medical treatment of congenital heart disease (CHD) has improved dramatically over the past 20 years creating a new group of children who grow up with CHD and parents who deal with challenges of the disease. Although it is clear that having a child born with CHD rapidly increases demands and stress placed on the family, little is known about the specifics of parental experience and factors determining family adaptation. In the article we review previous studies on parental well-being and mental health, caregiving demands, parent-child interactions, family functioning and satisfaction with medical care. We describe several psychosocial factors which threaten parents' well-being and promote their resilience and positive adaptation. Finally, we discuss conclusions and challenges for future researches as well as practical implications of rewieved studies.

# **Key words**

Congenital heart disease, parents, psychological functioning.

Congenital heart disease (CHD) affects approximately 1 in 125 live births which means that 1 million babies are born each year with cardiac disease (Tchervenkov et al., 2008). There are various cardiac malformations with varying degree of severity ranging from minor defects that may spontaneously correct themselves, to severe defects that demand surgical intervention (Berant, Mikulincer et al., 2003). Advancement in medical treatment of CHD has dramatically reduced mortality among patients (Moller, Taubert et al., 1994) creating a new group of children who grow up with CHD and parents who deal with challenges of the disease. Although it is clear that having a child born with CHD rapidly increases demands and stress placed on the family (Svavarsdottir, McCubbin, 1996), little is known about the specifics

According to Moller, Taubert et al., (1994), in the nineties survival to adulthood among patients with CHD increased to 85 %.

of parental experiences in the changing course of the disease and factors determining family adaptation (Lawoko, 2007). Several studies indicate that important proportion of children and adolescents with CHD continue to exhibit emotional, behavioral and cognitive disturbances (Amianto, Bergui et al., 2011). Similarly, recent data show that approximately 1/3 of parents of children with CHD is at risk of long-standing psychosocial morbidity, suggesting that psychological intervention may be beneficial to that group (Lawoko, Soares, 2006). In the article we review previous studies on psychological functioning of parents of children with CHD and discuss conclusions and challenges for future researches.

# Parental stress and adaptation according to theoretical models

For three decades now several models have been proposed to describe how parents adapt to stress of a child's chronic illness and what factors influence eventual outcomes. In 1975 D. Drotar described a sequence of parental reactions to the birth of a child with congenital malformation, including heart disease: phase of shock, denial, sadness-anger, adaptation and reorganization (Drotar, Baskiewicz et al, 1975). The model was based on analysis of interviews with parents of children 0-5 years old, who described their perceptions of the ill child, parental feelings and attachment, effects of the disease for the family and coping strategies. Adaptation phase is described as increasing comfort and confidence in caring for a child as well as awareness of its physical vulnerability whereas reorganization phase involves long-term acceptation of the child, greater sense of stability and social support. Duration and intensity of the phases vary significantly among parents, with those who achieve adaptation with time and those who experience prolonged crisis. To establish which factors determine positive and negative outcomes several models were created, most of them adapted from the theory of stress and coping described by R. Lazarus and S. Folkman in 1984 (Mussatto, 2006). In the Resiliency Model of Family Adjustment and Adaptation proposed by M. and H. McCubbin (McCubbin, McCubbin et al, 1993; in: Svavarsdottir, McCubbin, 1996) family's response to stress occurs in two phases. The adjustment phase focuses on events that require few changes in family functioning but if the changes are not adequate, the family moves into a crisis and disorganization where major changes are necessary. During adaptation phase family attempts to achieve balance and well-being and multiple variables influence this process on an individual and family level (Svavarsdottir, McCubbin, 1996). The Transactional Stress and Coping Model of Adjustment to Chronic Illness proposed by R. Thompson describes the association between determinants of maternal and child's adjustment (Thompson et al., 1993, 1994). Maternal adaptation process includes several cognitive factors (perception of daily hassles and illness tasks, maternal self-efficacy and health-locus of control), methods of coping (adaptive and palliative strategies) and perception of family functioning (supportive, conflicted or controlling). These factors are moderated by illness variables and demographic parameters (type and severity of the disease, child's age and parental socioeconomic status). Both M. and H. McCubbin's and R. Thompson's models are frequently used in studies exploring determinants of parental adaptation to child's congenital heart disease (Davis, Brown et al., 1998, Mussatto, 2006).

#### Studies on parental well-being and mental health

According to metaanalysis of studies on well-being among parents of children with CHD carried out in 1985-2005, there is a consensus that this group is faced with more psychosocial problems than parents of healthy children (Lawoko, 2007). Parents of children with CHD generally report concerns about their offspring's psychosocial adaptation, medical prognosis, financial and caregiving burdens associated with the illness. They are more likely to manifest symptoms of depression and anxiety, more marital problems and lower quality of life. When compared to parents of children with non-cardiac diseases like cystic fibrosis and asthma, they report more distress (Lawoko, 2007). Majority of studies indicate that illness severity does not determine parents' well-being and mental health (Davis, Brown et al., 1998; Tak, McQubbin, 2002; Lawoko, Soares, 2002). However, perceived impact of the disease (defined as psychological, social and financial consequences of CHD for the family) as well as availability of social support, socioeconomic status and gender are considered main factors responsible for parents' wellbeing (Lawoko, 2007).

In a prospective longitudinal study among 630 Swedish parents of children with CHD, S. Lawoko and J. Soares (2006) revealed that important proportion of them manifests significant depression (18%), anxiety (18%), somatization (30%) and hopelessness symptoms (16%), whereas in 22% of mothers and 7% of fathers these symptoms persist over 1-year period.

Mothers exhibit more than twice as much symptoms as fathers and it is associated with mothers' higher caregiving burden (defined as how much time, above the ordinary, individual parent devotes to caring for the child with CHD every day) and worse financial situation. Perceived social support defined either as an availability of deep emotional relationships or availability of social networks (social integration) is another determinant of well-being among parents of children with CHD. As parents' social support availability and financial situation improves with time it is followed with significant improvement in reported mental health.

Several cognitive factors mediating between social burdens and psychological adjustment among American mothers of small children with CHD were investigated in older study conducted by C. Davis and R. Brown et al. (1998). According to R. Thompson's model mothers coping strategies, perception of daily hassles and illness tasks, maternal self-efficacy, locus of control and mental health were assessed. Coping strategies were divided in two categories: palliative coping (emotion-focused, avoidance, wishful thinking and self-blame) and adaptive coping (problem-focused, cognitive restructuring, seeking information and social support) referring to R. Lazarus and S. Folkman model (1984, in: Davis, Brown et al., 1998). Similarly to S. Lawoko and J. Soares findings (2006), authors revealed that above 1/3 of mothers met the criteria of poor psychological adjustment. Maternal poor mental health was associated mainly with predominance of palliative methods of coping, particularly avoidance and self-blame as well as high levels of perceived daily stress. Self-efficacy in illness tasks and locus of control were unrelated to mothers' adjustment (Davis, Brown et al., 1998).

In Australian longitudinal study on psychological adjustment to child's cardiac surgery (Menahem et al., 2007) mothers' mental health and locus of control were assessed prior to the operation and 12–50 months after. One year after child's surgery, mothers still manifested strong tendency to attribute events to luck or chance (external locus of control) despite significant decrease in anxiety and depression symptoms.

In summary, previous studies seem to support the notion that parents of children with CHD, especially mothers, are at increased risk of depression or anxiety symptoms and other psychosocial problems. Data suggest that palliative methods of coping are related with poor mental health, while social support availability and higher socioeconomic status is related with improvement in mental health.

### The impact of congenital heart disease on family life

There are several studies investigating the impact of congenital heart disease on family life. Those studies are focused on caregiving demands, marital satisfaction and general family system functioning.

Caregiving demands. As child's health status is one of numerous factors that influence parenting practices, L. Carey and B. Nicholson et al. (2002) compared the early child-rearing practices between mothers of children with congenital heart disease (CHD) and mothers of healthy children. Contrary to the authors' expectations, both maternal groups reported similar nurturing and disciplining practices. The only significant difference that emerged from observational data concerned parental expectations, which were lower for mothers of children with CHD. Qualitative data collected in the same study revealed that unexpected diagnosis of serious health condition was an important aspect of maternal experience. Mothers struggled with significant uncertainty regarding their child's future and maintained heightened levels of vigilance regarding their children's ongoing health status.

Being a parent of CHD infant is associated with specific caregiving demands. Svavarsdottir and McCubbin (1996) examined which of them were the most difficult and time-consuming. Mothers identified feeding the infant as the most time-consuming and the third most difficult caregiving task, while the most difficult task for them was providing emotional support for the partner. Fathers of infants with CHD reported that the most time-consuming and the most difficult caregiving task was providing emotional support for the partner. The authors suggest that mothers and fathers of CHD infants assume different roles in maintaining good functioning of the family system. The mother may be more responsible for the physical care of the infant, while the father may provide more emotional support for the partner, infant and other children in the family.

The fact that mothers identify feeding the infant as a very demanding caregiving task may be related with problems that may occur during the feeding process, such as shortness of breath or cyanosis. Other possible explanations are the mother's insecurity in reading the infant's cues and her lack of information on how to handle the infant during feeding (Svavarsdottir,

McCubbin, 1996). M. Lobo (1992) examined parent-infant interactions during feeding. Infants with CHD were significantly less responsive to their caregivers than healthy controls. They also scored lower on Clarity of Cues subscale. Parent-infant interactions during feeding play important role in bonding, therefore question arises about the quality of attachment in infants with CHD. According to S. Goldberg study (et al. 1991) there are significantly fewer infants with CHD than healthy controls that are considered to have secure relationships with their mothers. There is no relationship between the quality of infant-mother relationship and mothers' well-being.

Marital satisfaction and general family system functioning. The ongoing stress faced by the parents and siblings of an infant with CHD may have important implications for the functioning of the family system. E. Berant and M. Mikulincer et al. (2003) examined the contribution of illness severity and attachment style to marital satisfaction among mothers of CHD infants. The findings clearly indicated that the severity of the infant's CHD and mothers' attachment style contributed to their marital satisfaction during the infant's first year of life. The more severe the infant's CHD and the higher the mother's attachment anxiety and attachment avoidance, the lower reported marital satisfaction. Maternal avoidant attachment at the time of infant's diagnosis was also the best predictor of deterioration in the mothers' marital satisfaction over the 7-year period, especially in a subgroup of women whose children had severe CHD.

In J. Wray and L. Maynard (2005) study 53% of parents of children with congenital or acquired cardiac disease reported that there was no change in their relationship with a partner, whereas 37% of them rated their relationship as more positive. Authors conclude that under the cardiac condition the family relationships remain stable or improve in nine out of ten families. They also suggest that the cardiac condition affects the siblings.

Studies suggest that parents of children with CHD struggle with specific caregiving demands, but also with significant uncertainty regarding their child's future and heightened levels of vigilance regarding their children's ongoing health status. Studies so far do not allow to build the conclusive model of the family system functioning in the situation of CHD. For example Svavarsdottir, McCubbin (1996), Lobo (1992), Berant, Mikulincer et al. (2003) studies seem to support the notion that CHD is a major challenge and significant burden for each parent and family relationship as well, yet other

studies (Wray, Maynard, 2005) suggest that under the cardiac condition the family relationships remain stable or improve.

### Satisfaction with care among parents of children with CHD

Studies on satisfaction with care among parents of children with CHD offer a possibility to recognize their needs and evaluate quality of health care from patients perspective. According to metaanalysis conducted by S. Lawoko (2007) there are several domains of health care that parents consider important: medical care quality, information about the ill child, supportiveness of the staff and participation in care and decision making. The literature on parental satisfaction seems inconsistent. Most parents of children with CHD express high satisfaction with care in general or when compared to parents of children with non-cardiac diseases. However, an important proportion of parents (18–36%) reports that they do not receive adequate information about the child's condition, treatment and prognosis. There is an agreement that parents' psychological distress, insufficient information and social support, financial burden and younger child's age are associated with poor satisfaction however, the causality of this relationship remains controversial (Lawoko, 2007).

S. Lawoko and J. Soares (2004) conducted a study among over 1000 Swedish parents of children with CHD compared with those with non-cardiac diseases and healthy children. They confirmed that relation between parental distress and poor satisfaction with care is mediated by availability of information about the child's condition. Thus, psychoeducation and parental participation in care and decision making may reduce their anxiety and increase satisfaction. Authors revealed also that poor satisfaction with care is more often reported by parents of younger children and those with limited social networks (social isolation). They explain that parents of younger children need time to acquire information about the illness and develop coping strategies and self-efficacy. Parents who feel isolated may have poorer communication skills and more problems with gaining information and support from the staff, which results in more misunderstandings.

#### Conclusions

In this section, methodological and other limitations of reviewed studies are discussed. Based on the previous findings and discussion, guidelines for future research are proposed.

Most of the previous studies about family functioning is based on data gathered from mothers of children with CHD, without bringing to light perspective of fathers. Predominance of mothers' self-reports in literature on psychological functioning of parents of children with CHD puts several limitations to our knowledge about its determinants. There is general agreement between researchers that self-reports from a single family member do not allow to draw conclusions about functioning of whole family system (Drotar, 1997). With limited use of other measures of parental functioning (e.g. assessing fathers' perspective, parent-child and family interactions) we may overvalue relationships between individual, social and family variables which influence adaptation to child's chronic illness.

Despite the growing literature on the subject there are some aspects of parental functioning that we know very little about. Although specific demands due to child's medical condition were examined (Svavarsdottir, McCubbin, 1996) there is no relevant studies addressing the transition to parenthood in this conditions. Research on attachment shows that mother-child separation and the risk of losing a child associated with disease and medical treatment of the infant may cause specific difficulties in mother-infant bonding (Feldman et al., 1999). What is more, there are several studies which indicate that CHD may influence the quality of mother-infant interactions. For example, parent-infant interaction during feeding may be less rewarding for mothers of children with CHD than in parents of healthy children (Lobo, 1992). These findings support the need for more information about the quality of parent-infant relationship in families touched by this specific illness.

Another potentially important direction of research is examining the role of "secure attachment" in process of recovery of infant. The results of S. Goldberg (1991) study suggest that secure attachment in children with CHD is associated with subsequent improvement in health. This line of study could also be focused on behavior of parents building this kind of protective factor securing children in process of healing, bringing practical implications for psychosocial interventions addressed towards family.

Few studies focus on changes in relationship between parents after the child's birth and on factors that influence the quality of marriage in positive and negative way (what is explored most often is the level of marital satisfaction). Despite great interest in perceived social support as a factor that facilitates parental adaptation, little is known about exactly what kinds of support parents find important; there is also no research on negative aspects of social support. Finally, parental stress and coping should be taken into consideration. Most studies that examine coping strategies are based on R. Lazarus and S. Folkman model (1984, in: Mussatto, 2006) where the strategies focused on changing the inner state of the parent (e.g. emotions) are seen as less adaptive than direct problem solving strategies. The question arises what are the adaptive coping strategies for parents who face child's CHD, a major and uncontrollable stressor. According to E. Band and J. Weisz concept of primary and secondary control (1988), optimal adjustment to relatively uncontrollable stressors (e.g. medical procedures) may require adjusting oneself to the situation rather than trying to alter stressors themselves (Weisz et al., 1994). Thus, palliative and emotion-focused coping may be considered as an adaptive strategy for dealing with uncontrollable stressor such as life-threatening illness. Probably the use of different methods to measure coping in further studies could shed more light on strategies used by parents of children with CHD.

The infants with CHD are a very heterogeneous group. For example, depending on the type of defect their treatment involves none to several surgical interventions and therefore the duration of hospitalization varies greatly (Berant, Mikulincer et al., 2003). We suggest that there is a need to control variables associated with the severity of the treatment. Physicians' assessment alone does not seem to be fully sufficient.

Findings of the studies on psychological functioning of parents of children with CHD are sensitive to cultural differences such as quality of medical care. Conclusions from reviewed studies are limited to developed countries. In these countries focus has been moved from effort to decrease post-operative mortality to now improving quality of life. While 90% of children across the world does not have access to basic congenital cardiac care (Tchervenkov et al., 2008). Different countries and even particular hospitals may differ vastly regarding important aspects of medical care addressed towards families of children with CHD.

There is insufficient knowledge about differences and similarities between parents of children with CHD and other diseases, because of the small number of studies with control groups. Comparing families affected with different chronic conditions would allow us to examine whether experiences and adaptation are determined to greater extent by general factors (e.g. fear of medical procedures) or by illness-specific variables (e.g. cardiac surgery) (Lemanek, 1994). When children with non-cardiac conditions are treated as one homogenous control group, those effects might be lost.

Finally, in further studies there is a strong need to determine more precisely what are the individual differences in parents' psychological functioning and how many of them need professional support when coping with their child's disease. Identifying families with difficulties is vital, but we also need to recognize those factors that promote resiliency and good adaptation (Wray, Maynard, 2005). Little is known about long-term effects of having a child with CHD for parents. Research findings remain contradictory, with some indicating prolonged psychosocial morbidity and some reporting more optimistic outcomes. Where longitudinal studies are concerned, we need projects extending over more than one year period.

# **Practical implications**

Studies indicates that parents of children with CHD might experience significant depression, anxiety, somatization and hopelessness symptoms (Lawoko, Soares, 2006). To prevent the development of psychopathology especially in mothers - it seems to be important to diagnose mental health of parents and provide psychological help to those who meet the criteria of poor psychological adjustment. Studies (Lawoko, 2007, Lawoko, Soares, 2006, Lobo, 1992, Goldberg, 1991) point the need for psychosocial interventions aimed to support both parents mental health and mother-infant bonding. Research conducted by C. McCusker et al. (2010) shows that psychosocial interventions have a positive impact on mothers outcomes such as more satisfaction from the feeding practices, reduced maternal anxiety and less pessimistic appraisal of the situation. As limited, social networks are related with poor satisfaction with care (Lawoko, Soares, 2004) but also with poor parents' well being (Lawoko, 2007, Lawoko, Soares, 2006) it also seems to be important to encourage parents to integrate with other parents of children with CHD (support groups, websites and forums for CHD etc.). Important practical applications provide studies on satisfaction with care (Lawoko, Soares, 2004) which indicates that sufficient information about the child's health, psychoeducation and parental participation in medical care and decision making may reduce their anxiety and increase satisfaction.

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