

CASE REPORT

Analysis of the psychosocial impact of caretaking on the parents of an infant with severe congenital heart defect

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SUMMARY

This case report considers the psychosocial burden of caring for an infant with a severe congenital heart defect (CHD) on parents. Improved prenatal diagnostics and postnatal surgical intervention have created a new and increasing demographic of children and adults with CHDs that require lifelong medical care. For this reason, primary caregivers spend excessive amounts of time in hospitals and medical facilities, and must regularly decipher vast amounts of unfamiliar medical terminology and concepts with varying levels of assistance from medical personnel. This often leads to marked psychological morbidities in parental caregivers, such as stress, anxiety and depression. The financial cost of caring for infants with CHD, including loss of employment opportunities, is another important factor that impacts the quality of life of caregivers. Frequent and extended travel to seek specialised medical care, often at distant medical centres, represents an additional burden.

CASE PRESENTATION

The patient, a Caucasian male, was born at 37 weeks of gestation to a 28-year-old, gravida 1 para 1 mother in Be'er Sheva, Israel. At gestational week 17, the parents were informed that their son suffered from Tetralogy of Fallot (ToF), a congenital heart defect (CHD) characterised by four specific morphological cardiac defects, including (1) pulmonary stenosis; (2) right ventricular hypertrophy; (3) ventricular septal defect and (4) overriding aorta.¹ The combinatory effect of the malformations seen in ToF impedes the flow of blood from the heart to the lungs, resulting in hypoxaemia.² The parents were urged by their obstetrician, who had little experience dealing with such cases, to terminate the pregnancy. However, after consulting a paediatric cardiologist at another hospital, they were assured that the CHD was operable. At birth, the patient weighed 1950 g and was delivered via emergency caesarean section, at which time he required emergency cardiopulmonary resuscitation. He had an Apgar score of 4 and was kept in the neonatal intensive care unit at Soroka Hospital immediately after birth, where he remained for 7 days.

Prior to his surgery, the patient required check-ups twice per week, at a local clinic and at Soroka Hospital, where he would undergo cardiac ultrasound and his oxygen saturation was measured. His first surgical intervention took place when he was 5.5 months old. The fees associated with his check-

ups, diagnostic tests and surgery were all covered by the family's government-subsidised health maintenance organisation (HMO). However, there is still a significant financial burden placed on the family as a result of their son's condition. The mother is now his fulltime caretaker, with no prospect of returning to work any time in the near future. The father has been picking up extra night shifts at the factory where he works in order to compensate for the loss of wages. Both parents had to accompany and remain with the patient in Petah Tikva before, during and after the surgery that would take place at Schneider's Hospital. They had to cover the expenses of their accommodation while they were there and the father had to take time off work. This displacement was also emotionally challenging, since they were in an unfamiliar place without their family or friends to offer support.

GLOBAL HEALTH PROBLEM LIST

- ▶ Lack of access to mental health professionals from the point of diagnosis.
- ▶ Absence of collaboration between physicians and parents in making medical decisions.
- ▶ Spending excessive amounts of time in the hospital.
- ▶ Deciphering unfamiliar medical terminology.
- ▶ Financial burden of caring for a sick child.
- ▶ Necessity to travel and remain far from home in order to obtain specialised medical care.
- ▶ Emotional strain of caring for a sick child.

GLOBAL HEALTH PROBLEM ANALYSIS

Global burden of disease: CHD and ToF

CHDs are the most common congenital anomalies found in neonates, with a prevalence of 0.34 per 1000 live births.³ ToF was first described by Louis Arthur Etienne Fallot as 'la maladie bleue'; it represents 7–10% of all CHD cases worldwide, making it the most frequent cause of cyanotic CHD.⁴ Without surgical repair, only 66% of patients with ToF survive their first year of life and only 24% live to age 10.⁵ Vast improvements in prenatal diagnostics, as well as postnatal surgical interventions, have resulted in a massive decline in mortality from CHD in the past century.³ Correspondingly, these breakthroughs have created a new and increasingly large demographic of children and adults with CHD that require lifelong medical care.⁶ Investigations into the global health burden related to the increasing costs of the diagnostic, medical



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and surgical needs of individuals with CHD are therefore becoming more crucial. The availability and quality of care provided to neonates with CHD varies vastly worldwide due to the relatively high costs associated with its diagnosis and treatment.⁶ In countries where medical care is accessible, much of the remaining burden of the disease falls on the parents of patients with CHD, who often act as their primary caregivers.⁷

Global health problems identified in this case

The mother of the patient described the initial diagnosis of her son as being 'very hard to digest' because 'like everyone, [they] wanted a healthy child.' Despite the diagnosis, she was adamant about continuing the pregnancy and was determined to maintain as much normalcy as possible. She also noted that she had to undergo an extensive amount of prenatal testing and that at first, she was overwhelmed by the medical terminology being used. However, from the moment she received the diagnosis, she invested a significant amount of time into researching her son's condition and treatment, so that she would be able to keep up with all of the medical concepts and terminology that the doctors would use in future appointments. The mother also felt that the doctors did not always present her and her husband with all of the possible treatment options. In particular, the doctors who initially made the diagnosis pressured her to terminate the pregnancy, and she and her husband had to seek out a specialist on their own in order to get the information they needed. The patient's mother felt that many of the tests that they insisted on performing, prenatally and postnatally were excessive and unwarranted. It is clear that if the tests performed were necessary, their necessity was not sufficiently explained or justified to the parents. She also expressed that the doctors were frequently inconsiderate of their religious beliefs and seemed unwilling to find common ground.

The parents reported that the experience of being away from home for their son's surgery was very challenging, emotionally and physically. They had to sleep in a room with other people and felt that they never had any privacy, which was particularly difficult considering the intensity of their situation. Additionally, it was difficult for them that their family was not able to visit them, since it was too far away. Being the primary caregiver to a child with a CHD had a significant impact on the mother's stress and anxiety levels; she reported that she was constantly worrying about her son and feared that he would not survive. She also noted that there were many days when she felt depressed and questioned why this was happening to them. In her experience, the most helpful coping mechanism that she employed was religion or faith.

Lack of access to mental health professionals from the point of diagnosis

The first time that anyone in the healthcare system inquired about, or even acknowledged, how the parents were coping with their son's diagnosis was only months after he was born, when they arrived at the hospital for his surgery. At Schneider's Hospital, the parents were put in contact with a social worker and a psychologist. The mother recalled that this was the first time that she and her husband had even considered their own state of mind and how the whole situation had been affecting them, since they had been so concerned with their son's health. They emphasised that while it was nice to have been offered support at that point, it would have been far more beneficial to them at the beginning of this process, when they had initially received the diagnosis, as they had felt 'very alone' during that

time. Since the surgery, the parents have expressed that their stress levels have decreased significantly.

Absence of collaboration between physicians and parents in making medical decisions

In perinatal cases, the consent of parents ultimately decides the course of treatment for the patient. The process of shared decision-making between physicians and parents has been shown to be in the best interest of the patient, and can return a sense of control and autonomy to parents.⁸ Studies have identified that clear explanations of medical information and mutual respect are integral parts of the relationship between a physician and caregiver,⁸ both of which were neglected in this case. *Boss et al*⁹ found that central contributors to the decision-making of parents include religion, spirituality and hope and that these consistently superseded the physicians' prognoses of morbidity and mortality. Furthermore, they found that in situations where these values were disregarded by the physician, the parents reported feelings of abandonment.⁹ This is consistent with the experiences of the parents in this case, who felt that the doctors did not respect their religious views on termination of the pregnancy. Moreover, the physician who first made the diagnosis in this case was so averse to the shared decision-making process that he did not even present the parents with information on the alternative course treatment of surgical repair of the defect.

Spending excessive amounts of time in the hospital and deciphering unfamiliar medical terminology

Patients with CHD require frequent visits to healthcare facilities, and in cases where the CHD is diagnosed in utero, these visits begin before the child is even born.¹⁰ The presence of CHD is associated with a high rate of comorbidity with extracardiac and chromosomal congenital anomalies, thus necessitating many additional screening tests than that are performed in an uncomplicated pregnancy.¹¹ In addition to the direct circulatory complications such as cyanosis generally associated with CHD, affected infants are highly susceptible to certain infections. For example, ToF is associated with a particularly high risk of infective endocarditis.⁷ Between the frequent diagnostic tests, as well as the hospitalisations for acute illnesses and perioperative care, parents acting as the primary caregivers to a child with CHD must spend extensive amounts of time in hospitals and in medical settings, which can impose a massive emotional burden on them.¹⁰

Furthermore, caring for a child with CHD and making medical decisions on their behalf also necessitates learning a certain amount of medical terminology.^{12 13} Too often, there is little emphasis on explaining to parents, in lay terms, the condition of their child.¹⁴ This barrier between the medical world and the parents who must care for their sick child can be a major source of anxiety.^{10 12} Parents of sick children often report having to turn to the internet in order to decipher the massive amount of medical terminology that is thrown at them, which can lead to issues of miscommunication and misinformation.¹⁵ In Israel, one of the most frequently reported reasons for seeking medical information online is for self-interpretation of test results. Unlike in many western countries, test results are given directly to the patient to bring to their doctor.¹⁶ In order to try to understand the results in the period of time between receiving them and seeing their child's physician, parents often turn to the internet which results in misinterpretations that only increase their stress and anxiety.¹⁶ Another significant factor contributing to parental stress levels is the perceived (as opposed to actual) severity of their child's illness, which further

underlines the necessity of ensuring that the information that parents have about their child's condition is accurate and properly communicated to them.¹⁷

Having medical personnel available to answer questions and explain the treatment process is vital for adherence to the doctor's treatment plans and ultimately, the improvement of patient outcomes. It can also have significant impact on the mental state of the parents.¹⁸ It is important to ask parents what they have heard or read regarding their child's illness and its treatment, as well as to provide them with the opportunity to ask any questions that they may have.¹⁹ With virtually universal access to internet, it is inevitable that parents seeking information regarding their child's health will continue to do so online. Rather than ignoring or discouraging this reality, physicians should use it as a tool. They can avoid the parents being misinformed by providing guidance regarding which online resources are most credible, and advise parents so that the information they encounter online does not unnecessarily increase their anxieties.^{15 18}

Financial burden of caring for a sick child

The financial burden associated with caring for a sick child has been demonstrated to have an even more significant negative impact on quality of life than the severity of their child's illness.^{20 21} *Lawoko et al* demonstrated that parents of children with CHD that were experiencing financial difficulty were two to three times more likely to present with psychiatric outpatient levels of distress than those who did not have such difficulties. They also found that these parents were at significantly higher risk of developing depression, somatisation and experiencing suicide ideation.²²

While many basic medical costs in Israel are financed by the National Health Insurance, much of the financial burden of healthcare falls on the individual. The amount of 'out of pocket' fees that Israelis must pay is considerably higher than the majority of European countries.²³ While healthcare for children is generally less expensive than it is for adults, since the cost of the copay increases based on age,²³ there is a loophole that can lead to unexpected costs. The Israeli National Health Insurance Law only covers newborns after their initial release from the hospital. Prior to that, infants are regarded as a 'by-product of birth'²⁴ and their healthcare expenses are therefore covered by maternity insurance. Since the copay will be based on the mother's age instead of her child's, significantly more of the financial burden is placed on the individual. Revision of this policy, and others that specifically disadvantage parents of hospitalised neonates, would be a step in the right direction for improving the financial burden on these individuals.

In addition to the direct costs of caring for a sick child, there is a significant additional cost associated with the opportunity loss to the primary caregivers.²⁵ A parent of a child with ToF must constantly be observing their child to assure that their blood oxygen saturation does not reach critically low levels, which would require immediate emergency medical intervention; thus day care is not an option, necessitating one of the parents to be the primary caregiver to the child.²⁵ The many doctor's appointments that their child requires also contributes to the practical impossibility of maintaining employment.²⁵

Necessity to travel and remain far from home in order to obtain specialised medical care

Medical services for CHD are often highly specialised and are frequently only available in select hospitals, necessitating travel in order to gain access.²⁵ Travelling for medical care poses many

potential problems. The financial burden of travelling to medical centres to seek treatment includes the cost of transportation and accommodation.²⁵ Furthermore, travelling also tends to mean being away from family and friends, and being without a support system is particularly detrimental to the psychological state of the parents.²⁶ During perioperative hospitalisation in a non-local medical centre, factors that contribute to the distress of parents include accommodation and sleeping arrangements, privacy, eating and showering.²⁶ In many cases, one parent is unable to accompany the other parent and their child, as they must continue to go to work in order to support their family financially, which may lead to prolonged separation.²⁶ In order to avoid the stress and anxiety associated with such separation, efforts should be made to discharge patients to medical facilities closer to home as early as possible.

Emotional strain of caring for a sick child

All of the previously described global health problems compound and cause significant physical and emotional strain on parents caring for a child suffering from CHD.¹³ Parents of children with CHD are at significantly higher risk than parents of healthy children of developing anxiety, depression, somatisation and feelings of hopelessness as a result of the psychosocial burden.^{27 28} Furthermore, there is evidence to suggest that these psychosocial morbidities persist in the long term.²⁷ With so much of their time consumed with taking care of the health of their sick child, parents tend to neglect their own needs and mental health.²¹

Much of the emotional strain experienced by parents of children with chronic illness stems from their lack of control over the situation. Not being able to heal or prevent the suffering of their child, which is the instinctive role of parents, is a major challenge that these parents must endure.²⁹ In infants undergoing complex surgical procedures, the preoperative and postoperative periods represent significant fluctuations in parental stress and anxiety levels, as a result of this perceived lack of control.^{21 29} *Menahem et al*²⁹ observed a surge of anxiety and feelings of distress in parents just prior to their child's surgery. In a study by *Landolt et al*²¹ that looked at parental

Learning points

- ▶ More guidance must be given to caretakers of infants with CHD to help them decipher the vast amount of unfamiliar medical terminology that they are confronted with and insure that they do not turn to inaccurate sources on the internet.
- ▶ Greater financial support should be given to those caring for an infant with CHD to lessen the financial burden of associated indirect costs, which at present are having negative effects on the quality of life and emotional well-being of caretakers.
- ▶ Medical services should be provided close to where the patient lives whenever possible, due to the difficulties involved with frequent travel to receive appropriate medical care.
- ▶ Psychosocial therapies show promise in their ability to reduce chronic stress and emotional strain in caretakers of infants with CHD.
- ▶ Parental emotional support from healthcare and social workers should be made available as early as possible in order to maximise their benefit and efficacy.

health-related quality of life in parents of children undergoing open-heart surgery, the time period immediately following surgery was marked by a substantial decrease in parental mental health. While improvements to the parental mental health were observed at the 6-month postsurgery point, parents of children whose illness continued to have significant impact on their daily lives failed to show improvements in their mental health.²¹

Other forms of therapy that focus on restoring parents' 'internal locus of control' have also demonstrated efficacy in reducing stress levels in parents acting as the primary caregiver to a sick child.²⁸ Involving parents in any way possible can help give them a sense of control and involvement in the treatment of their child during extended hospitalisations in the neonatal intensive care. Simply involving parents in the feeding, bathing, diaper changing and oral medication administration can have a positive impact on them.^{19–30} In addition, cognitive behavioural therapy has been shown to be a beneficial intervention to help parents develop healthy coping mechanism, while reducing chronic stress and anxiety.³¹

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