# Health problems experienced by the caretakers attending the children with cardiac problems

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## ABSTRACT

Cardiac disease is difficult enough when it strikes adults but it can be especially tragic in children. Many different types of heart problems can affect children. They include congenital heart defects, viral infections that affect the heart and even heart disease acquired later in childhood due to illnesses or genetic syndromes. The good news is that with advances in medicine and technology, many children with heart disease go on to live active full lives. The present study makes an attempt to understand the variable on health problems experienced by the caretakers attending the children with cardiac problems. The results revealed that with respect to caretaker's health problems such as asthma, high blood pressure, headache, mental worries etc, 47 per cent faced severe level of health problems, 38 per cent faced moderate problems and only 15 per cent had mild health problems due to child's ill health.

**Keywords:** Health; caretaker; children; cardiac problems

## INTRODUCTION

Becoming a parent is one of the most powerful of the human experiences; is often accompanied with feelings of celebration and relief, but it can also be a time of anxiety and stress.

Children with cardiac problem present special challenges ie it has biological, behavioural and social manifestations for the child and for the family. One can only imagine the increase in stress that takes place when the hopes and dreams of the perfect pregnancy, labour and delivery are shattered with the revelation of a heart disease and the grieving process that ensues as parents cope up with the challenges of having an infant with heart disease.

Cardiac disease, also called cardiovascular disease, mainly affects older people and there are problems with the heart and blood vessels. The heart is the center of the cardiovascular system. Through the body's blood vessels, the heart pumps blood to all of the body cells. The blood carries oxygen which the cells need. Cardiovascular disease is a group of problems that occur when the heart and blood vessels aren't working the way they should. Some of the problems that go along with cardiovascular disease are arteriosclerosis (also called hardening of the arteries), atherosclerosis (a build up of cholesterol and fat that makes the arteries narrower so less blood can flow through), angina (people with angina feel a pain in the chest that means the heart isn't getting enough blood), heartattack (when a blood clot or other blockage cuts blood flow to a part of the heart) and stroke (when part of the brain doesn't get enough blood due to a clot or a burst blood vessel).

Kids usually don't have any symptoms of heart and blood vessel problems. But by starting heart-healthy habits in time, kids can reduce the chance they will ever need to worry about cardiovascular disease.

Paediatric cardiac problems are prevalent throughout the world with 1.5 million new cases diagnosed each year. Congenital heart defects (CHDs) are the singular most common congenital anomalies and account for a significant fraction of childhood mortality and morbidity. CHD occurs in about 1 per

cent of livebirths globally and often requires surgical interventions to improve quality of life and survival of patients. The prevalence and clinical presentations of CHD within specific populations provide a clearer overview of the burden of CHD and informs appropriate interventions (Thomford et al 2020). In 2007, 989 live births were recorded of babies with cardiovascular abnormalities.

Congenital heart disease is an umbrella term which encompasses all heart defects that are present when a child is born. The child may have one or multiple defects at birth which can either be detected by a scan ante-natally or are diagnosed soon after birth. Although the diagnosis of CHD is now becoming easier, some diagnoses of the condition do not happen till late in life.

Congenital heart disease is now not just a problem of the child; many people with the condition are now living into adulthood. Treatment for congenital heart conditions has changed rapidly over the last 50 years. Now surgical management is needed in most cases however some defects will either resolve themselves or require medication. Surgical treatment has changed in recent times; fewer patients are requiring open heart surgery and more are receiving a catheterisation technique. Around 3,100 operations and 725 interventional cardiac catheterisations are performed each year on babies and children with CHD (https://www.ukessays.com/essays/sciences/the-congenital-heart-disease.php).

The effects of surgical interventions on cardiopulmonary function have been thoroughly researched in the past. The studies have concluded that surgery does improve lung and cardiac function and reduces secondary complications (Picchio et al 2006). Exercise is widely known as the best treatment for most musculoskeletal problems but its effects on the cardiopulmonary system has only recently been researched into (Cullen et al 1991). Pulmonary and cardiac rehabilitation have now been shown to have an effect in adults but the research into paediatric rehabilitation classes is not widely known about.

The studies looking at cardiac rehabilitation all have an exercise programme set up for their patients either at home (Moalla et al 2006) or in an outpatient setting. These sessions ranging in therapy time from one hour alternate days to one hour once a week, all show an increase in either cardiopulmonary performance or in exercise tolerance. This shows that a rehabilitation programme is appropriate for these patients and does have a positive effect on the participant's life. Rhodes et al (2006) studied that it had the greatest effect on the patient's final outcome. Not only did most of the testing result in significant effects but the large range of outcome measures used means that we can assess not only the cardiovascular performance of the participant but also look at the pulmonary effects of the exercise and their effects of the heart and the cardiac system.

Steyn et al (2005) found that the individuals who have many risk factors, the chance of suffering a heart attack grows exponentially with each additional risk factor. This principle can be illustrated by considering a person with three risk factors. The chance of suffering a heart attack does not increase by 3 + 3 + 3 equalling 9 but increases by 3 x 3 x 3 equalling 27, thus the risk increases exponentially with multiple risk factors.

Leeder et al (2004) found that premature deaths caused by heart and blood vessel diseases (cardiovascular diseases) in people of working age (35-64 years) are expected to increase by 41 per cent between 2000 and 2030. The negative economic impact of this will be enormous. Yusuf (2002) found that the polypill would be particularly cost-effective in developing countries as patients take single-pill combinations more religiously than several tablets at a time. This approach would also reduce the supply and transport costs. Barker (1989) found that low birth-weight babies are not only at risk of developing complications soon after birth but tend to develop risk factors for heart disease at an early age.

## METHODOLOGY

Twin cities of Hyderabad and Secunderabad were selected for conducting the study because these are the cosmopolitan cities with people of varied backgrounds and with varied range of occupations from industry to caste-based occupations, living in this place. The study was conducted at Niloufer Hospital, Osmania Medical College, Lotus Children Hospital and Lazarus Hospital of the area.

Caretakers who were ready and willing to extend their cooperation for in depth interview were selected as population for the study adopting self-

selected sampling method of non probabilistic sampling. In total 60 caretakers comprising 21 male and 39 female were selected purposively for conducting the present study. The sample was limited to primary caretakers/ parents. Research on family care was focused only on children below 15 years.

## RESULTS and DISCUSSION

The data were collected to understand the health problems experienced by the caretakers attending the children with cardiac problems (Table 1, Fig 1).

The results revealed that caretakers experienced the problems like asthma, high blood pressure, headache, mental worries etc while looking after the children with cardiac problems. In case of male caretakers most of them (43%) experienced severe health problems followed by moderate (33%) and mild (24%). The trend was almost same in case of female caretakers with maximum of them (49%) having severe problems followed by moderate (41%) and mild (10%).

In overall, about half of the respondents (47%) of the respondents faced severe problems, 38 per cent moderate and 15 per cent the mild problems.

Sood et al (2018) reported that fathers often described stress from not being able to protect their child from CHD and the associated surgeries/pain and from difficulties balancing employment with support for their partner and care of their CHD child in the

Table 1. Severity of health problems faced by the caretakers

| Category based on mean ± SD | Male (n= 21) | | Female (n= 39) | | Total (n= 60) | |
|---|---|---|---|---|---|---|
| | f | % | f | % | f | % |
| Mild level | 5 | 24 | 4 | 10 | 9 | 15 |
| Moderate level | 7 | 33 | 16 | 41 | 23 | 38 |
| Severe level | 9 | 43 | 19 | 49 | 28 | 47 |

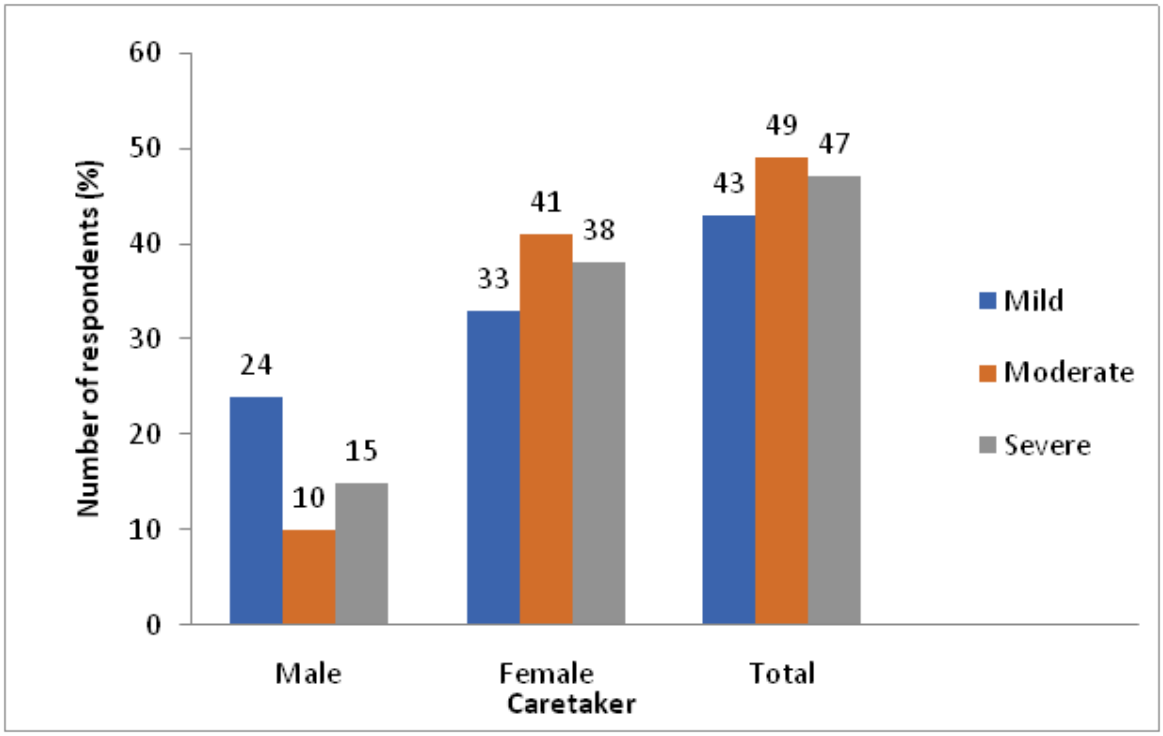


**Fig 1. Health problems faced by the caretakers**

hospital. When reflecting on the time period from CHD diagnosis through discharge to home after cardiac surgery, both mothers and fathers described feelings of stress, fear, overwhelmedness, frustration and guilt. Sabzevari et al (2016) reported the catastrophic burden of childcare on mothers that included tension resulting from the disease, involvement with internal thoughts and difficulties of care process.

## CONCLUSION

It can be concluded that the caretakers undergo various stresses and health problems owing to their diseased child with cardiac disease. The impact was almost similar in both male and female caretakers. In case of male caretakers most of them (43%) experienced severe health problems followed by moderate (33%) and mild (24%). In case of female caretakers, maximum of them (49%) were having severe problems followed by moderate (41%) and mild (10%). In overall, about half of the respondents (47%) faced severe problems, 38 per cent moderate and 15 per cent the mild problems.

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