



INTERNATIONAL JOURNAL OF ACADEMIC RESEARCH IN BUSINESS & SOCIAL SCIENCES



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To Link this Article: <http://dx.doi.org/10.6007/IJARBSS/v12-i9/14884>

DOI:10.6007/IJARBSS/v12-i9/14884

Received: 18 July 2022, **Revised:** 21 August 2022, **Accepted:** 30 August 2022

Published Online: 13 September 2022

In-Text Citation: (Zulkhairi & Johari, 2022)

To Cite this Article: Zulkhairi, A. S., & Johari, K. S. K. (2022). Exploring the Role of Parents on Healthcare of Children with Ventricular Septal Defect (VSD). *International Journal of Academic Research in Business and Social Sciences*, 12(9), 721 – 732.

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Vol. 12, No. 9, 2022, Pg. 721 – 732

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Exploring the Role of Parents on Healthcare of Children with Ventricular Septal Defect (VSD)

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Abstract

This study explored parents' experiences in caring for children with Ventricular Septal Defect (VSD) health problems. This study uses a qualitative method with a case study design. The respondents of this study were six parents of Ventricular Septal Defect (VSD) patients at the National Heart Institution, Kuala Lumpur. Data collection was done through interviews, observations and documentation. Data were analyzed using thematic techniques. The sampling used was purposive sampling. The findings of the study found that all respondents have a clear understanding of the health care for children with VSD heart problems. The results show that there are three main themes, namely: (i) the role of parents on children's health care, (ii) pressure experienced by parents on the healthcare of children and (iii) challenges for parents on children's healthcare. Implications of this study focus in detail on parents and society. Parents should play an important role of parents on children's healthcare. All parental behaviour will be an example in their part of taking care welfare of the children. Society is also an important element to correct their perception of VSD patients. This study suggests that it will be important to improve this theme for future studies. Thus, through the success of the findings of the study, it has given a new knowledge to parents, the community and for future studies to be used as a guide.

Keywords: Role of Parents, Health Care of Children, VSD

Introduction

Ventricular Septal Defect (VSD) is a common congenital heart disease, especially in children and women (Lin et al., 2020). In most countries, almost a quarter of all children die before age five (King, 2011). This is because they have health problems when born. Those diseases are known as congenital heart diseases or known as perforated heart diseases. This heart defect is due to the structure imperfections of the atrium septum (Atrial Septal Defect, ASD) or ventricular (Ventricular Septal Defect, VSD). This causes the parents to play the right role in ensuring the children's illness can be treated properly.

Parents' role in children's health care has been widely discussed and used as scientific research materials. However, the role of parents toward heart patients through the method of multiple stent therapy is far more foreign than in other diseases. This therapy turns out to be more effective from the perspective of the overall recovery process (Guan, 2018). Therefore, taking care of children health is the duty of parents. As parents, they should play

their roles correctly, supervise, and monitor children's activities wisely and carefully (Sulaiman, 2015). If their children are suffering from dangerous diseases, parents should take action immediately and treat them properly.

An estimated 2500 heart cases happen in a year, and most of these patients require medical and psychological support (Mood, 2019). Parents of children with congenital heart diseases have more stress, anxiety, and depression due to a lack of knowledge of proper care (Zhang, 2021).

Clearly stated here that the role of parents is very important to the health care of children with ventricular septal defect (VSD). Therefore, to ensure the well-being of a family institution, both parties, the father and mother, should play their roles properly. In Islam, parents are responsible for educating and raising their children (Rahman, 2002). Without family institutions, the formation of a country would not be perfect.

Hence, the objectives of this study are to:

- 1) Explore the role of parents in the health care of their children who have Ventricular Septal Defect (VSD).
- 2) Identify the pressure experienced by parents on the healthcare of their children who have VSD heart problems.
- 3) Identify the challenge parents face when taking care of their children with VSD heart problems.

Literature Review

Role of Parents on children's Health Care

As the Malay proverb says, 'bend the bamboo, let it be from the shoot' because children are likened to white cloth patterned by their parents. So, it is up to the parents to shape their children's lives towards goodness or vice versa. According to Halimah and Kamariah (1993), parents play an important role in children's personality formation. A perfect early education can ensure children's success in the future so that they do not get stuck or fall into negative things or actions.

The previous study by Rahman (2002) discusses the functions and roles played by family institutions and also reviews the role of the family to socialize with new family members. The institution of the family is the foundation that shapes the life of society. Therefore, as stated him, the function and role of the family are to provide basic needs, apply the values and culture of society, meet economic needs, care about safety and be responsible for providing education to children (Marimuthu, 1996).

Thus, he also stated that the role of a man in the family institution in this country is in terms of instrumental, that is, men provide shelter, food, clothing, and economic needs for the family. At the same time, women play an expressive role in managing the household, nurturing, and caring for children to ensure the well-being of a family institution and give birth to perfectly healthy children. So coinciding with Asilah (2017), she also stated that parents play an important role in providing food for children. Thus, children who are poorly given a good source of protein to themselves can indirectly experience growth problems (Bauer et al., 2011).

Besides, according to Abd Rashid (2006) they discuss about the crisis of family functioning faced with influences and new challenges that require parenting skills and enhanced parenting education. Family institution is an institution that is so dominant and important in Malaysia. A family institution's integrity and understanding will lead to a country's integrity,

stability, progress, and harmony. Parents have the role and responsibility that is more challenging in managing households in new millennium. Hence, they also focus on parents' role in tackling adolescents' increasingly contagious social problems. To realize its role, the family must exist as a powerful institution. The family, as the backbone of society, holds great trust to ensure that children are educated perfectly with admirable values. Parenting behavior was strongly related to child adaptive behavior (Posner et al., 1998).

Thus, it can be understood as a whole that Parents play a role as guardians, educators, nannies, leaders, nurses, advisors and researchers in terms of physical, mental and spiritual children. Communication between parents and children include listening, understanding problems, helping children whenever needed and being assertive about what is right and what is wrong. Be a firm but tolerant parent. Parents must also be wise in dealing with their children. The additional way that parents communicate also plays a very important role between parent and child.

Therefore, a good example should be shown to their children. Malnutrition (excess or lack of nutrients) during childhood will have a long-term effect (Yap, 2018). Hence, the practice of a healthy diet since childhood is very important for their growth and development so that they can grow up perfectly and healthy.

In the study written by Sulaiman (2005), he says that every parent wants a child who is healthy and free from any dangerous diseases. Parents also want their children to grow up in good health and cheerful until adulthood. Therefore, taking care of children's health care is the duty of parents. Parents should play their role properly, and supervise and monitor children's activities wisely and carefully. If their children are suffering from dangerous diseases, parents should take action immediately and treat them properly. He further explained the healthcare of these children from infancy to adulthood. Parents should know and learn how to take care of a baby even after birth. Parents have given various guidelines to ensure their children grow up healthy and away from all misfortunes.

Thus, it is undeniable that children can be taken care of and treated by Sunnah practices and Islamic medicines. Therefore, parents also can practice those methods on their children. In addition, Ibrahim (2018) also discusses in her writings that life is a precious gift of God. It starts with the first heartbeat when we were in our mothers' womb and ends with the last beat. Practices of Prophet Sunnah are a good example, can be practiced and, with His permission will heal again.

Pressure Experienced by Parents on the Healthcare of Children

According to Bujang (2019), parents who have children with disability will experience higher levels of stress compared to those who have normal children. They receive high level of stress from various perspective especially financial constraints. This includes if there is a lack of money to carry up medical treatment to fulfill needs of children with disabilities in order to ensure their physical well-being, and even have implications for the development of their psych tension.

Hence, the study by Jamiah (2017), also show that several main factors contribute the pressure to the parents on taking care for their children, such as lack information on the child's disability, no effective support either from medical practitioners, social workers, family, neighbors as well as the surrounding society. Economic factors also become a major issue that leads to stress in managing children with disabilities.

In addition, children with disability also need all day care. This is because they are unable to take care of themselves. Indirectly, it is found that mothers are more domain in playing the

role of the main carer compared to fathers. Thus, it has been proven empirically that mothers are at more high risk of experiencing stress problems and depression compared to fathers (Sivabalan, 2018).

Next, a study also found that parents of children with disability suffer from many stress disorders and have high levels of anxiety (Choudhary et al., 2011). Parents will go through several processes of acceptance of the presence of OKU children. In the theory of Kubler Ross, a person will go through 5 stages of stress changes when dealing with problems such as the born of OKU children. Parents who fail to pass through each stage of these stressful changes will face problems in accepting the situation and the existence of their children. According to Ferlis (2014), if the parents do not have high level of patience and often experience prolonged support from their family, this can cause neglect and abuse to the child.

Challenges for Parents on Children's Healthcare

The challenge of caring for a child with a disability is a significant challenge for parents. In addition, parents do not have extra knowledge due to it is a rare disease. In fact, this situation can be decreased if family members help and collaborate between parents and medical officers or hospitals such as medical social workers (Ariffin, 2019).

According to him, most of society today pays less attention to the defects of children who is born with nutritional and maternal care problems during pregnancy or related to genetics. This may also happen with disseminating information or reproductive health education that is still not widespread and does not reach certain groups. Moreover, the vast network of social contacts that can provide information on health and health care is still limited to urban populations and the middle or upper class. Financial problems are also an important issue for most countries.

Problem Statement

This study will focus on the role of parents on children's healthcare as a primary element while heart health problems perforated VSD as a secondary element. It consists of two (2) things related to stress and challenge.

Empirical evidence suggests that challenges of caring for children with disabilities cause mothers to be at higher risk for experiencing stress problems and depression compared to fathers (Sivabalan, 2018).

Purpose of Study

The purpose of this study is to explore the role of parents in the health care of their children who have Ventricular Septal Defect (VSD), identify the pressure experienced and challenge faced by parents when taking care of their children who have VSD heart problems.

Methodology

Research methodology is important so that the research conducted has the most suitable and effective methods for answering research problems and achieving the study's objectives. According to Mohamed (2001), a methodology is an approach used in research to collect data. Therefore, this study uses a qualitative method with data collection techniques through field studies (observations), interviews and document review.

The respondents involved are family institutions, namely mothers and fathers of pediatric patients with Ventricular Septal Defect (VSD) at the National Heart Institute, Kuala Lumpur.

The number of members is 4 people. Therefore, the sampling used in this study is purposive sampling. In addition, this study was also conducted regardless of race or religion.

Result and Discussion

The Role of Parents on Children Healthcare

All respondents understood well that each parent has their own role and not forgetting their role in children's health care. According to all respondents, this is because children's health care is very important to ensure their fit and healthy growth.

According to Respondent (AK1), he clearly understands children's health care.

"..From what Sue understands, we as parents need to be healthy as well. When we are healthy, we can take care of our children. Take care of these children's diet, healthy children start from their diet.. " (AK1)

Similarly, AK2, AK3 and AK4 also stated that the family should play an important role in maintaining children's health and should act immediately to seek treatment if the child is not healthy.

"..We as parents, are the main pillars of the family. We have to take care of these children's health. Avoid getting sick, inappropriate things or danger. If you know your child is sick, act early. Bring them for treatment and there should be knowledge about the health care of these children.." (AK2)

"..For the role of parents, if there is a child who is sick, they have to take good care of it. Take care of their health. Diet, hygiene. Make sure you don't let him play dirty things; he will get sick easily later. When you know your children are sick, the parents need to take action immediately. Don't procrastinate.." (AK3)

"..It's easy, the role of parents when they know the child is sick. Act immediately. It is important to take care of a completely healthy child is not easy. Many external diseases are dangerous. Parents must always be careful. Don't take it easy to take care of this child. Children is God's grace, entrust. Take good care.." (AK4)

This in turn, focuses more on the parents themselves on the health care of their child who has VSD. The researcher has also classified several role scopes for respondents to describe in detail. For example, in terms of scheduling daily activities, food care and patient rest time. This is to make it easier for respondents to explain the role.

According to AK1, AK2, and AK3 daily scheduling of patients should be established to ensure their health condition is controlled but not restrict their daily activities.

"..In terms of schedule to the child this VSD is there. Because it's not what, we have to really take care of him having that heart health".(AK1)

"..This table, it's got to be there. It's not a schedule to separate their lives. But the schedule is to keep their meals, their activities and their rest time.." (AK2)

"..The schedule for Nabil, I did. Because he's not only a VSD patient but the result of his surgery has left his brain nerves damaged (cerebral palsy). So the schedule for him is there. Schedule in terms of eating him, sleeping him, resting him. Have to drink milk every 3 hours. Then my husband and I also found another alternative to get him healed. But there's no way he wants to heal. In terms of care now Nabil, we bring the physio to the physio every Monday and Wednesday.." (AK3)

Meanwhile according to AK4, there is no special scheduling for patients because children are able to live life as usual.

"..Scheduling all his activities, I do not mind as long as it does not exceed the limit. As long as he is getting enough sleep and breathing well was enough. I will monitor In terms of her daily schedule, his diet and all his activities. No special scheduling so can cause him stress and depression. Because I am confident in his ability.." (AK4)

However, one variation is present in the parents of these VSD perforated heart patients by playing its role through the method of multiple stent therapy. The result of therapy can be seen to be able to speed up the recovery process.

"..At first, many people did not know this multiple stent therapy, but it is an initiative of parents to treat their children better.." (AK1)

"..I admit that this approach is the best way for my children, parents who have same fate as us need to take a role.." (AK2)

"..This is the only role that needs to be played by the parents which is very different with other diseases.." (AK3)

"..Although for other people, playing a role in stent therapy is hard, for me this is the best way for all of us.." (AK4)

It can be seen that all parents clearly understand this method of multiple stent therapy. According to Guan (2018), using these stents has also been shown to be effective in lowering the rate of restenosis (re-narrowing of arteries).

Furthermore, for the care of food and children's rest time, all respondents agreed to perform the appropriate role of always monitoring their nutrition and rest time. This is because nutrition is very important to ensure perfect growth. What is emphasized by all respondents is to constantly monitor and monitor the daily routine and act immediately if there is any suspicion about their health.

"..In terms of diet, Sue starts to realize that Sue needs to monitor and know what she eats. Make sure she eats on time such as breakfast,

lunch, and dinner. During the break, Sue will make sure that every 3 hours her child will sleep after drinking milk. Have a good rest..” (AK1)

“..Even if you eat, do not simply eat everything” Act immediately if you know your child fall sick. Children with VSD cannot be simply left there. If they have fever should be taken to see a doctor, if coughing should be given medicines. Otherwise, there will be bacterial infection. When they rest and sleep, I will ensure that they get enough sleep and milk. If they do not cry, later they will be short of breath. I realize that taking care of him is very important. Do not forget that they should always be monitored..” (AK2)

“..In the past, we took care of what he ate after the operation, but we give him what food our family used to eat since he was growing up. All you have to do is to crush the food first because Nabil is not very good at chewing. Nabil also had a hard time sleeping, so we had to stay awake and make sure until he fell asleep. Hence the parents please be aware ... don't skip the monitoring of the child..” (AK3)

“..Once we know that our children suffer from heart problems, take appropriate actions such as go to see a specialist for treatment to ensure the health and balance of life is guaranteed. Especially like children with VSD. This disease can be treated from time to time. Only his diet and health should be taken into account. Be a sensitive mother to know that children with VSD need always to be monitored, because VSD cannot be exposed to other people who have colds, coughs, fevers and so on. When you find out that the child is sick, take him to the hospital. The role of parents is important. Don't ever make a mistake..” (AK4)

In conclusion, parents need to play an important role in caring for and treating their children's health. All parental behaviours will be an example and the attention of the public because parents are the main pillars in playing their roles to look after the welfare of children. Family institution that exists form a society coloured with harmony and happiness. In the process of growing up, children need careful attention both spiritually and physically. Care is the first step towards the formation of responsible individuals and members of society. Awareness of the role of parents is very important for the happiness of a family.

Pressure Experienced by Parents on the Healthcare of Children

According to all the respondents stated that stress will exist normally when they are too tired.

“..The pressure on myself will be unstable when I start to get tired. My husband needs to work, other children also need to be taken care of. I start to feel depressed sometimes, but I have to stay strong..” (AK1)

“..Sometimes I am too tired, I need give extra attention to this special child. Sometimes I almost give up, but I have to stay strong. These are all tests..” (AK2)

“..Parents who have children with disabilities will experience higher levels of stress compared to parents who have normal children. Especially stress that related with financial and their needs. I have to stay strong, all of us have to stay stress... but when I’m too tired... the pressure starts to become erratic..” (AK3)

“..When my husband and I are too tired... for sure we want to scold our children. Sometimes we will get into quarrel. This is because the pressure on us is not stable... We have no problems to take care of special children, because even these children understand us, I am strong because of the children..” (AK4)

For all respondents, they also mention that taking care of a special child is not a burden for them. Sometimes they feel overwhelmed by their lack of rest. In addition, if they have financial problems meeting the children’s household and equipment expenses. This also makes the respondents agree that financial problems are also a stressor for them when caring for this special child.

Thus for AK3, he stated that when a misunderstanding occurs between the husband and wife, it also makes him face pressure when taking care of children. He also advised that the husband and wife should help each other and understand each other in caring for this special child. Reaction of children when seeing their parents under pressure, they also feel the atmosphere. Children will start fighting with each other and will cause other problems. The children will start fighting with each other, and this will cause other problems.

Plus, AK1 and AK2 state that each of their behaviors is often observed by children. If parents often fight, understand and face-to-face, then the children will be the same. To them, this special child is very unique. Every behavior of their parents understands and no problems arise as long as they care for this special child.

In conclusion, these special children also have the privilege of absorbing stress. The more depressed the parents, the more the negative energy will come out. The parents will see for themselves that the child will become sleepier and more difficult to sleep. Parents need to learn how to control their stress. Avoid hearing negative stuff from others. This is because they are not in our place, and they cannot feel it. Parents also can do things of joy by celebrating their children’s achievements even when they are still young. Therefore, apply in your heart and yourselves that everything that happens has a thousand pearls of wisdom from God.

Parents’ Challenges to Children's Healthcare

According to all respondents stated that the challenges they faced were not a burden. In fact, those challenges help them to learn something about life. The session for this time is not only to find out the challenges faced but to build the parents' spirit back.

“..Challenges in taking care of my child, it is a lie to say there is not much. There are many challenges, challenges to survive, challenges to raise him up. This test really made me understand about my life and death for the sake of the children..”(AK1)

“..In our life we cannot run away from tests. Everything has its own tests... however since my child is growing up, I have faced various

challenges. From small to large, the challenges are different. To understand a special child is a challenge for me. Sometimes I keep silent... stiff... but God is fair... He wants us to understand, all these are worldly pleasures for us to feel..” (AK2)

“..As a mother with special children for 24 hours... make me realize that my children’s lives are gifts for me. It is really challenging to take care of them since they are small, do not want to eat, throw away the medicines, and cry for 24 hours... I am tired but I understand as a mother I have to be strong. They need me. It is really challenging but I need to be patient..” (AK3)

“..To be honest, it is really challenging to take care of him since he was small. I do not have knowledges. I am stuck. Parents out there must realize and understand that knowledge is important, especially health knowledge. Understanding of health knowledge is very important, don't just understand but don't apply knowledge..” (AK4)

Therefore, given that almost all respondents stated that parents should have a deep understanding and extensive knowledge of their child's health. In conclusion, the challenge in caring for this special child is enormous. There is also no denying that the challenges of caring for this special child are very challenging, and each parent also has their own unique experiences. Various challenges and obstacles that parents have faced. Yet each of these challenges can be overcome well if parents have extensive knowledge regarding proper care. In addition, parents must also play their role well to prevent other things from happening. In the current era of globalization, parents can refer to various ways and initiatives as a guide.

Discussion

Is the role of parents through multiple stent therapy methods more effective for patients with perforated heart VSD?

The findings of the study show that all the respondents agree and admit that roles through the multiple stent therapy methods are more effective from the perspective of the overall recovery process. The outcomes of this study are supported by the latest findings, which can be said to be a good thing in medicine field today because the data released by the World Health Organisation (WHO) in April 2018, the number of deaths due to VSD in Malaysia decreases to 22,701 people or 22.18 percent from the total results from the use of stent methods (Guan, 2018). In addition, according to him, this therapy turns out to be more effective in terms of the overall recovery process.

What stress do parents often experience in the care of VSD children?

This study finds that stress usually experienced by the parents on the healthcare of VSD children is primarily the stress closely related to financial problems and their needs. The findings of this study can be adapted to previous studies by Bujang (2019), which is high pressure, especially financial constraints. The absence or lack of financial assistance in medicine to meet the children’s needs will affect a person's well-being.

Implications and Recommendation

Implications focus in detail on parents and society. Parents should play an important role of parents on children's healthcare. All parental behaviour will be an example and public concern as these parents are the main pillar in playing their part in taking care of the welfare of the children (Posner et al., 1998). Society is also important to correct their perception of VSD perforated heart patients. The thinking of today's society has assumed that the individual with this heart disease is weak and cannot afford to work. Sulaiman (2005), Therefore, society needs to inculcate good values in itself in order to produce a harmonious community life. This study also suggests that it will provide importance in improving this theme for future studies. Thus, through the success of the findings of the study, it has given new knowledge to parents, the community and for future studies to be used as a guide.

Conclusion

This study is carried out to explore the role of parents in the healthcare of children with Ventricular Septal Defect (VSD) perforated heart problems, especially to the role through the multiple stent therapy method. As well as identifying the stresses and challenges faced by parents when caring for a child with VSD heart problems. This study was conducted at the National Heart Institute, Kuala Lumpur based on previous studies, which also stated that the role of parents of VSD heart patients needs to be further expanded. Therefore, in this study, the role of the multiple therapy stent method has been highlighted. However, this therapy is also supported by WHO which is more effective in terms of the overall recovery process for VSD patients.

Hence, healthcare for heart diseases is an initial step towards the formation of responsible individuals and communities. Awareness of the role of parents is also very important for the happiness of a family. It is clear that the role of parents is very important in their children's healthcare. Therefore, all parental behaviours will be an example and public attention because these parents are the main pillars in playing their role to take care of the welfare of children. The existing family institution will form a society colored with harmony and happiness.

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