

Do Congenital Heart Disease Patients Need Gender-Sensitive Care?

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Abstract: *Background:* Congenital heart disease is a collection of birth defects that adversely impact the normal functioning of the heart. This disease is the most common birth complication. The main aim of this study is to examine whether congenital heart disease patients require gender-sensitive care. *Methods:* The researcher adopted the suggestions of the research onion to decide on the design to use. The research approach used was qualitative and it involved conducting structured interviews among congenital heart disease patients and practitioners. The approach of data analysis was thematic analysis. *Results:* Twenty individuals engaged in the study, where twelve were patients and eight were medical practitioners. Out of the twenty participants, male respondents were eleven, while females were nine. The results revealed that both male and female patients required gender-sensitive care when managing congenital heart defects. *Conclusion:* Congenital heart disease patients require gender-sensitive care due to the differences in the occurrence and severity of the disease between men and women. The results acquired via this study signify that the application of gender-sensitive care in the management of congenital heart disease is rare due to the minimal amount of supporting literature.

Keywords: Congenital heart disease, birth defects, gender-based differences, gender-sensitive care, CHD

1. Introduction

Background

Congenital heart disease, otherwise abbreviated as CHD, reflects a range of birth complications that negatively affect the functioning of the heart. The adoption of the term congenital implies that the condition occurred since the birth of a child. Zaidi and Brueckner claimed that the disease is the most prevalent form of birth defects and the recent medical advances have led to more adults living with the condition than children [1]. The prevalence of the condition is significant since a study by Williams, Carson, and Lo indicated that the disease affects approximately one percent of all infants born annually [2]. Gender-sensitive care represents an awareness and understanding of the distinctions, inequalities, and the varying requirements of females, males, transgender, and intersex individuals. Also, this form of care entails a conceptualization of the interrelationship of sex identities with patient histories, economic situations, and treatment requirements.

Research Problem

The main issue under evaluation is the lack of providence of gender-sensitive care for congenital heart disease patients. The significance of gender-sensitive care stems from the differences in the development of the disease. For instance, a study carried out by Bots, Peters, and Woodward revealed that men had a five times higher likelihood of developing CHD compared to women [3]. Therefore, solving this problem is essential to guarantee that patients receive appropriate care based on their gender, thus guaranteeing overall improved outcomes.

Research Aim and Questions

The main goal of this study is to examine whether congenital heart disease patients require gender-sensitive care. The following questions will help in fulfilling this aim:

- What are the different categories of congenital heart disease patients?

- Do gender-based differences impact treatment decisions for congenital heart disease patients?
- What is the current rate of application of gender-sensitive care among congenital heart patients?
- Do congenital heart disease patients require gender-sensitive care?
- What are the challenges of integrating gender-sensitive care for congenital heart disease patients?

Research Significance

This study is vital as it will educate the public about the challenges encountered by congenital heart disease patients and why it is necessary to deliver gender-sensitive care to them. Consequently, CHD patients will benefit from the study as they will learn about the expectations they should have when visiting the hospital and the kind of care that will ensure excellent outcomes. Also, hospitals and governments will benefit from this study's results as they will acquire guidance on the type of care they should deliver to congenital heart disease patients and establish suitable policies for encouraging gender-sensitive care. Furthermore, this research will contribute to existing literature by availing sufficient information on the significance of giving CHD patients gender-sensitive care. Therefore, future researchers can use the findings derived via this study to guide the direction their studies take or criticize the outcomes and derive new arguments on the study topic.

2. Literature Survey

Categories of Congenital Heart Diseases

There are various forms of congenital heart diseases that affect different patients during birth. They consist of aortic valve stenosis, whereby the aortic valve stenosis undergoes narrowing, affecting the stream of oxygen-rich blood from the heart to the body. This situation may cause the thickening of the left-ventricle muscle since the pump works harder. The second type of CHD is truncus arteriosus, which occurs where the pulmonary artery and the aorta fail to develop fully, remaining as a singular vessel [4]. Such an instance triggers the flow of excessive blood to the lungs,

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which may ultimately lead to breathing difficulties and the damage of lung blood vessels and failure to treat this condition may cause death. The third form of CHD is hypoplastic left heart syndrome, which is where the left adjacent of the heart is too small, resulting in little oxygenated blood flowing throughout the body [5]. Another category of CHD is septal defects, which can be atrial or ventricular. These conditions result from a hole forming between the left and right atria and the left and right ventricles, respectively. Moreover, Ebstein's anomaly occurs where the tricuspid valve fails to develop well, causing blood to flow the wrong way [6]. The other type of congenital heart disease is total anomalous pulmonary venous connection (TAPVC), which reflects a situation where the four veins involved in transporting oxygenated blood to the left side of the heart do not connect normally but instead connect to the right side [7]. Tetralogy of Fallot is another type of CHD that entails a combination of various defects inclusive of overriding aorta, right ventricular hypertrophy, ventricular septal defect, and pulmonary valve stenosis. Patent ductus arteriosus is where the connection between the mother and the baby during pregnancy fails to close after birth, causing the pumping of excessive blood to the lungs, making the heart and the lungs to work harder [8].

Gender-based Differences and Treatment Decisions for Congenital Heart Disease Patients

Previous researchers have examined the influence of gender-based differences and treatment decisions for congenital heart disease patients. For instance, a cross-sectional study carried out by Freilinger et al. revealed that there were extensive differences between men and women concerning congenital heart disease. The study revealed that females had a higher tendency of developing "tetralogy of Fallot," "atrial septal defects," in addition to patent ductus arteriosus. On the contrary, men demonstrated predominance in aortic valve insufficiency and the transposition of the great arteries. Further, the pervasiveness of coronary artery illness was higher in males, whereas females showcased a higher degree of pulmonary hypertension and neurologic restrictions, and other comorbidities. Additionally, the results revealed that men had a higher tendency of consulting their physicians concerning CHD-related problems, while 54.4 percent of the women reported that they had never received a referral to institutions specializing in CHD. The mental health requirements of females were also higher than those of men [9]. The arguments presented in this study imply that men and women have varying needs and the prevalence of different types of congenital heart disease varies between the genders. Similarly, a study carried out by Diogenes et al. evaluating the gender differences in the prevalence of congenital heart disease among patients with Down's syndrome revealed that females were at a higher risk of atrioventricular septal defects compared to their male counterparts [10]. This factor implies that the treatment options for CHD between males and females should be different since some complications are more prevalent in one gender than the other.

Application of Gender-Sensitive Care among Congenital Heart Disease Patients

The evidence of the application of gender-sensitive care for congenital heart disease patients is minimal since very few studies have studied the concept. Another cause for this is this topic is a new study area and its consequent adoption is new. The need for more studies is a lingering requirement in the field since specialists require more information to inform their practice and how to handle congenital heart disease patients. An article by Kuhlmann indicated that there are very few studies adopting a gender-sensitivity approach when evaluating the requirements of CHD patients since most factors involving diagnosis, treatment, and therapy adopt a masculine perspective [11]. This perception implies that the application of gender-sensitive care in the care of CHD patients is rare since this field tends to ignore the needs of women and focus more on the male perspective of the disease as pointed out by the author [11]. In another study, Shams et al. illustrated that when managing heart disease, it is vital to adopt gender-sensitive policies that concentrate on the different needs of male and female patients [12]. This argument insinuates that currently, the rate of application of gender-sensitive care in the entire heart disease domain is low, hence the need to integrate such interventions.

Challenges of Incorporating Gender-Sensitive Care among CHD Patients

Multiple studies have explored the various difficulties that patients with congenital heart disease face when seeking care. The main arguments presented include that by Hays et al. who claims that CHD patients complain about a lack of psychological support [13]. The absence of such kind of support implies that they do not have a place to air their grievances and receive appropriate help. Thus, it becomes challenging for them to communicate about their need for gender-sensitive care. Another challenge that negatively affects the incorporation of gender-sensitive care within congenital heart disease patients is the lack of access to care. This problem signifies that it will be difficult for patients to communicate about requiring gender-sensitive care if they cannot receive the basic services. More importantly, Etnel et al. argued that there lacks sufficient patient information on congenital heart disease since their knowledge of the sector is limited [14]. This factor challenges the adoption of gender-sensitive care as patients lack information concerning its meaning and importance.

3. Methods

For this study, the researcher integrated the suggestions of the research onion to develop the methodology to incorporate in this study. Developed by Saunders, this approach is vital as it enables researchers to understand the relevant decisions to derive with reference to the research design to adopt.

Research Philosophy

Research philosophies are either positivism or interpretivism. Positivism entails attaining data via

observation. The advantage of the approach is its accuracy [15], while the shortcoming is that it fails to avail detailed information. Thus, the researcher decided to use interpretivism, which involves the inference of study elements by incorporating a subjective assumption of included entities [16]. The researcher decided to use this method as it permits the utilization of social construction to examine reality. The integration of this approach permitted the researcher to comprehensively evaluate whether congenital heart disease patients need gender-sensitive care and why they require it. Another advantage of this technique is that it allowed the researcher to establish a future narrative to offer insight on what to expect. Nonetheless, the subjective aspect of the approach presented challenges during the study.

Research Approach

The most common types of research approaches are the deductive and inductive approaches. The deductive approach entails conducting scientific studies and its primary advantage of this approach is that it facilitates the examination of causal linkages. Nonetheless, the main shortcoming of this approach is that it limits researchers' creativity since it does not encourage divergent thinking. The researcher decided to adopt the inductive approach, which involves the generation of hypotheses on topics with minimal literature such as the one under evaluation. The benefit of the approach is that it allowed the gathering of diversified observations and the consequent formation of hypotheses. The challenge of the approach is that the data collected through this approach is susceptible to invalidation [17].

Research Strategy

The two most prevalent types of research strategies are case studies and grounded theory. The case study approach involves the evaluation of events as they occur in the real world. The pro of this technique is that it does not require sampling since it relies on recorded data [18]. However, its con is that its chances of errors are significantly high. The researcher used the grounded theory technique since it is appropriate for conducting qualitative research. The choice of this approach was due to its ability to identify contradictory issues, while its shortcoming was that the method requires extraordinary research capabilities.

Research Choices

Research methods are quantitative, qualitative, or mixed. The quantitative approach entails the evaluation of numerical information and its main benefit is that it facilitates the gathering of information from an extensive sample size. Its shortcoming is that it is costly. The qualitative approach, which the researcher adopted, involves the gathering of non-numerical data. The pro of this method is that it saved money. Also, the method allowed the deeper conceptualization of respondents' perceptions as pointed out by Aspers and Corte [19]. Nevertheless, the approach was unreliable due to a lack of statistical evidence.

Time Horizon

Time horizons can be longitudinal or cross-sectional. Longitudinal studies involve conducting studies over an extended period such as months or years. Its advantage is that it allows the realization of trends and changes, whereas its shortcoming is that it consumes a lot of time and resources. On the other hand, cross-sectional studies involve examining issues at a particular time. The researcher chose this approach due to its benefits such as ensuring the analysis of the reasons why congenital heart disease patients require gender-sensitive care. Nonetheless, this approach failed to detail the requirements and changes over time.

4. Research Techniques and Procedures

Data collection

The gathering of information can occur through primary or secondary sources. Primary data collection entails acquiring first-hand information from participants. The advantage of this method is that it ensures the collection of updated information [20], while its shortcoming is that it consumes a lot of time. Secondary data involves gathering data from previous studies. The advantage of the approach is that it saves time and ensures the gathering of extensive data. On the other hand, the disadvantage is that the information may be outdated. At that juncture, the researcher selected the primary method of data collection since there lacks sufficient literature on the topic under evaluation.

Instrument

For this study, the researcher adopted structured interviews. The approach permits researchers to evaluate study responses and evaluate them against the nonverbal cues of participants, hence reliability. Nonetheless, the shortcoming encountered in using this approach is that it consumed a significant amount of time. The interviews comprised of two groups, CHD patients and CHD doctors. The interview questions examined the views of the two groups toward gender-sensitive care. The interview contained eight questions that examined the experiences that patients and practitioners had when seeking treatment for CHD and when dealing with patients, respectively as shown below:

- 1) Patients' Questions
 - Have you ever heard about gender-sensitive care?
 - Have you experienced gender-sensitive care?
 - Explain the experience of receiving this kind of care?
- 2) Practitioners' Questions
 - Have you ever delivered gender-sensitive care?
 - Explain the experience of delivering this kind of care?
 - Do you think the healthcare system is equipped to deliver gender-sensitive care?
- 3) General Questions
 - Do you understand what gender-sensitive care means?
 - Do you think gender-sensitive care is necessary?
 - What do you envision as the importance of gender-sensitive care?

- Are you content with the quality of gender-sensitive care?
- Do you have sufficient knowledge about gender-sensitive care?

Data Analysis

Thematic analysis was the most suitable for this study. The approach entails the identification of prevalent themes and linking them together to identify significant trends. The main benefit of this approach is that it facilitated data categorization and implementation [21]. Also, the method was flexible and permitted the researcher to evaluate extensive texts gathered from the structured interviews. However, this approach was difficult to execute from scratch.

Ethical Issues

One of the most vital ethical issues considered by the researcher was informed consent. The approach involves educating participants about the study details and the expectations the researcher has towards them [22]. This factor ensured that the respondents were aware of the study details and their contribution to it. The researcher presented a consent document to the researchers two weeks before engaging in the study to give them sufficient time to examine the contents and decide whether they wanted to cooperate. Most importantly, the researcher observed the ethical issue of voluntary participation by giving respondents the autonomy to withdraw from the study whenever they felt uncomfortable. Hence, this ensured that the participants did not feel coerced to participate, thus allowing the delivery of genuine information.

5. Results and Discussion

Results

The participants included in the study were twenty, whereby twelve were patients and eight were medical practitioners. Out of the included participants, eleven were male and nine were female. All the respondents engaged in the interviews until the end and cooperated with the researcher to give genuine answers based on the research question. The patients included had varying congenital heart diseases inclusive of aortic valve stenosis, tetralogy of fallot, and septal defects. The participants, through their responses, revealed that they did not receive gender-sensitive care at the medical facilities they visited for check-ups and treatment. They also indicated that they required gender-sensitive care since it allowed the fulfillment of their varying medical needs. The need for this form of care was more prevalent in females than men since the women engaged in the study indicated that the mental issues caused by the disease did not receive appropriate address. The male participants indicated that conducting some cardiac rehabilitation activities was challenging since they did not receive appropriate guidance from practitioners. They argued that this lack of support made it hard for them to abide to the necessary lifestyle and physical activity prescriptions. Hence, this indicates the need for cardiac rehabilitation to support male patients. Further, most of the

participants included in the study stated that gender-sensitive care was vital as shown in Figure 1. The percentage of respondents who stated gender-sensitive care was vital was higher in women than men as evident in Figure 2. More importantly, the practitioners revealed that they were unable to deliver gender-sensitive care since they did not have enough information and training on how to guarantee it. Therefore, the main themes identified were the benefits of gender-sensitive care and how to ensure its execution. The responses given by patients and doctors were similar in that they both supported the necessity of gender-sensitive care and had received or delivered this form of care. However, the primary difference between the responses given by the patients and practitioners is that many patients did not understand the meaning and importance of gender-sensitive care.

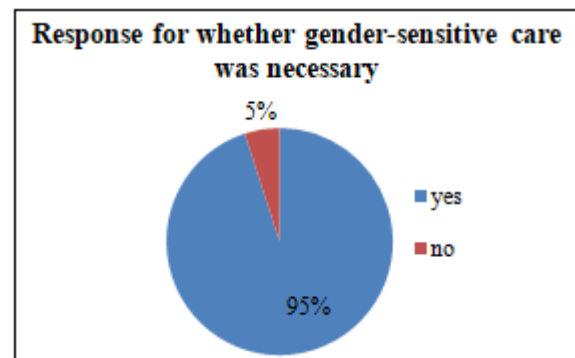


Figure 1: Percentage of responses on the question of whether gender-sensitive care was necessary.

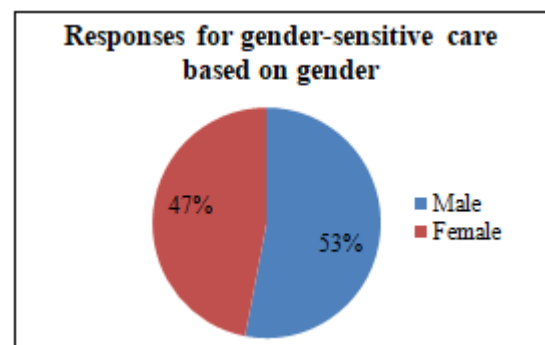


Figure 2: Percentage of genders that supported the integration of gender-sensitive care

6. Discussion

Benefits of Gender-Sensitive Care for CHD Patients

Based on the results acquired from the study, it remains evident that congenital heart disease patients need gender-sensitive care. The cause for this conclusion is that this approach ensures patients receive appropriate care since gender has a significant impact on morbidity and mortality. For example, a study conducted by Sarikouch, Boethig, and Beerbaum indicated that gender impacts the size and function of the heart during childhood up to adolescence [23]. This argument implies that gender affects the chamber size and the prevalence of complications like tetralogy of fallot since biventricular volumes are higher in men compared to females. A similar study by Hagdorn et al. showcased that males with repaired tetralogy of fallot had

higher volumes and masses of indexed ventricular than females [24]. Consequently, functional impairment was more severe in males than females. These arguments indicate that it is vital to adopt gender-sensitive care since the occurrence and prevalence of congenital heart diseases varies from males to females. Therefore, adopting one approach to manage the condition of both genders is not practical and specialized care remains essential.

Additionally, the integration of gender-sensitive care benefits congenital heart disease patients since practitioners handle them while bearing in mind the various inequalities patients encounter and handling them appropriately. Such a situation allows patients to respond to care well since the doctors consider their varying needs. Other than that, gender-sensitive care is beneficial to CHD patients since it allows them to express their concerns without the fear of judgment. Hence, this incidence reduces the occurrence of mental health issues associated with having the disease. In some instances, this form of care involves the integration of a multi-disciplinary team involving mental health specialists. Ultimately, the thorough application of gender-sensitive care could lead to the establishment of subsequent policies that make the delivery of gender-sensitive care to congenital heart disease patients mandatory. From the interview, all the respondents agreed that they would be more comfortable receiving and delivering treatment in an environment that considered the gender of patients, eliminating the possibilities of discrimination.

Approaches to Ensuring Gender-Sensitive Care of CHD Patients

Currently, there is an absence of sufficient literature detailing the various ways to ensure the delivery of gender-sensitive care to congenital heart disease patients. This literature gap challenges the integration of the concept into the medical domain. Nonetheless, the interviews with the practitioners led to the realization that the most suitable tool for encouraging gender-sensitive care is providing training to medical personnel dealing with CHD patients. Training is an efficient tool as it will educate practitioners on the importance of this type of care and how they can deliver it to patients. From the interview, four out of eight respondents reported not having an idea of how to deliver gender-sensitive care. Thus, training can deal with this issue by providing relevant information to doctors and nurses. The second approach realized from the interviews is engaging with expert groups. This suggestion implies that doctors should collaborate with other groups that are passionate about congenital heart disease patients and gather suitable information for facilitating gender-sensitive care. Expert groups always have extensive data gathered via research that is vital in guiding practice and ensuring the meeting of all patient needs.

7. Conclusion

In summary, congenital heart disease patients require gender-sensitive care due to the differences in the occurrence and severity of the disease between men and women. The results acquired via this study signify that the application of gender-sensitive care in the management of

congenital heart disease is rare due to the minimal amount of supporting literature and the responses given by patients. Furthermore, medical practitioners involved in the study indicated that they did not have sufficient training to allow them to spearhead the integration of gender-sensitive care to CHD patients. The arguments supporting the integration of gender-sensitive care imply that the approach triggers numerous advantages such as ensuring the proper delivery of care since patients do not undergo any form of discrimination based on their gender.

This study has contributed to the current literature by presenting an argument for why congenital heart disease patients require gender-sensitive care. This topic is significantly under-studied since very few secondary sources address the issue, hence the integration of a primary research method. The evidence presented in this research could benefit medical practitioners in the congenital heart disease domain as it will educate them about the significance of gender-sensitive care and how they can use the approach to improve patient outcomes and guarantee equality. Other than that, patients can use the information to learn about gender-sensitive care and why they must demand it at the hospitals they attend. Through this, it will be easier for patients to communicate openly with doctors and air their concerns without feeling that they are demanding too much than they deserve.

Conversely, the main shortcoming of this study is that the researcher adopted a cross-sectional research approach. A cross-sectional design did not allow the evaluation of data over a significant period, thus increasing the chances of presenting biased results. Also, the approach was not relevant in studying rare conditions over a short time. Another limitation of the study is the small sample size since the researcher only included twenty respondents. The disadvantage of this situation is that the results generated are representative of the included participants, thereby increasing the possibility of bias since the perceptions held by the participants may not be representative of the opinions of all CHD patients and doctors. Thus, these two factors could negatively affect the quality of the study, particularly in instances where the situation changes in the future.

8. Future Scope

The literature gap evident in this study implies that more research into the topic is essential to acquire more supporting evidence as to why congenital heart disease patients require gender-sensitive care. Thus, future researchers should focus on conducting more primary studies to understand whether CHD patients require gender-sensitive care and the associated advantages. Primary research will guarantee first-hand information that reflects the needs of patients. When conducting these studies, researchers should adopt a longitudinal design and include large sample sizes to increase the reliability of the generated outcomes. Also, future researchers should concentrate on identifying the relevant approaches that medical practitioners can take to ensure the delivery of gender-sensitive care to CHD patients. Future researchers should also consider the reasons for female CHD patients requiring more psychological help than male patients. The availability

of extensive information on the topic will raise awareness concerning this form of care and prevent the limitations that arise from the failure to integrate gender-sensitive care.

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