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The Relationship Between Parents' and Caregivers' Demographics and Their Knowledge about Congenital Heart Disease

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Walden University

College of Health Sciences

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Adeola Animasahun

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Walden University
2019

Abstract

The Relationship Between Parents' and Caregivers' Demographics and Their Knowledge
about Congenital Heart Disease

by

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MPH, University of Lagos, 2007

MB; BS, University of Ilorin, 1997

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

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Abstract

The lack of knowledge regarding congenital heart disease (CHD) among the Lagos populace is leading to late presentation, late diagnosis and poor outcomes. The purpose of the research was to document the level of knowledge of parents and caregivers regarding CHD using the Leuven questionnaire for assessing knowledge of parents on CHD (LKQCHD). A quantitative correlational cross-sectional study, with purposeful convenience sampling strategy was used. Health belief model was the theoretical framework used. Primary data of demographic information such as gender, age, the level of education, and the number of years of accessing care were obtained using a survey. The data were analyzed using Chi-Square, Fisher's exact test, and Pearson's correlation coefficient. There was poor knowledge of CHD among the subjects as the level of knowledge of parents of children with CHD on CHD was lower than 80% of correct answers using the LKQCHD. There were negative correlations between the level of knowledge of the subjects and their age, level of education and number of years of accessing care at the study center. A critical area of need for education and training in the field of public health in Lagos is health education of parents and caregivers of children with CHD in Lagos on CHD, which will help improve awareness of the populace in Lagos on CHD, thereby encouraging early presentation of the children with CHD in Lagos, improve the compliance of parents and caregivers of children with CHD to treatment, medications and clinic follow up. All the above effect of health education will have a positive effect in the quality of life and life expectancy of patients with CHD in Lagos.

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Dedication

This dissertation is dedicated to the glory of God, and to all children with congenital heart diseases in Lagos, Nigeria, especially those whose parents and caregivers participated in this study.

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Chapter 1: Introduction to the Study

Introduction

Congenital heart diseases (CHD) are a group of structural malformations of the heart and/or major blood vessels near the heart or heart valves which develop during intrauterine life. The timing of the clinical manifestation of symptoms and signs of CHD does not preclude diagnosis, as some patients with CHD may manifest in the neonatal period and others much later in life as they grow older. Lagos is a cosmopolitan city in Nigeria which has helped to create a platform for training of parents, patients and caregivers at the Lagos State University Teaching Hospital in Ikeja, Lagos (LASUTH). The trained parents and caregivers will be expected to use the knowledge acquired in counselling other patients with CHD and their parents. Improvement in the knowledge of parents regarding CHD will reduce morbidity and mortality among patients with CHD. The cost of care will also be reduced and there will be a positive effect in the quality of life and life expectancy of patients with CHD in Lagos (Animasahun, 2016).

The more knowledge that parents have about their children's heart disease, the greater likelihood of compliance to medication, less anxiety, and better health-related behavior and reduced risk-taking habits for the child (Yang, Chen, Wang, Gau, & Moons, 2013). This chapter presents background information on CHD, a problem statement, the significance of this study, its theoretical and conceptual frameworks, and delimitations, limitations, and assumptions. The current study was carried out at the Lagos State University Teaching Hospital. The importance of this study will be discussed further in Chapter 2.

Background

CHD are one of the causes of morbidity and mortality in children as they are the most frequent birth defects in children (Animasahun, Kehinde, Falase, Odusanya, & Njokanma, 2014). They are the main cause of death among children with congenital malformations (Animasahun et al., 2017). CHD may be acyanotic or cyanotic depending on the presence or absence of cyanosis respectively. The absence of cyanosis does not necessarily lead to a better prognosis and outcome for the children with acyanotic congenital heart disease (ACHD). ACHD is the most prevalent amongst the congenital heart diseases. They have been recorded in up to 69% of all CHDs (Otaigbe & Tabansi, 2014).

The common types of ACHDs are ventricular septal defects (VSD), Atrial septal defects (ASD), patent ductus arteriosus (PDA), atrioventricular canal defect (AVCD), aortic stenosis (AS), pulmonary stenosis (PS) and coarctation of the aorta. Of the ACHDs, the most common is the VSD (Asani, Aliyu, & Kabir, 2013). The cyanotic congenital heart diseases (CCHDs) include Tetralogy of Fallot (TOF), Truncus Arteriosus, transposition of the great arteries (TGA), total anomalous pulmonary venous returns (TAVR) and Tricuspid atresia (Animasahun, Madise-wobo, & Kusimo, 2017).

The etiology of CHD is unknown. A combination of chromosomal, genetic, and environmental factors has been implicated. Some risk factors include maternal diabetes mellitus, maternal exposure to drugs such as Indomethacin, first-trimester rubella exposure, and residence at high altitudes. Also, infants with abnormalities of other parts

of the body such as the head, spine, legs, hand, and those with syndromes related to karyotype abnormalities are also at high risk (Richards & Garg, 2010).

The onset and clinical manifestations of children with CHDs depend on the types, degree of defects, and associated comorbidities. Common presentations include tachycardia, tachypnea, cough which are features of heart failure, growth impairment, and recurrent chest infections. Furthermore, the systemic examination of children with dysmorphologies or another congenital anomalies may reveal a CHD. In others, an incidental finding of a murmur during a routine physical examination may identify an asymptomatic CHD. A combination of clinical presentation and echocardiographic reviews are required to make a diagnosis of CHD (Zühlke, Mirabel, & Marijon, 2013). Compared to developed countries, cases of CHD are identified in-utero with fetal echocardiography and for those who are symptomatic or for whom a high index of suspicion is present, diagnosis is made soon after birth. The delayed presentation of patients with CHDs in Africa is related to social issues involving poverty, poor health-seeking behavior, illiteracy, reliance on traditional treatment, and weak health systems. Therefore, diagnosis of patients with CHD may be delayed even for those who are symptomatic earlier in life. However, in the last decade, more hospitals in sub-Saharan Africa have a facility for echocardiography (Zühlke et al., 2013).

The management of children with CHD is multidisciplinary. Medical treatment may be combined with surgical correction of the defects. The cost implication is enormous and shared by the family, hospital, and government. The cost of procuring medication and surgical treatment is usually more than anticipated. For most cases,

surgical corrections will be at facilities in developed countries, and this is unaffordable for the average family (Falase et al., 2013). Aside from the financial stress, family members may also experience lost work days due to taking care of their children when they are sick. The diagnosis of a CHD alone also comes with psychological issues such as depression, anxiety, sleep disorders, guilt, and despair. Involvement of family often drains their energy, financial resources, and leisure time. For the government, resources are lost daily to medical tourism and the development of a medical workforce in the care of such patients with CHD is reduced because of medical tourism (Lobe, Geyer, Grosser, & Wessel, 2011).

Children with CHD and their parents have little knowledge of heart defects, its causes, clinical features, mode of treatments, medications, prevention, and complications (Animasahun et al., 2014; Lesch, Specht, Lux, & Frey, 2013; Van Deyk et al., 2010). Many researchers found that the more knowledge that parents have about their children's heart disease, the more compliant to the medication they are likely to be and the less anxious. Also, the well-informed parent is likely to inculcate better health-related behavior and reduced risk-taking habits in the child (Lesch et al., 2014; Ndile & Kohi, 2011).

Problem Statement

CHD occurs in 0.5-0.8% of live births (Okoroma et al., 2008). CHD has a great impact on children's morbidity and mortality as well as health costs. They represent the main cause of death among children with congenital malformations (Animasahun et al., 2017). CHD is an important cause of morbidity and mortality among Nigerian children

(Asani et al., 2013). The current study is focusing on the problem of CHD for children attending the Lagos State University Teaching Hospital in Lagos.

There is inadequate knowledge of CHD among children with CHD and their parents (Animasahun et al., 2014). Most young people with CHD are not able to describe their heart lesions (Lesch et al., 2014). The knowledge of parents of children with CHD regarding the side effects of their cardiac drugs, food, and interactions with other non-cardiac drugs are small and correlated positively with the parents' educational backgrounds (Ndile & Kohi, 2011). Nigerian children with CHD often present late to the healthcare setting due to the knowledge gap (Animasahun et al., 2014). Lagos State University Teaching Hospital is an urban tertiary center located in the heart of Lagos, Southwestern Nigeria. It serves as a referral center for public and private hospitals in Lagos and her neighboring states like Oyo, Ogun, and Osun, and serve a population of more than 30 million Nigerians (Falase et al., 2013). The hospital provides care in all fields of internal medicine, including a particular expertise in cardiology, with its Coronary Intensive Care Unit (CICU). Also, it provides renal dialysis, obstetrics and gynecology services, and pediatrics and child health services, including pediatric cardiology. The center is unique in Nigeria as the busiest tertiary institution, with a heavy load of patients from various part of the country, and it is one of the two tertiary institutions where diagnosis and management of CHD is carried out in Lagos. At LASUTH, children below 12 years of age are treated free, unlike the other tertiary institution (Lagos University Teaching Hospital where fees are paid for every service rendered. The free medical services policy for children below 12 years of age at

LASUTH makes it preferred by parents and caregivers as the first point of call. The problem was that how much knowledge the parents at LASUTH have on CHD was unknown. The lack of data on the knowledge of parents of children with CHD attending LASUTH makes it difficult for health policy makers in Lagos to plan any educational programs as intervention to increase the level of knowledge of parents of children with CHD. Children with CHD in Lagos often present late hence diagnosis is made late, which leads to complications. The late presentation is due to the poor knowledge of parents with CHD on the disease. The poor knowledge of parents of CHD on the disease also leads to poor compliance with follow up, cardiac medications, surgical and non-surgical treatment, and poor outcomes (Animasahun et al., 2014). The poor knowledge of parents and caregivers of children with CHD regarding CHD increases anxiety in the parent, disruptions in family, and burdens on household income and community resources, thereby leading to more burdens on the economy due to the high costs involved in corrective surgery and management of complications of CHD (Falase et al., 2013)

Purpose of the Study

The purpose of the research was to document the level of knowledge of parents and caregivers regarding CHD using the Leuven questionnaire for assessing knowledge of parents on CHD. The study also aimed to describe the relationship if any between the level of knowledge of parents and caregivers regarding CHD measured using the Leuven questionnaire for knowledge on CHD and the demographic characteristics of the parents

of children with CHD such as age, gender, level of education, and number of years in which the parents and caregivers have been assessing care.

Research Question & Hypotheses

The research questions were:

RQ1: What is the level of knowledge of parents of children with CHD attending the Lagos State University Teaching Hospital on CHD?

H₀₁: The level of knowledge of parents of children with CHD attending the Lagos State University Teaching Hospital on CHD is not lower than 80% of correct answers using the Leuven knowledge questionnaire on CHD.

H_{A1}: The level of knowledge of parents of children with CHD attending the Lagos State University Teaching Hospital on CHD is lower than 80% of correct answers using the Leuven knowledge questionnaire on CHD.

RQ2: How does age, level of education, occupation, and number of years of accessing care affect the level of knowledge of parents at the Lagos State University Teaching Hospital regarding CHD?

H₀₂: There is no statistically significant relationship between parents' demographics (age, the level of education, occupation, and number of years of accessing care) and level of knowledge regarding CHD.

H_{A2}: There is a statistically significant relationship between parents' demographics (age, level of education, occupation, and the number of years of accessing care) and level of knowledge regarding CHD.

Variables

The independent variables (IV) were age of parents or caregivers in years, gender, level of education, socioeconomic status, and the number of years of accessing care at LASUTH in Ikeja, Lagos. Age as a continuous variable was recorded in years. For gender, male respondents were represented with 0 while females were represented with the numerals 1. For the marital status of the participants, a respondent who was unmarried was represented with the numeral 0 while those married were represented by the numeral 1 while widows were represented by the numeral 2 and widower 3. The categorization of the subjects was also done for the respondents' place of residence, ethnicity and religion. Subjects who lived in Lagos were represented with the numerals 0 while those from outside Lagos were represented with the numerals 1. For ethnicity, respondents who were Yorubas were assigned to numeral 0 while Ibos and Hausas were assigned numerals 1 and 2 respectively. Regarding religion, respondents who were Muslims were assigned numeral 0, those who are Christians 1 while those who believe in traditional religion and atheist were assigned 2 and 3 numerals respectively

The socioeconomic classes were graded using the occupation and educational level of both parents. Socioeconomic status was determined by the following parameters: Parents educational status and the working status of the parents, using the model developed by Oyedeji in 1985 (Appendix A), where the mean of four scores (two each for both father/caregiver and mother/caregiver) approximated to the nearest whole number was the social class assigned to the subject. The system defines five socioeconomic classes, I to V, in descending order of privilege. Those in social classes I, II were grouped as upper class,

social class III as middle class, while those in social classes IV and V were grouped as lower class (Animasahun et al., 2014). Parents and caregivers in the lower socioeconomic group were scored 0, those in the middle socioeconomic class were scored 1 while those in the upper socioeconomic class were scored 2.

The number of years of accessing care was graded from 0 to 4 (parents whose children with CHD had been attending LASUTH for less than a year were scored 0, those whose children with CHD had been attending LASUTH for one year to less than two years were scored 1, parents who had been assessing care for their children with CHD for up to two years to less than five years were scored 2, those parents who children with CHD had been accessing care at LASUTH for up to five years to less than 10 years were scored 3 while parents whose children with CHD had been accessing care at LASUTH up to 10 years and above were scored 4).

The dependent variable (DV) was the level of knowledge of the parents and caregivers of children accessing care at LASUTH regarding CHD. Their level of knowledge was evaluated using the Leuven questionnaire for or assessing the knowledge of parents on CHD. The questionnaire consisted of twenty-five questions which assessed the knowledge of parents and caregivers on the different aspect of knowledge on CHD including the diagnosis, causes, medications, complication, outcome and prognosis. The Leuven coding manual for the Leuven knowledge questionnaire for congenital heart diseases was used to interpret the participant response Each of the twenty-five questions were scored a maximum of 4, a parent or caregiver was scored 0 if the parent or caregiver did not know the answer to the question, a score of 2 was given if the parent or caregiver

got the answer to the specific question partly while a score of 4 was awarded if the parent or caregiver provided the correct answer to the question. The total score for each participant on all the twenty-five questions were added. The level of knowledge of a participant on CHD was said to be poor if the total score was 0 to 20%, and this was graded as 0, the level of knowledge of the participant was said to be average if the total score was 20 to 50% and this was graded as 1, the knowledge of the participant was said to be good if the total score was 51 to 70% and was graded as 2, the knowledge of the participant was said to be very good if the total score was 71 to 90% and was graded as 3 while, the knowledge of the participant on CHD was said to be excellent if the total score was greater than 90% and was graded as 4.

Theoretical Framework

Health Belief Model

The health belief model was used to relate the health behavior of parents and caregivers of children with CHD regarding their knowledge of CHD. The health belief model was used to emphasize the effect poor knowledge of parents of children with CHD on CHD which include late diagnosis of CHD, which leads to complications, poor compliance with follow up, cardiac medications, surgical and non-surgical treatment, and poor outcomes in children with CHD (Animasahun et al., 2014). It also emphasizes the increased anxiety in the parent, disruptions in family, and burdens on household income and community resources, thereby leading to more burdens on the economy due to the high costs involved in corrective surgery and management of complications of CHD (Falase et al., 2013). The health belief model is an interpersonal model which has been

used to design preventive and interventional programs used for health promotion. It was created in the early 1950s because of the failed free tuberculosis screening program which was carried in the United States of America (Burke, n.d). The health belief model examines the perceptions and attitudes of someone towards a disease and the side effect of a negative attitude such as poor knowledge of CHD. Behavior change is due to three actions that occur at the same time: individual perceived susceptibility and severity of a disease, modifying factors (perceived threat to the person, environmental factors, and cue to action) and perceived benefits and barriers (likelihood of action) (Burke, n.d.; Glanz, Rimer, & Viswanath, 2015).

Nature of Study

Design

The research design was quantitative using was a quasi-experimental method. It was a prospective and correlational cross-sectional survey. A quantitative design was used because the study described the relationship between variables. A non-probability sampling method was used, and it was purposeful and consecutive. The rationale for the chosen method was because the researcher was interested in assessing the knowledge of parents of children with CHD attending the LASUTH, Ikeja, Lagos on CHD. The quantitative research method has the advantage of giving a numeric description of a population. It does calculate sample size, use the instrument to carry out the research which may be a questionnaire or an interview or an online survey for a study design (Creswell, 2009).

Definitions

In the study, several terms were used to describe the illness and the person involved in the research study:

Congenital heart diseases (CHD): This is a group of structural malformations of the heart and/or major blood vessels near the heart or heart valves which develop during intrauterine life. The timing of the clinical manifestation does not preclude the diagnosis, as some children may manifest in the neonatal period and others much later in life. CHDs are one of the causes of morbidity and mortality in children as they are the most frequent congenital disabilities in children (Animasahun et al., 2014).

Assumptions, Scope and Delimitations

It was assumed that subjects were not interviewed twice during the period of clinic attendance to avoid obtaining data from the same subject more than once to avoid duplication. The study design was quantitative; its limitations included the involvements of a larger sample size which made the study to be for a longer period of time. The use of non-probability sampling will prevent generalization of the results of the study among the parents of children with CHD in Lagos and even Nigeria. The quantitative design used might not have been in-depth enough to study perceptions of parents and caregivers regarding CHD because it does not address the perception of the participants which could have explained the reason for the poor knowledge of the participants on CHD. The collection of primary data required a longer time and incurred more expenses such as the cost of typing and printing of the questionnaire, data collection and data entry, the use of

a secondary data would have reduced the duration of the study and the cost of conducting the research.

The study was affected by internal and external validity. The internal validity included the dropout rate from the study, timing, and duration of the study. The internal validity of the study ensured that the attrition level was kept to the barest minimum of zero, because there was no dropout from the study, and it was carried out within a period of one month to ensure that patients that visited the outpatient clinic more than once within a short time were not interviewed twice, so that this does not serve as a confounder in the study.

One of the other factors which could have affected the validity of the study was the instrument. The instrument used was a questionnaire which was a modification of the Leuven knowledge questionnaire for CHD. The Leuven questionnaire was modified to provide demographic information of the participants. To ensure the content validity of this instrument, a face validity of the questionnaire was done to ensure it adequately assessed the knowledge of parents and caregivers of children with CHD in Lagos regarding the causes of CHD, clinical features, treatment modalities, complications, and prevention strategies. Face validity of this questionnaire was ensured by consulting specialists in the field of CHD to look at the questionnaire. Two specialists practicing in Lagos were consulted, and they confirmed that the questionnaire could assess the knowledge of the participants on the causes, clinical features, treatment modalities, complications, and prevention strategies of CHD.

Face validity of the designed questionnaire was also ensured by comparing it with the Hannover Inventory of Parental Knowledge of CHD. The Hannover inventory of parental knowledge on CHD is also a questionnaire for the assessment of knowledge about congenital heart CHD for use in parents. It consists of eight subscales covering general knowledge of cardiac functioning, signs and symptoms of the child's individual CHD *before* and *after* treatment, type of individual CHD and treatment, management of CHD, surveillance of deterioration, endocarditis, and physical activity.

Potential Significance of the Study

CHD is an important cause of morbidity and mortality among Nigerian children (Asani et al., 2013). Animasahun et al., (2014) reported poor knowledge of CHD among caregivers and parents of children with CHD using a non-validated questionnaire. Community health education is an effective means of preventing CHD; this is because educating parents and caregivers of children with CHD attending LASUTH in Lagos will help increase the awareness of the parents and caregivers of children with CHD attending LASUTH on CHD, including signs in patients which are suggestive of CHD. Being aware of pointers which lead to CHD will encourage early presentation at healthcare centers, early diagnosis, and prompt treatment, thereby reducing morbidity and mortality from CHD.

Assessing the current knowledge of parents at the Lagos State University Teaching Hospital in Ikeja, Lagos has helped to create a platform for training of this group of parents and caregivers. The parents and caregivers of children with CHD attending LASUTH when trained and educated on CHD will be expected to use the

knowledge acquired in counseling other patients with CHD and their parents.

Improvement in the knowledge of parents regarding CHD is expected to reduce morbidity and mortality among patients with CHD. The cost of care of children with CHD would also be expected to be reduced, and outcomes are also expected to improved positively leading to better quality of life, improved morbidity and mortality from CHD.

Chapter 2: Literature Review

Introduction

The purpose of the research was to document the level of knowledge of parents and caregivers of children with CHD accessing care at LASUTH on CHD using the modified Leuven questionnaire for assessing knowledge on CHD. The study also aimed to describe the relationship if any between the level of knowledge of parents and caregivers of children with CHD accessing care at LASUTH measured using the modified Leuven questionnaire for assessing knowledge on CHD and their demographic characteristics such as age, gender, level of education, and number of years in which the parents and caregivers have been accessing care at LASUTH. The independent variables were: Age of parents or caregivers in years, gender, the level of education, socioeconomic status, and the number of years of accessing care at LASUTH.

Literature Search Strategy

The search included publications before October 2017. It was limited to publications in English and a subset of medical databases. Searches were performed using PubMed, Medline, Web of Science, PsychInfo and CINAHL, Google, Access to Research for Development and Innovation (ARDI), Health InterNetwork Access to Research Initiative (HINARI), JSTOR ARCHIVES, EBSCO HOST, OhioLINK, DOABOOK. Keywords *used* were: *congenital heart disease, congenital heart diseases, congenital heart anomalies, congenital heart defects, knowledge of parents of children with congenital heart disease, knowledge of parents and caregivers on congenital heart disease, awareness of parents on congenital heart disease, parents of patients with*

congenital heart disease, caregivers of patients with congenital heart disease, and patients with congenital heart disease. The materials used included textbooks, journals, magazines, newspapers, policy documents, academic papers, conference papers, Internet materials which consist of abstracts, reviews, dictionaries, and encyclopedias.

Theoretical Foundation

The research topic was the relationship between parents and caregivers' demographics and their knowledge of CHD. Parents and caregivers of children with CHD in Lagos, including the patients themselves, have very poor knowledge of CHD and its causes, prevention, clinical features, mode of diagnosis, complications, medications, and treatment alternatives when their knowledge on CHD assessed using a self developed questionnaire by Animasahun et al., in 2014. Nigerian children with CHD often present late to LASUTH due to the knowledge gap.

A theoretical framework guides one's research, and it helps to determine what to measure and the relationship between the variables. In conducting research, it is important to find out what is known, it is also important to find out if there is an established theory related to the research. If a lot is known already about the subject of the research and there is an established theory on the subject of the research, then a theoretical framework is used in conducting the research; however, if little is known about the subject and there is no established theory, then the study is conceptual. A conceptual framework is an analytical tool which is used to make distinctions and organize ideas. Theories help to standardize and improve the quality of health education research and practice. It provides a scientific basis for research, giving an opportunity to

learn from the experience of others. Theories also help to improve the effectiveness of health promotion by making it reproducible. Since, there are many literatures and reports on the poor knowledge of caregivers and patients in other parts of the world on CHD, a conceptual framework is not appropriate.

Health Belief Model

The health belief model was based on the general health beliefs and knowledge of individuals, and how these knowledge and belief affects the individual's health. The health belief model was designed in the 1950s after the failure of the free tuberculous screening program in the United States of America. The health belief model examined the perceptions and attitudes of an individual towards a disease and the side effect of such action. Behavior change is due to three actions that occur at the same time (Burke, n.d).

The health belief model also helps to achieve interventions that aim to alter the cost-benefit analysis of engaging in health-promoting behavior, increasing perceived benefits and decreasing perceived barriers, by providing information about the efficacy of various behaviors to reduce risk of disease, identifying common perceived barriers, providing incentives to engage in health-promoting behaviors, and engaging social support or other resources to encourage health-promoting behaviors (Glanz, Rimer, & Viswanath, 2008). The health belief model is limited because it does not account for other factors that influence health behaviors such as social, economic, and environmental factors (Janz & Marshall, 1984). Also, some individuals engage in health-related behaviors for reasons unrelated to health (e.g., exercising for aesthetic reasons; Janz &

Marshall, 1984). Environmental factors outside an individual's control may prevent engagement in desired behaviors (Janz & Marshall, 1984).

Precaution Adoption Process Model

One of the theories that might also have been used in the study was the precaution adoption process model. The precaution application process model helps to describe changes in health as occurring in stages rather than in a single equation. Also, it helps to group the members of the community into the various stages so that health professionals can apply specific stage targeted interventions to each group thereby making interventions more effective rather than applying the same intervention to people in different stages of health behavior (Glanz et al., 2008). One of the limitations of the precaution adoption process model is its interpretation which may be misunderstood as risk perception only. Another limitation is the analysis of the data obtained since the people may be in different stages of health behavior. Also precaution adoption process model can only be applied to a single health condition at a time, it cannot be used when health behavior is complex, and the patient has more than one health issue (Glanz et al., 2008).

Transtheoretical Model of Change

Another potential theory that could have been used in the was the transtheoretical model of change. The transtheoretical model is appropriate for use in the prevention of Chronic diseases such as CHD because the transtheoretical model emerged from a comparative analysis of twenty-five leading theories of psychotherapy, conducted to integrate a field that had fragmented into more than 300 theories of psychotherapy hence

it is superior to other theories. Also, the transtheoretical model uses stages of change to integrate processes and principles of change across major theories of intervention. It would have also been appropriate because it emphasized the benefit of the preventive measures (dietary modification and exercise) and the cost of not taking the preventive action hence could provide decisional balance (Glanz et al., 2015). One of the limitations of the transtheoretical model is the fact that its effectiveness may be affected by culture, it may require major adaptation in some cultures. Given the global application of the transtheoretical model, it will be important to determine the cultures in which the transtheoretical model can be applied effectively and the cultures for which it may require major adaptations. Also, the Transtheoretical model is more effective in reducing risks than in preventing risks (Glanz et al., 2015).

The Staged Theory of Organization Changes

The staged theory of organization changes, although applicable to the community requires a concerted effort whereas CHD is diagnosed on individuals and needs individual and group effort to manage it (Go et al., 2013). Therefore, use of the staged theory of organization change alone would not have been effective in assessing the knowledge of parents and caregivers on CHD. Also, the diffusion of innovation theory was not applicable in assessing the knowledge of parents and caregivers on CHD because it is mostly used in interventions aimed at preventing injuries (Burke, n.d)

The health belief model and transtheoretical model are the both practical, easily applied and intuitive. They both have constructs. Also, both models rely on the individual's belief that they could change. Also, both models require that individual have

a cue to action, triggering the desire to change. Also, the transtheoretical model considers the future while the health belief model does not.

The Rationale for using the Health Belief Model

The Health Belief Model may increase perceived susceptibility to and perceived seriousness of a health condition by providing education about prevalence and incidence of disease, individualized estimates of risk, and information about the consequences of disease (e.g., medical, financial, and social consequences) which can then help encourage a healthier decision. (Glanz et al., 2008).

Key Literature

CHD

Definition of CHD. CHD are a group of structural malformations of the heart and or major blood vessels near the heart or heart valves which develop during the intra-uterine life Bakhtyar, Zeb, Ahmed and Achakzai (2013) described CHD as the most common congenital abnormality found in Pediatrics. CHD is one of the most common congenital disabilities and accounts for nearly one-third of all major congenital anomalies (Dolk, Loane, & Garne, 2011). It is an important cause of childhood morbidity and mortality worldwide (Hoffman, 2013; Richards & Garg, 2010; Vander Bom et al., 2011). CHDs including mild ones also constitute a potential risk of sudden cardiac death in adulthood (Koyak et al., 2012). CHD represents a spectrum of diseases ranging from simple defects with no symptoms to complex defects with the severe life-threatening symptom (Hoffman, 2013). They exclude minor changes in the vena cava drainage that have no clinical significance, arrhythmias unassociated with structural malformations and

some structural abnormalities that are genetically determined but usually present after infancy e.g. hypertrophic cardiomyopathy (Hoffman, 2013). Exceptions to the definition of CHD are some lesions that are included though not present at birth. Example of such lesion which is grouped with CHD but not present at birth is sub-aortic stenosis; because it resembles other congenital forms of left outflow tract obstruction (Hoffman, 2013). The timing of the clinical manifestation does not preclude the diagnosis, as some children may manifest in the neonatal period and others much later in life. The CHD are important causes of morbidity and mortality in children as they are the most frequent congenital disabilities in children (Fahed et al., 2013; Fernandes et al., 2011; Hoffman, 2013; Richards, & Garg, 2010).

Epidemiology of CHD. The incidence of CHD is similar in all countries (Hoffman, 2013). Worldwide prevalence of CHD among newborns and infant vary between 5 and 12 per 1000 live births (Hoffman, 2013). Some population-based epidemiological studies on CHD, have indicated a prevalence ranging from 4 to 50 per 1,000 live births (Bernier, Stefanescu, Samoukovic, & Tchervenkov, 2010; Bernstein, 2016 p. 2182). The incidence of CHD is even higher in cases of premature children, stillbirth or spontaneous abortion (Bernstein, 2016 p. 2182; Contran, Kumar, & Collins, 2013). Each year more than 4.3 million children in the United States are born with CHD and about 1 million children are estimated to be living with the defects. According to UNICEF (n.d), in Nigeria, about 70 000 children are born with CHD annually, based on seven million annual births and a global CHD incidence of 1%. CHD is the leading cause of congenital disabilities associated infant illness and death (Fernandes et al., 2011;

Richards, & Garg, 2010) accounting for about 4.2% of all neonatal deaths. When infectious diseases are excluded, CHD accounts for more deaths in the first year of life than any other condition (UNICEF, n.d). In Nigeria, a CHD incidence of 4.6 to 10 per 1000 children has been documented in hospital-based studies (Animasahun et al., 2014). Also, Otaigbe and Tabansi in 2014 documented a prevalence of 14.4 per 1000 population among children in the Niger Delta region of Nigeria.

Etiology of CHD. The etiology of most types of CHDs is still unknown and not completely understood. However, the role of genetics is an important one in the etiology. Studies from the Baltimore-Washington infant study (Ferencz, 2014), found multifactorial causes for CHD due to genetic predisposition, consanguinity and environmental influences (Gillian et al., 2012; Shawky, Elsayed, Zaki, Nour, & Kamal, 2013). Most of the known causes of CHD are sporadic genetic changes, either focal mutation or deletion or addition of segments of DNA (Kumar, & Clark, 2012). About 8.5% of CHD is caused by large chromosomal abnormalities such as trisomy's 21,18 and 13 (Bernstein, 2016 p. 2183; Rosendorff, 2013). Trisomy 21 is the most common genetic cause of CHD (Animasahun et al., 2015; Kumar, & Clark, 2012). Other chromosomal abnormalities that frequently lead to CHD, are microdeletion of the long arm of chromosome 22 (22q11, DiGeorge syndrome), the long arm of chromosome 1(1q21), the short arm of chromosome 8(8p23) and many other as shown by high resolution genome-wide screening (array comparative genomic hybridization) (Bernstein, 2016 p. 2183; Park, 2014 p. 34). Other genetic condition associated with heart defects includes Turner syndrome, Marfan syndrome, Noonan's syndrome, LEOPARD syndrome and Costello

syndrome (Bernstein, 2016 p. 2183; Park, 2014 p. 34-50). Known environmental factors associated with CHD include certain infection during pregnancy e.g. rubella; drugs (alcohol, hydantoin, lithium, and thalidomide) and maternal illness (diabetes mellitus, phenylketonuria and systemic lupus erythematosus) (Park, 2014 p. 34). CHDs are also associated with increased incidence of other body defects known as VACTERL association (Park, 2014 p. 34, 47, 50).

Pathogenesis of CHD. CHDs usually result from a destructive process affecting the complex orderly sequence of the events that result in a normal well-formed heart (Bernstein, 2016 p. 2157). Development of the heart starts on day 15 when the cells that will become the heart exist in two horseshoes shaped band of the middle tissue layer (mesoderm) and some cells migrate from a portion of the outer layer (ectoderm) (Bernstein, 2016 p. 2157). On day 19 of development, a pair of vascular elements, the ‘endocardia tubes’ form. The tube fuse when cells between them undergo programmed deaths and cells from the first heart field migrate to the tube and form a ring of heart cells (myocytes) around it by day 21 (Bernstein, 2016 p. 2158-9). On day 22, the heart begins to beat and by day 24, blood is circulating. On day 22, the circulating system is bilaterally symmetrical with paired vessels on each side and the heart consisting of a simple tube located in the midline of the body layout (Bernstein, 2016 p. 2159). The portions that will become the atria and will be located closest to the head are the most distant from the head. From day 23 through 28, the heart tube folds and twists, with the future ventricles moving left of the center (the ultimate location of the heart) and the atria moving towards the head (Bernstein, 2016 p. 2159). On day 28, areas of tissue in the heart tube begin to

expand inwards after about two weeks, these expansions, the membranous “septum primum” and the muscular “endocardia cushions”, fuse to form the four chambers of the heart (Bernstein, 2016 p. 2160). A failure to fuse properly will result in a defect that may allow blood to leak between chambers. After this happens, cells which have migrated from the neural crest begin to divide the bulbous cordis, the main outflow tract is divided into two by the growth of a spinal septum, becoming the great vessels- the ascending segment of the aorta and the pulmonary trunk (Bernstein, 2016 p. 2159). If the separation is incomplete, the result is a persistence truncus arteriosus. The vessels may be reversed resulting in transposition of the great vessels. The two halves of the split track must migrate into correct position over the appropriate ventricles. A failure may result in some blood flowing into the wrong vessel (overriding aorta).

The circulation of the heart in utero is termed parallel because the lung is unexpanded. This circulation is maintained by the foramen ovale that allows circulation from the right atrium to the left atrium and the ductus arteriosus that allows blood from the pulmonary artery to the aorta (Bernstein, 2016 p. 2161). With birth, the circulation becomes a serial one because of (1) removal of the low resistance placental circulation leading to an increase in systemic vascular and closure of ductus venosus; (2) the mechanical expansion of the lungs and an increase in arterial partial oxygen pressure, resulting in rapid decrease in pulmonary vascular resistance and (3) reversal of shunt in the ductus arteriosus and its eventual functional closure within 10-15 hours after birth (Bernstein, 2016 p. 2162). The increased systemic pressure in the left atrium also leads to the functional closure of the foramen ovale (Bernstein, 2016 p. 2162). When congenital

structural cardiac defects are superimposed on these dramatic physiologic changes, they often impede this smooth transition and markedly increase the burden on the newborn myocardium. Also, because the ductus arteriosus and the foramen ovale do not close completely at birth, they may remain patent in certain congenital cardiac lesions (Bernstein, 2016 p. 2162). Patency of these fetal pathways may either provide a lifesaving pathway for blood to bypass a congenital defect; (a patent ductus in pulmonary atresia or coarctation of the aorta or a foramen ovale in transposition of the great vessels) or present an additional stress to the circulation; (patent ductus arteriosus in a premature infant, pathway for right to left shunting in infants with pulmonary hypertension). The major decline in pulmonary resistance from the high fetal levels to the low adult levels in the human infant at sea level usually occurs within the first 2-3 days but may be prolonged for seven days or more (Bernstein, 2016 p. 2162). Over the first several weeks of life, pulmonary vascular resistance decreases even further and influences the timing of the clinical appearance of many congenital heart lesions that are dependent on the relative systemic and pulmonary vascular resistance (Bernstein, 2016 p. 2162). The left to right shunt through a ventricular septal defect may be minimal in the first week after birth when pulmonary vascular resistance is still high. As the pulmonary resistance decreases in the next week or two, the volume of the left to right shunt through an unrestrictive VSD increase and eventually leads to symptoms of heart failure (Bernstein, 2016 p. 2187).

Management of Children with CHD. The management of children with CHD is multidisciplinary (Radu et al., 2016) Medical treatment may be combined with surgical

correction of the defects. The cost implication is enormous and is shared by the family, hospital and the government. The cost of procuring medication and surgical treatment is usually more than anticipated (Czosek & Anderson, 2016; Falase et al., 2013a; Hoffman, 2013) For most cases, surgical corrections are needed. The needed definitive surgical correction for most of the subjects is not available in Nigeria (Animasahun, Madise-wobo, Gbelee & Bode-Thomas, 2016; Falase et al., 2013). For most cases, surgical corrections will be sort at facilities in developed countries and this is unaffordable for the average family. Aside from the financial stress, family members may experience loss work days in taking care of their children when they are sick. The diagnosis of CHD alone also comes with psychological issues such as depression, anxiety, sleep disorders, guilt despair to mention a few. The extreme involvement of family often drains the family of energy, financial resources and leisure time. For the government, resources are lost daily to medical tourism and the development of the medical workforce in the care of such patient is reduced because of the medical tourism.

At best in Nigeria, some palliative surgeries such as a Blalock-Taussig shunt is performed for subjects with tetralogy of Fallot. In recent times, however, few cases of tetralogy of Fallot had the intracardiac repair done in Nigeria with the support of experts from abroad. Cardiac surgeries for congenital heart diseases is still generally at the infancy stage in Nigeria. (Falase et al., 2013). Most subjects still have to travel abroad to earn the required surgery; this is not within reach of an average Nigerian citizen (Animasahun, Madise-Wobo, Gbelee, & Omokhodion, 2017b).

Complications of CHD. Children with CHD are at increased risk of developing complications which may be systemic or localized. These complications also depend on the underlying cardiac defect. The problems include; Arrhythmias, amongst the complications encountered in patients with CHD (Cannu & Snyder, 2013, p. 894, 904). Arrhythmias feature prominently with an incidence that increases with age. The etiology of arrhythmias in these patients are multiple and includes congenitally malformed or displaced conducting systems, altered hemodynamics, mechanical or hypoxic stress and residual or postoperative sequelae (Batte et al., 2016). An arrhythmia occurs in 27.3% of children with CHD studied by Batte et al., in 2016.

Heart failure is another known complication of CHD, children with CHD are prone to having heart failure because the conditions that lead to heart failure are prevalent in them (Park, 2014, p. 738). These include ventricular dysfunction, volume and pressure overload (Hinton & Ware, 2017). The incidence of heart failure depends on the type of CHD and is commoner in children with lesions that lead to pulmonary over-circulation (volume overload) or with lesions associated with outflow tract obstruction (pressure overload) (Sadoh & Osarogiagbon, 2013). The prevalence of heart failure in these patients, therefore, depends on the underlying CHD (Otaigbe & Tabansi, 2012; Sadoh & Osarogiagbon, 2013).

Also, pulmonary hypertension is another common complication of CHD. Pulmonary hypertension in children with CHD is caused by pulmonary over circulation, pulmonary vasoconstriction and pulmonary vascular disease, either alone or in combination. It is common in patients with large left-to-right shunts; with about 50% of

patients with large ventricular septal defects developing the pulmonary vascular disease (Beinstein, 2016, p. 2208). This is one of the most serious complications of CHD because it can progress and become irreversible and ultimately lead to death (Hoffman & Weisy, 2013, p. 932).

Recurrent pneumonia is also a common complication of patients with CHD especially those with lesions associated with increased pulmonary blood flow (Sadoh & Sadoh, 2013). With pulmonary overload, there is edema which encourages infection. Among patient that had pneumonia Sadoh and Osarogiagbon in 2013 found out that 11.57% was due to underlying CHD. Infective endocarditis is an infection of the lining of the heart, valve or both, it is a rare complication of CHD in children. However, in children with infective endocarditis, about 51% had background CHD (Moges et al., 2015). Children with CHD are prone to neurological complications which include cerebrovascular accident, cerebral abscess and developmental delays. The risk of developing ischemic stroke was almost 11 times higher in young patients with CHD than in the general population, although the absolute risk is low (Mandalenakis et al., 2016) Patients with CHD also represent about 20% of all stroke in the young (Dowling et al., 2013). Poor oxygen supply causes gross motor delay and learning difficulties during early life which may affect the development of the brain (Hoffman & Weisy, 2013, p. 941). Many CHD patients are prone to malnutrition due to anorexia, increased metabolism and easy satiety. About 70% of children with CHD had malnutrition (Asani et al., 2013). Children with long-standing uncorrected CHD could present with

glomerular or tubular dysfunction (Amoozgar, Basiratnia & Ghasemi, 2014; Zheng, Yao, Han & Xiao, 2013).

Prevention of CHD. CHDs may not be preventable (Hoffman, 2013). Oster et al., (2013) recommended a primary prevention strategy tailored to consumption of enough multivitamin containing folic acid by all women of childbearing age. Also, fortification of food with folic acid has been recommended (Hoffman, 2013; WHO, 2017). Screening for and control of chronic illnesses such as diabetes and hypertension during pregnancy, immunizations for vaccine-preventable intrauterine infections like rubella is also very important in the prevention of CHD (Oster et al., 2013). During pregnancy, drugs that are potentially teratogenic such as retinoic acid, anticonvulsants, opioid analgesics should be avoided. Also, smoking and alcohol consumption, as well as exposure to heavy metals, pesticides, and, organic solvents, should be avoided (Oster et al., 2013). Women of childbearing age who are obese should be enrolled in weight reduction programs because obesity has also been shown to increase the risk of CHD in pregnancy (Centre for Disease Control & Prevention, 2017).

Also, genetic counseling should be offered to families with an increased chance of having a child with CHDs (National Birth Prevention Network, 2017). Also, fetal echocardiography can be done in the second trimester at about 18 to 22 weeks to enable detection of any heart disease in the fetus (Kleinman, Glickstein, Krishnamurthy & Votava-Smith, 2013, p.1306. Early identification of children CHD by pulse oximetry screening soon after delivery is being advocated in some centers even though not all

CHDs are detected after birth (Center for Disease Control and Prevention, 2017; Hoffman & Weisy, p. 1180).

Epidemiological Information on Congenital Heart Disease,

Prevalence and Incidence of Congenital Heart Disease Among African Children

..... Few data are available about the pattern of CHD in West Africa (Jordan & Scoll, 1989, p.38). The availability of a few data is attributable to the fact that Paediatric echocardiography has not been widely available in Nigeria and some other African Countries. In the few centers where Paediatric echocardiography services are available; its optimal use is being hampered by factors such as cost, scarcity of skilled workforce, personnel and absence of appropriate probes. Echocardiography is a cheap, portable and non-invasive tool which provides reliable and reproducible information on the structure, function and hemodynamic status of the heart (Wyman, 2006).

Ibadin, Sadoh, and Osarogiagbon (2005) at the University of Benin reviewed 10,549 children aged 16years and below over a nine-year period (1995-2004) who attended the out-patient department and found Only 49 with CHDs. Commonest Acyanotic CHD was VSD 55.1%, with AVCD and ASD at 8.1% and 4.1% respectively. TOF was the commonest Cyanotic with 28.6%.

Asani, Sani, Karaye, Adeleke and Baba (2007) reported the echocardiogram in Aminu Kano Teaching Hospital of 108 children aged two weeks to 18 years over a period of 24 months and found abnormal echocardiogram in 88 children with CHD having a higher percentage of 62.5%. ventricular Septal Defect (VSD) was the commonest echo diagnosis present in 56(45.9%), 15(12.3%) had ASD. 32(26.2%) had TOF, which was the

most frequent cyanotic anomaly. Okoromah, Ekure, Ojo, Animasahun, and Bastos (2008) in Lagos reported the echocardiographic findings of 297 children aged four weeks to 15 years over a period of two years and documented structural heart disease in about 90% of the children with significantly higher proportion (84%) of them having CHDs. 41.7% had VSD, 20.2% had ASD. Commonest cyanotic was TOF with 11.8%, PS with 3.1% then Single ventricle and TGA, each with 2.2%.

Furthermore, Chinawa et al., (2013), at the University Teaching Hospital, Enugu reviewed cases of 31,795 children attending outpatient department over a 5year period (2007-2012) aged 6month-12years. Only 71 had CHDs, giving a prevalence of 2.2 per 1000. 29.6% had VSD, AVCD 5.7%, and ASD 4.2%. TOF was the commonest Cyanotic with 19.8%, Tricuspid atresia 4.2%. Similarly, Massoure et al., (2013) in their analysis of the echocardiogram of 156 children aged 1month-15yrs over a period of two years between 2009-2010, in Djibouti found cardiovascular disease in 32 (20%) of them. 27(84%) had CHD, VSD was the commonest Acyanotic CHD with 28% followed by ASD with 13%. TOF was the commonest Cyanotic 9% and TGA 2%.

Tantchou et al., (2011) at the St Elizabeth Catholic Hospital, Cameroun, recruited 292 subjects over a period of six years; (2002-2008) using presence of murmur and/or cardiomegaly on Chest X-ray examination, or CHD on transthoracic Doppler echocardiography examination and found CHD in 95.5% of the subjects. Isolated VSD was seen in 38.8% followed by PDA 12.4%. TOF was also found as the commonest Cyanotic CHD with 26.1% and double outlet right ventricle (DORV) 2.1%.

Ibrahim, Abdelrahman, and Elshazali (2012) studied the pattern of heart diseases in children at Ahmed Gasim Cardiac center, Khartoum over a period of 5 months of children with suspected heart diseases aged 16 years and below. Out of 180 patients with suspected cardiac disease from history and clinical examination, 143(89.4%) had congenital heart disease. VSD was the commonest Acyanotic CHD with 34.3%, PDA 9.1%, and ASD 7%. TOF was the commonest Cyanotic with 13.3%.

Also, Kennedy and Miller (2013) reported an analysis of the echocardiogram of 250 children who presented at an outpatient clinic in Malawi over 37 months and found heart disease in 139 of them; 55.6% had CHD. VSD was found to be the commonest Acyanotic with 24%, PDA 7.2% and AVCD 5.2%. TOF was 10%, TGA 3%. Although the age range of children was not specified.

Mortality, Morbidity, and Healthcare Burden of Congenital Heart Disease

CHD is the most common inborn defect and the main cause of infant death from congenital disabilities. (Boneva et al., 2001; Fernandes et al., 2011). CHD is a cause of morbidity and mortality in children as they are the most frequent congenital disabilities in children (Animasahun et al., 2014; Animasahun, 2016). Worldwide prevalence of CHD among newborns and infant vary between 3 and 14 per 1000 live births (Hofmann, 2013). Each year more than 4.3 million children in the United States are born with CHD and about 1 million children are estimated to be living with the defects; CH are the leading cause of death in infants with congenital anomalies (Animasahun, 2017a; Gilboa et al., 2016). According to the World Health Organization (2011), it accounts for about 4.2% of all neonatal deaths after excluding infectious diseases. CHD account for more deaths

in the first year of life than any other condition (World Health Statistics, 2011). In Nigeria, a CHD incidence of 4.6 to 10 per 1000 children has been documented in hospital-based studies (Ibadin et al., 2005; Okoromah et al., 2008). The cost implication of CHD is enormous and is shared by the family, hospital and the government. The cost of procuring medication and surgical treatment is usually more than anticipated (Czosek & Anderson, 2016; Falase et al., 2013; Hoffman, 2013).

Literature Review

Mahdi, Hashim, and Ali (2009), surveyed 100 Sudan children with age between 6 months and 15 years with CHD and their parent on the knowledge, attitude, and practice of parent towards their children with CHD, and the impact of their knowledge on the growth of the children. Only 30% of the parents were able to name their children heart defect correctly, 21% were able to indicate their children heart defect on a heart diagram correctly. Parent knowledge of their children heart defect was significantly correlated with the parent educational level, cardiac diagnosis and the occupation of the parent. Only 36% had a good knowledge of CHD, while 64% had a poor knowledge.

It has been observed that parents of children with CHD or other heart defects face challenges when caring for these children, as most of these defects require long-term treatment and care. However, there has been no published study in Tanzania to identify parents' knowledge levels about their children's CHD. Ndile and Kohi (2011) assessed the knowledge of parents of children with CHD about their children's CHD, their medication and the prevention of complications at a hospital in Dar es Salaam, Tanzania using a modified version of Leuven's questionnaire for assessing parents' knowledge

about their children's CHD in 84 parents. The study was quantitative, descriptive, cross-sectional in design. Up to 43% of the parents could not give a meaningful explanation of their child's CHD and 76.2% were unable to mention the symptoms of deterioration of the child's specific heart defect. Knowledge about the side effects of drugs and interactions with other drugs or food were low. Parents' understanding of their children's CHD or heart defects were found to have correlated with the parents' educational backgrounds.

Fernandes et al., (2011) in a multicenter study administered questionnaires to parents of children with moderate and complex CHD to assess parental knowledge regarding lifelong CHD among 500 parents. The patient age ranged from 2 to 18 years. Up to 81% of the parents understood that their child would need LLCCC but only 44% understood that their child cardiology care should be guided by an adult cardiologist when the child becomes an adult. Parental knowledge was significantly associated with parental education, previous discussion on long life congenital cardiac care and an underlying cardiac surgical diagnosis. The study concluded that a substantial number of parents of children with moderate and complex CHD lack knowledge about LLCCC but most of the parent were willing to learn more about the care that their child will require as an adult. Development of an educational program to increase awareness of LLCCC in the different phases of care transition was recommended. In the minimum sample size was not calculated, subjects were not selected randomly but by convenience making generalizing the findings of the study difficult. Also, only parents of children with only four categories of cardiac defects were included in the study

Patients with CHD and their parents need to have enough knowledge on their condition, treatment, medication, and preventive measures. Yang et al., (2013) translated the LKQCHD into Chinese to test its validity to be used in patients with CHD and their parents in 89 pairs of adolescents with CHD and their parent. Five experts in CHD and research methods were involved in testing the content of the questionnaire. The study showed a high item-level content validity index, (>0.78 in all except two items), high scale-level content validity index (>0.90), high free-marginal multirater Kappa (>0.75), and low average proportion of missing values (0.49% in adolescents; 0.51% in parents), showing an excellent content validity. The study also confirmed a hypothesized positive correlation between parental knowledge and parental educational level and between patient's knowledge and patient's age, as well as the hypothesis that parents have more knowledge than their children, were confirmed. The authors concluded that the Chinese version of the LKQCHD was valid to assess the level of knowledge in patients with CHD and their parents.

Lobe et al., (2011) administered the Hannover Inventory of Parental Knowledge of Congenital Heart Disease; which consisted of eight subscales covering general knowledge of cardiac functioning, signs and symptoms of the child's individual CHD before and after treatment, type of individual CHD and treatment, management of CHD, surveillance of deterioration, endocarditis, and physical activity to one hundred thirty-seven mothers immediately after their children underwent CHD surgery. The questionnaire has satisfactory psychometric properties. Knowledge on most dimensions was satisfactory, but it was rather poor concerning important subscales as endocarditis

and surveillance of deterioration. Parents had satisfactory knowledge of CHD in some areas, but knowledge about preventive behaviors turned out as rather poor. There is a need for improvement in mother's knowledge was recommended to make parents capable to take their share of after-treatment care.

Yang et al., (2013) evaluated patient and parental knowledge of CHD to explore the related factors of their respective disease knowledge in 116 adolescents with CHD aged 12–18 years, and one of their parents comprising mothers mainly using the Leuven Knowledge Questionnaire for Congenital Heart Disease. A correct rate score to determine the overall disease knowledge of the respondents were calculated. The corrected rate score for the adolescents was 38.8% while that of the parent was 51.4%. Parent's knowledge was found to be significantly related to their educational level ($p < .001$) while those of the adolescents was significantly related to age. Parents and patient's knowledge of CHD were found to be suboptimal, although parents had significantly greater disease knowledge than their children. An educational intervention which should target both adolescent patients and parents was recommended.

Animasahun et al., (2014) evaluated the effect of socioeconomic class on the perceptions of 300 caregivers of children with CHD using a descriptive and cross-sectional questionnaire survey in a tertiary pediatric cardiac center over a four-year period. Forty percent of the caregivers had not heard about CHD; those in the upper socioeconomic class had better awareness ($P = .02$). Seven (2.3%) of the respondents had a good knowledge of the indicators, while 9.6% had a fair knowledge, almost 60% of the respondent had a poor knowledge, and up to 30% had no knowledge of the pointers to

CHD. Nearly one-fifth (19.3%) of the respondents were not aware of any treatment options for children with CHD. However, 12.7% of the respondents knew the best mode of treatment, and only 43% of the respondents believed CHD could be prevented. They concluded that most parents of children with CHD had poor knowledge of CHD, its indicators, its best mode of treatment, and its preventability, irrespective of their socioeconomic class and suggested an urgent need to develop an educational program to promote a better understanding of CHD among caregivers. Unfortunately, the above article did not state any research questions and hypothesis, neither was any theoretical or conceptual framework used, although the questionnaire was self-generated. It was neither validated nor was the sample size calculated. Also, the article did not set out to cause any social change, or be a voice for children with CHD through advocacy; to the management of LASUTH, politicians at the local government, state and federal level, opinion leaders and policymakers on health.

Lesch et al., (2014) assessed the level of disease-specific knowledge, information Preferences, and sources of information for children, adolescents, and young adults regarding their illness of 596 patients aged 10-30 years in a cross-sectional survey. Only 52.7% were able to name their defect correctly. The knowledge of the defect was significantly related to age as children gave fewer correct answer compared with adults. Those with moderate to complex lesion were more likely to name their defect correctly compared with those with the milder lesion. Male patients with CHD were more interested in information concerning work and career issues while females were more interested in information concerning pregnancy and family planning. The information

preference differed based on age. About 71% of the subjects got information on their heart defect from doctors, 58.2% from family and friends and 37.5% from the internet. Female patients used the internet more than males. The study concluded that the subjects had substantial knowledge gaps. A multi-disciplinary patient-centered education program which should start from childhood was recommended.

Staveski et al., (2015) carried out a pilot study on to generate preliminary data, on the feasibility and acceptability of the nurse-led structured discharge program, on an Indian pediatric cardiac surgery unit using a pre-/post-design. Questionnaires were used to evaluate role acceptability, nurse and parent knowledge of discharge content, and utility of training materials of 40 nurses and 20 parents. They found that the Nurses' discharge knowledge increased from a mean of 81% to 96% ($P = .001$) after participation in the training. Nurses and parents reported high levels of satisfaction with the education materials (3.75-4 on a 4.00-point scale). Evidence of discharge teaching documentation in patient medical records improved from 48% (12 of 25 medical records) to 96% (24 of 25 medical records) within six months after the implementation of the PEDI program. They concluded that structured nurse-led parent discharge teaching program demonstrated feasibility, acceptability, utility, and sustainability in the cardiac unit and suggested future studies to examine nurse, parent, child, and organizational outcomes related to this expanded nursing role in resource-limited environments.

Daily et al., (2015), asserted that parental understanding of their children's heart disease was inadequate, and may contribute to poor health outcomes. The authors determined what parental knowledge was important in the care of children with heart

disease from the perspective of parents, nurses, and physicians using a qualitative research method. Focus groups were formed with parents of children with single ventricle CHD, biventricular CHD, and heart transplantation, and with nurses and physicians who provide care for these children. A nominal group technique was used to identify and prioritize important parental knowledge items and themes. The voting data for each theme were reported by participant type – parent, nurse, and physician – and patient diagnosis – single ventricle CHD, biventricular CHD, and heart transplantation. Parents, nurses, and physicians were found to have both common and unique views regarding what parents should know to effectively care for their children with single ventricle CHD, biventricular CHD, or heart transplantation. Specific targeted parental education that incorporates these findings was recommended to be provided to each group. Further development of questionnaires regarding parental knowledge with appropriate content validity was also suggested. The above study had a small sample size of 34 parents who participated, the minimum sample size was not calculated, subjects were not selected randomly but by convenience, making generalizing the findings of the study difficult.

Survivors of CHD are at risk for life-threatening complications as they age. Jackson, Tierney, Daniels, and Vannatta (2015) examined the association of knowledge of future health risks, perceived risk, and health behaviors among 199 adolescents and adults with CHD aged 15-39 years with simple, moderate and complex lesions. CHD survivors reported poor risk knowledge and consuming high-fat diets. Adolescents reported more physical activity than young adults. Greater risk knowledge was associated with lower fat intake, and participants who exercised more expected fewer future

complications, and this difference remained statistically significant when accounting for education and age. The authors concluded that CHD survivors, regardless of age, have poor risk knowledge and diets. Survivors may benefit from an emphasis on future health risks and health behaviors from both pediatric and adult providers.

Parental knowledge of a child's heart disease, treatment, and prevention of complications may promote a better health-related behavior towards the care of the child. Asani, Aliyu, and Gambo (2016) observed that most of the children with CHD under their care often present with failure to thrive which the parents were not associating with the disease. The authors aimed at determining the knowledge of parents of children with CHD and the impact of the disease on their growth in their cross-sectional study consisting of parents and children with CHD attending the Pediatric cardiology clinic of Aminu Kano Teaching Hospital. Using pre-tested questionnaires containing data such as age, anthropometric parameters, educational level of parents and knowledge of their children's cardiac defect on 103 parents. Only parents who had been attending the Paediatric cardiology clinic for at least six months were included. The study showed that only 88.3% of the parents knew the correct cardiac diagnosis. The knowledge of the diagnosis had no statistically significant association with their educational status. Maternal educational status was found to be statistically significantly associated with their ability to name the medications ($p=0.008$). The authors concluded that adequate knowledge will ensure better compliance with medications which can reduce morbidity and early mortality before surgical intervention. Continuous patient/caregiver education was recommended to ensure long time survival of patients with CHD.

Gaps in Prior Research

All the report assessed the knowledge of parents or patients with CHD. The problems although stated, evidence to support the problems were provided and the implication on the subject. However, the research questions were not stated, the hypothesis was also not stated in some of the studies, there was also a lack of calculation of sample size. To the best of this researcher's knowledge, and after a careful literature search. There appears to be no report on the knowledge of parents and caregivers of children with congenital heart disease in the South-western part of Nigeria. Especially those accessing care at LASUTH for CHD hence the need for this study which aimed to assess the knowledge of parents and caregivers of children with CHD accessing care at LASUTH using a modification of the LKQCHD (Van Deyk et al., 2010).

Summary

The literature review indicated that congenital heart disease is an important cause of morbidity and mortality among children causing a high burden on the healthcare system, especially in a resource-poor setting like Africa. Parent education is important to ensure early presentation, diagnosis and management to be able to ensure compliance to medication, treatment, follow up and preventive measures. Unfortunately, a various report has indicated poor knowledge of congenital heart disease among parents, and caregivers. The current research aimed to assess the knowledge of parents and caregivers of patients with congenital heart disease on the disease. Chapter 3 presented the information on the methodology of the research.

Chapter 3: Research Method

Introduction

The current study documented the knowledge of parents and caregivers of children with CHD accessing care at the Lagos State University Teaching Hospital (LASUTH) using LKQCHD and the relationship between the demographics of the caregivers and parents of children with CHD and their knowledge on CHD.

Consequently, the goal of the study was to present data on the level of knowledge of these caregivers and parents on CHD. The study has supported the need for regular and periodic training and education of parents and caregivers as a way of improving awareness regarding CHD among parents and caregivers in Lagos and among policymakers and the government at the federal, state, and local government level.

Improved awareness of parents and caregivers of children with CHD accessing care at LASUTH on CHD is expected to lead to improved awareness of CHD in Lagos which is expected to translate into early recognition of the symptoms suggestive of CHD among children with CHD in Lagos. It will, in turn, encourage early presentation, diagnosis, and intervention, improved drug compliance, follow up, and prognosis in patients, and reduce morbidity and mortality due to CHD among Nigerian children, reducing the burden of the disease on families and the health system. In this chapter, I presented major components of the research methodology, design, rationale, role of the researcher, participants, setting, procedure, data analysis, ethical considerations, and informed consent as permitted by the Institutional Review Board (IRB).

Research Design and Rationale

The research questions that guided the study were:

RQ1: What is the level of knowledge of parents of children with CHD attending the Lagos State University Teaching Hospital regarding CHD?

RQ2: How does age, level of education, occupation, and number of years of accessing care affect the level of knowledge of parents at the Lagos State University Teaching Hospital regarding CHD?

Variables

The research design was quantitative, using a quasi-experimental method. It was a prospective and correlational cross-sectional survey. A quantitative design was used because the study involved collection of numerical data which described the relationship between variables. This study used a nonprobability sampling method which was purposeful and consecutive. Studies with quantitative design also has the advantage of being able to study larger sample sizes compared to a qualitative design. It takes less time and less protocol is involved concerning entry into LASUTH to obtain permission to carry out the study. In studies with quantitative design, the researcher may not have direct contact with the subjects and participants in the study because questionnaires can be sent and filled online. Studies with quantitative design involves the validation of a theory; studies with quantitative design focuses on giving answers to specific research questions or hypotheses. Also, studies with quantitative design deal with variables which include dependent and independent variables, and data are generated and analyzed using appropriate statistical methods which are also used to answer research questions. The

results obtained from studies with quantitative design can be presented using text, charts, and tables (Creswell, 2009).

The challenges that I faced during data collection for the study included the high costs of typing, printing, photocopying questionnaires used in the collection of the data. This was because a large sample size was involved. It was also time-consuming, which translated to higher costs in terms of time involved in the data collection which also increases the costs of collecting the data. The qualitative research method also requires obtaining more permissions from the management of LASUTH and individual participants since more intimate questions in terms of perceptions are usually involved, it is more in-depth than the quantitative research method. Also, qualitative methods include smaller sample sizes which do not often require calculation of minimum sample size, hence the result cannot be generalized. It takes a longer time for data collection and analysis. It involves direct participation of the researcher and may involve personal inquiries from the participants. The result obtained from a qualitative study may be affected by the personal bias of the researcher due to the involvement of the direct interaction of the researcher with the participants.

Description of the Study Center

LASUTH is one of the two teaching hospitals in Lagos. It is a 550 bedded hospital and the estimated population of Lagos is 21 million people. The hospital is an urban tertiary center located in the heart of Lagos, Southwestern Nigeria. It serves as a referral center for public and private hospitals in Lagos and her neighboring states like Oyo, Ogun, and Osun and serves a population of more than 30 million Nigerians.

LASUTH has seven clinical units which are internal medicine, behavioral sciences, family medicine, obstetrics and gynecology, pediatrics and child health, community health, and the primary health care unit. It also has nonclinical units including pathology units such as morbid anatomy and forensic medicine, hematology and blood transfusion, blood chemistry and chemical pathology, and parasitology and microbiology. The hospital provides care in all fields of internal medicine, and is known for its special expertise in cardiology, with its own CICU. It also provides renal dialysis, obstetrics and gynecology services, pediatrics, and child health services including pediatric cardiology. Also, all fields of surgery services are available (including endoscopy and day-case surgery), ophthalmology, and ear, nose, and throat (ENT).

In addition to the clinical services, the hospital also provides laboratory services in all non clinical units including radiological and radiotherapy services. The hospital has facilities for inpatients and outpatient care. Also, the hospital is attached to a college of medicine, the Lagos State University College of Medicine (LASUCOM), it has accreditation of both Postgraduate Colleges in Nigeria. The National Postgraduate Medical College of Nigeria, and The West African Postgraduate Medical College to train resident doctors in all the various clinical and non-clinical units and their subspecialties as mentioned. The hospital also has accreditation of the Medical and Dental Council of Nigeria for internship for the newly graduated doctors, pharmacist, radiographers, and physiotherapists. Apart from the training of doctors, the hospital is also the center for the acquiring of clinical and non-clinical skills by medical students under training at LASUCOM.

LASUTH is unique in Nigeria as the busiest tertiary institution, with a heavy load of patients from various part of the country (Animasahun, Ubuane, Gbelee & Njokanma, 2017). The center also receives students on elective posting from various parts of the World. It serves as a referral center for not only more than twenty general hospitals in Lagos, but also private hospitals and federal medical center in Lagos. It receives patients from South Western Nigeria and from all over the country especially Paediatric patients due to the free health policy for the under twelve years of age (Animasahun et al., 2017; Animasahun, Madise-wobo, Falase & Omokhodion, 2016a)

The current study was carried out at the Paediatric general outpatient department of LASUTH. The Department of Paediatrics has an 83 bed-ed ward (Animasahun et al., 2015b). The department also has an outpatient unit which runs a general outpatient clinic on weekdays and subspecialty clinics including Pediatric cardiology clinic where a Paediatric Cardiologist oversees the unit. Children are referred from within the state and in the sub-region for cardiac evaluation (Animasahun, Madise-wobo & Gbelee, 2016b). Patients referred to the cardiology unit of the Department are evaluated and treated as required (Animasahun et al., 2015b).

Role of the Researcher

As a researcher, I was the primary observer and collector of information from the participants. I collected data on the knowledge of caregivers and parents of children with CHD on CHD and the relationship of their demographics with their knowledge on CHD. I administered a questionnaire which contained information on the participant's demographics and questions used in assessing knowledge on CHD as in the modified

version of the Leuven Knowledge Questionnaire for CHD (LKQCHD) (see Appendix B). I also used the coding manual for LKQCHD to interpret the participant response. The LKQCHD was used after obtaining permission from Phillip Moon who is the author (see Appendix C). I also scored the knowledge of the participants and interpreted the level of knowledge of each participant, I did the data entry, analysis, and interpretation.

Methodology

Population Definition

My study populations were caregivers and parent of children with CHD which were either on admission at the Paediatric ward or attending the Paediatric cardiology clinic at the outpatient unit of the Department of Pediatrics at LASUTH. Parents and caregivers of children with CHD were the populations I concluded the findings of the study on. I also defined the sampling unit which was a single member of a sampling population. For the proposed study the sampling unit was either a parent or caregiver of children with CHD which were either on admission at the Paediatric ward or attending the Pediatric cardiology clinic at the outpatient unit of the Department of Paediatrics at LASUTH.

Sampling

Sample Size Calculation

The necessary sample size for the study was calculated, after considering the following three items: Statistical Power, alpha and effect size (Buckholder, n.d). Statistical Power also called power is the probability that a given statistical test will detect a real treatment effect or real relationship between variables. For my study to

detect a real relationship, a large sample size was required to ensure the likelihood of detecting a difference (or relationship) if it existed in the population. A high power also helped to prove that my finding was not due to chance alone. A power of 0.8 (80%) was used which means, if my study were repeated 100 times, the null hypothesis would be correctly rejected 80 times if there was indeed a real effect/relationship (Buckholder, n.d).

A pre-determined alpha (α) level was also used for my study. An alpha of 0.05 was used. A higher alpha level was preferred to a value of 0.01 to enable me to expand the rejection of the null hypothesis more correctly and also give my study a higher power. With an alpha of 0.05, it means that there was only a 95% chance that I arrived at the right conclusion and a 5% chance that I arrived at the wrong conclusion (Buckholder, n.d). Unlike power and alpha which were predetermined, I ideally should have calculated the effect size from a prior research on the subject. However, in my region (Africa) after a careful literature search, there did not appear to have been a previous research on the evaluation of caregivers and parents of children with CHD on their knowledge on CHD. Hence a medium effect size of 0.5 was used (Buckholder, n.d).

The sample size was calculated by running a G*Power to determine the appropriate sample size for the study, the pre-determined power and alpha were stated as 0.80 and 0.05 respectively. A medium effect size of 0.5 was used (Sheperis, n.d; Trochim, 2006). The required sample size was calculated for each statistical method that was used in the analysis of the data (Pearson correlation coefficient, ANOVA). The highest of the figure calculated was taken as the desired sample size (Sheperis, n.d). For

example, to calculate the desired sample size for means difference between two independent means, with a pre-determined alpha of 0.05, the power of 0.80 respectively and a medium effect size of 0.50 (Buckholder, n.d).

Using G*power as the sample size calculator, a sample size of 56 was calculated (Animasahun, 2016; Sheperis, n.d). Another method of calculating sample size is the use of tables. I assumed .05, 2-tailed tests. For each test, the effect size was across the top, and the power was listed down the left column. I focused on Power=.80 (Buckholder, n.d). A sample size of 60 was calculated for the independent t-test, 28 for each sample for the correlation test. The higher sample size of 60 calculated was taken as the sample size.

Type of Sampling

The sampling strategy used for the research was a purposeful convenience sampling strategy. It was purposeful because only parents and caregivers of children with CHD were studied, it was also purposeful because it was specific on CHD. It was a convenient sampling because it did not involve randomization but consecutive, willing parents and caregivers of children with CHD which were either on admission at the Paediatric ward or attending the Paediatric cardiology clinic at the outpatient unit of the department of pediatrics LASUTH were studied. The purposeful convenient sampling strategy was a non-probability sampling method (Frankfort-Nachmias, 2015). One of the advantages of the purposeful convenient sampling strategy was that, it was convenient, cheaper, and did not require the researcher to have had the sampling frame (consisting the lists of parents and caregivers of children with CHD in the whole hospital which might have been difficult to obtain from the hospital) (Frankfort-Nachmias, 2015).

Snowball samples which were another type of non-probability sampling was not used because it was not expected that some of the caregivers and parents of children with CHD were hard to reach or hidden or undocumented (Frankfort-Nachmias, 2015). It was also called chain sampling or referral sampling. It is a way of identifying future participants in a research using current participants. It is a form of purposive sampling (Sample, n.d)

The quota sampling method is another type of non-probability sampling method. that the researcher deliberately sets the proportions of levels or strata within the sample which is independent of the population characteristics. Quota sampling could be controlled and uncontrolled. In controlled quota sampling, certain restrictions are introduced which limit the researcher's choice of samples. Uncontrolled is like convenient sampling where the researcher chooses sample group members as desired. Quota sampling differs from stratified sampling because the samples are selected non-randomly (Research Methodology, 2016). It was not used because a convenient and purposeful sampling of only willing participants who gave consent to participate in the study were used. If a quota sampling was used, some of the participants in some quota might not have given their consent to participate, this would have prolonged the duration of the study unduly and affect the external validity of the study.

A probability sampling method could specify the probability at which each sampling unit of the population would be included in the sample (Frankfort-Nachmias, 2015, p. 148). It was not used because it required that the researcher obtain the list of parents and caregivers of children with CHD which was either on admission at the

Paediatric ward or attending the Paediatric cardiology clinic at the outpatient unit of the department of pediatrics from the management of LASUTH. To obtain the list of parents and caregivers accessing care at LASUTH would have required obtaining the permission from the management to use this. The permission might also not have been granted.

How the Sample was Drawn

I defined the sampling unit which was a single member of a sampling population. For the study, the sampling unit was a caregiver or parent of children with congenital heart disease which were either on admission at the Paediatric ward or attending the Paediatric cardiology clinic at the outpatient unit of the department of Pediatrics of LASUTH (Frankfort-Nachmias & Nachmias, 2008).

The inclusion criteria were consenting caregivers or parents of children with CHD which were either on admission at the Paediatric ward or attending the Paediatric cardiology clinic at the outpatient unit of the department of pediatrics LASUTH, whose child diagnosis of CHD was made at LASUTH about 6 weeks or more before recruitment. Caregivers and parents whose child diagnosis of CHD was made at LASUTH less than 6 weeks before recruitment (Asani, Aliyu & Gambo, 2016) and those who did not consent to participate in the study were excluded from the study. The strength of the sampling strategy I used was the fact that it was convenient, cheaper, and did not required the researcher to have had the sampling frame and made recruitment faster (Frankfort-Nachmias, 2015).

Instrumentation and Materials

Level of Measurements

One of the levels of measurements which was carried out in this study was the nominal level to document the gender of the respondents, their marital status, place of residence, ethnicity, and religion. For example, a respondent who was unmarried was represented with the numeral 0 while those married were represented by the numeral 1 while widows were represented by the numeral 2 and widower 3. The categorization of the subjects was also done for the respondents' ethnicity and religion. Subjects who lived in Lagos were represented with the numerals 0 while those from outside Lagos were represented with the numerals 1. For gender, male respondents were represented with 0 while females were represented with the numerals 1. For ethnicity, respondents who were Yorubas were assigned to numeral 0 while Ibos and Hausas were assigned numerals 1 and two respectively. Regarding religion, respondents who were Muslims were assigned numeral 0, those who are Christians 1 while those who believe in traditional religion and atheist will be assigned 2 and three numerals respectively.

One of the ordinal measurements which were carried out in my study was the socioeconomic status level of the respondents and also their knowledge regarding CHD. The socioeconomic status of the subjects was assessed using the educational status and occupation of both parents using the scheme proposed by Oyedeji, (1985) dividing subjects into five groups I to V in descending order of privilege. Socio-economic index scores (one to five) were awarded to each subject, based on the occupational and educational levels of parents. The mean of four scores (two for the father and two for the mother) to the nearest whole number, was the social class assigned to the child. For the study, classes I and II were grouped together as an upper social stratum, class III was

taken as the middle stratum and classes IV and V as lower social stratum (Animasahun et al., 2014). The strength of the modified LKQCHD that I used was that it had been modified to assess all other aspects of CHD. The modified LKQCHD had also been validated by getting the opinion of another specialist on it.

Additional Information from Conducting a Pilot Study

A pilot study was done by administering the questionnaire to about 5 parents and caregivers of children with CHD attending the general outpatient clinics in the department of pediatrics and child health in LASUTH. Data obtained were subjected to statistical analysis and interpreted. Statistical analysis further helped to show any ambiguity in the measuring instrument which could affect the validity of my measurement. The need for the researcher to go through the hospital record of the child of each subject individually, to be able to score the responses of the subjects to the modified LKQCHD was detected, addressed and incorporated into the study.

Data Collection and Data Analysis

Data Collection

A primary data collection method was used. The inclusion criteria were caregivers or parents of children with congenital heart disease which were either on admission at the Paediatric ward or attending the Paediatric cardiology clinic at the outpatient unit of the department of pediatrics LASUTH. The purpose of the study was explained one-on-one to each participant who satisfied the inclusion criteria. Informed and written consent was obtained from qualified participants. The researcher obtained information from the participants and filled out a questionnaire one-on-one and face-to-face. The information

obtained during the Paediatric cardiology clinic at the Paediatric out-patient unit of the Paediatric Department of LASUTH. Data collection was over a period of two months (March-April 2018). Obtaining information and filling out the questionnaire for each participant took at least half an hour for each participant. The data were imputed to the researcher's personal computer.

Secondary quantitative data are data which had been collected previously by other researchers. Secondary quantitative data are available from national, state, regional and local sources. A type of secondary quantitative data is population data such as case reports, surveillance data, and census data. Other examples of secondary data are health status data, health indicators, and health service data. The advantage of quantitative data obtained from a secondary source included the fact that the data is already collected, mostly available in the downloadable electronic format, it usually gives a larger sample size and the data may be more reliable. (Van Dijk, 2012,). The current study did not use a secondary data because, after a careful literature search, the author was not aware of any such data in the African continent.

The challenges that I faced in collecting quantitative data for my community health assessment included the high cost of expenses involved in the collection of the data, this was because a large sample size was usually involved. It was also time-consuming which translated to higher cost involved in the data collection which also increased the cost of collecting the data. Another challenge was the fact that the method of collecting quantitative data was inflexible because once the study started the research instrument such as questionnaire could not be modified. (Van Dijk, 2012,).

Data Analysis

Data were analyzed using the statistical package for social sciences (SPSS) version 21.0. (Frankfort-Nachmias, & Nachmias, 2008; Laureate Education, 2014). The data on the respondent's age, gender, religion, ethnicity, place of residence, number of years of accessing care at LASUTH were. Tables and charts were used to depict those variables. A measure of central tendencies such as mean, median, and mode were documented for continuous variables while proportions were used for nominal variables. Continuous variables for caregivers and parents were compared using the Student t test, and proportions using the Chi-square test. The relationship between the knowledge of caregivers and parents and their demographics was assessed using Pearson's correlation coefficient and ANOVA. Knowledge of caregivers and parents depending on the number of years of accessing care were compared using ANOVA. Level of significance was set at $p < 0.05$. (Frankfort-Nachmias, & Nachmias, 2008; Laureate Education, 2014).)

In analyzing the data, age was measured as a continuous score with the mean calculated while gender was categorical. The scores from the samples were determined if they were normally distributed or not if normally distributed t-test or analysis of covariance were used to compare the two groups and determine if the statistical tests were significant. (Frankfort-Nachmias, & Nachmias, 2008; Laureate Education, 2014). The results were presented in tables and figures and will be interpreted using statistical tests after which a conclusion from the result was used to answer the research question. It was stated if the result supports the hypothesis or contradict it, the reason for the results

was given using the theory and past literature, the implication of the result for practice and future research on the topic was stated.

Issue of Trustworthiness

Trustworthiness is important in data collection and its review, to ensure that the participant information was kept confidential. Interpreting the result was also very important to ensure that the information obtained was correct and that the questions were answered appropriately (Creswell, 2009). To ensure the data obtained was correct, I explained the importance of the result and how it would help improve the care of children with CHD to the participant. Other criteria recommended by Creswell (2009) for validity during data collection was followed.

Establishing Validity

In carrying out my study, the measurement was the level of knowledge of caregivers and parents on CHD. I ensured the validity of the design by choosing my subjects among the caregivers and parent of children with congenital heart disease randomly after stratifying them into groups based on their socio-economic groups, and the number of years assessing care, ethnicity, age, gender and religion. I also ensured the internal validity of the design by ensuring that the attrition level was kept to the barest meaning minimum, and the study was carried out within a short time to ensure factors that referral of patients or interventions over time did not serve as a confounder in my study.

The instrument I used was a questionnaire which was a modification of the LKQCHD. To ensure the content validity of this instrument. I did a face validity of the

questionnaire to ensure it adequately assessed the knowledge of caregivers and parents of children with CHD in Lagos on the type of CHD, the clinical features, treatment modalities, complications and prevention of CHD. The face validity of this questionnaire was also done by consulting specialists in the field of CHD to look at the questionnaire and commented if the questionnaire could assess all the various aspects of information on CHD listed. I also ensured the face validity of the designed questionnaire, by comparing it with another questionnaire that had been designed to assess knowledge on CHD, such as the Hannover Inventory of Parental Knowledge of Congenital Heart Disease (Lobe, Geyer, Grosser, & Wessel, 2012). There was a consensus among the specialist and the comparison with another questionnaire.

I also ensured there was sampling validity of the measurement by ensuring that the questionnaire covered questions on all aspect of CHD. I also ensured this by ensuring that the questions in the questionnaire were clear enough to be understood by a non-medical person. To ensure the empirical validity of my measurements in assessing the knowledge of parents and caregivers in Lagos on congenital heart disease. I correlated the result gotten with my measuring instrument with the result gotten using another method of assessing their knowledge on this subject.

To ensure the construct validity of the questionnaire to ensure the validity of my measurement, I administered the questionnaire to some parents and caregivers attending the general outpatient clinics in the department of pediatrics and child health in LASUTH. Administering the questionnaire to these parents helped to show any

ambiguity in the measuring instrument which could affect the validity of my measurement.

Establishing Reliability

I ensured that my measuring instrument was reliable by using the split-half method or the parallel for technique. The test-retest method had a limitation because some of the parents or caregivers might have taken note of the questions in the questionnaire which when re-administered to them may make their responses change and hence give the impression that the questionnaire was not reliable. The test-retest method may also be limited by the fact that some of the parents or caregivers might have been transferred from the initial unit before the re-test.

Dependability and Confirmability

As already done above under the sections on population definition and how the sample was drawn, the detail of the process of selecting participants has been well documented. I also ensured that similar procedure was used for obtaining information from all the participants during the data collection process. The documentation was checked and re-checked intermittently throughout the process. Changes in the setting if any and how it may affect the study approach would have been well documented (Trochim, 2006, p. 1). A detailed documentation has been done to make other investigators replicate this study and also explore an area of further research on the knowledge of caregivers and parents of children with CHD.

Ethical Considerations

Written permission to conduct the study was obtained from the Research and Ethics committee of LASUTH. Permission was also be obtained from the Institution Review Board of Walden University. Informed and written consent was obtained from each participant after explaining the goals of the study to them. Confidentiality and privacy were maintained. The participants were identified with numbers and not name. The participants were free to choose whether to participate or not at any given time during the research study. There was no known risk to participants in the proposed study. Although participants might have experienced emotional issues such as sadness, regrets, denial or guilt but no physical harm resulted from taking part in the study. Data were treated with the utmost care and safety (Creswell, 2013; Rudestam and Newton, 2015). The researcher validated the result and was the only one who had access to the data.

Summary

Parents and caregivers of children with CHD have poor knowledge of CHD. The purpose of Chapter 3 was to describe the research design and methodology and explain the criteria used for the selection of the participant recruitment. The rationale for choosing the research design, data collection, data analyzes, and sample population was also provided. I also included a discussion on credibility, dependability, reliability and ethical considerations for participation in the study.

Chapter 4: Results

Introduction

To answer the two research questions, the statistical tests that were used were Chi-Square, Fisher's exact test, Pearson's correlation coefficient, and Analysis of variance (ANOVA) These tests had the combined result of determining if there were associations between the independent and dependent variables. A total of 60 caregivers of patients with CHD participated in the study. One of the independent variables assessed in the current study was the age of the parents and caregivers of children with CHD. The age distribution of the subjects is shown in Figure 1.

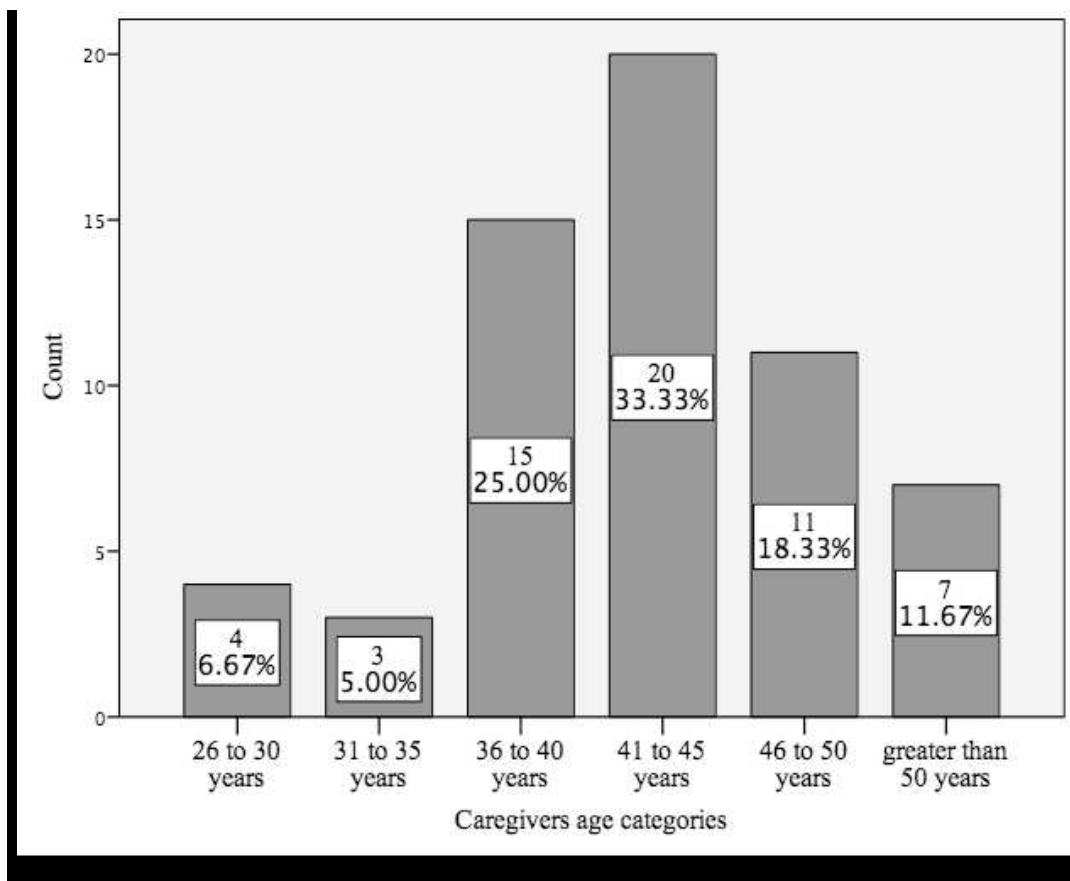


Figure 1. A bar chart showing the frequency of the age distribution of the subjects in years.

The age range of the subjects was 28 to 60 years with a mean \pm SD of 42.35 ± 7.24 years. The majority (83%) of the respondents were above 35 years of age, with 12% above 50 years of age. The age bracket above 35 years of age where the majority of the subjects belong is considered middle age. Also, the age category with the highest frequency of parents and caregivers of children with CHD is age 41-45. The mean age of the subject and the relationship between age and the level of knowledge of subjects on CHD will be needed to answer the RQ2 in the current study. Of importance also is the age of children with CHD whose parents and caregivers were the subjects in the current study. The age category of children with CHD whose parents were studied is enumerated in Table 1.

Table 1

Age Range of Patients with CHD whose parents and caregivers were subjects

Age of patients with CHD	Frequency	Percent
Less than 1 year	3	5.0
>1 to 5 years	5	25.0
>5 to 10 years	22	36.7
> 10 to 15 years	17	28.3
>15 to 20 years	3	5
Total		60 100.0

The age range of children with CHD whose parent were subject in the current study was 6 months to 19 years, with the highest proportion of patient with CHD between the ages of 5 and 10 years of age. Only 5% of the children with CHD were less than one-year-old or above 15 years respectively. The majority (95%) of children with CHD whose parents and caregivers were studied were above 1 year of age. This may suggest delayed diagnosis or intervention (surgical or nonsurgical) in children with CHD whose parent were studied. Delayed diagnosis or intervention may reflect poor knowledge of CHD among the subject which was addressed by RQ1. The gender of the subjects is one of the independent variables in the current study. Accordingly, 85% of the subjects were males while 15% were females. The relationship of the subjects to patients with CHD is enumerated in Figure 2.

Up to 53 (88.3%) of the subjects were married, 3 (5%) were single, 2(3.3%) were widowed, 1(1.67%) was divorced and 191.67% was also separated. The relationship between gender of the subjects and the level of knowledge of subjects on congenital heart disease will be needed to answer the RQ2 in the current study. The level of education of the subjects is also one of the variables assessed in the current study. The highest level of education of the subjects is shown in Table 2.

Table 2

Level of Education of the Subjects

Highest Level of Education	Number	Percentage
None	1	1.67

table continued

Primary	32	53.3
Junior secondary	3	5
Senior Secondary	21	35
Tertiary	3	5
<hr/>		
Total	60	100

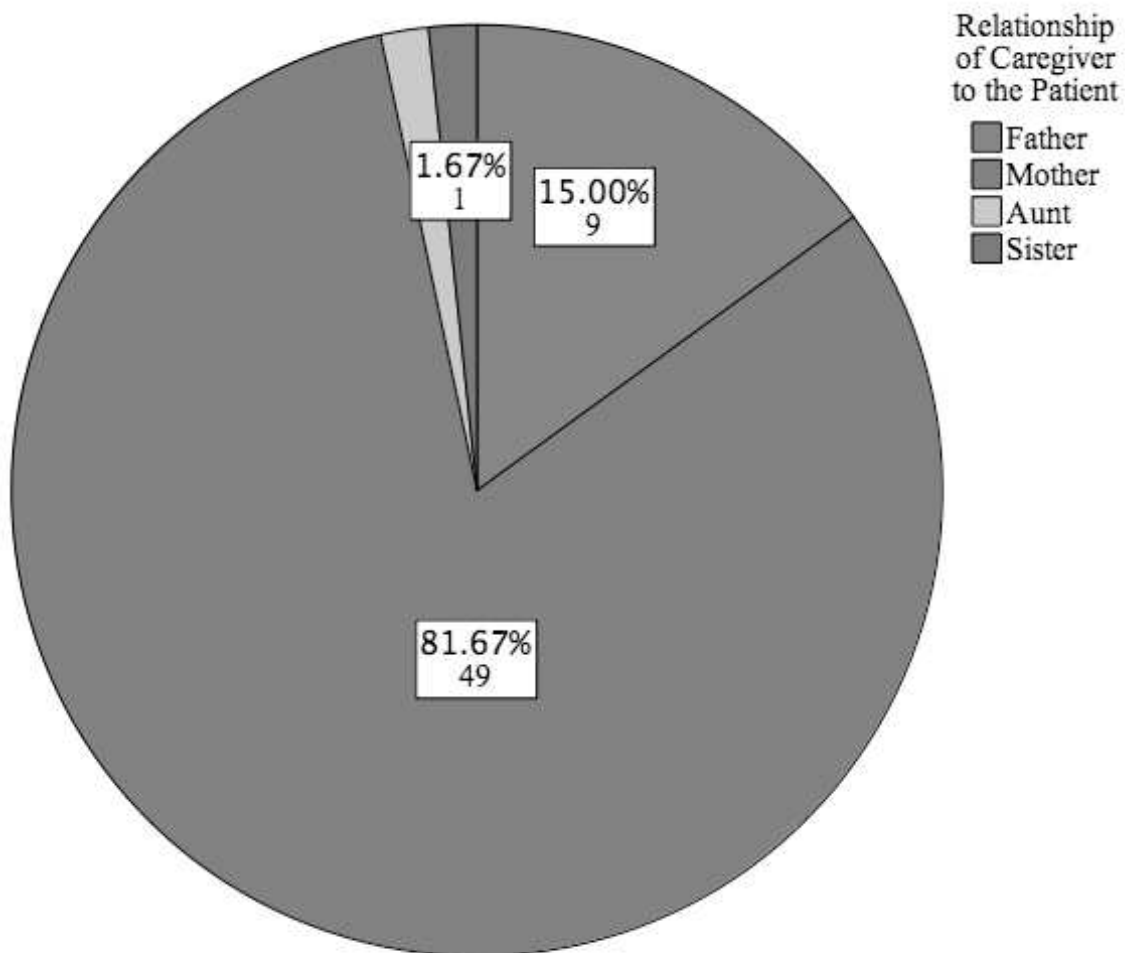


Figure 2 Pie chart showing the relationship of subjects to patients with congenital heart disease.

More than half of the subjects had only a primary school education. About 40% had secondary school education and only 5% of the subjects attained the tertiary level of education. There was no statistically significant difference in the level of education of the subjects ($p = .8$).

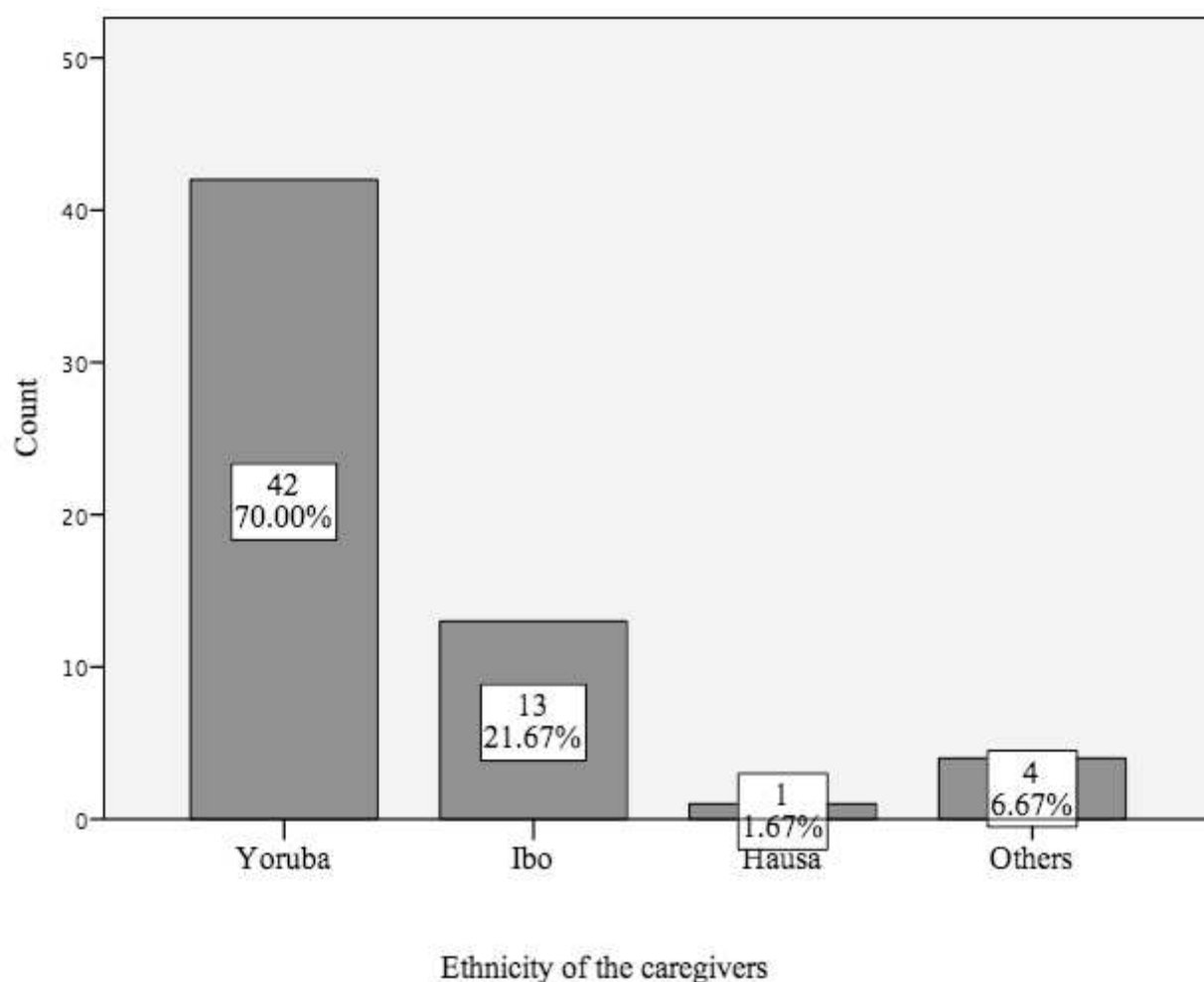


Figure 3: A bar chart showing the ethnical characteristics of the subjects

One of the demographic characteristics of the subjects assessed as an independent variable was the ethnicity of the subjects. The bar chart shows the ethnic distribution of the subjects. The majority (70%) were of the Yoruba ethnic group, followed by the Ibo ethnic group and the others. Hausa ethnic group was the least represented. There was no statistically significant difference in the various ethnic distribution ($p = .8$). Another demographic characteristic which was assessed in the subjects as an independent variable was the religious beliefs of the subjects.

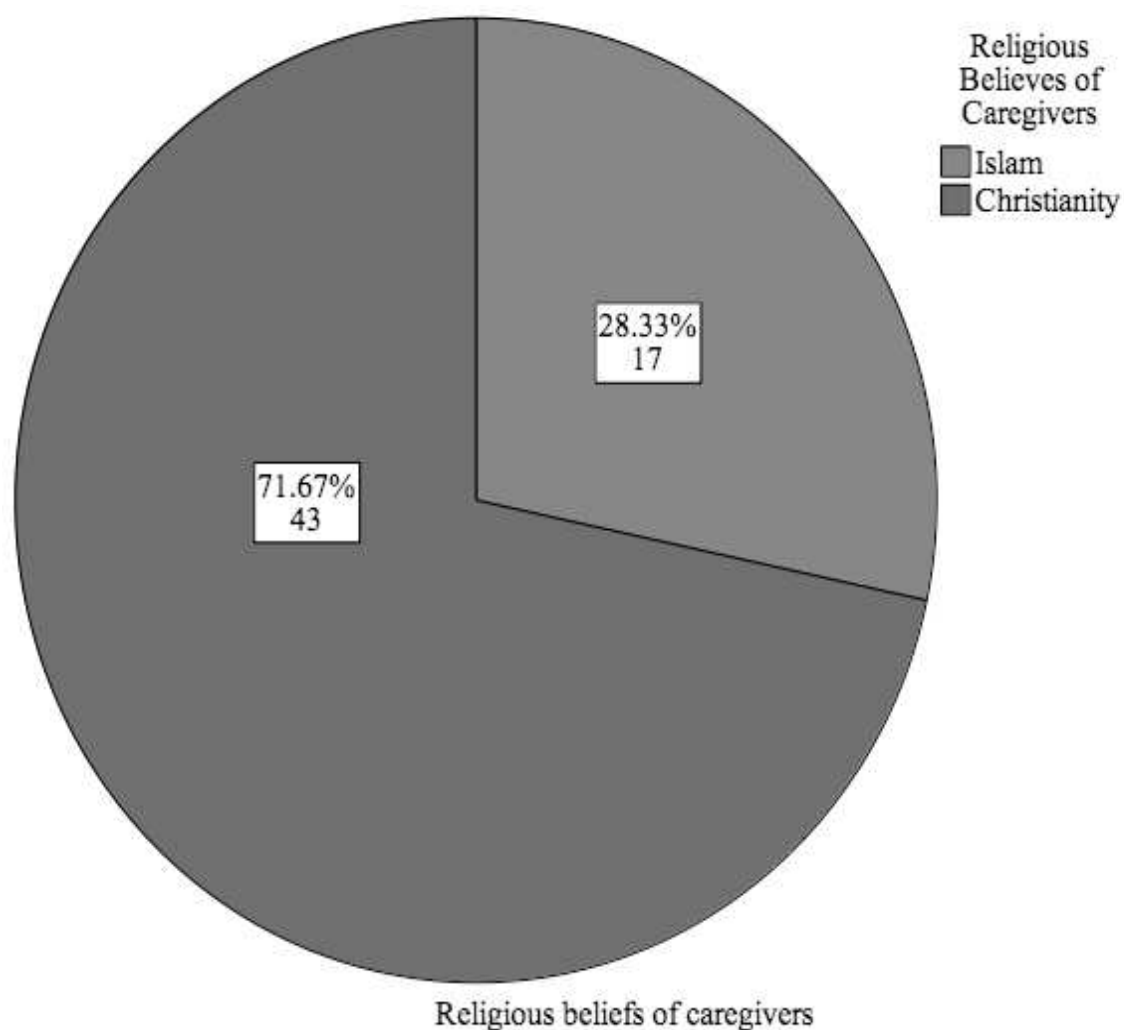


Figure 4: A pie chart showing the religious beliefs of the parents and caregivers of children with CHD studied. The majority (71.67%) of the subjects were Christians while others were Muslims. There was no statistically significant difference in the religious beliefs of the subject ($p = .2$). The socioeconomic status of the subjects was assessed using the educational status and occupation of both parents using the scheme proposed by Oyedeji, (1985) dividing subjects into five groups I to V in descending order of privilege. Socio-economic index scores (one to five) were awarded to each subject, based on the

occupational and educational levels of parents. The mean of four scores (two for the father and two for the mother) to the nearest whole number, was the social class assigned to the child. For the study, classes I and II were grouped together as an upper social stratum, class III was taken as the middle stratum and classes IV and V as lower social stratum (Animasahun et al., 2014). The socioeconomic distribution of the participants is shown in Table.

Table 3.

Socioeconomic Classes of the Subjects

Socioeconomic class	Frequency	Percent
Upper	29	48.4
Middle	22	36.7
Lower	9	15.0
Total	60	100

There were more subjects in the upper socioeconomic class, followed by the middle socio-economic class, with the lower socioeconomic class having the least proportion of 15%. There was a statistically significant difference among the various socio-economic classes ($p = .02$). Hence there were more subjects in the upper socio-economic class, the more subjects in the higher socio-economic group are expected to translate to more knowledge among the subjects to be able to address the RQ1.

Also, one of the independent variables assessed in the current study is the number of years of accessing care at the study center, the Paediatric cardiology services at the

study center commenced in 2007, about 11 years ago. The distribution of the number of years in which subjects have been accessing care is shown in Table 4.

Table 4

Number of Years Subjects Have Been Accessing Care at the Study Center

Number of years	Frequency	Percent
less than 1 year	5	8.3
1 to 2 years	4	6.7
> 2 to 5 years	16	26.7
>5 to 10 years	20	33.3
> 10 years	14	23.3
5.00	1	1.7
Total	60	100.0

In terms of the number of years in which subjects have been accessing care at the study center for patients with congenital heart disease, the number of years ranged from 0.1 to 11 years with a mean \pm SD of 6.3 ± 3.4 years. It is interesting to know that some subject had been accessing care since the inception of the study center with a mean \pm SD of 6.3 ± 3.4 years; this reflects the chronic nature of congenital heart disease. There was a statistically significant difference among the subjects in terms of the number of years of accessing care at the study center ($p = .03$). In the current study, the first research question and accompanying hypotheses were:

RQ1: What is the level of knowledge of parents of children with CHD attending the Lagos State University Teaching Hospital on CHD?

H₀₁: The level of knowledge of parents of children with CHD attending the Lagos State University Teaching Hospital on CHD is not lower than 80% of correct answers on a reliable survey instrument.

H_{A1}: The level of knowledge of parents of children with CHD attending the Lagos State University Teaching Hospital on CHD is lower than 80% of correct answers on a reliable survey instrument.

The level of knowledge of parents and caregivers of children with CHD were evaluated using the Leuven questionnaire for or assessing the knowledge of parents on CHD. The questionnaire consisted of twenty-five questions which assessed the knowledge of parents and caregivers on the different aspect of knowledge on CHD including the diagnosis, causes, medications, complication, outcome and prognosis. The Leuven the coding manual for the Leuven knowledge questionnaire for congenital heart diseases was used to interpret the participant response Each of the twenty-five questions were scored a maximum of 4, a parent or caregiver was scored 0 if the parent or caregiver did not know the answer to the question, a score of 2 was given if the parent or caregiver got the answer to the specific question partly while a score of 4 was awarded if the parent or caregiver provided the correct answer to the question. The total score for each participant on all the twenty-five questions were added. The level of knowledge of a participant on CHD was said to be poor if the total score was 0 to 20%, and this was graded as 0, the level of knowledge of the participant was said to be average if the total score was 20 to 50% and this was graded as 1, 2 the knowledge of the participant was said to be good if the total score was 51 to 70% and was graded as, the knowledge of the

participant was said to be very good if the total score was 71 to 90% and was graded as 3 while, the knowledge of the participant on CHD was said to be excellent if the total score was greater than 90% and was graded as 4.

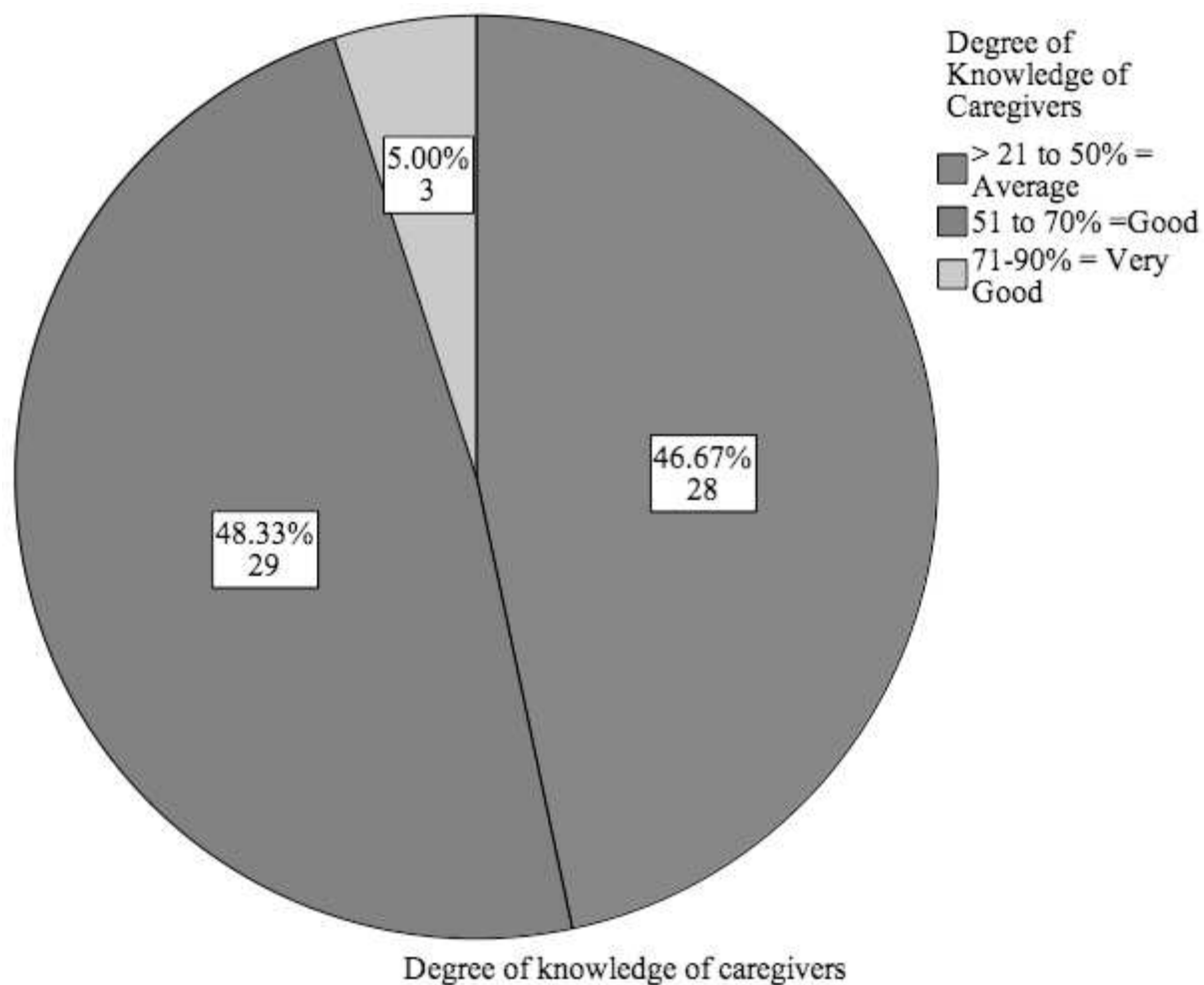


Figure 5: A pie chart showing the grades of the degree of knowledge parents and caregivers of children with CHD on CHD. The minimum score of the subjects was 30%, the maximum score was 72% with a mean score \pm SD of 52.7 ± 10.4 . Therefore, I reject the Null hypothesis and conclude that the level of knowledge of parents of children with

congenital heart disease attending the LASHUA on CHD is lower than 80% of correct answers using the Leuven questionnaire for or assessing the knowledge of parents on CHD.

The second research question in the current study was:

RQ2: How does age, level of education, occupation, and number of years of accessing care affect the level of knowledge of parents at the Lagos State University Teaching Hospital regarding CHD?

H₀₂: There is no statistically significant relationship between parents' demographics (age, the level of education, occupation, and number of years of accessing care) and level of knowledge regarding CHD.

H_{A2}: There is a statistically significant relationship between parents' demographics (age, level of education, occupation, and the number of years of accessing care) and level of knowledge regarding CHD.

In order to analyze the association between the parent demographics (age, the level of education, occupation, ethnicity, socioeconomic status and number of years of accessing care) and parents' level of knowledge about congenital heart disease, each of the parent demographic characteristics were chosen at each time as the independent variable while the level of knowledge of parents of children with congenital heart disease on congenital heart disease was chosen as the dependent variable. The relationship between each of the independent variable with the dependent variable was analyzed using the Pearson's correlation coefficient statistics.

The relationship between parents' demographics (age, the level of education, occupation, ethnicity, socioeconomic status and number of years of accessing care) and parents' level of knowledge about congenital heart disease is shown in table 5.

Table 5

Correlation between Subject Demographics and Their Level of Knowledge about CHD

Demographics	<i>r</i>	<i>p</i>
Age	-.103	.432
Level of education	-.134	.307
Number of years of accessing care	-.243	.060

Pearson's Correlation coefficient results and interpretation to show statistical significance association between variables in RQ2.

Table 6

Relationship between Subject Demographics and The Degree of Knowledge about CHD

Demographics	R	<i>p</i>
Occupation	-.242	.059
Ethnicity	-.770	.557
Socioeconomic Status	-.363	.001*

Eta results and interpretation to show statistical significance association between variables in RQ2 (*Significant).

There were negative correlations between each of the independent variables and the dependent variables, but this was significant statistically only in the socioeconomic classes as the independent variable. Hence, the researcher accepted the null hypothesis

for the RQ2 in the current study for the following independent variables; age, the level of education, occupation and number of years of accessing care and concluded that there is no statistically significant relationship between parents' demographics; (age, the level of education, occupation and number of years of accessing care) but rejected the null hypothesis for the independent variable; socioeconomic classes and concluded that there was a statistically significant relationship between parents' level of knowledge about congenital heart disease and their socioeconomic status.

Chapter 5: Discussion, Conclusion, Recommendations, and Areas of Future Research

Introduction

The purpose of the study was to document the level of knowledge of parents and caregivers of children with CHD accessing care at the Lagos State University Teaching Hospital (LASUTH) (using the modified LKQCHD) regarding CHD. The study also aimed to describe the relationship if any between the level of knowledge of parents and caregivers regarding CHD as measured using the LKQCHD, and their demographic characteristics such as age, gender, level of education, and number of years' parents and caregivers have been accessing care at the teaching hospital.

Interpretation of the Findings

The majority (83%) of respondents were above 35 years of age, with about 12% above 50 years of age. Above 35 years is considered middle age, in which most are expected to be at the peak of their career and proximate to retirement. Unfortunately, these caregivers may not be able to face the challenges of middle age as expected nor prepare adequately for retirement because of the burden of caring for these children with CHD. The burden of caring for these children, including frequent hospital visits and possible admissions, is likely to affect the attendance of these caregivers at work, and their productivity which will ultimately negatively affect the family economy and Lagos economy at large negatively (Lobe et al., 2011).

15% of the subjects were males who were the fathers of children with congenital heart disease. The involvement of subjects as fathers as caregivers in the current study almost doubles the finding of Animasahun et al., (2014) where 8% of the subject was a father. The reason for these observed differences is immediately unclear. The documented increase in the involvement of fathers could be because more females are now involved in contributing to the economic well-being of the home by having to engage in one vocation or the other. These working mothers might not be able to secure permission to be absent from work to attend clinics with children with congenital heart disease. Other earlier reports (Daily et al., 2015; Lobe et al., 2011; Mahdi, Hashim, and Ali, 2009; Ndile and Kohi, 2011; Fernandes et al., 2011; Yang et al., 2013) on this subject did not comment on the gender to allow for comparison.

As earlier discussed, the bulk of the subjects are in the middle age, the productive age where their contribution to the family, community and the social economy is immense. It is obvious that these subjects may not be able to contribute effectively to the development of the society due to their attention which is needed in their care of the children with congenital heart disease (Lobe, Geyer, Grosser, & Wessel, 2011). Also, fathers are expected to be the breadwinner who is expected to work to be able to generate income to meet the needs of their immediate and extended family. The need for regular hospital attendance by children with congenital heart disease which these fathers must attend to is likely to limit their capacity to attend to their vocation regularly and effectively, this may affect their ability to secure and maintain job which requires apt attention, thereby putting them at a disadvantage at the job market.

Similarly, 85% of the subjects were female, traditionally these women are expected to be at home to ensure general upkeep and wellbeing in the home but are now saddled with the additional responsibility of attending outpatient clinics and sometimes hospital admissions with children with congenital heart disease, ensuring drug compliance, these caregivers who are also expected to take care of the sibling of children with congenital heart disease are not likely to be able to perform this task optimally, thereby leading to neglect of the siblings of children with CHD, juvenile delinquency, depression in the sibling. Also, gone are the days when women were home keepers alone, in the current women are involved in various vocations and carrier and contribute significantly to the economy of the family, community and society. Women are also currently involved in directing the affairs of various companies and even occupy political positions. The subjects in the current study are unlikely to be concentrate maximally in their vocation and careers to be able to progress to such positions.

About 12% of the subjects were the only parent involved in the care of their children with CHD; some were single parents, some widowed while others were either separated or divorced. Other earlier reports (Animasahun et al., 2014; Asani, Aliyu and Gambo ,2016; Daily et al., 2015; Lobe et al., 2011; Mahdi, Hashim and Ali, 2009; Ndile and Kohi, 2011; Fernandes et al., 2011; Yang et al., 2013) on this subject did not comment on the marital status of their subjects to allow for comparison. It is imperative to assume that homes with single parents are likely to be dysfunctional, with the task of two parents being carried out by only one parent, which is likely to put the only parent under a lot of stress, having to care for children with CHD will be an additional stress on

such single parent, the additional stress may predispose the only parent to the risk of depression, drug dependence, and early death. Also, the only parent may be so overwhelmed with the care of the child with CHD, that the siblings may suffer neglect and its consequences including juvenile delinquency, depression, poor education to mention a few. Although about 88% of the subjects were married, the challenge of caring for a child with CHD is enormous, the much attention and care needed by children with CHD may lead to unintentional neglect of the other partner which can cause strains in a relationship leading to separation and even divorce.

In the ethnic distribution of the subjects' majority were of the Yoruba ethnic group. This is not surprising because the Yoruba are the dominant ethnic group in Lagos (World population review, 2018). Although Lagos, where the current study was carried out, is cosmopolitan, the most populous city in Nigeria, and the commercial capital of Nigeria where there is a better representation of the various ethnic groups in Nigeria compared with the other cities in Nigeria. Ethnicity is important because each ethnic group has its own peculiar culture which has a great influence on the attitude, beliefs and hence behavior of individuals. The Yoruba ethnic group tend to label children with chronic illnesses such as CHD as being possessed by a bad spirit and tend to want to use their believed spiritual means to solve the problem, with them only presenting to the hospital after this spiritual solution has failed or is ineffective, this can further explain why children with congenital heart disease tend to present to the hospital and are diagnosed late as discussed earlier.

The majority of the respondents were Christians, and the immediate reason for this is not clear, because Lagos is one of the six cities in Nigeria with a higher population of Muslims (Kemi, 2017, June 5). Religious beliefs are also an important determinant of individual beliefs, attitude, and culture. In the current study, all the subjects resided in Lagos, with none from outside Lagos. This may be because the data collection was for about two months to ensure that the study had internal validity (Frankfort-Nachmias, & Nachmias, 2008).

The socioeconomic status of the subjects was assessed using the educational status and occupation of both parents using the scheme proposed by Oyedeji, (1985) dividing subjects into five groups I to V in descending order of privilege. Socio-economic index scores (one to five) were awarded to each subject, based on the occupational and educational levels of parents. The mean of four scores (two for the father and two for the mother) to the nearest whole number, was the social class assigned to the child. For the study, classes I and II were grouped together as upper social stratum, class III was taken as the middle stratum and classes IV and V as lower social stratum (Animasahun et al., 2014).

There were more subjects in the upper socioeconomic class, followed by the middle socio-economic class, with the lower socioeconomic class having the least proportion of 15%. The above is contrary to the findings of Animasahun et al., (2014) where there were more subjects in the middle social class followed by the lower social class and the least proportion was in the upper socioeconomic class. The reason for this disparity is not immediately clear but may be attributed to the timing of the studies and

differences in the methodology. The earlier study recruited all consenting subjects regardless on when they presented to the clinic or when the diagnosis of CHD in their children were made while the current study excluded subjects whose children with CHD were presenting at the clinic for the first time and whose child diagnosis of CHD was made at the teaching hospital less than 6 weeks before recruitment (Asani, Aliyu & Gambo, 2016). Also, it may confirm that the socioeconomic status of the dwellers in Lagos has improved over time (Yomi Kazeem, 2016). Since the earlier study was carried out about five years earlier. Other earlier reports (Asani, Aliyu and Gambo, 2016; Daily et al., 2015; Lobe et al., 2011; Mahdi, Hashim and Ali, 2009; Ndile and Kohi, 2011; Fernandes et al., 2011; Yang et al., 2013) on the subject did not comment on the socioeconomic class of the respondents to allow for comparison.

One of the variables assessed in the current study is the number of years of accessing care at the study center, the Paediatric cardiology services at the study center commenced in 2007, about 11 years ago, it is interesting to know that some subject had been accessing care since inception with a mean \pm SD of 6.3 ± 3.4 years; this is a reflection of the chronic nature of CHD. Majority of the children with CHD will require long-term follow up even after having one form of intervention or the other. The mean number of years of accessing care is high, this suggests that a good proportion of the subject time would have been involved in the care of this children. The majority (85%) of the subjects had been accessing care for from more than two years to more than ten years. The earlier studies on the subject did not consider this variable to allow for comparison.

In terms of the educational status of the subjects, more than half of the subjects had only a primary school education. Only 5% of the subjects attained the tertiary level of education. Similarly, other earlier reports (Animasahun et al., 2014; Asani, Aliyu and Gambo ,2016; Daily et al., 2015; Lobe et al., 2011; Mahdi, Hashim and Ali, 2009; Ndile and Kohi, 2011; Fernandes et al., 2011; Yang et al., 2013) on this subject did not comment on the educational status of their subjects to allow for comparison. Education is expected to bring information and civilization to an individual, the level of education of an individual affects the individual ability to access and process information. Majority of the subjects having primary and at best secondary level of education, therefore will affect the type of information available to them on CHD and how they process the information. Subjects with only primary level of education will be limited in terms what they are able to read and understand especially if it is in English, also such subject may not have the proficiency to access information on the television, print media and social media, if they do sometimes they may not be able to process the information as required nor apply it appropriately. Maternal education has been shown to affect the outcome of an illness in a child.

The level of knowledge of parents of children with CHD on CHD has been documented to be low and significantly correlated with the educational level of the parent (Animasahun et al., 2014; Asani, Aliyu and Gambo ,2016; Daily et al., 2015; Lobe et al., 2011; Mahdi, Hashim and Ali, 2009; Ndile and Kohi, 2011; Fernandes et al., 2011; Yang et al., 2013) as is the finding in the current study. The knowledge of parents of children with CHD receiving care at LASUTH on CHD in the current study was lower than 80%

of correct answers on a reliable survey instrument. Majority of the subjects had average and good knowledge of congenital heart disease (< 70%) with only three of the participants scoring 72% on a reliable survey instrument. Hence the null hypothesis has been rejected for research question one in the current study.

The mean score \pm SD of 52.7 ± 10.4 also confirmed that the knowledge of subjects on congenital heart disease is low. In the current study only, about half of the participants had a good knowledge of CHD. The finding of up to half of the participants with a good knowledge of CHD is higher than 36% reported in Sudan by Mahdi, Hashim, and Ali (2009) and 24% in Tanzania by Ndile and Kohi (2011). The reason for this disparity may be attributed to differences in the methodology of the studies, the study by Mahdi, Hashim, and Ali (2009) did not use a standard nor validated questionnaire, neither was the sample size calculated for the study. Although the study in Tanzania by Ndile and Kohi (2011) had a similar methodology with the current study, the differences in the findings may be attributed to the differences in the ages of the patients with CHD whose parent were studied; the current study included parents of infants while the study in Tanzania by Ndile and Kohi (2011) studies parents of children from 2 to 18years of age. Yale et al., (2013) also studied parents of adolescents with ages 12-18years only. It would have been desirable for the subjects of this study who are parents and caregivers of children with CHD to have more knowledge on CHD because the more knowledge that parents have about their child's heart disease, the more likely the compliance to medication, less anxiety, and better health-related behavior and reduced risk-taking habits in the child (Yang, Chen, Wang, Gau & Moons, 2013).

One of the aims of the current study is to assess how age, the level of education, occupation, and number of years of accessing care affect the level of knowledge of parents at LASUTH on CHD. The knowledge of the subjects in this study had a weak negative relationship with the age, and ethnicity of the subjects which was not statistically significant, earlier reports on this topic did not assess the effect of age, and ethnicity to allow for comparison. The above finding in the current study may not be surprising since the occurrence of CHD cut across different race, culture, ethnicity, and geographical locations; the incidence of CHD is said to be the same all over the World (Hoffman, 2013).

Similarly, the knowledge of the participants in this study also had a negative relationship which was not statistically significant with the subjects educational level as earlier reported in Kano by Asani, Aliyu, and Gambo (2016) but contrary to the other earlier reports (Daily et al., 2015; Lobe et al., 2011; Mahdi, Hashim and Ali, 2009; Ndile and Kohi, 2011; Fernandes et al., 2011; Yang et al., 2013). The similarity may be because both studies were carried out in Nigeria, although the current study was carried out in the southern part of Nigeria while the former was conducted in the Northern part of Nigeria. The above finding is surprising as one would have expected those with higher level of education to have a generally increased awareness about diseases including CHD.

Also, the knowledge of the subjects had a negative relationship which was not statistically significant with the subject's occupation and the number of years of accessing care at the study center. As earlier mentioned earlier reports on this topic did not assess the effect of the number of years of accessing care to allow for comparison.

The reason for the above is not immediately clear, one ordinarily would have expected the subjects who had been accessing care for a longer period to have a significantly higher knowledge than those who just started accessing care. Also, these subjects would have been expected to be in a better position to educate other parents and caregivers of children with CHD who are newly diagnosed. Does it mean that caregivers and parents of children with CHD have not shown enough interest in getting to know about CHD which affects their children? Could it also mean that the nurses and doctors providing care for the children have not been counselling the caregivers and parents of children with CHD on CHD? Unfortunately, the above two questions are beyond the scope of the current study and further necessitates the need for a structured and regular educational program for the subjects on CHD.

However, the level of knowledge of the participants in the current Unlike the other previous reports, in the current study, the knowledge of parents on CHD had a negative relationship which was significantly correlated with their socio-economic status as earlier documented in the same study earlier by Animasahun et al., (2014). Caregivers in the upper socioeconomic classes were statistically less aware about CHD compared with those in the middle and lower socioeconomic classes, the reason for this may be because those in the upper socioeconomic classes are more involved in their vocation and visits the hospital less. The above result of a negative relationship of the subjects' level of knowledge on CHD with their socio-economic status calls for concern since it is expected that those in the upper socio-economic status would be more assessable to various media of information dissemination like radio and television which are the two commons media

in which those that knew about congenital heart diseases got the information as documented by Animasahun et al., (2014).

The earlier study however, did not state any research questions and hypothesis, neither was any theoretical or conceptual framework used, the questionnaire used was self-generated. It was neither validated, nor was the sample size calculated. Also the earlier research did not set out to cause any social change, nor aimed to be a voice for children with CHD through advocacy. Also, the earlier study did not assess the effect of subjects income and educational level separately as it was done in the current study. Unfortunately, the current study cannot be compared with the other earlier reports (Daily et al., 2015; Lobe et al., 2011; Mahdi, Hashim and Ali, 2009; Ndile and Kohi, 2011; Fernandes et al., 2011; Yang et al., 2013) because socio-economic status was not considered as a variable in them but the parent educational status. In the current study socioeconomic status was derived from the parent's educational level and their occupation, analysis of each of the above components of the socio-economic status with the level of knowledge of the subjects did not reach any statistical significance ($p = .31$ and $p = .06$ respectively). Hence, the null hypothesis for the second research question for the current study is accepted as there is no statistically significant relationship between parents' demographics; (age, the level of education, occupation and number of years of accessing care) and parents' level of knowledge regarding CHD.

Limitations of the Study

The study design was quantitative; its limitation included the involvement of larger sample size and only numeric description of the samples. The limitation of the

questionnaire was that it was used to access the knowledge of parents and caregivers in Lagos on CHD using a quantitative design method. A mixed method which involves a qualitative design in assessing the perception and beliefs of the subjects and how the perception and beliefs of the respondents affects their knowledge on CHD would have given more information on the subject. (Creswell, 2009). The use of a non-probability sampling will prevent a generalization of the result of the study. The quantitative design used might not have been in-depth enough to study the perception of the parents and caregivers on CHD. The collection of primary data required a longer time and in-cured more expenses (Creswell, 2009).

Also, since parents were interviewed after a diagnosis of CHD was made, a confounding influence relating to knowledge reinforcement cannot be eliminated. Defaults in follow up after diagnosis was not considered as this might affect how much the subjects knew about their child CHD, because defaults in follow up will limit the number of exposures to the care center and to the healthcare practitioner who would have been in a position to provide specific knowledge of each child's CHD to the parent.

The study was affected by internal and external validity. The internal validity included the dropout rate from the study, timing and duration of the study. The internal validity of the study was ensured by ensuring that the attrition level was kept to the barest minimum, there was no drop out from the study, and that the study was carried out within a short time to ensure that patient that visited the outpatient clinic more than once within a short time were not interviewed twice so that this does not serve as a confounder in the study (Frankfort-Nachmias, & Nachmias, 2008).

One of the other factors which could have affected the validity of the study was the instrument. The instrument used was a questionnaire which was a modification of the LKQCHD. To ensure the content validity of this instrument. A face validity of the questionnaire was done to ensure it adequately assessed the knowledge of parents and caregivers of children with CHD in Lagos on the causes of CHD, the clinical features, treatment modalities, complications and prevention of CHD. The face validity of this questionnaire was ensured by consulting specialists in the field of CHD to look at the questionnaire, two of such specialist practicing in Lagos were consulted, they confirmed that the questionnaire could assess all the various aspects of information on listed above.

The face validity of the designed questionnaire was also ensured by comparing it with other questionnaire that had been designed to assess knowledge on CHD such as the Hannover Inventory of Parental Knowledge of Congenital Heart Disease (Lobe et al., 2011). There was consensus among the specialist, the questionnaire was also comparable hence the questionnaire was used with confidence. The sampling validity of the measurement was ensured because the questionnaire covered questions on all aspect of congenital heart disease and the questions were clear enough to be understood by an average parent or caregiver. The empirical validity of the measurements used in assessing the knowledge of parents and caregivers of children with CHD in Lagos on CHD was done by correlating the result gotten with the measuring instrument used in this study with the result gotten using another method of assessing their knowledge on this subject. (Frankfort-Nachmias, and Nachmias, 2008).

Recommendations

The current study has shown that the level of knowledge of parents of children with CHD attending LASUTH on CHD is lower than 80% of correct answers on the LKQCHD, hence there is a need to develop a structured and well-coordinated educational program for parents and caregivers of children with congenital heart disease to improve the level of awareness of parents and caregivers of children with CHD. Because, if parents have more knowledge about their child's heart disease, they will be more compliant with medication, have less anxiety about the child, the care of the child and the treatments involved. Also, if parents have adequate knowledge on CHD, it will lead to a better health-related behavior and reduced risk-taking habits in the child (Lesch et al., 2014; Ndile & Kohi, 2011; Yang, Chen, Wang, Gau & Moons, 2013).

The knowledge of parents and caregivers of children with CHD on CHD can be improved by providing a routine health talk on care of children with CHD aided with audio-visuals on every outpatient clinic day before the commencement of the clinic. Also, the knowledge of parents and caregivers of children with CHD on CHD can be improved by ensuring that each parent and caregivers of children with CHD is re-counselled on the specific CHD the child has been diagnosed of, by each member of the health team including doctors, nurses, as part of the routine outpatient care at each clinic visit. In addition, the knowledge of parents and caregivers of children with CHD on CHD can be improved by allowing the parents to ask questions routinely on any part of the symptoms, investigations, diagnosis, treatment, complications and prevention of CHD. Similarly, each parent and caregivers of children with CHD should be re-counselled on the specific

CHD the child has each time the child requires hospital admission as part of the routine in-patient care. Also, training of parents and caregivers of children with CHD on how to train and mentor other parents and caregivers including creation of advocacy groups at every level; the community, local, state and federal government level will help increase the knowledge of parents and caregivers and other members of the community on CHD.

Improvement in the knowledge of parents on CHD is expected to reduce morbidity and mortality among patients with CHD (Animasahun et al., 2017). Also, improvement in the knowledge of parents and caregivers on CHD will lead to improvement in the quality of life of children with CHD, the cost of caring for children with CHD will also be reduced, the short-term and the long-term outcome of children with CHD is also expected to be better for these patients (Animasahun, 2016).

Ultimately, the great impact of congenital heart disease on a Nigerian child's morbidity and mortality as well as on the health systems cost will be reduced remarkably (Asani et al., 2013). Also, since CHD is the main cause of death among children with congenital malformations (Animasahun et al., 2017), improvement in the knowledge of the community on CHD will help increase the awareness of parents and caregivers and other members of the community on CHD thereby leading to early diagnosis and prompt treatment which will also reduce the number of children with congenital malformation who dies as a result of CHD.

Implications

Positive social change is defined as a “deliberate process of creating and applying ideas, strategies, and actions to promote the worth, dignity, and development of

individuals, communities, organizations, institutions, cultures, and societies” (Walden University Blackboard, n.d). The implications for positive social change from the findings of this study include an increased awareness of CHD among caregivers and parents of children with CHD. Also, there will be an improved sensitization regarding CHD among parents and caregivers of children with CHD attending LASUTH.

Also, a support for the need for training and retraining of parents and caregivers on CHD which will equip these parents with what they need to educate other parents and patients and the community on CHD. There will be improved awareness of the community on CHD, which will lead to the early presentation, reduce risk-taking behavior, improve compliance to treatment and improved overall outcome of the patients with CHD. Ultimately, the great impact of CHD on a Nigerian child’s morbidity and mortality as well as on the health systems cost will be reduced remarkably (Asani et al., 2013). Also, since CHD is the main cause of death among children with congenital malformations (Animasahun et al., 2017), improvement in the knowledge of the community on CHD will help increase the awareness of parents and caregivers and other members of the community on CHD thereby leading to early diagnosis and prompt treatment which will also reduce the number of children with congenital malformation who dies as a result of CHD. The expected positive change to be made in the management of children with is the motivation I had for enrolling in the Ph.D. for Public Health program. Hence the need for this study.

Conclusion

The level of knowledge of parents of children with CHD attending LASUTH on CHD is lower than 80% of correct answers on a the modified LKQCHD. There is poor knowledge of CHD among parents and caregivers of children with CHD. Majority of the caregivers were above 35 years of age. The age range of the children of the subjects studied were 6 months and 19 years of age with the age range > 5years to 10 years having the highest proportion, hence most of the children of the subjects were above five years of age, thereby suggesting late interventions in these children with CHD as a result of the poor knowledge of congenital heart disease among the subjects.

Majority of the parents and caregivers were women hence other roles these women are expected to perform in the home may be affected. I, therefore, rejects the null hypothesis and conclude that the level of knowledge of caregivers and parents of children with attending LASUTH on CHD is lower than 80% of correct answers on the modified LKQCHD. There is no statistically significant relationship between parents' demographics; (age, the level of education, occupation and number of years of accessing care) and parents' level of knowledge about CHD. Hence, the null hypothesis for the second research question for the current study is accepted as there is no statistically significant relationship between parents' demographics; (age, the level of education, occupation, and number of years of accessing care) and parents' level of knowledge regarding CHD.

There were some negative correlations between the socio-economic status of the subjects as independent variables and the level of knowledge of subjects as a dependent

variable, which was statistically significant. Subjects in the upper socio-economic class had lesser knowledge of CHD. Hence, the researcher rejected the null hypothesis for the independent variable; socioeconomic classes and concluded that there was a statistically significant negative relationship between parents' level of knowledge about CHD and their socio-economic status.

Areas of Future Research

A mixed method study which involves both quantitative and qualitative design in assessing the knowledge of the respondents would have given more information on the subject (Creswell, 2009). It will involve lesser sample size and give both numeric description of the samples and also give an in-depth information on the perception, attitude, and beliefs of the parents and caregivers on congenital heart disease (Creswell, 2009).

Also, a multi-centered study of The Relationship Between Parents' and Caregivers' Demographics and Their Knowledge of Congenital Heart Disease. This can be done in the six geopolitical zones in Nigeria and will better give information on the above subjects on Nigerian children. The study will involve more subjects, and hence have a higher power than the current study, it is likely to yield a result which can be generalized. Also, the multi-centered study will likely involve the use of a probability sampling method which will then make generalizing the result of the study to Nigerian caregivers and parents of children with congenital heart disease possible.

Also, it will be desirable to study the Relationship Between Doctors, Nurses, Pharmacists' Demographics and their knowledge regarding CHD. Doctors and Nurses and pharmacists are commonly in contact with these patients and their caregivers

compared with other health workers. Healthcare workers such as nurses, pharmacists and doctors are in a position to educate the caregivers and parents of children with CHD. It will be important to document their current knowledge on CHD. Educating nurses, pharmacist and doctors at LASUTH will equip the doctors, pharmacists, and nurses with what they need not only to educate the parents and patients with CHD, it will also enable the health care workers to educate the populace in Lagos. This will not only help improve awareness of the Lagos community on CHD, but will also encourage early presentation, reduce risk-taking behavior, improve compliance to treatment and overall outcome of the patients with CHD (Offord, Cross, Andrews and Aponte, 1972; Beeri, Haramati ,Rein and Nir, 2001). For example, nurses, pharmacists, and doctors with a good knowledge of CHD and who have the right perception on the causes of CHD and the importance of early presentation and treatment are more likely to impact the same knowledge and perception on patients and caregivers under their care. Such a health worker will be equipped to make well-informed decisions and counsel the parent appropriately compared with health workers who are not well informed about CHD or have a wrong perception of the causes and treatment of CHD.

Also, another important study to consider is the relationship between children with CHDs' demographics and their knowledge about CHD. Ferencz, Wiegmann, and Dunning (2009) found that most young persons with CHD were not able to describe their heart lesion. Deyk et al., (2010), assessed knowledge of adolescents with CHD using the modified LKQCHD and concluded that there is a significant gap in the knowledge of the subjects on CHD. Also, it will be helpful to study the relationship between medical and

nursing students' demographics and their knowledge regarding CHD. This is to be able to document their current knowledge on CHD and establish the need to introduce the training on CHD in terms of the symptoms, investigation, diagnosis, treatment, complications, and prevention to their curriculum of training, this will help improve the awareness of the community on CHD and equip these subjects early since they will ultimately graduate to be nurses and doctors who have the closest contact with patients and are in a better position to pass information to patients.

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Appendix A: Socioeconomic Classification by OYEDEJI

Class	OCCUPATION
I	Senior Public Servants, Professionals, Managers, large scale traders, businessmen and contractors.
II	Intermediate grade public servants and senior school teachers.
III	Junior school teachers, professional drivers and artisans.
IV	Petty traders, laborers and messengers.
V	Unemployed, full time housewives, students and subsistence farmers.
Class	EDUCATION
I	University graduates or equivalents.
II	School certificate holders, Ordinary Level (GCE) who also had teaching or other professional training.
III	School certificate or Grade II teachers certificate holders or its equivalent.
IV	Modern three and primary six certificate holders.
V	Those who could either just read and write or were illiterate.

Note: The mean of four scores (two for the father and two for the mother) approximated to the nearest whole number was the social class assigned to the child. For example, if the mother was a junior school teacher (score = 3) and the father a senior school teacher (score = 2) and the educational attainment of the mother was primary six (score = 4) and the father was a school certificate holder (score = 2) and the socioeconomic index score for this child was: $(3+2+4+2)/4$
 $= 11/4 = 2.75$. (To the nearest whole number = 3).

Appendix B: Questionnaire

Knowledge of Parents and Caregivers of Children with Congenital Heart Disease on Congenital Heart Disease in Lagos.

The Modified Leuven Knowledge Questionnaire for Congenital Heart Diseases

Instructions:

This questionnaire aims to ascertain how much knowledge parents and caregivers of children with a congenital heart disease have about the condition, the treatment, and measures to prevent complications. This questionnaire allows to determine the topics on which parents and caregivers need to be given more information. Please read each question carefully. Select what you consider to be the correct answer and fill in the appropriate square. Only one answer is correct unless stated otherwise in the question. If you do not know the answer, don't worry – simply mark the square “Don't know”. Please answer every question. The questionnaire is confidential.

Thank you for your cooperation!

Sociodemographic Background of Parent/Caregiver

1. What is your Age? -----
2. Relationship to child: Father Mother Aunty Uncle Brother Sister ; Others (specify) _____
3. Marital Status: Single Married Divorced Separated Widowed
4. Your level of education: Primary Junior Secondary Senior Secondary Tertiary Post-Graduate

5. Are you currently in any employment? Yes No
6. If yes, specify your occupation

7. Your family structure a) Monogamous b) Polygamous
8. Family size (total no. of all children and parents) _____
9. Educational level of child's parents: Father's _____ Mother's

10. Occupation of child's Parents: Father's _____ Mother's _____
11. Ethnic group: Hausa Ibo Yoruba Others
12. Religion: Christianity Islam Traditional Others
13. What is your family average monthly income in Naira? < 25,000 25-50,000 50-75,000 75,000-100,000 100,000 – 150,000 150,000-200,00 >200,000

Sociodemographic profile of Children with congenital Heart Disease

1. What is the position of this child in the family? _____
2. Age of child _____
3. Sex of child _____
4. Is your child registered in any form of social services for children with disabilities?
Yes No
5. If Yes, specify _____

Disorder and treatment

1. What is the correct name of your child's heart defect?

- Ventricular Septal Defect (VSD) = an opening between the two ventricles
- Atrial Septal Defect (ASD) = an opening between the two atria
- Open Ductus Arteriosus Botalli = an opening between the two great arteries
- Pulmonary Stenosis = a narrowing of the pulmonary valve of the right ventricle
- Aortic Stenosis = a narrowing of the aortic valve of the left ventricle
- Coarctation of the Aorta = a narrowing of the aorta
- Tetralogy of Fallot = an opening between the ventricles and a narrowing of the pulmonary valve of the right ventricle
- Transposition of the Great Arteries = reversal of the position of the great blood vessels
- Other:
- Don't know

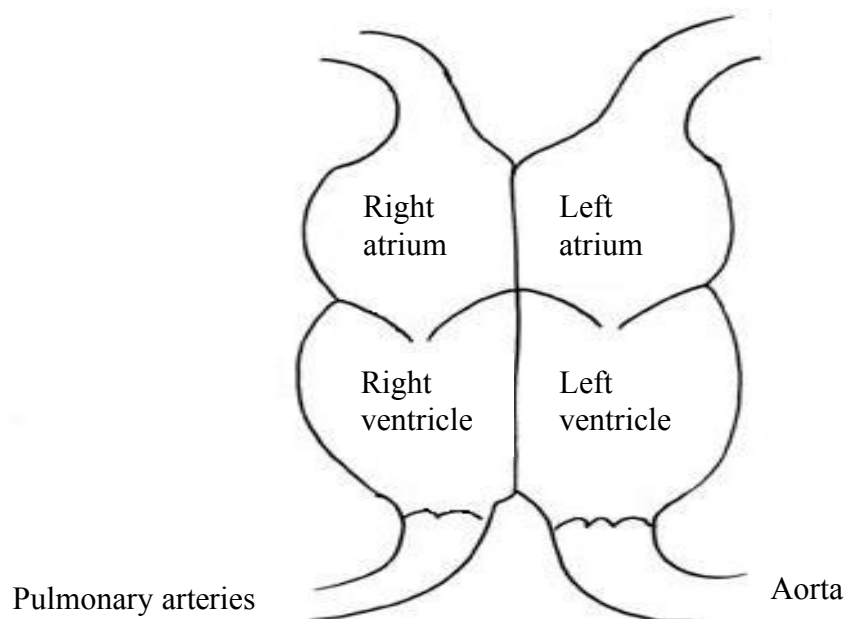
2. Describe below, or indicate on the diagram where your child's heart is located

Description (or go to the diagram):

.....

.....

Indicate on diagram

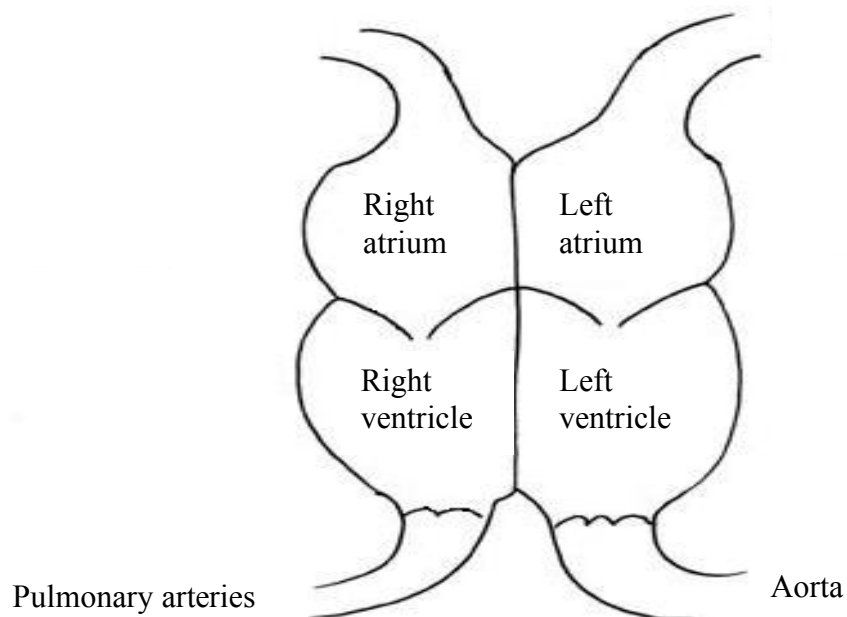


Don't know

3. How often does your child have to come to the clinic for follow-up of the heart disease?

- every five years
- every two years
- every year
- every six months
- other:
- don't know

Indicate on diagram

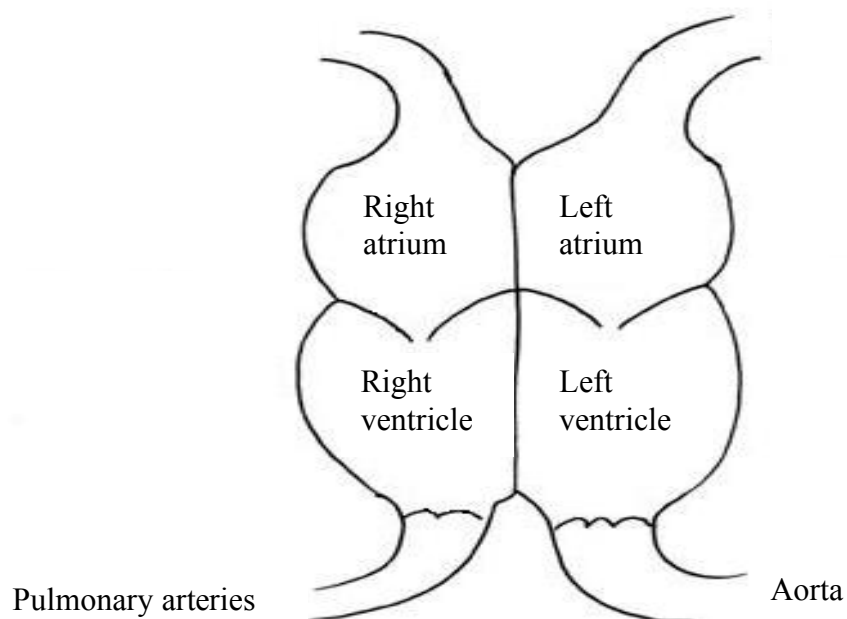


Don't know

3. How often does your child have to come to the clinic for follow-up of the heart disease?

- every five years
- every two years
- every year
- every six months
- other:
- don't know

Indicate on diagram



Don't know

3. How often does your child have to come to the clinic for follow-up of the heart disease?

- every five years
- every two years
- every year
- every six months
- other:
- don't know

4. What is the main purpose of this follow-up?

(You may enter more than one answer)

- routine check, no specific reason
- personal reassurance
- to detect any unexpected deterioration
- to continue treatment using the latest techniques
- the doctor wanting to line his pockets
- other:

5. How has your child's heart condition been treated to date?

(You may enter more than one answer)

- with surgery = a heart operation
- with catheterization:
 - balloon dilatation
 - stenting
 - closing an ASD using umbrella technique
- with medication
- no treatment
- other:
- don't know

6. If your child is on medication, please answer the following questions.

Use one box for each medication.

- What is the name of the medication?
- What dose do you have to take (+ method of administering)?
- When do you have to take your medication? : morning, afternoon, evening,
not important
- What is the effect or function of the medication?
- What are the frequent or major side-effects?
- Were you advised that certain medications or foods can influence the effect of your medication? For example, do they reinforce or reduce the effect, etc.?
- don't know

- * Name:
- * Dose:
- * Time to be taken: morning – afternoon – evening – not important
- * Function:
- * Possible side-effect:
- * Possible interaction:

- * Name:
- * Dose:
- * Time to be taken: morning – afternoon – evening – not important
- * Function:
- * Possible side-effect:
- * Possible interaction:

- * Name:
- * Dose:
- * Time to be taken: morning – afternoon – evening – not important
- * Function:
- * Possible side-effect:
- * Possible interaction:

- * Name:
- * Dose:
- * Time to be taken: morning – afternoon – evening – not important
- * Function:
- * Possible side-effect:
- * Possible interaction:

7. If your child experience side-effects of the medication, is it indicated that you stop giving the medication?

(Please also answer this question if you are not on medication now)

- yes
- no
- don't know

8. Do you have to follow a diet for your child? If you answer “yes”, please indicate the type of diet.

- no
- yes:
 - a low-salt diet
 - a salt-free diet
 - a salt-rich diet
 - a low-fat diet (low saturated fatty acid content)
 - a diabetic diet (low in sugars)
 - Other:
 - don't know

9. Please mark all symptoms which may occur if your child's heart condition deteriorates and for which you have to contact your cardiologist.

- | | |
|---|--|
| <input type="checkbox"/> dizziness | <input type="checkbox"/> fainting |
| <input type="checkbox"/> skin rash | <input type="checkbox"/> tiring more quickly |
| <input type="checkbox"/> shortage of breath | <input type="checkbox"/> urinating more frequently |
| <input type="checkbox"/> diarrhea | <input type="checkbox"/> pain on urinating |
| <input type="checkbox"/> palpitations | <input type="checkbox"/> swollen feet and legs |
| <input type="checkbox"/> chest pain | <input type="checkbox"/> don't know |

10. If the cardiologist informs you that everything is alright, does that mean that your child does not need further follow-up?

- yes
 no
 don't know

Prevention of complications

11. What is endocarditis?

- a disruption of the heart rhythm
 an infection of the inner wall of the heart and the heart valves
 an enlarged heart
 a blockage of the blood vessels of the heart
 don't know

12. Indicate the most characteristic or typical sign of endocarditis.

- | | |
|--|---|
| <input type="checkbox"/> palpitations | <input type="checkbox"/> chest pain |
| <input type="checkbox"/> fever lasting more than five days | <input type="checkbox"/> shortage of breath |
| <input type="checkbox"/> a headache | <input type="checkbox"/> fainting |
| <input type="checkbox"/> tiredness | <input type="checkbox"/> don't know |

13. Can your child only get endocarditis once in your lifetime?

- yes
 no

don't know

14. Some risk factors for endocarditis are listed below. Do you think these factors contribute to the onset of endocarditis?

	Yes	No	Don't know
Contaminated needles in drug users	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Smoking	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Bacteria from skin infections	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Tooth abscesses	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sexual activity	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Poor nail and skin care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Body piercing and tattooing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

15. As your child have a congenital heart disease, the child should take antibiotics immediately if the child has a temperature (without consulting a doctor).

yes

no

don't know

16. Your child should have a dental check-up at least once a year.

yes

no

don't know

17. Your child should take antibiotics before every visit to the dentist.

yes

no

don't know

18. Bleeding gums need extra attention.

yes

no

don't know

19. Your child should clean the teeth at least once a day.

yes

- no
- don't know

20 Smoking is more harmful to someone with a congenital heart disease than for someone without such a disorder.

- yes
- no
- don't know

21. Consuming three or more alcoholic drinks per day is more harmful to someone with a congenital heart disease than for someone without such a disorder.

- yes
- no
- don't know

Physical activity

22. Your child may take part in competitive sports (regional or national) requiring daily training?

- yes
- no
- don't know

23. You should choose an occupation that is not too physically demanding, as you should be careful not to over-exert yourself.

- yes
- no
- don't know

Sexuality and heredity

24. May your child engage in all physical sexual activity of which you feel the child is capable?

- yes
- no
- don't know

25. What is the chance that your child children will have a congenital heart disease?

- the chance is not increased
- the chance is slightly increased
- the chance is moderately increased
- the chance is greatly increased
- don't know

If you would like more information on a particular item, please state your question below.

.....

.....

.....

Appendix C: Permission to use the Leuven Knowledge Questionnaire for CHD

From: Philip Moons philip.moons@kuleuven.be

Subject: RE: Automatisch Antwoord: 'Leuven Knowledge Questionnaire for Congenital Heart Disease

Date: November 30, 2017, at 3:32 PM

To: Deola Animasahun deoladebo@yahoo.com

Dear Dr. Animasahun

Thank you for your mail and for completing the user agreement form. Permission to use it in your study is granted, free of charge. Please, find attached the instrument in word format, to facilitate the translation process, if needed.

I am also attaching the coding manual. In this manual, you can see what the boxes in the Margin indicated with A, B, C, D represents. Since the instrument requires an individual scoring, based on the profile of the patient, it is needed to have a place where you as the researcher can indicate if the answer that the patient provided was correct, incomplete or incorrect.

As I understand from your completed form, you plan to use the questionnaire in parents. Indeed, you can make it a parental questionnaire. This has been done by Yang as well (see articles in attachment), in which the second person has been changed into the third person.

Hope this information is helpful.

Best wishes

Philip Moons