SCHOOL OF PUBLIC HEALTH

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CAREGIVERS' WILLINGNESS TO PAY FOR BONE MARROW TRANSPLANT TO CURE SICKLE CELL DISEASE IN CHILDREN

BY

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DECLARATION

I, Adwoa Afriyie Wilson, hereby declare that this thesis is a result of my independent work. References to other works have been duly acknowledged. I further declare that this work has not been submitted for award of a degree elsewhere.

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DR. JUSTICE NONVIGNON **DATE**
(ACADEMIC SUPERVISOR)

DEDICATION

I first dedicate this work to the Almighty God for His grace, protection and faithfulness. Secondly, I also dedicate this work to my husband Ing. Jesse Annan Wilson and son Dilyn Asante Wilson for their support and encouragement.

ACKNOWLEDGEMENT

I would first thank God for the abundance of His grace and life to be able to undertake this research. Next of all, I am indebted to my project supervisor Dr. Justice Nonvignon for his guidance, time, direction, patience, critiques, and comments before, during and after the writing of this thesis.

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ABSTRACT

Background: The opening of a Bone Marrow Transplant centre at the Greater Accra Regional hospital, the first centre in Ghana, provides an opportunity for caregivers to access the option of Bone Marrow Transplant as a cure to sickle cell disease. Since it is a new service, it is important to estimate how much caregivers are willing to pay for it.

Objective: The objective of this study was to determine caregivers' willingness to pay for Bone Marrow Transplant as a cure to Sickle Cell Disease (SCD).

Method: The study was a hospital-based cross-sectional study. The entire population of caregivers who bring children to the SCD clinic were recruited, using a structured interviewer administered questionnaire. The data was analysed using STATA version 15.0 and results presented in tables and figures. Chi-square, logistic regressions were used to determine factors associated with caregivers' willingness to pay for BMT for their children.

Results: The results showed that 78.6% of caregivers were willing to pay for Bone Marrow Transplant, but all below the actual amount of GH¢125,000. The mean amount caregivers were willing to pay was GH¢1567.38. About 57.1% had inadequate knowledge on BMT. Senior high school education of caregivers (aOR = 328.68; 95% CI = 5.21 – 20747.39; p = 0.006), caregivers in the second quintile (aOR = 2301.57; 95% CI = 7.93 – 667773.20; p = 0.007) and third quintile (aOR = 627.05; 95% CI = 3.35 – 117219; p = 0.016) had increased odds of WTP. A one year increase in age (aOR = 6.05; 95% CI = 1.67 – 21.91; p = 0.006), moderate sickle cell disease condition (aOR = 84.10; 95% CI = 1.32 – 5375.37; p = 0.037) had significantly increased odds in their willingness to pay for BMT. Those with inadequate knowledge (aOR = 0.09; 95% CI = 0.01 – 0.75; p = 0.027) had a reduced odds of WTP.

Conclusion: There is inadequate knowledge on bone marrow transplant among caregivers. Even though most caregivers are willing to pay for Bone marrow transplants, the amounts they are willing to pay are below the threshold. Age of child, severity of disease, educational level of care giver, wealth index and knowledge are factors associated with willingness to pay for bone marrow transplant.

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LIST OF ABBREVIATIONS

BMT - Bone Marrow Transplant

GDHS - Ghana Demographic Health Survey

SCD - Sickle Cell Disease

WTP - Willingness to Pay

WHO - World Health Organization

DEFINITION OF SIGNIFICANT TERMS

Allogeneic Transplant: Transplantation between individuals of the same species.

Autologous Transplant: Transplant comprised of an individual's own tissue, transferred from one part of the body to another.

Bone Marrow Transplant: The transference of bone marrow from one human to another for a variety of purposes.

Caregiver: Parent or Guardian of the child with Sickle cell disease.

Morbidity: The proportion of patients with a particular disease during a given year per given unit of population.

Mortality: Deaths reported in a given population.

Willingness to pay: the maximum amount a buyer is willing to pay for a commodity

CHAPTER ONE

INTRODUCTION

1.0 Background of the study

Sickle cell disease (SCD) is a genetic disease caused by a disorder in haemoglobin and occurs when an individual inherits the haemoglobin variant, haemoglobin S gene, from both parents. The commonest form of the disease is the homozygous HbSS type. However, there is the Hemoglobin C disease HbSC and sickle cell-β-thalassemia (Oringanje, Nemecek, & Oniyangi, 2016). The disease is characterised by distortion in the shape of the red blood cells, these sickle-shaped cells gets trapped in small blood vessels leading to very painful crisis, stroke and organ failure from reduced blood flow to end organs. These complications and crises lead to frequent hospitalisation, reduced life expectancy, morbidity and mortality (Walters et al., 1996). The median age at death for sickle cell disease patients is 48 years and 42 years among females and males, respectively. Among those who die, 18% get organ failure usually renal failure and 33% die from an acute sickle crisis; 78% with pain, acute chest syndrome or both, 22% with stroke (Lambe et al., 2011).

According to the World Health Organization, 5.2% of the world's population has Sickle Cell Disease (SCD), with Sub-Saharan Africa (SSA) having the greatest population and greatest global burden. Seventy nine percent of the over 300,000 annual deaths (Treadwell, Anie, Grant, Ofori-acquah, & Ohene-frempong, 2014) occur in SSA with a childhood mortality rate of 70% to 90% (Grosse et al., 2011). In Ghana, reports show a 30% carrier rate of the SCD trait and about 2% of new-borns in Ghana have sickle cell (Kyerewaa Edwin, Edwin, & Etwire, 2011).

Bone Marrow Transplantation (BMT) is a form of Hematopoetic Stem-cell transplant (HSCT), and it involves the giving of hematopoietic (blood forming) cells to replace deformed red blood. These hematopoietic cells then begin producing normal cells thus curing sickle cell. Studies have reported overall survival and survival without complications as greater than 90% and 80%, respectively (Oringanje et al., 2016). Another study reported 93% survival and 86% survival without complications in a study among children less than 16 years, making Bone Marrow Transplant a cure to SCD (Majumdar et al., 2010).

1.1 Problem statement

The greatest global burden of sickle cell disease (SCD) is found in Sub-Saharan Africa (Piel et al., 2013). Seventy percent of childhood deaths because of SCD is preventable (WHO, 2006). Despite the fact that first published report of Sickle cell disease was over a decade ago (Odame et al., 2011), the possibility of Bone Marrow transplant (BMT) for SCD has not been explored much in Ghana. Bone Marrow Transplant as a cure to SCD is a new service in Ghana and most studies have focused on new-born screening, advocacy and training programs (Odame et al., 2010; Ohene-Frimpong et al., 2008; Treadwell et al., 2014). Though the work of Odame et al., (2010) discussed the possibility of haematopoietic cell transplantation in the management of SCD. The very absence of a Bone Marrow Transplant centre at the time of most these research works in Ghana did not present the opportunity for most families to explore the option of BMT as a cure to SCD and as such not much studies have been done.

A major barrier to the uptake of Bone marrow transplant is the cost. The median cost is USD12,500 (range 10,331–39,367) and USD17,914 (range 10,832–44,701) for autologous and allogeneic transplants respectively in India (Sharma et al., 2014).

Setting up of a BMT centre is marked by challenges such as lack of trained personnel and expensive cost of setup (Hashmi et al., 2017). In June 2018 a centre was opened at Greater Accra Regional Hospital (Ridge Hospital) in Ghana, where the service is offered to clients who meet the inclusion criteria and can afford the service. The establishment of the centre provides an opportunity for significant research to be conducted into whether families would be willing to pay for BMT as a cure to SCD.

The cost of BMT at this centre is between USD20,000 to USD25,000 and this amount is subsidised. Data obtained from the World Health Survey conducted from 2002-2004 revealed that one out of every four families in across 40 developing countries had to sell or borrow assets, or both to afford healthcare (Kruk, Goldmann, & Galea, 2009).

It is, therefore, important for this study to be carried out to assess the knowledge caregivers' of children with SCD have on BMT, to introduce the service to them, and to know the monetary value they will place on the service as this will guide in formulation of policies, involvement of insurance and guide further studies on BMT in Ghana.

1.2 Objectives of the study

1.2.1 General objective

The general objective of this study was to determine caregivers' willingness to pay for Bone Marrow Transplant and associated factors.

1.2.2 Specific objectives:

The specific objectives of the study were to:

1. Assess caregivers' knowledge on Bone Marrow Transplant.
2. Determine the willingness to pay for BMT among caregivers.

3. Determine the factors associated with willingness to pay for Bone Marrow Transplant.

1.3 Research questions

1. What is the level/extent of knowledge caregivers have on Bone Marrow Transplant?
2. What is the willingness to pay for BMT among caregivers?
3. What are the factors associated with willingness of caregivers to pay for Bone Marrow Transplantation?

1.4 Conceptual framework

The willingness to pay for Bone Marrow Transplantation would initially rest on the adequacy of the knowledge caregivers have on the entire process as cure to SCD (Figure 1). The attendant medical problems with sickle cell disease such as co-morbidity, frequency of hospitalization and the frequency of crises would influence how caregivers would be willing to find and pay for any cure of SCD specifically Bone Marrow Transplant. However, considering the cost of a BMT procedure, the socio economic status of the caregiver may affect their willingness to pay. Education could be a factor, since it is associated with financial stability and may be associated with a better understanding of the entire BMT procedure. Certain demographic factors such as age and gender influence the willingness of individuals to pay for healthcare. Younger individuals with a higher life expectancy, by various studies, have been found to be willing to pay for healthcare.

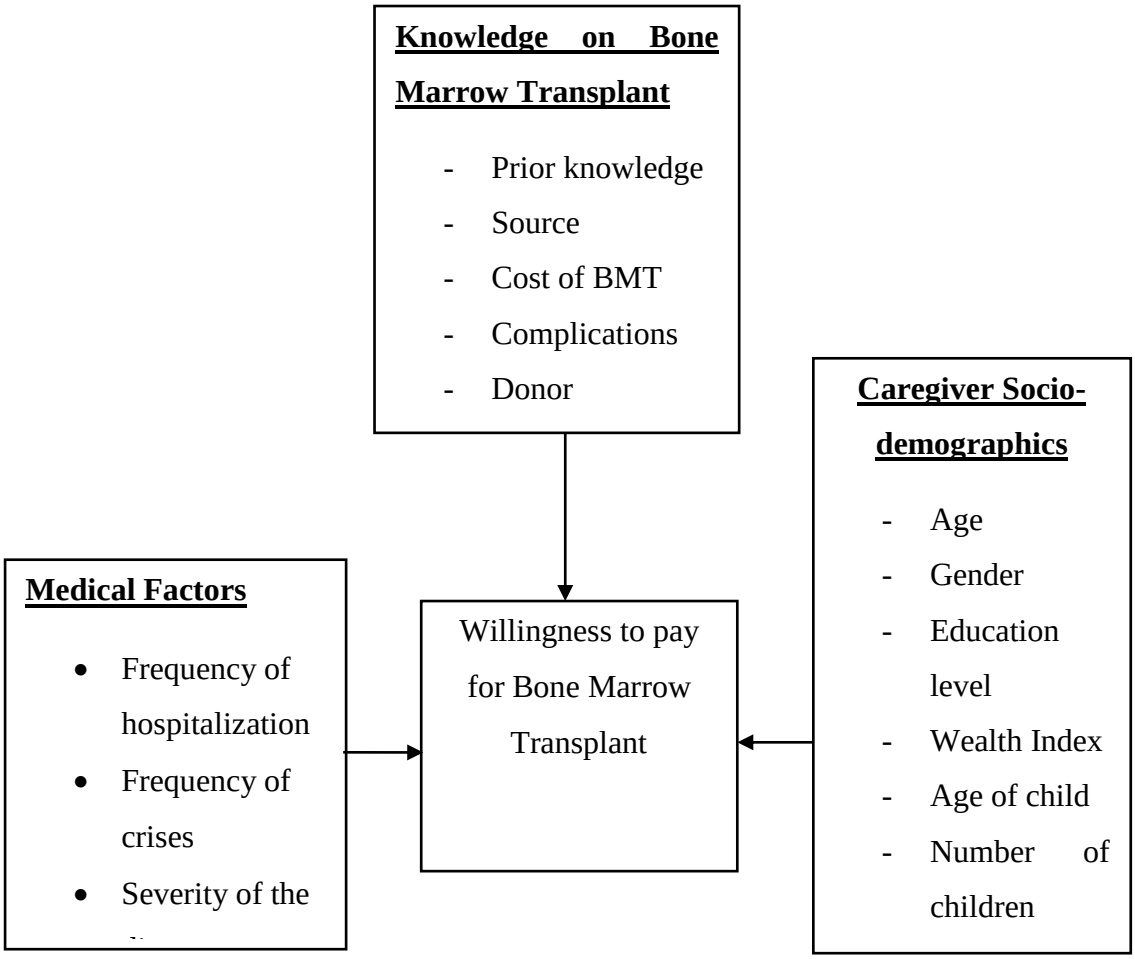

Figure 1. Conceptual Framework on caregivers' willingness to pay for bone marrow transplant to cure sickle cell disease in their children

1.5 Justification of the study

This study will be an early documentation on caregivers' willingness to pay for BMT for their children with SCD. It will also provide baseline information for health policy makers such as Ministry of Health, Ghana Health Service and other stakeholders; civil society organisations and religious organisations on providing financial support systems as payment mechanisms for BMT. This study also provides evidence on the constraints and enablers within the health care system as well as socio-economic factors that influence caregivers' willingness to pay for Bone Marrow Transplant as a cure to SCD.

CHAPTER TWO

LITERATURE REVIEW

2.0 Introduction

This section will review existing literature relevant to the topic, caregivers' willingness to pay for Bone Marrow Transplant to cure Sickle Cell Disease in their children. The literature will be reviewed as follows: Knowledge on Bone Marrow Transplant; this part will discuss various studies on SCD and knowledge on BMT. The next will be Willingness to pay; this section will review different studies, measurements of WTP and the Contingency Valuation (CV) method of measuring WTP. The last section will review literature on some factors influencing Willingness to Pay.

2.1 Sickle Cell Disease

SCD is a genetic disorder and is characterised by the presence of the haemoglobin S (HbS) and one other abnormal haemoglobin. In sickle cell disease, there is a mutation in the haemoglobin gene; there is substitution of valine for glutamic acid at position 6 of the beta-globin chain leading to the formation of sickled cells which are weak and have a shorter life spam and this causes chronic haemolytic anaemia and vaso-occlusive crises (Ilesanmi, 2010). This renders the red blood cells incapable of carrying adequate amount of oxygen the body needs because the red blood cells become sickled shape and these irregular shaped cells can get anchored to small blood vessels and reduce blood flow to parts of the body causing intense pain known as crisis (Edwin K. et al., 2011). SCD is by autosomal recessive inheritance; with the homozygous form HbSS being most common phenotype (55%). The other forms are heterozygous and are less symptomatic, these include HbSC, HbSD, HbS/beta-thalassemia, HbSO-Arab.

Sickle cell disease (SCD) is the most prevalent genetic haematological disorder worldwide (Baskin et al., 2000), predominantly affecting populations of West African and African Caribbean descent, as well as populations of Asian, Middle Eastern, and Mediterranean. According to the World Health Organisation (WHO), 5.2% of the world's population has sickle cell disease (Modell & Darlison, 2008). In the United States, approximately 100,000 people live with SCD. The disease is found in one in 13 black or African-American births and one in 16,300 Hispanic-American births (Centers for Disease Control and Prevention, 2017). Two hundred thousand (200,000) new-borns are delivered annually with SCD in Africa, with births in Sub-Saharan Africa accounting for 80% of this. Over 95% of children born with SCD die before the age of five (Dennis-Antwi et al., 2008). Study conducted at the Ghana institute of clinical Genetics (GICG), Korle-Bu Teaching Hospital, among patients aged 13 to 87years revealed that 55.7% of the patients had the HbSS phenotype. Fifty three (68.8%) out of 77 referred to the orthopaedics unit were radiologically diagnosed with Avascular Necrosis, 18% of the 86 patients were diagnosed at the ophthalmology unit as sickle cell retinopathy, 51.9% (28) out of 54 patients were diagnosed with priapism by the urologist.

2.1.1. Management of SCD

The management of SCD must be multi-disciplinary involving specialists from different backgrounds and involves both medical and non-medical interventions. Some non-medical interventions involve eating a balanced diet, keeping warm, malaria prevention, adequate hydration is crucial to the wellbeing of the sickle cell patient.

Medical interventions such as the use of penicillin twice daily, analgesia for painful crisis, antimalarial when crisis is precipitated by malaria parasite infection and antibiotics based on blood culture results. Transfusions are done for patients who come with anaemia and series of Exchange Blood Transfusion for patients with stroke or at risk of stroke. Hydroxyurea is a medication which works by increasing the formation of fetal hemoglobin (HbF) and can half the episodes of painful crisis (Agrawal, Patel, Shah, Nainiwal, & Trivedi, 2014; Galadanci et al., 2014; Ilesanmi, 2010).

2.2 Bone Marrow Transplant

Bone marrow transplant is a form of Hematopoietic stem cell transplant (HSCT), where stem cells from the bone marrow of a host is used to replace diseased stem cell of the of an individual with SCD with an aim of producing normal stem cells that will produce cells that express normal haemoglobin. Stem cells can also be harvested from peripheral blood and umbilical cord blood (Walters et al., 2001).

The first case of BMT as a cure to Sickle Cell Disease was done in 1984, this was for a patient with both acute myelogenous leukemia and SCD, the individual was free of both the cancer and SCD after the transplant and since then BMT as a cure to SCD has been studied (Oringanje, Nemecek, & Oniyangi, 2016). BMT is usually done for patients less than sixteen (16) years who have symptomatic disease for example, stroke, acute chest syndrome, sickle nephropathy, recurrent vaso-occlussive painful crises because adults (persons above 16 years) are more likely to reject transplant (Vermylen et al., 1991).

A hospital based descriptive study conducted among undergraduates in Ile-Ife, Nigeria revealed a 21.6% prevalence of SCD among those admitted over the five year study period, 68% had significant pain in the last one year, 44% psychological burden

and 37.3% socio-cultural burden (Olagunju, Faremi, & Olaifa, 2017). Approximately 5% to 10% of SCD patients will suffer a clinically overt stroke in their childhood (Adewoyin, 2015) and 5% to 18% will have renal failure with early mortality (Geard, Pule, Chelo, Bitoungui, & Wonkam, 2016) and this can averted by BMT as a cure to SCD. However, this is not to say BMT comes without complications such as infertility or the risk of developing chemotherapy-induced malignancy (Platt & Guinan, 1996).

2.3 Knowledge on Bone Marrow Transplant

A multi-centre study among health workers in seven tertiary hospitals in Nigeria, revealed 64.5% of respondents were aware of BMT as a cure to SCD, only 67.8% of those aware believed BMT could actually cure SCD. Knowledge levels ranged from 17.9% to 81.5% among the participating hospitals, even though the knowledge level was fair, only 49.7% would accept BMT despite the knowledge (Adediran et al., 2016), another study among 466 health workers in Nigeria revealed that even though 94.6% were aware of BMT, the mean knowledge score of participants was about 38.4% (Adediran, 2018).

There is paucity of study on knowledge on BMT from Ghana and most parts of the world. A study on sickle cell control in Ghana acknowledged BMT as a cure to SCD, however, this study discussed the ethics surrounding prenatal diagnosis and selective abortion among affected foetuses, and did not assess knowledge of respondents. Most studies have focused on screening in new-born babies, sickle cell advocacy and training programs (Odame et al., 2010; Ohene-Frimpong et al., 2008; Treadwell et al., 2014). Therefore it is important to assess the knowledge people have on bone marrow transplant.

2.4 Willingness to Pay

Willingness to pay is the maximum price an individual will accept to pay for a given quality goods and services. It can be measured by observing consumers purchasing practices, revealed pricing, or by giving specified amounts for potential consumers to state how much they are willing to pay. This can be done with open-ended and closed ended questions. In open-ended, the respondents are required to state an amount they are willing to pay for a service, while in close-ended prices in bids are given in either ascending or descending order and the respondent is asked series of questions to determine the highest price they are willing to pay for a good or service (Aizuddin, Sulong, & Aljunid, 2014). Methods for assessing willingness to pay include conjoint-based analysis, contingency valuation (CV) and choice modelling. This study will focus on the CV method.

2.4.1 Contingency Valuation Method

The contingency valuation method is one of the most widely used method of price elicitation. The method is the most widely used measure of passive use value (Carson, Flores, & Meade, 2000). CV can measure the monetary value that clients place on certain health care services (Pavel, Chakrabarty, & Gow, 2015). CV is often referred to as a stated preference model (Mataria, Donaldson, Luchini & Moatti, 2004) in contrast to price-based revealed preference model (Mark & Swait, 2004). The CV model is utility based where people are allowed to indicate how much money they would be willing to pay to access, maintain or improve services or activities (Pavel et al., 2015). The CV method is a methodically a survey (Klose, 1999). It is a hypothetical and direct method to assess the monetary value clients' place on improvements in medical technologies (Klose, 1999). CV questions are used to estimate the demand function or the willingness to pay distribution of consumers

(Carson et al., 2000). WTP questions are asked in two stages: patients are first asked whether they would be willing to pay a fee to access a specific health service, and only in case of an affirmative response, are they asked about the maximum amount they are willing to pay (Pavel et al., 2015). This method has been used to assess WTP not only in health but also social and environmental studies (Markandya, Ortiz, & Chiabai, 2018). The contingent valuation method has been validated for use in health and this method consists of 'iterative bidding'; amounts are set and a dichotomous (yes/no) question 'are you willing to pay?' asked , then using the "double-bounded" approach, goes on to ask for another amount. The new amount is higher if respondent answered 'yes' to previous amount, and lower if respondent answered 'no' till an amount the respondent is not willing to pay beyond, that amount becomes their willingness to pay amount (Hanemann, Loomis, & Kanninen, 1991).

2.4.2 Willingness to pay from other studies

A study done in Canada on caregivers' willingness to pay for Alzheimer's medication with 216 respondents reported that most (68%-93%), depending on the efficacy of the drug and adverse effect, were willing to pay USD214-277 out of pocket for treatment using a hypothetical drug (Oremus et al., 2015). Another WTP study done in Iran for health services in general revealed that respondents who could move about without difficulty anywhere were willing to pay USD295 and those who were completely bedridden were willing to pay an average of USD596 (Javan-Noughabi, Kavosi, Faramarzi, & Khammarnia, 2017).

A study on willingness to pay for a kidney for transplant in the United States showed that 78% of the 107 respondents were willing to pay for a kidney (Herold, 2010), it however did not focus on how much respondents were willing to pay. A WTP study in Nigerian with 125 respondents assessing if they were willing to pay for

Tuberculosis treatment for themselves and the poor (altruistic WTP) assuming it was no longer free revealed a majority (80%) of the participants willing to pay an average of USD174.48 (Ochonma & Onwujekwe, 2017) . The study also reported that 62.4% of respondents were willing to pay an average of USD14.06 for the poor (altruistic WTP).

There is no study on willingness to pay for bone marrow transplant in Ghana. Most WTP studies in Ghana have not focused on chronic disease, for example, 'household willingness to pay for improved solid waste management services' (Boateng et al., 2019), 'Willingness to pay for safer vegetables in Tamale, Ghana' (Tawiah et al., 2018). However a study on willingness to pay for malaria insurance, revealed that 98% of respondents were willing to pay between GH¢10 to GH¢50 with a mean premium of GH¢25 per month (Asafu-Adjaye & Dzator, 2003). This study will be one of the first WTP studies for chronic disease in Ghana and the first on BMT for SCD.

2.5 Factors affecting Willingness to Pay

Different studies have shown several factors that affect an individual's willingness to pay an amount for goods and services. Factors include Knowledge of the good or service, demographics, socio economic status, income and health status (Herold, 2010; Meier, Dioguardi, & Kamani, 2015; Chen et al., 2016; Centers for Disease Control and Prevention, 2017; Liso, Neri, Maglietta, La Russa, & Turillazzi, 2017). A study on WTP for health care revealed that factors such as age, education, income, household size/dependency ratio, perception, healthcare service quality influences WTP. It also revealed price does not influence willingness to pay for healthcare (Aizuddin, Sulong, & Aljunid, 2012). A study in Taiwan on willingness to pay (WTP) for a cure for chronic obstructive pulmonary disease revealed that those with more

serious disease and co-morbidities were willing to spend more on treatment, and the presence of different co-morbidities in a patient may affect their WTP for a cure (Chen, Ying, Chang, & Hsieh, 2016). It also showed younger patients were more willing to pay for a cure than older patients (Chen et al., 2016), however there was not a strong age correlation in other studies (Herold, 2010).

Gender influences WTP. Some studies have shown that more men were willing to pay than women for a cure for themselves. Others have shown caregivers' are more willing to pay for a cure for their male children than female children as revealed in a WTP study for a care for childhood diarrhoea (Amin & Khondoker, 2004; Herold, 2010).

In a WTP study for TB in Nigeria, income was identified as factor influencing WTP positively but the COPD study in Taiwan showed income had no correlation with willingness and income was not a positive factor (Chen et al., 2016; Ochonma & Onwujekwe, 2017). Educational level has been noted to affect WTP (Chatterjee, Triplett, Johnson, & Ahmed, 2017). Poor health status that is, individuals who suffer more, are more likely to be willing to pay for a cure (Herold, 2010; Javan-Noughabi, Kavosi, Faramarzi, & Khammarnia, 2017; Oremus et al., 2015), as compared to individuals with fair health. A WTP study for malaria insurance premium in Ghana revealed that income, educational level and number of people per household influenced WTP (Asafu-Adjaye & Dzator, 2003).

2.6 Summary

Bone marrow transplant is a cure for SCD and various factors account for willingness to pay for a health care service. There is paucity of literature on factors associated with WTP for BMT. Literature has been reviewed on Sickle cell disease, Bone marrow Transplant and Willingness to pay for cure for other curative treatment of

other medical conditions and healthcare in general in this chapter, however there is no data on WTP for BMT in Ghana. Assessing the willingness of caregivers to pay for BMT and factors associated with the amounts they are willing to pay, may provide useful information for policy makers and insurance organisations to take steps to increase accessibility to BMT in Ghana.

The next chapter will tackle methods that will be employed to carry out this study.

CHAPTER THREE

METHODS

3.0 Introduction

This chapter presents the methods that were used for the collection and analysis of data in this study.

3.1 Study design

The study was a hospital-based cross-sectional study. This study used quantitative approach to collect and analyse the data.

3.2 Study area

The study was conducted at the Greater Accra Regional Hospital. The hospital is the only hospital in the country that has a Bone Marrow Transplantation Center (this is run privately and not solely under Ghana Health Service).

The Greater Accra Regional Hospital also called the Ridge Hospital was established in 1928. It became a regional hospital in 1997. It provided health care to people from all over the Greater Accra Region of Ghana. It is an ultra-modern 600-bed facility and provides a range of services, which includes Pediatric care. The pediatric unit has a SCD clinic, which has enrolled about 120 patients since its inception in March 2018. A Bone Marrow Transplantation Center, the first of its kind in the country opened at the facility in June 2018. This Hospital also provides the following services: Internal Medicine, Surgery, Paediatrics, Obstetrics and Gynaecology, Dental, Clinical Psychology, Ophthalmology, Neurosurgery, Dermatology, Anaesthesia clinic, Diabetic clinic, Urology, Orthopaedics, Spinal Clinic, CT Scan, and Mammography (GNA, 2017).

3.3 Study Population

The study population were primary caregivers of all children enrolled at the sickle cell clinic at the Greater Accra Regional Hospital during the period of the study. The total number of children enrolled from March 2018 to March 2019 were 120. Due to the small number, the study recruited all caregivers attending the clinic.

3.4 Inclusion criteria

Caregivers of children with Sickle Cell Disease presenting at the sickle cell clinic and willing to respond.

3.5 Exclusion criteria

Caregivers who have already paid, and awaiting BMT for their children were not included in this study.

3.6 Data collection method and instruments

Structured interviewer-administered questionnaires were given to all caregivers who came to the sickle cell clinic. Caregivers who met the inclusion criteria were interviewed after seeking an informed consent.

The data collection tools were questionnaires. The questionnaires had three sections; Section A collected data on socio-demographic information including the wealth index assessing their possessions. Section B assessed knowledge of BMT, adapted from a study conducted in Nigeria by Adediran et al. (2016). Section C assessed willingness to pay in accordance with CV method (Hanemann, Loomis, & Kanninen, 1991).

3.7 Quality control

Researcher collected the data. Pretesting of questionnaire and observation checklist was done to assess the clarity of the questions. Returned questionnaires were scrutinized for mistakes and completeness. Questionnaires that had unclear responses

or a lot of missing information were excluded in the analysis. Entered data was crosschecked to reduce entry errors and to make the data more reliable.

3.8 Study variables

Table 1. Dependent and Independent variables

Dependent Variable	**Operational Definition**	**Scale of measurement**
Willingness to pay	1. Whether respondent is willing to pay for BMT as a cure to SCD (Yes or No) 2. How much they are actually willing to pay (Amounts in Ghana cedis)	Nominal Discrete
Independent Variables	**Operational definition**	**Scale of measurement**
Age	1.Respondents age at last birthday 2.Age of child at last birthday	Discrete
Gender	Male, female	Nominal
Educational status	1.Highest level of formal education attained by respondent (i.e. No formal education, Primary School, Junior High School/ Senior High School)	Ordinal
Employment status	Current employment status (i.e. unemployed, employed, retired)	Nominal
Wealth index	Socioeconomic status quintiles (lowest, second, middle, fourth, highest)	Ordinal
Knowledge	1.Whether respondent has prior Knowledge about BMT 2.The level of knowledge on BMT respondent has (adequate knowledge, inadequate knowledge)	Nominal Ordinal
Health Status (severity)	Severity of child's disease (Severe, moderate, mild)	Ordinal

3.9 Data processing and analysis

Data were entered into Microsoft Excel and reviewed by two other people. Data was then imported into STATA version 15 for analysis. Descriptive statistics was employed to describe the factors that influence caregivers' willingness to pay for Bone Marrow Transplant by summarizing them into percentages, proportions and frequencies. Mean and standard deviation were computed for age. Frequencies and percentages were presented with the aid of tables and charts. The principal component analysis technique was used to estimate the wealth index, assessing the possession of participants. An abridged version of items used by the Ghana Demographic Health Survey (GDHS, 2014) was selected to reflect an urban setting. Based on the index, the participants were categorized into quintiles; with those with 20%, 40%, 60%, 80% and 100% of the possessions ranked as lowest, second, middle, fourth and highest, respectively. Chi-square test was used to test for associations between the dependent (willingness to pay) and categorical independent variables. T-test was employed to compare the average age among those who were willing to pay and those who are not.

Series of questions were asked to assess knowledge and responses were ranked as adequate and inadequate. Participants who rightly answered that sickle cell had a cure, knew the right definition of BMT and answered that any compatible person could be a donor were scored as adequate knowledge. WTP was assessed by Contingent Valuation method of price elicitation. Iterative bidding with dichotomous ('Yes' or 'No') questions were asked for stated amounts and the estimated price for the service, USD25,000 (GH¢125,000) was used as starting price and this amount adjusted upwards or downwards by 20% depending on the answer given by the participants. Those who answered 'no' to the lowest bid were then be asked the open-ended 'how much are you willing to pay' of which they stated their WTP amounts. Univariate

analysis using simple logistic regression was used to assess association between dependent and independent variables. Factors identified after the univariate analysis to significantly predict Willingness to pay for BMT were then fitted into multiple logistic regression models. The level of significance for all statistical test was at 5%.

3.10 Ethical considerations

Ethical approval was obtained from the Ghana Health Service Ethical Review Committee (ERC). A letter was sent to the Regional Health Directorate asking for permission to carry out the research. Approval was sought from Greater Accra Regional Hospital as well.

3.10.1 Participant's consent

The aim of study was clearly explained to participants of the study and informed consent sought.

3.10.2 Voluntary consent

Participants were told they could opt out from the research whenever they want to and there will be no penalties for voluntary withdrawal.

3.10.3 Privacy and confidentiality

Participant privacy and confidentiality was assured. Collected data will be destroyed after a period of at most 5 years.

3.10.4 Compensation

Participants received no financial or material incentives for this study.

3.10.5 Potential risks/ benefits

There was no potential harm in this study aside the discomfort of sharing of personal demographic information. In contrast, the findings will help improve awareness on Bone Marrow Transplantation and will inform policies on SCD management.

3.10.6 Conflict of interest

I hereby declare that there is no conflict of interest. This research is only because of academic and public health relevance.

3.11 Pretesting

The data collection tools was first pretested and necessary modifications made.

CHAPTER FOUR

RESULTS

4.0 Socio-demographic characteristics of respondents

The results in Table 2 below shows the socio-demographic respondents of respondents. The mean age of caregivers was 36.0 years ± 6.8 SD. Most of the caregivers 41.1% (46/112) had up to tertiary education. Majority of the caregivers 76.8% (86/112) were employed. Also, 91.9% (103/112) of caregivers were married. Nearly half of the sickle cell children 50.9% (57/112) of the respondents were females. The mean age of the children of the caregivers was 4.1 years ± 2.9SD. Majority of the children in the study had some form of formal education (68.7%, 77/112) as compared to those who had no formal education. The mean number of children was 2.3 ± 1.1 SD while the mean number of children who have sickle cell was 1.1 ± 0.3 SD.

Table 2. Socio-demographic characteristics of respondents (n = 112)

Variables	Frequency	Percent (%)
Age of caregiver in years (M ± SD)	36.0 ± 6.8	
Educational level of caregiver		
Primary school	14	12.5
Junior high school	14	12.5
Senior high school	38	33.9
Tertiary	46	41.1
Employment status		
Unemployed	25	22.3
Employed	86	76.8
Retired	1	0.9
Marital status		
Single	3	2.7
Married	103	91.9
Co-habiting	5	4.5
Separated	1	0.9

Variables	Frequency	Percent (%)
Sex of child		
Male	55	49.1
Female	57	50.9
Educational level of child		
No formal education	35	31.3
Pre-school	47	41.9
Primary	30	26.8
Wealth quintile		
1st quintile	2	1.8
2nd quintile	17	15.2
3rd quintile	41	36.6
4th quintile	45	40.2
5th quintile	7	6.2
Mean age of child in years (M ± SD)	4.1 ± 2.9	
Mean number of children (M ± SD)	2.3 ± 1.1	
Mean number of children who have sickle cell (M ± SD)	1.1 ± 0.3	

4.1 Knowledge of respondents on bone marrow transplant

Table 3 reports knowledge of respondents on bone marrow transplant. Assessing knowledge of respondents on bone marrow transplant, 65.2% of respondents indicated knowledge of a cure for sickle cell anaemia and 33.9% of respondents correctly chose "a procedure whereby stem cells are harvested from a suitable donor and infused into a recipient" as their knowledge of what bone marrow transplant was. Meanwhile, 35.7% did not know what bone marrow transplant was.

Respondents who correctly stated any compatible person as the donor for BMT were 55 (49.1%) and 53.6% indicated a donor would have no problem (healthy) after donation.

Forty seven respondents (42.0%) indicated that they knew about complications after BMT.

Death is the most common complication indicated by respondents 70 (62.5%) and was the most feared complication 70 (62.5%).

Twenty of the respondents (17.9%) knew somebody who had done bone marrow transplant. Out of this, 60% of them indicated the outcome of the bone marrow transplant was good. More than half of respondents (53.6%) had no idea how much it cost to have a BMT in Ghana. Overall knowledge was assessed by scoring those who knew SCD could be cured, knew the definition for BMT (knowledge on bone marrow transplant), knew any compatible person could be a donor and knew donor will have no problem after donation (Problem after donation). Those who scored two out of these four questions right were scored adequate knowledge, anything short of that as inadequate knowledge. Forty-eight of the respondents had adequate knowledge and 64 (57.1%) inadequate knowledge.

Table 3. Knowledge of respondents on bone marrow transplant (n = 112)

Variables	Frequency	Percent (%)
Cure for sickle cell anaemia		
Yes (correct)	73	65.2
No	7	6.3
Don't know	32	28.5
Knowledge on bone marrow transplant		
Don't know	40	35.7
Infusion of blood cells after collecting it from a suitable donor	21	18.8
Surgical operation done by cutting the bone of a suitable donor and implanting it on recipient	13	11.6
A procedure whereby stem cells are harvested from a suitable donor and infused into a recipient (correct)	38	33.9

Variables	Frequency	Percent (%)
Best person to donate bone marrow		
Relative to relative	57	50.9
Anybody compatible (correct)	55	49.1
Problem after donation		
Probable death	20	17.9
Low haemoglobin	22	19.6
Serious illness	10	8.9
Healthy	60	53.6
Complications known		
Rejection	46	41.1***
Sterility	24	21.4***
Obesity	18	16.1***
heart disease	19	16.9***
Diabetes	11	9.8***
Donor cells attacking the host cells	42	37.5***
Death	70	62.5***
None of the above	18	16.1***
Not sure	7	6.3***
Complications feared the most		
Rejection	11	9.8***
Sterililty	7	6.3***
Obesity	3	2.7***
Heart disease	7	6.3***
Donor cells attacking the host cells	12	10.7***
Death	70	62.5***
None of the above	18	16.1***
Not sure	7	6.3***
Knowledge of anybody that has done bone marrow transplant		
Yes	20	17.9
No	92	82.1
Outcome of the bone marrow transplant		
Good	12	60.0
Bad	5	25.0
Don't know	3	15.0

Variables	Frequency	Percent (%)
Cost of bone marrow transplant in Ghana		
No idea	60	53.6
Less than 20,000	25	22.3
20,000 - 50,000	13	11.6
Greater than 50,000	14	12.5
Overall knowledge on bone marrow transplant		
Adequate knowledge	48	42.9
Inadequate knowledge	64	57.1

*****multiple response**

4.2 Willingness to pay for bone marrow transplant

Out of the 112 caregivers' whose children had sickle cell disease, 78.6% were willing to pay for bone marrow transplant (p = 0.78; 95% CI = 0.69 – 0.86), as shown in Figure 2.

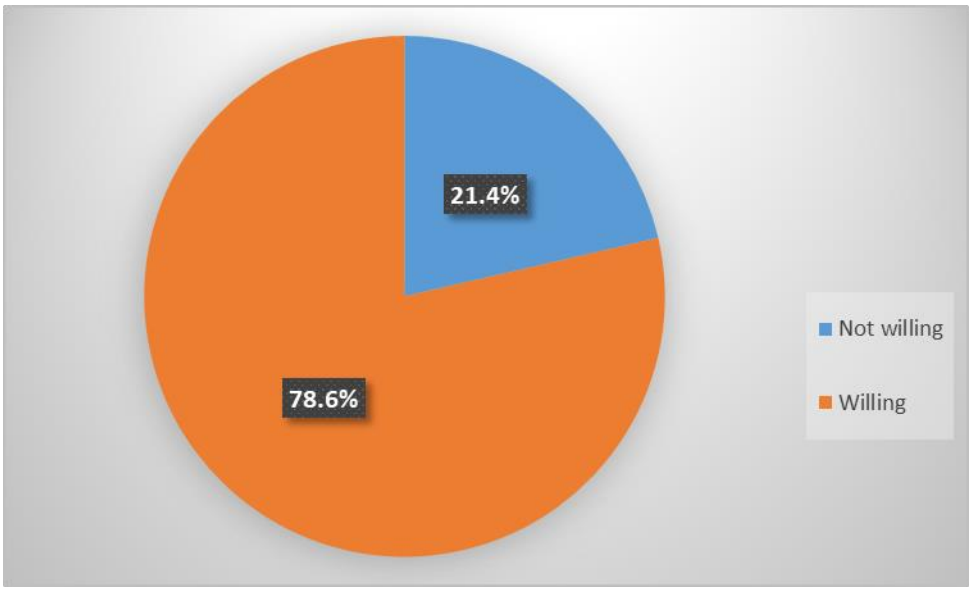

Figure 2. Proportion of respondents willing to pay for bone marrow transplant

However, none of them was willing to pay the start price (actual cost) of GH₵125,000 and above or GH₵100,000 and GH₵75,000 (Table 4). When asked how much they were willing to pay, the least amount respondents were willing to pay was GH₵50

and the maximum amount was GH₵20,000. The median amount was GH₵800. The average amount they were willing to pay was GH₵1567.38 ± 2973SD. Majority of respondents were willing to pay GH₵5,000.00 or less for a BMT for their SCD child.

Table 4. Amount respondents were willing to pay

Minimum	50.00
Maximum	20000.00
Mean	1567.38
Median	800.00
Standard deviation	2973.49
Standard error	316.9751
Coefficient of variation	1.89%
Interquartile range	1150
Amount in Categories (GH₵)	**n (%)**
<5000	84(95.4)
5001-10000	2(2.3)
10001-20000	2(2.3)

4.3 Factors associated with willingness to pay for Bone Marrow Transplant (Bivariate analysis)

Most socio-demographic factors (Age, Sex of the child, Employment Status, Marital Status, Number of Children, Number of Children Who Have Sickle Cell) did not show statistically significant association with willingness to pay for BMT as shown in Table 5. However, educational level of caregiver (p=0.025) classified as no formation education, primary school, junior high school, senior high school, tertiary; educational level of child (p=0.000) classified as no formal education, pre-school and primary school; wealth quintile (p=0.002) classified as 1st, 2nd, 3rd, 4th and 5th quintiles; severity of the disease (p=0.014) classified as mild, moderate and severe; and overall knowledge on bone marrow transplant (p=0.009) classified as adequate knowledge

and inadequate knowledge all showed statistically significant association with willingness to pay for BMT.

Table 5. Factors associated with willingness to pay for BMT

Variables	**Willingness To Pay**		χ^2
	Willing(n = 88)	Not Willing (n = 24)	p- value
Age (M ± SD)	36.1 ± 7.2	35.6 ± 5.2	
Age of child	4.54 ± 2.9	2.51 ± 1.9	
Sex of the child			0.792
Male	45(77.6)	13(22.4)	
Female	43(79.6)	11(20.4)	
Educational Level of Caregiver			**+0.025***
No formal education	0(0.0)	0(0.0)	
Primary school	8(57.1)	6(42.9)	
Junior high school	11(78.6)	3(21.4)	
Senior high school	35(92.1)	3(7.9)	
Tertiary	34(73.9)	12(26.1)	
Employment Status			+0.831
Unemployed	19(76.0)	6(24.0)	
Employed	68(79.1)	18(20.9)	
Retired	1(100.0)	0(0.0)	
Marital Status			+0.779
Single	3(75.0)	1(25.0)	
Married	79(79.0)	21(21.0)	
Co-habiting	5(83.3)	1(16.7)	
Separated	1(50.0)	1(50.0)	
Educational Level Of Child			**0.000***
No formal education	20(57.1)	15(42.9)	
Pre-school	38(80.8)	9(19.2)	
Primary school	30(100.0)	0(0.0)	

Variables	Willingness To Pay		χ^2
	Willing(n = 88)	Not Willing (n = 24)	p- value
Wealth quintile			**+0.002***
1st quintile	1(14.3)	6(85.7)	
2nd quintile	37(82.2)	8(17.8)	
3rd quintile	35(85.4)	6(14.6)	
4th quintile	14(82.4)	3(17.6)	
5th quintile	1(50.0)	1(50.0)	
Severity of the Disease			**+0.014***
Mild	39(68.4)	18(31.6)	
Moderate	37(92.5)	3(7.5)	
Severe	12(80.0)	3(20.0)	
Overall knowledge on Bone Marrow Transplant			**+0.009***
Adequate knowledge	44(91.7)	4(8.3)	
Inadequate knowledge	44(68.8)	20(31.2)	
Number of Children (M ± SD)	2.3 ± 1.2	2.6 ± 0.9	
Number of Children Who Have Sickle Cell (M ± SD)	1.1 ± 0.3	1.1 ± 0.3	

+ (fisher's exact) *(statistically significant, p≤0.05)

4.4 Results from multiple logistic regression of factors associated with WTP for BMT

Table 6 shows the results from multiple logistic regression of factors associated with willingness to pay for BMT had p-values ≤ 0.1 (educational level of caregiver, educational level of child, wealth quintile, severity of the disease, knowledge on bone marrow transplant, complications after bone marrow transplant, cost of bone marrow transplant in Ghana) in the chi square analysis done earlier (Table 5).

Educational level of the caregiver showed statistically significant association with willingness to pay for BMT. The odds of willingness to pay for BMT was

significantly 8.75 times as high among caregivers who had up to senior high school education as compared to caregivers who had up to primary school education. This association was statistically significant after adjusting for all other variables (aOR = 328.68; 95% CI = 5.21 – 20747.39; p = 0.006).

The wealth quintile of caregivers showed statistically significant association in their willingness to pay for BMT. Caregivers in the second quintile (cOR = 27.75; 95% CI = 2.92 – 263.47; p = 0.004), third quintile (cOR = 35.00; 95% CI = 3.55 – 344.69; p = 0.002), fourth quintile (cOR = 28.00; 95% CI = 2.39 – 326.74; p = 0.008) had significantly higher odds in their willingness to pay for BMT as compared to the first quintile. However after adjusting for all other variables, caregivers in the second quintile (aOR = 2301.57; 95% CI = 7.93 – 667773.20; p = 0.007) and third quintile (aOR = 627.05; 95% CI = 3.35 – 117219; p = 0.016) had significantly increased odds in their willingness to pay for BMT.

Caregivers whose children had moderate sickle cell disease condition had significantly 5.69 times the odds in their willingness to pay for BMT as compared to caregivers whose children had mild sickle cell disease condition. This association was statistically significant after adjusting for all other variables (aOR = 84.10; 95% CI = 1.32 – 5375.37; p = 0.037).

Overall knowledge of respondents on BMT was also significantly associated with their willingness to pay for BMT (p = 0.009). Respondents with inadequate knowledge had significantly 80% reduction in the odds of their willingness pay for BMT as compared to those who had adequate knowledge about BMT. This association was still statistically significant after adjusting for all other variables (aOR = 0.09; 95% CI = 0.01 – 0.75; p = 0.027).

A one year increase in age of a child with sickle cell disease significantly increased the odds of the caregivers' willingness to pay. This association was significant after adjusting for all other variables (aOR = 6.05; 95% CI = 1.67 – 21.91; p = 0.006).

Table 6. Factors associated with willingness to pay for BMT (multiple logistic regression)

Variables	cOR (95% CI)	p – value	aOR (95% CI)	p - value
Educational level of caregiver				
Primary school	Ref			
Junior high school	2.75(0.52 - 14.44)	0.232	21.08(0.79 – 561.93)	0.069
Senior high school	**8.75(1.79 - 42.67)**	**0.007***	**328.68(5.21 – 20747.39)**	**0.006***
Tertiary	2.13(0.61 - 7.39)	0.236	0.99(0.05 – 21.90)	0.998
Educational level of child				
No formal education	Ref			
Pre-school	2.49 (0.92 - 6.78)	0.073	1.82 (0.12 – 28.12)	0.667
Primary school	**8.27 (1.69 - 40.57)**	**0.009***	0.02 (0.00008 – 4.54)	0.156
Wealth quintile				
1st quintile	Ref			
2nd quintile	**27.75 (2.92 - 263.47)**	**0.004***	**2301.57 (7.93 – 667773.20)**	**0.007***
3rd quintile	**35.00 (3.55 - 344.69)**	**0.002***	**627.05 (3.35 – 117219.30)**	**0.016***
4th quintile	**28.00 (2.39 - 326.74)**	**0.008***	550.96 (0.62 – 492530.20)	0.069
5th quintile	6.00 (0.18 - 196.28)	0.314	606.05 (1.12 – 3.29)	0.859
Severity of the disease				
Mild	Ref			
Moderate	**5.69 (1.55 - 20.94)**	**0.009***	**420.74 (2.75 – 64339.44)**	**0.019***
Severe	1.85 (0.46 - 7.36)	0.385	1.05 (0.11 – 9.63)	0.966
Knowledge On Bone Marrow Transplant				
Adequate knowledge	Ref			
Inadequate knowledge	**0.20 (0.06 - 0.63)**	**0.006***	**0.005 (0.0001 - 0.17)**	**0.003***

Variables	cOR (95% CI)	p – value	aOR (95% CI)	p - value
Age of child	**1.47(1.13 – 1.92)**	**0.004***	**6.05(1.67 – 21.91)**	**0.006***

*(statistically significant, p≤0.05)

CHAPTER FIVE

DISCUSSION

5.0 Introduction

This chapter seeks to summarize the study and findings of analyzed data. The findings are compared to existing literature, and similarities and differences discussed. Researcher also explains the strength as well as the limitations encountered during the study.

5.1 Summary of study and findings

This study sought to assess the knowledge caregivers of children with SCD had about BMT, to assess their Willingness to pay for BMT and the factors associated with it. This was achieved by estimating how much knowledge they had about the procedure and comparing their knowledge level and other socio-demographic characteristics to their Willingness to pay.

5.2 Knowledge of caregivers on Bone Marrow Transplant

The study revealed that a majority (57.1%) of respondents had inadequate knowledge of BMT. This finding was similar to a study that showed that a majority of respondents did not rightly answer questions about the procedure. Another study assessing the knowledge of health workers in general revealed a mean knowledge of 38.4±2.06% (Adediran, 2018; Adediran et al., 2016). However this finding was different from that of a study conducted in the United States in which a majority of respondents had adequate knowledge but that study was conducted among BMT nurses who had practiced for a mean of 7.05 years (Pederson & Parran, 1997). Therefore, the inadequate knowledge of respondents in this study could be because BMT is new in Ghana (June 2018), as compared to the US where the first case was done in 1984 (Ashorobi & Bhatt, 2019). In addition, not much awareness has been

created in Ghana. Also the study that showed good knowledge was among specialised nurses with experience in BMT.

5.3 Willingness to pay for BMT among caregivers

Results obtained from the analysis of this study revealed that a majority were willing to pay for BMT. This is in contrast to findings of a study conducted in Malaysia where a majority (72.2%) were not willing to pay for drugs for both chronic and acute disease (Puteh, Ahmad, Aizuddin, Zainal, & Ismail, 2017). However, a study conducted in the US revealed 78.5% were willing to pay for a kidney for transplant (Herold, 2010).

In this study, amounts they were willing to pay, however were below the threshold (mean GH¢1567.38) compared with the amount needed for the service. This finding is in contrast to a study in Canada where diabetic patients were willing to pay 157.70 Can dollars which was higher than usual price of 50 Can dollars for inhaled insulin. This amount was three times the asking price (Sadri, MacKeigan, Leiter, & Einarson, 2005). Though the disease conditions, relative cost and socio-economic status of respondents in these studies are different, lessons can be drawn from comparing these two studies. Ghana has a minimum wage of GH¢10.69, which is less than USD3 (Minimum wage - Ghana, 2019). If respondents had the socioeconomic characteristics of those in the Canadian study, they may have offered to pay an amount higher than the starting price.

5.4 Factors associated with WTP

This study revealed that educational level of caregivers, wealth index, age of child and severity of disease were significant factors associated with willingness to pay for BMT. In addition, there was a 91% decrease in odds of WTP with inadequate knowledge on BMT compared to adequate knowledge.

Level of education was associated with WTP. Logistic analysis revealed a significant relation in the WTP of respondents with the highest level of education being senior high school (p = 0.006). The other levels did not show any statistically significant difference. No trend in the educational level and the WTP was observed, unlike a study in Vietnam with patients with cardiovascular disease, which showed that those with level of education above high school are more willing to pay (Xuan et al., 2018).

The wealth index of respondents was a positive predictor of WTP. This study showed that respondents within the second quintile (aOR = 2301.57; 95% CI = 7.93 – 667773.20; p = 0.007) and third quintile (aOR = 627.05; 95% CI = 3.35 – 117219; p = 0.016) had significantly increased odds in their willingness to pay for BMT. This finding was different from a study conducted in Taiwan with patients with COPD, which revealed that wealth had no correlation with WTP. The proposed reason could be that those at the extremes of education and wealth usually think the government should pay for most things.

Severity of disease was associated with respondents WTP. This study revealed that those with children with moderate disease had a higher WTP compared to mild disease but the WTP for those with severe disease was not significant. This is in contrast to studies by Herold (2010) and that of Oremus (2015) that suggested that those with more severe disease were more willing to pay. This observation could be due to the fact that, in those studies they were paying for themselves and not their children. Also parents with children with severe disease may have already tried other forms of management and may have given up.

This study also showed that those with inadequate knowledge were less likely to pay for BMT compared to those with adequate knowledge and this is consistent with

findings in WTP literature (Herold, 2010; Meier, Dioguardi, & Kamani, 2015). The proposed explanation to this finding could be the theory of the 'fear of the unknown' where people are generally scared to venture paths unknown and especially in this study where their children are involved.

5.5 Strength and limitations

The collection of data for the study was by Interviewer-administered questionnaire, which ensured the data was accurately collected. The whole population was recruited for the study eliminating selection bias. However, due to the small size of the study population and the fact that it was done at one centre, care must be taken in projecting findings to the general population.

CHAPTER SIX

CONCLUSION AND RECOMMENDATION

6.0 Conclusion

This study aimed at assessing the knowledge of caregivers of SCD children attending the SCD clinic at Greater Accra Regional Hospital about bone marrow transplant, that is, if they knew it could cure sickle cell disease in children. The study was also to determine if the caregivers were willing to pay and how much they are willing to pay.

The study revealed that, more than half of the respondents had inadequate knowledge on BMT, as already discussed in the literature review. Bone marrow Transplant was not an option in Ghana until June 2018 so it is new to most caregivers.

Even though most of the caregivers were willing to pay for Bone marrow transplant for their children, they were not willing to pay any of the stated amounts. All respondents opted to state the amount they were willing to pay and the mean WTP (GH₵1567.38) amount was below the threshold amount.

Educational level of caregivers, age of the child, severity of the disease, wealth index and knowledge significantly affected caregivers' willingness to pay for Bone marrow Transplant.

6.1 Recommendations

From the study, it is observed that the respondents had inadequate knowledge on BMT and it affected their WTP for BMT. It was also observed that even though most of the respondents were willing to pay for BMT, the amounts were below threshold. It is my recommendation that:

1. There should be sensitization and awareness creation on BMT as a cure to sickle cell disease. Caregivers should be given enough information about the procedure to help make an informed decision

2. Advocacy should be made to draw the attention of policy makers, so that some of the chemotherapy drugs and interventions done as part of BMT; which adds to the cost, should be covered under the national health insurance scheme to relief some of the financial burden of BMT on the parents. This would make it more affordable and encourage the patronisation of this life saving procedure.
3. Further studies should to be conducted on whether insurance companies (private and public) are willing to add BMT to their health insurance package since no respondent was willing to pay the actual price.
4. A multi-centre research should also be done to make a better generalisation of the results of this study.

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APPENDICES

APPENDIX 1. PARTICIPANTS INFORMATION SHEET

Introduction

Title: CAREGIVERS' WILLINGNESS TO PAY FOR BONE MARROW TRANSPLANT TO CURE SICKLE CELL DISEASE IN THEIR CHILDREN

Principal Investigator: ADWOA AFRIYIE WILSON

Address: **SCHOOL OF PUBLIC HEALTH**

DEPARTMENT OF HEALTH POLICY PLANNING AND MANAGAMENT

UNIVERSITY OF GHANA, LEGON

Phone No.: **+233269605969**

Background and Purpose of research

My name is ADWOA AFRIYIE WILSON. I am a graduate student of University of Ghana School of Public Health undertaking a research on CAREGIVERS' WILLINGNESS TO PAY FOR BONE MARROW TRANSPLANT TO CURE SICKLE CELL DISEASE IN THEIR CHILDREN.

Nature of research

The study seeks to find out whether or not you will be willing to pay Bone Marrow Transplant to cure Sickle cell disease for your child. The study will also seek to find how much you are willing to pay for this service. Participants are required to share

information on their socioeconomic status as well as other information on the medical condition of your child by responding to questions.

Participants Involvement

Participants will be required fill questionnaires at their own free will in private/ confidential setting.

Duration

This is a one-time survey and will need no follow up.

Possible risk and Discomfort

Be assured that the research comes at no physical risk except the discomfort of sharing personal information.

Possible Benefits

Participating in this study affords an opportunity for the participants to gain some knowledge and awareness on Bone Marrow Transplant as a cure for Sickle Cell disease. In addition, findings from this study will be shared with hospital authority, and stakeholders, which may inform policy that improves the overall delivery of health services.

Cost

Be assured that the research comes at no cost except your precious time that will be used to fill the questionnaire.

Compensation

Participants will not be compensated financially or with any item

Privacy

Participant's privacy will be respected during data collection.

Confidentiality

Personal information that will lead to identification of clients or the child will not be included in the questionnaire. Questionnaire clients will respond to, will be anonymous (will not bear names of participants) so you will not be identified. However, be assured that your privacy and confidentiality will be respected. You can choose a place of convenience to answer the questions. Participant information will be kept on a computer with a secured password. Filled questionnaires will be kept under lock and key, with only the principal investigator having access.

Voluntary Participation/ withdrawal

You participate in this research at your own free will. You may decide to discontinue or withdraw. Nobody will be upset if you decide to discontinue/ withdraw at any time while answering the questionnaire.

Feedback to participants

There will be no feedback to participants after study.

Funding information

The principal investigator will solely fund this study.

Sharing of participant information/data

The principal investigator owns the data, and personal information will be kept confidential.

Provision of information and consent form

A copy of both the information and consent form will be given to participants after it is signed or thumb-printed to keep.

For further Clarification/Questions

Please Contact

Adwoa Afriyie Wilson (Principal investigator)

University of Ghana

School of Public health

Maameafriyie1@gmail.com

+23326 9605969

For further clarification on ethical issues, please contact

The Ethical Review Committee (ERC) Office

ERC Administrator

Hannah Frimpong

0507041223

APPENDIX 2. PARTICIPANTS' STATEMENT

The above document describing the benefits, risks and procedures for the research title

"CAREGIVERS' WILLINGNESS TO PAY FOR BONE MARROW TRANSPLANT TO CURE SICKLE CELL DISEASE IN THEIR CHILDREN" has been explained to me.

As a caregiver, I have read or have had someone read all of the above in English [ ] ,Ga[ ], Twi[ ], Ewe[ ] or Hausa[ ]. I have asked questions, received answers regarding participation in this study, and am willing to give consent to participate in this study as a volunteer. I understand that I can withdraw from this research even after I sign this form.

I voluntarily agree to be part of this research.

Name or Initials of Participant…… ID Co……..

Participants' Signature/Thumb-Print…….

Date:…….

INTERPRETERS' STATEMENT

I interpreted the purpose and contents of the Participants' Information Sheet to the afore named participant to the best of my ability in the English [ ] Ga[ ], Twi[ ], Ewe[ ] or Hausa[ ] language to his/her proper understanding.

All questions, appropriate clarifications sort by the participant and answers were also duly interpreted to his/her satisfaction.

Name of Interpreter……

Signature of Interpreter…… Date:……

Contact Details

STATEMENT OF WITNESS

I was present when the purpose and contents of the Participant Information Sheet was read and explained satisfactorily to the participant in the language he/she understood English [ ] Ga[ ], Twi[ ], Ewe[ ] or Hausa[ ]

I confirm that he/she was given the opportunity to ask questions/seek clarifications and same were duly answered to his/her satisfaction before voluntarily agreeing to be part of the research.

Name: ……

Signature/Thumb-print of participant:……...……..

Date:……

INVESTIGATOR STATEMENT AND SIGNATURE

I certify that the nature and purpose, potential benefits, possible risks associated with participating in this research have been duly explained to the above individual and the participant has been given ample time to read about the study and all questions have been clarified.

Researcher's name…….

Signature …….

Date…….

APPENDIX 3. STATEMENT TO COMPLY WITH ETHICAL PRINCIPLES

I , ADWOA AFRIYIE WILSON, The Principal Investigator (PI) of this study write to state that I will comply with all ethical principles and guidelines throughout the conduct of the study.

I shall conduct the study in accordance with the approved protocol.

Name of Student ……..Signature……..

Name of Supervisor…….. Signature ……

APPENDIX 4. ETHICAL APPROVAL

GHANA HEALTH SERVICE ETHICS REVIEW COMMITTEE

In case of reply the number and date of this Letter should be quoted.

MyRef. GHS/RDD/ERC/Admin/App
Your Ref. No. 19/087

Research & Development Division
Ghana Health Service
P. O. Box MB 190
Accra
Tel: +233-302-681109
Fax + 233-302-685424
Email: ghserc@gmail.com
20th March, 2019

Adwoa Afriyie Wilson
University Ghana
School of Public Health

The Ghana Health Service Ethics Review Committee has reviewed and given approval for the implementation of your Study Protocol.

GHS-ERC Number	**GHS-ERC 010/03/19**
Project Title	Caregivers' Willingness to pay for Bone Marrow Transplant to Cure Sickle Cell Disease in their Children.
Approval Date	20th March, 2019
Expiry Date	19th March, 2020
GHS-ERC Decision	**Approved**

This approval requires the following from the Principal Investigator

- Submission of yearly progress report of the study to the Ethics Review Committee (ERC)
- Renewal of ethical approval if the study lasts for more than 12 months,
- Reporting of all serious adverse events related to this study to the ERC within three days verbally and seven days in writing.
- Submission of a final report after completion of the study
- Informing ERC if study cannot be implemented or is discontinued and reasons why
- Informing the ERC and your sponsor (where applicable) before any publication of the research findings.
- Please note that any modification of the study without ERC approval of the amendment is invalid.

The ERC may observe or cause to be observed procedures and records of the study during and after implementation.

Kindly quote the protocol identification number in all future correspondence in relation to this approved protocol

SIGNED.....
DR. CYNTHIA BANNERMAN
(GHS-ERC CHAIRPERSON)

Cc: The Director, Research & Development Division, Ghana Health Service, Accra

QUESTIONNAIRE

QUESTIONNAIRE FOR CAREGIVERS' WILLINGNESS TO PAY FOR BONE MARROW TRANSPLANT TO CURE SICKLE CELL DISEASE IN THEIR CHILDREN

A.SOCIODEMOGRAPHIC INFORMATION		
QN	**QUESTION**	**RESPONSE**
1	Age of caregiver in completed years	…….
2	Highest level of education of caregiver	1. No formal education [ ] 2. Primary School [ ] 3. JHS [ ] 4. SHS [ ] 5. Tertiary [ ]
3	Employment status of caregiver?	0. Unemployed [ ] 1. Employed [ ] 2. Retired [ ]
4	Marital status of caregiver?	1. Single [ ] 2. Married [ ] 3. Co-habiting [ ] 4. Divorced [ ] 5. Separated [ ] 6. Widowed [ ]
5	Age of child in completed years	……

6	Level of education of child	1. No formal education [ ] 2. Primary School [ ] 3. JHS [ ] 4. SHS [ ]
7	How many children do you have? (Please state)	……..
8	How many of your children have sickle cell disease?	…….
9	Wealth Index a) Does your household have the following functional items? A wall clock? A radio? A television? A mobile telephone? A refrigerator? A freezer? Electric generator/invertor(s)? Washing machine? Computer? Digital photo-camera? Non-digital photo-camera? Video deck? DVD/VCD?	Yes (1) No (0) [ ]

	Sewing machine? Bed? Table? Cabinet/cupboard?	[ ] [ ] [ ] [ ]	[ ] [ ] [ ] [ ]
	b) Does any member of this household own a functioning Bicycle? Motorcycle or motor scooter? Car or truck?	 [ ] [ ] [ ]	 [ ] [ ] [ ]
10	Severity of the Disease (CLINICAL CLASSIFICATION CRITERIA)		
10a	**I Age at diagnosis** Less than 12 months 12-24 months 25 months -5 years More than 5 years		SCORE 3 2 1 0
10b	**II Number of hospitalizations (**per month**)** 5 or more 2-4 1		 3 2 1
10c	**Ill. Crisis** Sequestration Aplastic Thrombotic (requiring hospitalization)		 3 2 1
10d	**IV. Pneumococcal sepsis**		3
10e	**V. Major organ involvement Cerebrovascular accident** Pulmonary infarct,		 3

	or retinopathy Pneumonia, renal or bone involvement, priapism, leg ulcer, or congestive heart failure	2 1
10f	**VI. Failure to thrive** < 3 percentile, height and weight < 10 percentile < 25 percentile	 3 2 1
B.KNOWLEDGE ON BONE MARROW TRANSPLANT		
11	Do you believe sickle cell anaemia can be cured?	1. Yes [ ] 2. No [ ] 3. Don't know [ ]
12	17. Have you heard of bone marrow transplantation (BMT) before	1. Yes [ ] 2. No [ ]
13	If yes, where did you hear about it?	1. A sickle cell patient [ ] 2. Media [ ] 3. Friends [ ] 4. relative [ ] 5. A health worker [ ] 6. Others [ ] Others Specify _____
14	What do you know about BMT?	1. I don't know [ ]

	(tick your option)	2. Infusion of blood cells after collecting it from a suitable donor. [ ] 3. A surgical operation done by cutting the bone of a suitable donor and implanting it on the recipient. [ ] 4. A procedure whereby stem cells are harvested from a suitable donor and infused into a recipient [ ]
15	Who do you think is the best person to donate bone marrow?	1. Mother to father [ ] 2. Mother to a girl [ ] 3. Father to a boy [ ] 4. Brother to a boy [ ] 5. Sister to a girl [ ] 6. Brother or sister to anybody [ ] 7. Anybody compatible can donate [ ]
16	What problem do you think the donor will have after donation?	1. Probable death [ ] 2. Low haemoglobin [ ] 3. Serious illness [ ] 4. Healthy [ ]
17	Tick any of the complications of BMT you know. **(tick as many as apply**)	1. Rejection [ ] 2. Sterility [ ] 3. Obesity [ ] 4. Heart disease [ ] 5. Diabetes [ ] 6. Donor cells attacking the host cells [ ]

		7. Death [ ] 8. None of the above [ ] 9. Not sure [ ]
18	Of all the complications of BMT, which ones do you fear most?	1. Rejection [ ] 2. Sterility [ ] 3. Obesity [ ] 4. Heart disease [ ] 5. Diabetes [ ] 6. Donor cells attacking the host cells [ ] 7. Death [ ] 8. None of the above [ ] 9. Not sure [ ]
19	Do you believe that not everybody that do BMT suffer from any of these complications?	1. Yes [ ] 2. No [ ] 3.I don't know [ ]
20	Do you know anybody that has done BMT?	1. Yes [ ] 2. No [ ]
21	If yes, what is the outcome?	1. Good [ ] 2. Bad [ ] 3. I don't know [ ]
22	Do you have any idea about the cost of the Bone Marrow Transplant in Ghana cedis?	1. No idea 2. Less than 20,000 [ ] 3. 20,000 – 50,000 [ ]

		4. greater than 50,000 [ ]
C. WILLINGNESS TO PAY		
23	Will you be willing to pay for Bone Marrow transplant as cure for your child's sickle cell disease?	0. No [ ] 1. Yes [ ]
24	If yes (23), will you be willing to pay GH₵ 125,000 for Bone Marrow transplant as cure for your child's sickle cell disease	0. No [ ] 1. Yes [ ]
25	If no (24), will you be willing to pay GH₵100,000 for Bone Marrow transplant as cure for your child's sickle cell disease	0. No [ ] 1. Yes [ ]
26	If no (25), will you be willing to pay GH₵ 75,000 for Bone Marrow transplant as cure for your child's sickle cell disease	0. No [ ] 1. Yes [ ]
27	If no (26) how much are you WTP for Bone Marrow transplant as cure for your child's sickle cell disease	……
28	If yes (23), will you be willing to pay	0. No [ ] 1. Yes [ ]

	GH₵ 150,000 for Bone Marrow transplant as cure for your child's sickle cell disease	
29	If yes (28), will you be willing to pay GH₵ 175,000 for Bone Marrow transplant as cure for your child's sickle cell disease	0. No [ ] 1. Yes [ ]