

**LIVED EXPERIENCES OF HEPATITIS B PATIENTS RECEIVING HEALTHCARE
SERVICES AT LIRA REGIONAL REFERRAL HOSPITAL, LIRA DISTRICT,
UGANDA**

**A POSTGRADUATE DISSERTATION SUBMITTED TO THE FACULTY OF HEALTH
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THE REQUIREMENTS FOR THE AWARD OF A MASTER'S DEGREE OF PUBLIC
HEALTH – HEALTH PROMOTION OF UGANDA MARTYRS UNIVERSITY, NKOZI.**

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DECLARATION

UGANDA MARTYRS UNIVERSITY

SCHOOL OF POSTGRADUATE STUDIES

Master's Dissertation

Declaration

I have read the rules of Uganda Martyrs University on plagiarism and hereby state that this work is my own.

It has not been submitted to any other institution for another degree or qualification, either in full or in part.

Throughout the work I have acknowledged all sources used in its compilation.

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APPROVAL

I, Margaret Joy Nalubega, affirm that this research dissertation titled **LIVED EXPERIENCES OF HEPATITIS B PATIENTS RECEIVING HEALTHCARE SERVICES AT LIRA REGIONAL REFERRAL HOSPITAL, LIRA DISTRICT, UGANDA** was conducted and developed under my guidance and supervision.

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DEDICATION

I dedicate this research dissertation to my lovely wife, Emily Atoo Akejo for her moral and emotional support and all the encouragement that she gave me right from the beginning of my studies at Uganda Martyrs University – Rubaga Campus.

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I wish to give glory and thanks to the Almighty God for his abundant Love and Grace and for giving me the wisdom and strength to come up with this research dissertation.

My sincere gratitude goes to my university supervisor, Ms Nalubega Joy Margaret, whom without her patience, guidance, supervision and support, I would not have been able to write this research dissertation. She created a conducive atmosphere for our interaction and deepened my understanding of phenomenological studies which made it possible for me to come up with a working methodology for this project. May God the Almighty richly bless her.

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ABSTRACT

Aims and objectives: *The specific objectives were: ascertaining the socio-cultural beliefs of the HepB patients about the disease, ascertaining the lived experiences of HepB patients before acquiring the disease and exploring the lived experiences of the HepB patients in living with the disease at Lira Regional Referral Hospital.*

Methodology: *A descriptive phenomenological qualitative study design was used in which 12 study participants were enrolled through purposive sampling technique. Data was collected using semi-structured open interviews, transcribed verbatim and coded using MAXQDA2020 software[®]. The thematic analysis model was used to extract themes.*

Results: *A total of 12 study participants whom 7 and 5 were males and females respectively while their minimum, maximum and average ages were 18, 58 and 35 respectively. They were all Lango and Christians from diverse religious background with diverse educational background ranging from illiterate to literate with the least and the highest being primary four and university bachelor's degree respectively and engaged in informal and formal employment and students. A total of 11 themes were extracted which revealed the experiences of the study participants. They included cultural practices, perceptions, knowledge, stigmatization, psychological impacts, failures, spiritual struggling, insufficient self-care, support, post traumatic growth which were both negative and positive and coping strategies.*

Conclusion: *The HepB patients before diagnosis had risky lifestyles that could have exposed them to contracting HBV. The negative experiences had detrimental impacts in their lives and lowered their quality of life and self-esteem in the communities while the positive experiences played a big role in improving the quality of life and conditions of the patients. The socio-cultural practices seemed detrimental to prevention of the spread and treatment of HepB in the community.*

Key words included: *Hepatitis B, Hepatitis B Patients, lived experiences and Lira Regional Referral Hospital.*

DEFINITIONS

Hepatitis: this is an inflammation of the liver, which is caused by the Hepatitis virus that can create a condition, which can be self-limiting or progress to fibrosis, cirrhosis or liver cancer (WHO, 2019).

Hepatitis B: is a viral infection as a result of Hepatitis B Virus that infects the liver causing both acute and chronic liver disease (WHO, 2019).

Lived experience: used to describe the first-hand accounts and impressions of living as a member of a minority or oppressed group.

Phenomenon: an event that happens and defines the life of an individual.

Phenomenology: a qualitative research approach through which new understandings of lived experiences while depending on personal accounts from participants normally only utilizing participant interviews by the researcher (Gentles *et al.*, 2015).

ACRONYMS

HAV = Hepatitis A Virus

HBV = Hepatitis B Virus

HCC = Hepatocellular Carcinoma and Cirrhosis

HIV = Human Immunodeficiency virus

LDHIS = Lira District Health Information System

LDLG = Lira District Local Government

LRRH = Lira Regional Referral Hospital

MoH = Ministry of Health

NGOs = Non-Governmental Organizations

WHO = World Health Organization

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CHAPTER ONE: INTRODUCTION AND BACKGROUND

1.0 Introduction

This chapter comprised of the background, problem statement, objectives, questions, conceptual and theoretical frameworks, significance, justification and scope of the study.

1.1 Introduction to Hepatitis B

Hepatitis B (HepB) is a highly contagious viral infection caused by Hepatitis B virus (HBV) that infects the liver leading to potentially life-threatening acute and chronic liver infections; hepatocellular carcinoma and cirrhosis (HCC) (Kahn, 2017; Seeto *et al.*, 2018; WHO, 2019; Freeland, 2021). HBV is capable of surviving outside the body for at least 7 days and can still cause infection of an unvaccinated individual (Ezbarami *et al.*, 2017; Stasi, Silvestri and Voller, 2017). HBV has an average incubation period of 75 days, though varies from 30 to 180 days and can be detected within 30 to 60 days after infection (WHO, 2019).

HBV is found in the blood and bodily fluids such as saliva, menstrual, vaginal, and seminal fluids (MoH of Uganda, 2018a; Graber-stiehl, 2019) and acquired either at birth (perinatal transmission from a mother to child) or person-to-person later in life through sexual routes, sharing needles, accidents, unscreened blood transfusion, needle stick injuries and having unprotected sex (Adekanle *et al.*, 2015; WHO, 2017; Seeto *et al.*, 2018).

Individuals who are at risk of contracting HBV include, those with multiple sex partners, sex partners of infected persons, infants born to infected mothers, those with any sexually transmitted disease, men who have sex with men, healthcare and public safety workers exposed to blood on the job, hemodialysis patients, household contacts of infected, travelers to regions with intermediate or high rates of Hepatitis B (HBsAg prevalence of $\geq 2\%$), those who engage in tattooing or piercings, using intravenous drugs, share needles and razor blades, undergo dental or

medical procedures, and having unprotected sex are at risk. (Centers for Disease Control and Prevention, 2017; Iamat, 2021).

HBV has effective preventive and treatment strategies such as vaccination which has a 95% effectiveness and suppressive antiviral therapy, both of which contribute to the prevention of vertical transmission (Mokaya *et al.*, 2018; Rajamoorthy, Taib, *et al.*, 2019; WHO, 2019). The Uganda National Expanded Program on Immunizations (UNEPI) successfully introduced HepB among the childhood immunization programs in 2002 (Ochola *et al.*, 2013; Bayo *et al.*, 2014).

1.2 Background of the study

About 2 billion people globally are infected with HepB virus (HBV), of which between 257 – 292 million people are chronically ill (Razavi-Shearer *et al.*, 2018; WHO, 2020), whom the majority were not aware of their infection (Hara *et al.*, 2017) and Sub-Saharan Africa harbours over 75 million of these cases (Allen *et al.*, 2017). This resulted in about 900,000 – 1.2 million deaths each year from liver complications worldwide and an estimated 87,890 deaths annually in sub-Saharan Africa (Spearman *et al.*, 2017; WHO, 2020; Freeland *et al.*, 2021).

The global burden of HBV remains unevenly distributed with Sub-Saharan Africa and Asia being highly affected (Le Gautier *al.*, 2021;). The global and Sub-Saharan African HepB surface antigen (HBsAg) prevalence was at 5% and 6.1% respectively (Afihene, Duduyemi and Khatib, 2015). However, according to estimates, Western Africa accounted for HBV prevalence of about 8% whereas Southern, Central and Eastern regions of Africa accounted for 5-7% (Bodo *et al.*, 2017).

Uganda's HepB prevalence was at 10% where 9 out of every 10 people did not know their status thus making HepB both a political and social burden (MoH of Uganda, 2018b; Wibabara *et al.*, 2019). The Northern region took the lead with 4.6% in mid-North where Lira Municipality (with 5.58%) is situated and lower in the rest of the country with a range of 0.8% in South West region to 2.7% in East Central region (UPHIA Survey, 2016). The unpublished data from the Lira District

Health Information System indicated the prevalence of HepB in Lira district from 2015-2016 to 2017-2018 financial years was at 5.56% (Lira District Health Information Systems, 08 July 2019).

Lived experiences of HepB patients are depicted as occurrences before, during and after a phenomenon in the course of their lives and they are the ones who can best narrate them (Creswell, 2014). There is therefore no way through which the outside world can understand a human being as a whole, without hearing their voices and it is only through their voices that one can understand how they feel about their situation (Mcphail, 1995). The lived experiences are normally connected with the socio-cultural beliefs which define the reasons why an individual performs certain actions relative to the norms of that society, which in turn directs a person's way of judgement towards an action (Solér, 1996). A person's intention to perform a behaviour determines his/her specific behaviour and is under a degree of volitional control (Ajzen & Fishbein, 1980).

Worldwide evidence indicated a strong association of the negative experiences such as social and psychological disorders like anxiety, stigma, discrimination, anxiety, shock, disbelief, sadness, depression, low quality of life, (Jiwani *et al.*, 2013; Adjei, Naab and Donkor, 2017; Ezbarami *et al.*, 2017; Valizadeh *et al.*, 2017; Franklin *et al.*, 2018; Mokaya *et al.*, 2018; Tu *et al.*, 2020; Le Gautier *et al.*, 2021;) and less or no treatment regardless of the discovery of antiviral treatment (Papatheodoridis *et al.*, 2014). Furthermore, HepB influenced the lives of individual patient socially and psychologically (Adjei, Naab and Donkor, 2017).

The consequences of living with HBV also impacted on least all levels of societal life including education, employment, healthcare and personal and families sphere as witnessed in other studies (Kan *et al.*, 2015; Leng *et al.*, 2016; Oketch & Opio, 2016; Wallace *et al.*, 2017; Chen *et al.*, 2018; Han *et al.*, 2018;) and cultural, social and economic domains were neither spared (Rafique *et al.*, 2014; Valizadeh *et al.*, 2017; Wallace *et al.*, 2017; Mokaya *et al.*, 2018).

However, the lived experiences of the HepB patients could not be limited to only negative side alone. Ezbarami *et al.* (2017), noted that HepB patients, besides negative experiences, they also had positive experiences such as having the hope of getting rid of the disease, spiritual growth, positive changes in lifestyle, strengthening the emotional relationship with relatives and appreciating life which shaped their lives for the better. Much as lived experiences studies on HepB had been carried out elsewhere, there was no such study carried out in Uganda, especially in Lira district.

Several other studies were carried out in Uganda on lived experiences such as lived experiences of women who developed uterine rupture following severe obstructed labor in Mulago hospital, (Kaye *et al.*, 2014), gender and fragile citizenship in Uganda: the case of Acholi women (Oosterom, 2011), lived experiences of women who underwent induced abortion: a case study of Rakai district (Nalubega, 2017), exploring health workers' experiences of mental health challenges during care of patients with COVID-19 in Uganda - a qualitative study (Muzyamba *et al.*, 2019), a study of knowledge, experience and beliefs about hepatitis B virus (HBV) infection in south western Uganda (Mugisha *et al.*, 2019), what causes non-adherence among some individuals on long term antiretroviral therapy? Experiences of individuals with poor viral suppression in Uganda (Bukonya *et al.*, 2019), experiences and effects of HIV-related stigma among youth living with HIV-AIDS in Western Uganda - a photovoice study (Kimera *et al.*, 2019) to mention but a few. However, there was no any study of lived experiences carried out on HepB patients in Uganda, which this study sought to fill in the gap that existed in the knowledge of what these patients go through in their daily lives.

1.2 Problem Statement

The global and Sub-Saharan African HepB surface antigen (HBsAg) prevalence was at 5% and 6.1% respectively (Afihe, Duduyemi and Khatib, 2015). Uganda's HepB prevalence was at 10% where 9 out of every 10 people did not know their status, with Northern Uganda leading at 4.6%

prevalence rate (MoH of Uganda, 2018b; Wibabara *et al.*, 2019), and the incidence and prevalence rates being at 5.41% and 5.56% respectively in Lira district from 2015/2016 to 2017/2018 (LDHIS, 2019). There was lack of literature on the lived experiences of these HepB patients at LRRH much as studies conducted elsewhere showed a strong association of the negative experiences with HepB (Jiwani *et al.*, 2013; Adjei, Naab and Donkor, 2017; Ezbarami *et al.*, 2017; Valizadeh *et al.*, 2017; Franklin *et al.*, 2018; Mokaya *et al.*, 2018; Tu *et al.*, 2020; Le Gautier *et al.*, 2021).

The government through the Uganda National Expanded Program on Immunizations (UNEPI) and MoH successfully introduced HepB vaccination among the childhood immunization programs in 2002 to prevent the occurrence of chronic HepB and carry out screening, testing and vaccination services respectively (Ochola *et al.*, 2013; Bayo *et al.*, 2014; LDHIS, 2019). The lived experiences studies carried out in Uganda did not cover those of HepB patients (Oosterom, 2011; Kaye *et al.*, 2014; Nalubega, 2017; Bukenya *et al.*, 2019; Kimera *et al.*, 2019; Mugisha *et al.*, 2019; Muzyamba *et al.*, 2019) and those carried out elsewhere could not provide enough scholarly evidence to show the lived experiences of the HepB patients in Lira district. Therefore, a scientific and scholarly exploration of the lived experiences of HepB patients in Lira district to produce locally important information was needed that would enable the creation of suitable policies interventions concerning the prevention and protection against HepB and treatment of HepB patients to improve their quality of life.

1.3 Objectives of the study

1.3.1 Main objective

To explore the lived experiences of Hepatitis B patients receiving healthcare services at Lira Regional Referral Hospital, Lira district, Uganda.

1.3.2 Specific objectives

- i. To discover the socio-cultural lived experiences of the HepB patients receiving healthcare services at Lira Regional Referral Hospital, Lira district, Uganda.
- ii. To determine the lifestyles' lived experiences of HepB patients receiving healthcare services at Lira Regional Referral Hospital, Lira district, Uganda before acquiring the disease.
- iii. To explore the post-trauma lived experiences of the HepB patients receiving healthcare services at Lira Regional Referral Hospital, Lira district, Uganda after acquiring the disease.

1.4 Research questions

1.4.1 The main question

- i. What were the lived experiences of Hepatitis B patients receiving healthcare services at Lira Regional Referral Hospital, Lira district, Uganda?

1.4.2 Specific questions

- ii. What were the socio-cultural experiences of the HepB patients receiving healthcare services at Lira Regional Referral Hospital, Lira district, Uganda?
- iii. What were the lived experiences of HepB patients receiving healthcare services at Lira Regional Referral Hospital, Lira district, Uganda before acquiring the disease?
- iv. What were the lived experiences of the HepB patients receiving healthcare services at Lira Regional Referral Hospital, Lira district, Uganda after acquiring the disease?

1.5 The conceptual framework

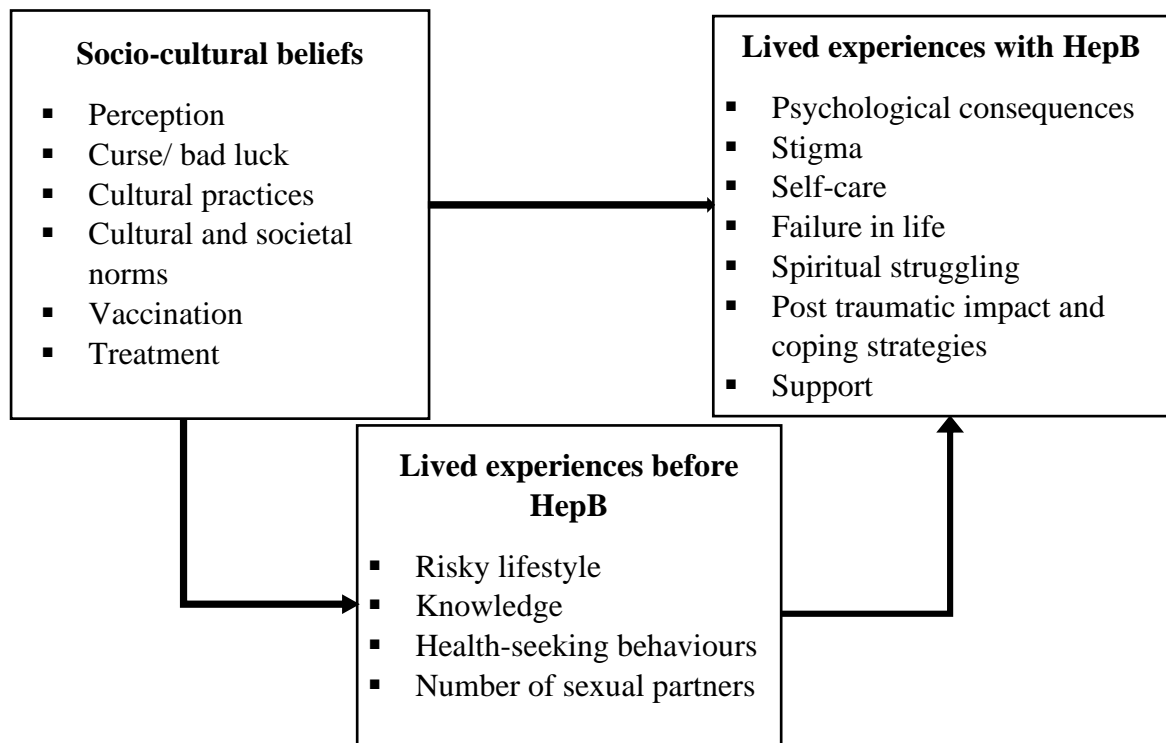


Figure 1.1: The conceptual framework for the lived experiences of Hepatitis B as adopted and modified from the Theory of Reasoned Action (Ajzen & Fishbein, 1980)

1.6 The theoretical framework

A person's intention to perform a behaviour determines his/her specific behaviour and is under a degree of volitional control (Ajzen & Fishbein, 1980). Human consciousness should be the primary unit of analysis in the study of human life (Mcphail, 1995). This means that there is no way through which the outside world can understand a human being as a whole, without hearing their voices. Through their voices, one can understand how they feel about a particular situation.

The significant others play a great role in the behaviours of others when they approve of such behaviours, whether good or bad (Fishbein, 2010). Therefore, the socio-cultural beliefs define the reasons why an individual performs certain actions relative to the norms of that society, which in turn directs a person's way of judgement towards an action (Solér, 1996). For example, the cultural beliefs of society towards vaccination against HBV shape the uptake of the service in the prevention of adverse outcomes.

The behaviour of an individual, which in most cases qualify within set norms of a society greatly determines the chances of acquiring the HBV. These behaviours that mostly are due to lack of proper knowledge about HepB such as tattooing, beliefs in curses, cultural circumcision among others, characterise the experiences of an individual may be termed as risky when compared with the scientific facts that put an individual at risk of acquiring HBV. The experiences of individuals change immediately after getting the results of diagnosis, which can result into positive such as lifestyle modification, spiritual growth and a hope of getting rid of HBV among others or negative experiences such as shame, fear, denial and social exclusion among others.

1.7 Significance of the study

The information obtained from the study would guide the different stakeholders to modify the way services such as counselling; education, treatment; rehabilitation therapies; awareness creation about HepB could be tailor-made to suit their needs to improve their quality of life, regain confidence in life and improve their capacity of overcoming the illness and its impacts.

The responsible authorities would channel resources appropriately and effectively utilize them to eradicate HBV and improve the quality of lives of the patients in Lira district, Lango sub-region, Uganda as a nation and the world at large.

The health care workers and health promotion practitioners would use the study findings to develop strategies that would best suit the demands of the HepB patients, most especially in areas of care needs, psychological and social consequences on life wholesomely.

The study results would provide a reliable and authentic source of information, which would be used for further studies by other scholars and, also, contribute to the wealth of knowledge as pertains the disease and its recommendations would lead to further studies in the area of HBV.

1.8 Justification of the study

Uganda has one of the highest HepB prevalence in Africa standing at 10% with 10% where 9 out of every 10 people not knowing their status and Northern Uganda leading at 4.6% prevalence rate (MoH of Uganda, 2018b; Wibabara *et al.*, 2019). Lira district has a prevalence of 5.56% (LDHIS, 2019). Studies on lived experiences of HepB patients affirmed that they experienced social and psychological disorders like anxiety, stigma, discrimination, anxiety, depression, low quality of life, lack of knowledge about the disease with HepB patients among others (Jiwani *et al.*, 2013; Adjei, Naab and Donkor, 2017; Ezbarami *et al.*, 2017; Valizadeh *et al.*, 2017; Franklin *et al.*, 2018; Mokaya *et al.*, 2018; Tu *et al.*, 2020; Le Gautier *et al.*, 2021) but no such a study had ever been carried out at LRRH in Lira district.

However, the lived experiences studies carried out in Uganda did not cover those of HepB patients (Oosterom, 2011; Kaye *et al.*, 2014; Nalubega, 2017; Bukenya *et al.*, 2019; Kimera *et al.*, 2019; Mugisha *et al.*, 2019; Muzyamba *et al.*, 2019). There was, therefore, a need to carry out this research to provide scientific and scholarly evidence which would produce locally important information to contribute to the body of knowledge and enable the creation of suitable policies interventions concerning the education, prevention and protection against HepB and treatment of the patients to improve their quality of life.

1.9 Scope of the study

1.9.1 Geographical scope

The research study on the lived experiences of Hepatitis B patients was carried out at LRRH located on Ngeta Road in Lira town, Lira district, Northern Uganda. Lira district is located in Lango sub-region at 2° 20' 0" N and 33° 6' 0" E, Northern Uganda and was selected as the area of study because of the high prevalence of Hepatitis B at 5.56% (LDHIS, 2019) and was earmarked for the mass screening and vaccination by the MoH in 2015. The district has 9 sub-counties

(Amach, Agali, Adekokwok, Ngeta, Ogur, Agweng, Lira, Barr and Aromo) and 4 divisions (Adyel, Ojwina, Central and Railways) (LDLG, 2019). Any HepB patient who originated from any of those sub-counties was eligible for recruitment in the study.

1.9.2 Content Scope

The study explored the lived experiences of Hepatitis B patients at LRRH in Lira district. The focus of the study was on firstly, the socio-cultural beliefs of the HepB patients about the disease. Secondly, the study also covered the lived experiences of HepB patients before acquiring the disease at Lira Regional Referral Hospital. Thirdly, another area of emphasis was on studying the lived experiences of the HepB patients in living with the disease at Lira Regional Referral Hospital, which identified the negative and positive experiences of living with the disease.

1.9.3 Time scope

The study was intended to run from June 2019 beginning with the identification of the topic through literature review to identify the gap, conceptual framework writing and presentation, topic approval, supervisor assignment, proposal writing, field data gathering, data analysis, report writing, report submission and dissertation defense in September 2021 as summarized in the Gantt chart on Appendix I.

CHAPTER TWO: LITERATURE REVIEW

2.0 Introduction

This chapter covered the review of the theoretical and empirical literature in line with study objectives and it involved literature related to the study variables. The research studies relevant to lived experiences of people living with Hepatitis B virus in their blood was reviewed to acknowledge that the gap existed and needed to be filled.

2.1 The socio-cultural lived experiences of the HepB patients receiving healthcare services at Lira Regional Referral Hospital, Lira district, Uganda.

Culture affiliation is important to recognize about the role beliefs, attitudes, and behaviours play in the diagnosis and treatment of a condition, with an example being of family members, mostly those interpreting for their parents, from the Middle East and Asia may not want the patient to know their diagnosis (Steel *et al.*, 2016). Those who violate the social norms, which are written or unwritten rules people are anticipated to follow, are normally stigmatised (Link and Phelan, 2015). Fear of violating these cultural norms forced people to hide diseases such as HIV and hepatitis which were acquired through what was believed to be bad behaviours, especially sexual acts, indicating lack of morals, thus living secret lives to protect the family name (Freeland *et al.*, 2020).

There is a belief by most people in the community that HepB is highly contagious that is easily transmitted through sweat and can easily be acquired through casual shaking of hands, touching and eating with an infected person from the same plate, sharing of toilets/bathrooms which in the long run leads to stigmatization of the patients because they are isolated (Adjei *et al.*, 2019; Mugisha *et al.*, 2019). Furthermore, this belief affected the patients in that they failed to get medical attention from the nurses and doctors. In Iran, healthcare professionals hesitated to attend to HepB patients after realizing that they had HBV because of the belief that they would get infected (Dehkordi, Mohammadi and Nikbakhat, 2016). However, the belief that HepB was highly

contagious and the effect of the belief, if indeed it existed, needed to be investigated among the HepB patients in Lira district.

HepB infection is linked to the belief of having bad luck for someone to have acquired the HBV among the many other healthy people. Bad luck was cited in a study on Hepatitis C where a patient had two liver transplant operations (Rosen, 2017). In Islamabad, the study participants described that being diagnosed with hepatitis B and/ or C was a result of bad luck since they did not know the cause and ways through which HBV or HCV was transmitted (Ranani *et al.*, 2020). Malik and Hana (2018) found out in their study that contracting Hepatitis C was a result of bad luck. Consequently, bad luck was identified as a contributing factor in the mutation of genes leading to the development of cancer in cancer patients (Belizário, 2018).

An area of great concern is the belief that is attached to superstition in that HepB is believed to be as a result of a curse by the gods for some wrongdoing (Adjei, *et al.*, 2019). Additionally, people believe that swollen abdomens and feet are a result of curses from the gods. This is mostly reported because most patients in advanced stages of HepB present with oedema, ascites and jaundice. Adjei and his friends (2017) identified that HepB was also linked to superstition in their earlier study in Ghana.

Notwithstanding, HepB was further linked to curses where 86% of the respondents acknowledged so due curses, in most cases, result into swellings of the feet and abdomen among the Ghanaians (Adjei *et al.*, 2018). A study with such a result has not yet been carried out among HepB patients in Lira district, thus it is a necessity in the body of knowledge to make recommendations. In some communities, rituals were performed as a way of seeking blessings and healings. A study carried out among Hmong Americans indicated that the Hmongs made offerings and sought blessings for their families and protection through worshipping and paying respect to their ancestors (Jorgensen *et al.*, 2016). Additionally, communication is maintained by the Shamans between the spiritual

world and the living, and they also determine the cause of sickness and treat illnesses through the performance of ritual ceremonies.

The act of using skin cutting cures as an alternative treatment procure for HepB is further accomplished by traditional healers in the communities. The skins of the victims were cut especially on the swollen parts to release out the bad blood. In the Binh Thuan province of Vietnam, skin cutting cures are commonly used in treatment of different diseases including HepB and C (Do *et al.*, 2015).

HepB is socially believed to be a very severe disease with poor prediction but that is easily transmitted, that leads to death hence, people who have HBV avoid the healthy individuals as a way of preventing themselves from getting it, which stigmatizes the HepB patients (Adjei, *et al.*, 2019). The belief that HepB is very severe was identified in the USA where the severity of HepB was perceived by the doctors (Upadhyaya *et al.*, 2015) and other participants even considered it to be more severe than HIV (Hamdiui *et al.*, 2018). Specialised health facilities that can monitor and provide support to HepB patients are few as per the WHO policy on treatment, management and support of HepB patients (WHO, 2015). The belief that HepB was very serious resulted in to the belief that it was very deadly led to living in fear and having constant thoughts of premature death (Valizadeh *et al.*, 2016).

The belief in the efficacy of herbal medicine in the treatment of HepB was another common area of influence majorly due to the information from the herbalists or cultural belief surrounding ailments. For example, about 80% of Chinese patients infected with Chronic HepB used the Chinese herbal medicine; either as a complement or as an alternative to the conventional anti-HBV drugs mainly because most of the modern drugs were too expensive for the patients to purchase (Zheng *et al.*, 2015; Nsibirwa, 2018). Herbal medicines were used in China to decrease the HepB viral load (Liang *et al.*, 2019).

Most herbalists believed that herbs could treat and prevent HepB infections (Stickel and Schuppan, 2007). Additionally, in a study carried out in South Western Uganda by Mugisha *et. al.*, (2019) on HepB knowledge, experience and beliefs of the community about HepB, a study participant acknowledged taking his child to an herbalist who gave 5 litres of herbal medicine and went back again after it was finished because the medicine which was given from the hospital was finished. Mugisha and his colleagues (2019) articulated that the delays in seeking health care were further attributed to a preference for herbal medicine.

The socio-cultural belief that was attached to the vaccination programs mainly organized by the government as a preventive measure to different health condition including HepB was negative which left the community vulnerable to infections or attacks by the disease-causing agents. Additionally, a common perception about these vaccinations in government health facilities was that they were supposed to be free to attract them. The common belief the communities always had about vaccination was that the government intended to kill them or make them lose their fertility. Majority of the individuals in rural areas and urban centres in Pakistan recorded that vaccination programs were intended to make them infertile and were provided at no cost the government owned health facilities to attract them (Ali, Suhail and Ali, 2018). The number of people worldwide who perceived vaccination as unsafe was on the increase which hindered the uptake of the vaccines (Dubé *et al.*, 2013).

Socio-cultural factors greatly affect individuals' health decisions, mainly in terms of screening and treatment. These factors might include protecting family's reputation by avoiding screening, lack of family support in cases where fathers make the family health decisions, fear of doctors and test results and having mistrust in the doctors and medical services (Jorgensen *et. al.*, 2016). These authors quoted one of their study participants saying that:

“We have a lot of fear when we go see the doctor because there are some good and some bad doctors. For example, some people's health conditions are not serious, but

doctors make the person sicker. For some people, they live normal, but when they go see the doctor, they don't come back (meaning they die). There were a few cases like these that have occurred, so we have fear and do not want to go see the doctor."

Socio-cultural beliefs of socialisation were always associated with the act of sharing drinks, especially the local brews, which led to communal drinking practices that was done to show an act of togetherness and a sense of belonging thus strengthening personal relationships (Parker, Kurien and Huppatz, 2014). The authors identified in their study that the practice of communal drinking put the participants at risk of acquiring HepB. Communal sharing of drinks presented a conducive environment for the spread of diseases and outbreak of HepA where its transmission was facilitated by the sharing of KAVA dink using the communal drinking vessel in (Parker, Kurien and Huppatz, 2014; Yang *et al.*, 2016).

The beliefs and practices that were given values to culture in a particular society greatly determined the health practices of the inhabitants. The beliefs and practices described above might not be any different among the people who attended HepB healthcare services at Lira Regional Referral Hospital, which, represented the people of their communities. This study therefore sought to find out the socio-cultural beliefs of the HepB patients receiving treatment at LRRH about the disease.

2.2 The lived experiences of HepB patients receiving healthcare services at Lira Regional Referral Hospital, Lira district, Uganda before acquiring the disease.

HepB patients were usually associated with lack of knowledge about the disease and unhealthy behaviours especially before diagnosis, unlike HIV which was widely known to HepB patients (Jane *et al.*, 2016; Adjei, Naab and Donkor, 2017) and exposure to risk factors (Gasim, Murad and Adam, 2013; Bayo *et al.*, 2014; Zenebe *et al.*, 2014).

Lack of proper knowledge about HepB, in general, put the HepB patients at risk of developing Chronic HepB (Seremba *et al.*, 2017). Most patients were not aware of HepB as a disease not until

they were diagnosed and many people had misperceptions about HepB and yet they were carriers (Adjei, Naab and Donkor, 2017; Ezbarami *et al.*, 2017). The knowledge on HepB, its transmission, signs and symptoms, treatment and prevention were crucial in managing HBV cases, which shaped the experiences of the patients. Preventive measures such as vaccination which protected individuals from HepB infection (Ochola *et al.*, 2013), was very low (Seremba *et al.*, 2017), which combined with vertical transmission from mother-to-child at birth and horizontal transmission resulting into the high rate of HepB infection (Kue and Thorburn, 2013).

Hepatitis patients faced a challenge in managing the disease as they were not equipped with good knowledge about the disease. In a study carried out among Hepatitis C, Hill *et al.*, (2014) justified that a lack of people's experiences was dominated by a lack of practical advice, information and support, which made it difficult in realizing the recommended lifestyle changes, hence leaving the patients feeling uncertain of disease management. This study, however, needed to find out how the HepB patients receiving healthcare services at LRRH were knowledgeable about the disease and the impact on the management of the disease.

Risk factors increased the chances of an exposed individual to acquiring an infection. An infected pregnant mother had a risk of infecting her unborn child through mother to child transmission those with multiple sex partners, sex partners of infected persons, infants born to infected mothers, those with any sexually transmitted disease, men who have sex with men, healthcare and public safety workers exposed to blood on the job, hemodialysis patients, household contacts of infected, travelers to regions with intermediate or high rates of Hepatitis B (Kue and Thorburn, 2013; Zenebe *et al.*, 2014; Centers for Disease Control and Prevention, 2017; Iamat, 2021;). Gasim *et al.*, (2014) conducted a study on HepB and C virus infections among pregnant women in Arab and African countries and found out that the infections were closely associated with coming in to contact with infected blood and its products, use of unsterile medical and dental processes, sharing

of sharp instruments, intravenous drug abuse and use of traditional practices such as female circumcision.

Common risk factors can be categorised as socioeconomic factors, medical history, occupational risk behaviours, and lifestyle-related behaviour risk factors (Rajamoorthy, Mohd, *et al.*, 2019). However, the literature of studies of risk factors of HepB infection among HepB patients before their diagnosis was lacking as most studies focussed on pregnant women, health workers, traders and men who have sex with fellow men as cited above. There was thus a need to identify what the HepB patients themselves considered as risk factors to HepB before their diagnosis.

HepB patients, before diagnosis, lived a kind of life behaviour which predisposed them to HepB infection as their immunity was deprived. These unhealthy behaviours included among others: alcohol consumption; cigarette smoking; irregular or no exercise; insufficient water, inadequate vegetable and fruits intake; and history of previous sexually transmitted infections (Jane *et al.*, 2016; Oliveira *et al.*, 2016). In Malaysia, The most common behaviours that increased the risk of individuals in acquiring HBV were sharing of nail cutters, body piercing, alcohol use and undergoing acupuncture (Rajamoorthy, Mohd, *et al.*, 2019). Furthermore, other risk behavioural activities included the act of sharing household tools such as toothbrushes, unsafe sexual activity and having multiple sexual partners also increased the risk of getting HepB (Rajamoorthy, Mohd, *et al.*, 2019).

It was a common practice of sharing sharp instruments such as sharing of syringes among HepB patients before diagnosis, which put themselves at risk of contracting HBV. In a study of HCV, HBV, and HIV seroprevalence, coinfections, and related behaviours among male injection drug users in Arak, Iran, it was found out that sharing of syringes was a common practice, which exposed them to high risks of acquiring the infections (Ramezani *et al.*, 2014). Some patients modified their behaviours before diagnosis, after knowing that their friends were diagnosed

positive of HBV out of self-conviction because of the kind of behaviour they had together. In a study carried out by Adjei and his colleagues (2017) in Ghana, some study participants acknowledged changing their lifestyles after learning that their friends were tested and diagnosed positive to HepB.

The HepB patients commonly did not have good health-seeking behaviour before their diagnosis with the disease. This could have been attributed to the fact that they felt healthy even when they were already infected with HBV due to the asymptomatic nature of the disease which could easily lead to being chronic HepB patients or carriers (Freeland *et al.*, 2021). Failure to visit health facilities for regular health check was a sign of inadequate self-care (Ezbarami *et al.*, 2017). It was common for the HepB patients to seek medical help following some period of feeling unwell. A study carried out among the African Immigrants in the United States highlighted that healthcare-seeking was mainly driven by availability of symptoms (Freeland *et al.*, 2021). Poor health-seeking behaviour could be attributed to stigma associated with HepB thus leading to poor adherence to drugs hence a low quality of life (Mokaya *et al.*, 2018; Freeland *et al.*, 2021).

The available literature cited above provided evidence on the lived experiences of HepB patients in other parts of the world. These experiences might not be any different from those experienced by the HepB patients in Lira. Therefore, there was a need to ascertain whether it was true and/ or there were some experiences which were localised and could be added to the existing body of knowledge.

2.3 The lived experiences of the HepB patients receiving healthcare services at Lira Regional Referral Hospital, Lira district, Uganda after acquiring the disease.

Worldwide evidence indicated a strong association of the negative experiences of living with HBV in the blood such as social and psychological disorders like anxiety, stigma, discrimination, anxiety, shock, disbelief, sadness, depression, low quality of life, (Jiwani *et al.*, 2013; Adjei, Naab

and Donkor, 2017; Ezbarami *et al.*, 2017; Valizadeh *et al.*, 2017; Mokaya *et al.*, 2018) and less or no treatment regardless of the discovery of antiviral treatment (Papatheodoridis *et al.*, 2014). Ezbarami *et al.* (2017), also noted that HepB patients, besides negative experiences, they also had positive experiences such as having the hope of getting rid of the disease, spiritual growth, positive changes in lifestyle, strengthening the emotional relationship with relatives and appreciating life.

2.3.1 The negative lived experiences of HepB patients receiving healthcare services at Lira Regional Referral Hospital, Lira district, Uganda in living with the disease.

HepB patients experienced both mental and physical discomfort (Shi *et al.*, 2013) while some HepB patients received supportive reactions from those close to them (Ezbarami *et al.*, 2017). In a study carried out among HIV patients co-infected with HepB, supportive reactions were rendered towards HIV-infected patients, which was, however, common in patients with HBV (Kittner *et al.*, 2013). HepB patients further experience numerous psychosocial, physical, and economical difficulties secondary to the symptoms and complications of the disease and influences the physical health, psychological status, social and spiritual aspects of an individual (Jiwani *et al.*, 2013).

Stigmatization was one area in which HepB patients suffer most after diagnosis and disclosure, where first of all diagnosis is done accidentally after blood donation or during routine pregnancy test in the case of pregnant women (Valizadeh *et al.*, 2016). Those who violate the social norms, which are written or unwritten rules people are anticipated to follow, are normally stigmatised (Link and Phelan, 2015). HepB stigma is theorised as an adverse social judgement leading to rejection, blame, exclusion, and/or devaluation, which can damage a person's self-esteem, impacting on socio-economic status, hence discrimination (Dam *et al.*, 2016).

Some patients isolated themselves from their relatives, colleagues and friends after their diagnosis (Valizadeh *et al.*, 2017). This was evidenced in a study by Valizadeh and others (2017), in studying

the social stigma experienced in patients with HepB infection in which he employed a phenomenological study approach of 15 study participants, a study participant stated that he withdrew from his friends and companions and had limited conversations with them, and, also avoided people who were seated in groups in order not to trouble them.

HepB patients experienced the sense of avoidance in their lives from the disclosure of their status to their family members and/ or their loved ones, (Adjei, *et al.*, 2019) and lived an evasive life. Due to stigma, a HepB positive person experienced a sense of humiliation, embarrassment and sadness, on being told that they were positive of HBV after testing (Valizadeh *et al.*, 2017; Adjei *et al.*, 2019). Notwithstanding, a patient might not only have to contend with the possible challenges to health, he/she might also be denied other life prospects that could define life such as interacting with a diverse cross-section of the society, employment, education and access to proper health care (Mokaya *et al.*, 2018).

HepB patients were required to take self-care programs after diagnosis to prevent transmission of the virus to uninfected people and also to halt the progression of the HBV to liver complications such as liver cirrhosis as a result of not following their medication schedule as advised by the healthcare workers (Ezbarami *et al.*, 2017). For instance, one of the respondents said in a study carried out in Iran by Ezbarami *et al.* (2017) that:

[“My husband and I are infected with the disease in a way that I check my tests every 6 months and my husband every 3 months, but honestly, we do not refer frequently since the costs of the tests are extremely high. Actually, this is a great concern in our family, which prevents any further follow-up action”].

The HepB patients required different forms of support in form of psychosocial, emotional, spiritual and financial from their loved ones including friends and relatives to live a better and good quality of life (Ezbarami *et al.*, 2017). Support from friends and relatives as well as health support always made the patients feel as though they were a burden to those who offered them help and they were sympathising with them (Freeland *et al.*, (2020).

Papatheodoridis *et al.*, (2014), noted that a substantial number of people who were suffering from HBV and HCV infections received no treatment at all in the European countries. Patients with chronic Hepatitis needed to carry out self-care activities and measures as they had positive influences on the hepatitis severity, decreased the hospitalization duration and re-admission, increased patients' self-confidence and use of appropriate adaptation mechanisms hence a reduction in the feeling of fear, hopelessness, distress and mental pressure (Mohammadi *et al.*, 2013). The authors further noted that it was quite common for HepB patients not to observe proper self-care as a result of lack of good knowledge that they had about the disease, which put them at risk of developing liver complications and transmitting the HBV to their loved ones.

HepB patients often tended to be socially isolated because of the negative attitude that the society had towards the disease and those who were carrying the disease, in that people often considered HepB to be like HIV/AIDS. These patients who were isolated were treated as outcasts in their communities (Adjei, *et al.*, 2019). In a study of the lived experiences of HepB patients in Iran in by Ezbarami *et al.* (2017), some patients stated that the biggest problem was that they were left alone when they informed others of their disease status, including at the time of marriage, one patient said that a friend whom he told of the result of the test told him straight that he had HIV and the friend left him forever. Sometimes, thoughts and fear of transmitting the HBV to the family members and friends cause the HepB patients to isolate themselves, which creates in them a sense of loneliness in that one study participant says that he could spend nights with friends but now he stays at home and feels HBV made him lonely (Valizadeh *et al.*, 2017).

Some patients had their utensils such as glasses, spoons and serving dishes separated from the rest of the family with the thinking that HBV could easily be transmitted to the healthy family members. A study carried out in Malaysia found out that believing that the disease could be transmitted through saliva was common among the majority of the study participants, which made them think that eating, sharing serving dishes and having close communication should be avoided

(Ng *et al.*, 2013). Meanwhile, in some circumstances, HepB patients were denied or restricted access to events and places (Butt, Paterson and Mcguinness, 2016). This could lead to the isolation of the patients in their communities (Mugisha *et al.*, 2019). However, this study was not carried out on patients of HepB but rather among the community members.

HepB patients suffered various forms of psychological consequences of carrying the disease such as victimization, fear of transmitting the disease to others, anxiety and depression among others (Ezbarami *et al.*, 2017). The HepB patients experienced the fear of being victimized for carrying the virus by those who are healthy in the community, which always force the patients to live a distorted psychological life. A study carried out among patients with chronic hepatitis C highlights that the patients portrayed a disrupted psychological well-being (Hill *et al.*, 2014). Besides, recurring brief depressions in the absence of interferon treatment was witnessed in a quantitative study which was conducted in Italy (Carta *et al.*, 2012).

2.3.2 The positive lived experiences of HepB patients receiving healthcare services at Lira Regional Referral Hospital, Lira district, Uganda in living with the disease.

HepB diagnosis did not only impact on the lives of the patients negatively but also positively, mostly as coping strategies after receiving the test results (Adjei, Naab and Donkor, 2017; Ezbarami *et al.*, 2017). HepB patients exhibited post-traumatic growth after the diagnosis and were supported spiritually, which was similar to the HIV positive patients who reveal status to their partners (Kamen *et al.*, 2016). A study carried out in Saudi Arabia on experiences of HIV patients showed that most study participants used religiosity and spirituality as a way of coping up (Omer, Lovering and Shomrani, 2014). Nonetheless, some patients always portrayed contracting HepB disease as a normal occurrence (Adjei, Naab and Donkor, 2017).

Religion played a great role in the lives of HepB patients to give them hope in life in that they were quick to attribute a health condition to an evil spirit, and, God as the only one who could

fight the evil spirits and planned for their lives while others said it was the will of God. A study carried out in Ghana by Adjei and his friends (2017), highlighted that most Ghanaians acknowledged that God was the sole determinant of the destiny of a person and therefore, whatever came their way was in line with God's plans, as, other participants depended on words of encouragement from their spiritual leaders. This increased closeness with their religious belief (Steel *et al.*, 2016). One study participant from the study was quoted saying that:

“As for me, I only depend on God for my healing. Sometimes, I go for a Bible and start reading. I do that because I believe God has the power to heal all diseases”.

HepB patients read books about God and perform godly activities to feel close to God. A study carried out by Abu-Raiya and his colleagues (2015) among HIV positive patients said that spiritual activities such as reading the Qur'an, daily prayers and participating in the pilgrimage to Mecca became a way of getting back to their relationship with Allah (God), and also individuals with HIV/AIDS always did reflect on their spirituality after being diagnosed with HIV/AIDS. This kind of getting along with the HepB as a disease might pose a negative effect on the healthcare-seeking behaviour of the HepB patients leading to delays in reporting to the health facility for monitoring, care and support thus poorer health and well-being, however, the patients' spiritual trust in God was improved through repentance (Abu-Raiya, Pargament and Exline, 2015; Adjei, Naab and Donkor, 2017).

It was not unfamiliar for the HepB patients to change their lifestyles after being told that they had the HBV in their blood to live a healthier life with improved quality of life and preventing the development of serious complications through abandoning of unhealthy lifestyles, improving on nutrition, participating in help-seeking behaviours and staying away from stressful situations (Abu-Raiya, Pargament and Exline, 2015; Adjei, Naab and Donkor, 2017; Ezbarami *et al.*, 2017). HepB patients tend to avoid the consumption of fatty foods, cigarettes, and alcohol besides incorporating exercises in their daily programs to improve their health conditions and live longer,

usually after receiving health education from their doctors (Adjei, Naab and Donkor, 2017). However, some of the lifestyles recommended for the patients, as found out by Adjei and his colleagues, were somehow worrying to the patients as they perceived the new lifestyles as a burden to them.

HepB patients after diagnosis, lived a life of denial which helped them shift their minds away from the disease to other important and developmental ventures that helped them fight depression, as was witnessed by Adjei (2017) in a study on beyond the diagnosis in Ghana. The patients, therefore, took life as normal, moved with their lives freely, took their drugs as advised by their health care providers and they did not concentrate their thoughts around their disease status. Denial encouraged the patients to put minimum attention to the infection. Some HepB patients chose not to take their drugs as advised by their doctors and therefore accepted to live a life of uncertainty, while patients who received treatment but unfortunately did not recover from the infection always lived a life of cure in future (Hill *et al.*, 2014).

Just like any other disease, HepB required care and love to be shown to the patients inform of support spiritually, emotionally, socially, financially, psychologically and mentally by relatives and friends. These kind of support strengthened the emotional relationship between the patients and the relatives and friends (Ezbarami *et al.*, 2017). Furthermore, the authors highlighted in their study that study respondents indicated the emotional support they received from their relatives that ensured they ate well and on time. Emotional support was always possible in circumstances where the HepB patients had disclosed their status to their relatives and friends as was the case with HIV/AIDS (Kamen *et al.*, 2016).

HepB patients encountered various positive experiences in their course of living with HBV which helped them in coping up with their situations. It was thus possible for them to cope up with life and lived a positive life with a better quality of life. They were as well able to fight stigmatization

as they shifted their focus away from the disease. The study therefore sought to explore the lived experiences of HepB patients receiving healthcare at LRRH in living with the disease and inform the different stakeholders to come up with strategies that enable the patients live a better quality of life and get rid of the disease where possible.

CHAPTER THREE: METHODOLOGY

3.0 Introduction

The chapter emphasised on the study area where the study was carried out, the study design used in the study, determination of the sample size of the participants, sampling procedure, inclusion and exclusion criteria applied, data collection tools used, data analysis and the ethical considerations that were considered in the study.

3.1 Study area

The study was conducted in Lira Regional Referral Hospital (LRRH), a government hospital located along Ngetta Road, in the central business area of Lira Municipality, Lira District, Northern Uganda. Lira city, formerly a municipal, is found at approximately 342 kilometres North of Kampala and 111 kilometres Southeast of Gulu city (Lira District Municipal Council, 2018). LRRH serves as the referral hospital for the districts of Lango Sub-region which includes; Lira, Apac, Amolatar, Dokolo, Kole, Oyam, Ouke, and Alebtong.

Lira district which is also found within the mid-North was declared epidemic to HepB where the government earmarked it for mass HBV screening and vaccination since 2015 as preventive measures (Ochola *et al.*, 2013; MoH of Uganda, 2018b; Katamba *et al.*, 2019). Hepatitis B caused great mayhem in Lira district and Lango sub-region at large, where families broke and people got disqualified from getting jobs, with the recent example being joining the Local Defence Unit, where Dokolo and Lira districts were the most affected districts (Oketch and Opio, 2016; Wandera, 2018). Additionally, according to the information from the Lira District Health Information System, 22 health facilities provided the testing, screening and vaccination services whereas treatment was done at LRRH as the only available treatment centre.

3.2 Study design

The study utilized a phenomenological qualitative study design which provided an avenue through which a deep understanding of the study was sought. This phenomenological qualitative approach provided an understanding of the lived life events in an individual's life in the real social world (Creswell, 2013). In-depth interviews are primary means of collecting information for a phenomenological study (Creswell, 2007). The participants were interviewed privately with a high level of attention through having guiding questions with pPat 11g questions in between for thorough understanding.

3.3 Study population

The study population of interest were the HepB patients who were 15 years old and above, true residents of Lango sub-region and accessed health care services from Lira Regional Referral Hospital. A 15-year-old person was believed to be emotionally, spiritually and psychologically mature to relate the past with the present and was able to eloquently explain their lived experiences effectively.

3.4 Sample size estimation

The size of the participants for a phenomenological qualitative research ranges from 5 to 25 participants (Creswell, 2007; Creswell and Creswell, 2009; Smith, Larkin and Flowers; 2009) and most especially studies that employ in-depth interviews (Mason, 2010). Data saturation provided a basis upon which sample size estimation was obtained in this phenomenological qualitative study (Guest, Bunce and Johnson, 2006). Data saturation, a point where the repetition of information without any evidence of new knowledge being noticed (Magrini and Manen, 2012; Saldana, 2015) occurred at 12th participant, and, therefore, this study utilized 12 HepB patients in LRRH in Lira district who provided sufficient in-depth information for this phenomenological study.

3.5 Sampling procedure

A mixed approach of purposive and snowball sampling techniques was employed to recruit study participants using the records available from the LRRH database. The purposive sampling enabled the researcher to identify respondents of interest from a population who are rich with particular information and obtain an in-depth understanding of a phenomenon under investigation (Creswell and Creswell, 2009). Purposive sampling depended on the assumptions that the study participants would give truthful, accurate, credible and complete information with openness. Snowball sampling technique was applied to identify possible study participants, if the recruited study participants knew of any patient who dropped out of treatment. This was on assumption and most likely that both the patients who were receiving health care services and those who dropped out had acquaintances. The sampling continued until the data reached the saturation point.

3.5.1 Inclusion Criteria

The following criteria had to be met for any prospective participant to be included in the study:

- HepB patients who started receiving health care services from Lira Regional Referral Hospital in the past six months and residents of Lango Sub-Region. This period assumed that the patient will have at least adjusted physically, mentally, emotionally and spiritually after diagnosis;
- Patients who are 15 years and above;
- Patients who enrolled for care but dropped out were eligible to be recruited in the study, as long as they were residents of Lango Sub-Region.

3.5.2 Exclusion Criteria

The following category of participants were left out of the study:

- All the HepB patients who were eligible for recruitment, but declined to consent to the study;

- All eligible HepB patients who were unconscious, mentally unsound and dumb would not be recruited because they might not give credible and trusted information that could easily be comprehended according to the phenomena being investigated.
- HepB patients who were receiving health care services but were diagnosed not later than 6 months from the start of the study data collection;
- All HepB patients who were receiving health care services at LRRH and were not residents of Lira district.

3.6 Study variables

These included both dependent and independent variables.

3.6.1 Dependant variables

The dependent variables included risky lifestyles, knowledge, cultural practices, contagiousness of HepB, curse, psychological consequences, stigma, self-care, failure in life, spiritual struggling, post traumatic growth, coping strategies, economic effects of HepB, the socio-cultural practices, the positive and negative consequences of HepB disease and the experiences before diagnosis.

3.6.2 Independent variables

These variables included among others: age, religion, occupation, information contact, level of education, demographic characteristics, reasons for behaviours, marital status, vaccination and number of sexual partners.

3.7 Data collection

3.7.1 In-depth interview

The data was collected by the use of face-to-face in-depth interviews where questions were written down to guide the interview sessions. The interview was conducted in Lango as a language the participants chose to use, which allowed the them to express their lived experiences with HepB

in a language they were most comfortable with. The study utilized the field notes to record the observations of the participants' body language and emotions. The interviews began with an informal talk to help build a cordial relationship and trust with the participants.

Open-ended questions were asked, which were further followed-up by other pPat 11g questions for clarity and better understanding. The analysis of the data collected from each session dictated the next interview with that particular participant whenever need arose. Each interview session lasted for about 40 to 60 minutes with breaks in between where necessary. The interview continued until a saturation point, where no new idea was being brought forward was achieved. Each interview was transcribed into a word processor as soon as possible. The transcriptions were read while listening to the audio-recordings to check for accuracy before analysis commenced.

The study employed the Guba and Lincoln's (1989) assessment criteria to ensure rigour. There was prolonged engagement with the data, member checks and triangulation of the data with maximum variation in sampling.

3.7.2 Tape recording

The interviews were recorded appropriately using the audio-tape recorder for later analysis. The study participants were made comfortable for the interview by informing them of the purpose of the study and confidentiality of the information brought forward. The audio-tape recording aided the capturing of every single detail of the interviews where important information was not omitted. At moments when the respondent did not allow his/her voice to be recorded, the information was written down in the field notebook.

3.8 Rigour

Guba and Lincoln's (1989) assessment criteria were used in this study to ensure rigour. There was prolonged engagement with the data, member checks and triangulation of the data with maximum variation in sampling.

3.9 Data management and data analysis

3.9.1 Data management

The researcher ensured that the data was kept confidential and out of reach to unauthorized people during and after data collection. The recorded data was transcribed verbatim by playing the audio recordings and typing into the Microsoft word processor, while translating in to English, followed by accuracy checking by listening to the recording while reading the text for the researcher to engross himself in the data.

3.9.2 Data Analysis

Each transcript was imported into MAXQDA 10 software®, for organizing and categorizing the information provided by the participants and analysed the content of the interviews. The Merrill and West's (2009) thematic analysis model was used for the analysis. The transcripts were coded, after which the codes were compared. Classification into categories followed and finally, the themes were extracted.

3.10 Ethical considerations

The research process was guided by sound ethical principles whereby the researcher sought for ethical clearance from the Faculty of Health Sciences, Uganda Martyrs University, which was presented to the Medical Superintendent of LRRH. Informed consent was availed to the participants after accepting to be included in the study before the interviews commenced. The participants were assured that this research was for academic purposes only.

The participation in the study was voluntary and participants were free to withdraw at any time without any penalty. A consent form was only signed and dated by both the researcher (principal investigator – PI) and the participant after it had been read or interpreted to and understood prior to the interview session to confirm his/her acceptance to participate in the study. The parents/guardians of the minors signed the assent forms on behalf of the minors to participate in

the study after understanding the purpose of the study and the roles of the minor, parent/guardian and PI in the study.

All participants were informed of the potential risks and benefits of participating in the study to ensure their safety, which appeared as a note in the consent forms. During the interview, emotional support services were provided in the form of counselling and comforting to any participant who became emotionally overwhelmed.

The participants decided on where and when the interview was to be conducted and how to be contacted. All interviews were conducted in places with only the participant and the PI except when the participant allowed someone to be present. This was done to allow privacy.

The participants were given codes to ensure confidentiality such that real names did not appear on any of the transcripts and post data collection.

Finally, all audio-taped materials, identifying information and all transcripts were properly safeguarded by the Principal Investigator (PI). All digital records or files were saved on password-protected computers. The recordings, transcripts, consent forms and all other related documentation were kept safely in protective material.

3.11 Dissemination plans of the study report.

Upon completion of the study, the researcher will submit copies of the study report to the Faculty of Health Sciences of Uganda Martyrs University for the academic award of Masters in Public Health – Health Promotion of Uganda Martyrs University-Nkozi. Four copies of the report will be printed and submitted for approval then, a copy will be given to the Faculty of Health Sciences of Uganda Martyrs University, a copy to the LRRH superintendent, a copy to the main library and one copy will remain with the researcher.

3.12 Study Limitations

Participants were chosen only basing on particular phenomenological criteria. Participants who did not attain six months from the date of diagnosis were left out and yet they could have provided useful information as regards the study. However, the participants selection was done to ensure good quality of respondents with maturity in reasoning.

There were only 12 study participants recruited to participate in this study, which, as a small number compared to the number of patients. This would mean the findings could not generalize the lived experiences of the entire population in Lira district and Lango sub-region at large. However, there was diversification of the participants' socio-cultural and educational backgrounds that helped in generating a wide range of lived experiences. Additionally, the study depended on the assumptions that the study participants gave truthful, accurate, credible and complete information with openness, which might not be the case with all participants about the study topic due to its sensitivity.

The rate of declining to be enrolled in the study and dropping out was high especially after prospect study participants knowing that the principal investigator was from Kampala. They feared those who were from Kampala that they were infected with Corona Virus Disease of 2019 and they would get infected too. The PI therefore offered nose masks and hand sanitizer and kept a distance of at least two meters apart in a quiet and private place.

Participants feared being exposed during the interviews due to the stigma and the surrounding noise. The interviews were conducted in private, calm and quiet room where there were no interferences and therefore, the study participants could be seen or heard by others.

CHAPTER FOUR: FINDINGS OF THE STUDY

4.1 Introduction

This chapter contains the findings following the objectives of the study as stated in chapter three in LRRH, Lira District. Codes of the respondents were used in data collection and report writing which served in observance of the confidentiality requirements. Data are presented according to the objectives but arranged according to the themes.

4.2 Characteristics and demographics of respondents

A total of 12 study participants were interviewed at the HepB section at LRRH which included HepB patients who started receiving health care services from Lira Regional Referral Hospital at least in the past six months and residents of Lango Sub-Region. They included seven males and five females. The minimum age of the study participants was 18 while the maximum age was 58 whereas the average age was 35. The study participants were all Christians from diverse religious background which included Catholics, Protestant, and the Pentecostal Assembly of God (PAG) being dominated by Catholics. All the study participants belonged to the Lango tribe and spoke Luo. The literacy level of the study participants was diverse from illiterate through semi-literate to literate. The lowest and highest levels of education attained were Primary four and bachelor's degree respectively. Out of the 12 study participants, eight married while four were single mostly because they were either still at school or had just finished school and only started working. Six study participants were engaged in informal employment mainly farming, fishing and hair dressing while four were in the formal employment in the field of accountancy, education, health and two were students.

Table 4.1 shows the participants' demographic data

Codes, age, sex	Place of origin	Marital status	Religion	Education level	Occupation	Duration of interviews
Pat 1, 18, M	Apac district	Single	Catholic	Senior 3	Student	42 minutes and 22 seconds
Pat 2, 28, M	Oyam district	Married	Catholic	PTC	Teacher	48 minutes and 22 seconds
Pat 3, 52, M	Oyam district	Married	Catholic	Primary Seven	Farmer	59minutes and 50 seconds
Pat 4, 41, M	Alebtong district	Married	Protestant	Primary Seven	Farmer	44 minutes and 19 seconds
Pat 5, 58, F	Otuke district	Married	Protestant	Primary Four	Farmer	49 minutes and 24 seconds
Pat 6, 27, M	Kwania district	Married	PAG	Primary Seven	VHT	48 minutes and 45 seconds
Pat 7, 22, F	Lira City	Single	PAG	Vocational	Hair dresser and health worker	54 minutes and 52 seconds
Pat 8, 33, M	Lira City	Married	Catholic	Degree	Teacher	50 minutes and 13 seconds
Pat 9, 19, F	Kwania district	Single	Protestant	Senior six	Student	49 minutes and 36seconds
Pat 10, 28, F	Dokolo district	Single	PAG	Senior two	Farmer	47 minutes and 53 seconds
Pat 11, 58, M	Amolatar district	Married	Catholic	Primary Seven	Fisherman	51 minutes and 09 seconds
Pat 12, 40, F	Kole district	Married	Protestant	Degree	Accountant	56 minutes and 22 seconds

4.3 Presentation of the findings

The summary of the study results is summarized in figure 4.1 below.

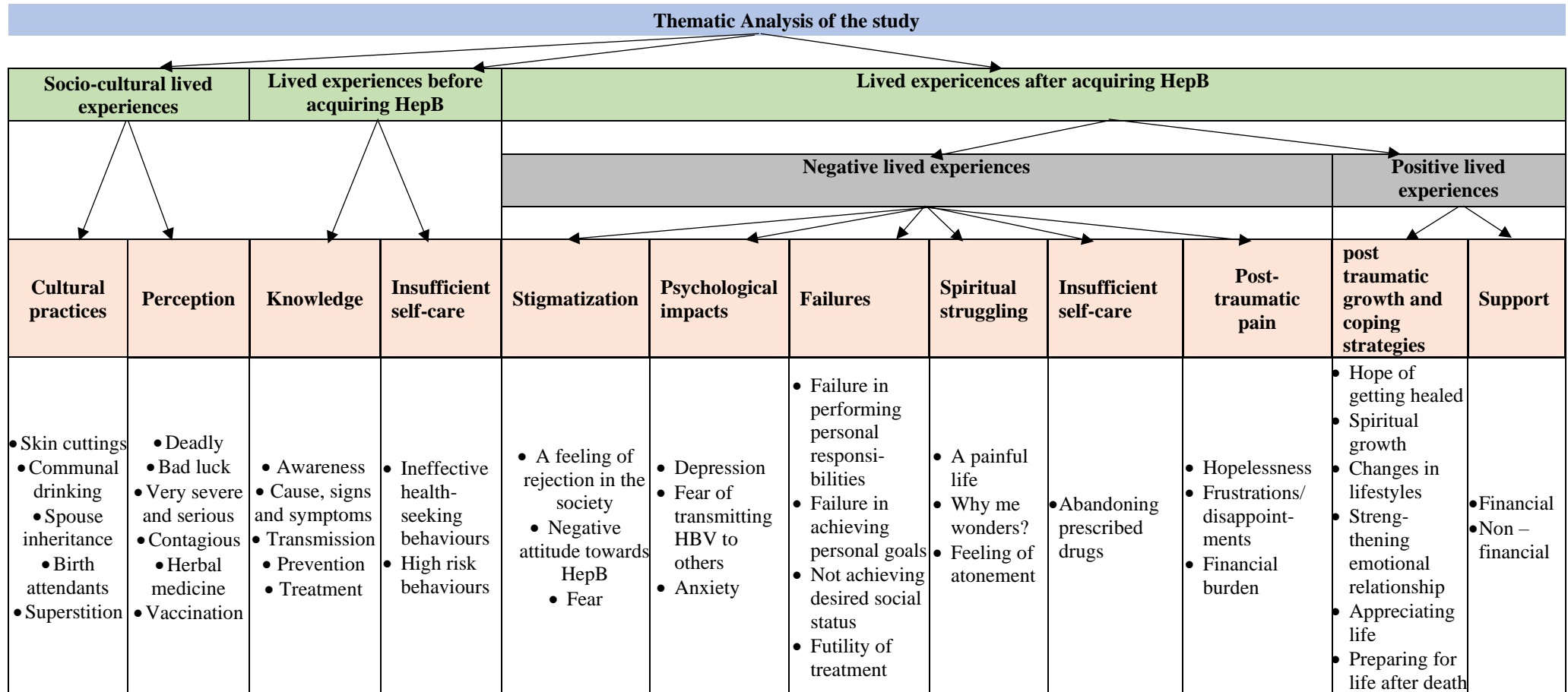


Figure 4.2: shows the themes generated from the findings of the study of the lived experiences of people living with Hepatitis B in LRRH)

4.4 Discovering the socio-cultural lived experiences of the HepB patients receiving healthcare services at Lira Regional Referral Hospital, Lira district, Uganda

The cultural beliefs and practices of the HepB patients in LRRH represented those of their society as described by the study respondents and greatly determined the behaviours, beliefs, attitude and perception of the society towards HepB as a disease which were captured and themes and sub-themes developed as illustrated below.

4.4.1 Cultural practices

Cultural practices which were considered rituals were performed whenever there was any kind of sickness to ensure healing to the affected people. Other practices were considered as a form of enjoyment especially at times of happiness and merry-making. Some of these practices included

4.4.1.1 Skin cuttings

The practice of cutting the skin using sharp objects such as razor blade was reported by many respondents to be a practice commonly done as one of the cultural rituals in circumstances where an ailment broke out in a family or community to provide healing. Pat 1 said:

“Skin cutting is a common practice, though somehow, on the decrease. But I think these skin cuttings can lead to the spread of HepB in the community.”

It is sometimes seen as a way of cleansing the victim off the bad omen. Pat 3 narrated:

“There are activities which are organized in homes whenever there are bad things sent by an enemy of that family to cause sicknesses and sometimes death, people of that home are scarified using the same razor blade as a way of letting out the bad blood from the bodies. The razor blades are sometimes shared because families may not have money to buy what is enough for everyone.”

In another statement, Pat 6 declared:

“In July this year, I had a swollen leg where I could not even walk and I was in great pain. Very many people came to me and advised me to go for body cuttings at the swollen part because I might have stepped on someone’s witchcraft. I refused to do it because I am a born-again Christian who does not believe in such acts.”

4.4.1.2 Communal drinking

Communal drinking was an activity that was done to show an act of sharing where a group of people share the local brew as they entertained themselves. Pat 3 said:

“Whenever there is any cultural activity, there is always ‘marwa’ inclusive which people always share straws. In one cycle of about 10 people, there could be only three or four straws/ tubes. Therefore, people have to share. There is also sharing of waragi in glasses whereby about 5 people can share waragi from one glass. There is always the exchange of saliva in the process of sharing these drinks.”

4.4.1.3 Inheritance of spouses

The practice of inheriting the deceased’s spouse by the brother-in-law was identified among the study respondents irrespective of what the deceased could have died of.

“There is this common practice of inheriting a brother’s wife when your brother dies which to me may lead to the spread of HepB because if one person is positive may infect the other healthy one.”

When probed why inheritance of spouses was carried out, Pat 3 responded:

“It is believed that the woman is already a property of the clan who can be inherited by the brothers-in-law if the husband dies.”

4.4.1.4 Birth attendants

The practice of giving birth while being attended to by a traditional birth attendant was witnessed among the study respondents. The traditional birth attendants used all most no protective wear during the process of a mother giving birth which exposed them to either transmitting or contracting HBV. Pat 5 disclosed:

“There are also women who give birth at the homes of the traditional doctors in my village at any time and they are very effective in their work. In most cases, people use bear hands when cutting the bodies of people. These are, however, not as common as they used to be before the introduction of the VHTs but are still being practiced.”

Pat 9 confessed:

“Hmm... ..My grandmother attended to more than 15 women whom I know but she did not at any one-time wear either gloves or polythene bags to protect herself, mother and the baby. Anything can happen in the process of attending to a mother who is giving birth.”

4.4.2 Perception

HepB as a disease, was viewed differently by the study participants which shaped the way they behaved towards the disease. The sub-themes developed under perception are documented below:

4.4.2.1 Deadly

HepB was perceived by many study participants to be a deadly disease that dictated how they lived their lives. Once someone contracts it, the chances of getting rid of it are very minimal. Pat 2 said:

“Ohh! HepB is a very deadly disease that needs a lot of care because it easily kills but can be treated though it takes a long time to disappear from the blood. But death is a plan of God irrespective of which disease you are suffering from.”

Pat 5 emphasised:

“I think this is a very deadly disease because many people in my village have died, for example, I know about eight people who have died since lockdown up to now, who had similar experiences as mine, but because they did not come to the hospital, they died of HepB.”

Pat 7 further reiterated:

“HepB is a very serious disease that is very lethal because it damages your liver silently without you knowing it. By the time it is detected in you when you are feeling pain in your stomach, your liver will be long damaged. In spite of all the treatment that my aunt received, she still died and that gives my thinking that I may also die even if I take my medication as instructed by the doctor.”

4.4.2.2 Very severe and serious

HepB was viewed by the respondents as a very severe and serious disease that damaged the liver without the patient knowing it. By the time an individual begins to feel the pain, the liver is already damaged. Pat 5 noted:

“I, This must be a very serious disease since it destroys the liver completely and causes very sharp pain in the liver like the liver is being cut into small pieces. HIV seems to be better”

Pat 6 also said:

“This is a very serious disease which destroys liver silently so, it can kill you silently because by the time it is discovered, the liver will have been destroyed long ago. It is also serious in that it weakens you over time to the extent that you will not be able to do any hard work and to some extent light work, for example, right now I have been prohibited from digging.”

4.4.2.3 Contagious

Some study respondents showed a clear perception that HepB is a disease that is easily transmitted from one person to another and protecting one’s self against it was very hard. Pat 7 noted:

“HepB is a disease which can give me some hard time. I live in fear because of the self-conviction that everyone knows my status or I can easily transmit it to other people even through mere handshake and sharing food. I stay away from them”

Pat 1 added:

“I can say that HepB is a very serious disease which can easily be transmitted that everyone must guard against because it can easily kill.”

Pat 2 also shared his view:

“It is very hard to protect yourself from acquiring HepB because I also do not know how I got it because I did not get involved in sexual activities before marriage and I lived a very good lifestyle.”

4.4.2.4 Bad luck

Contracting HBV was seen by some study respondents as just bad luck for someone. The study respondents believed whatever a person who mattered in their lives told them. Bad luck was a belief that resulted from someone getting a bad thing from among the many others who did not get it. Pat 2 said:

“Ahhhhh ... Some pastor prayed onetime and told me that you get HepB out of bad luck and I really believe so because I am the only one having it in my home.”

4.4.2.5 Herbal medicine

Herbal medicine was mainly prepared by the elders within the communities and sold to whoever needed it. Some people vended the local medicine usually in jerrycans of five liters. The HepB patients acknowledge the use of local medicines in the treatment of different conditions.

Pat 1 said:

“There is the use of herbal medicines which some people visit witch doctors for strange diseases.”

Pat 2 acknowledged:

“I have seen some people going for local herbs whenever there is something strange happening on them. I think the painful stomach can also make them visit the herbal medicines men. Also, sometimes I see some people being called by some elders and told to go and get some herbs, crushed and given to people to either chew or drink.”

Pat 3 added:

“Herbal medicines are still very common in my village and people use them a lot. They are always given in 5-liter jerrycans for people to drink to cure very many different diseases.”

Those who used local medicines had a belief that they worked better than the medically synthesized and approved modern medicines as put forward by Pat 7:

“What I know is there is the use of herbal medicines and I think they work better than the modern medicines from medical professionals.”

Some study respondents intimated that much as local medicines were in use for treating different kinds of conditions, it was not a good idea to be taking the local medicines and at the same time taking modern medication. Pat 3 said:

“I think the problem comes in when you are mixing herbal medicine with the modern medicines from the hospitals. So, to me, I think it is better to use only one, preferably the modern medicine, but not mixing the two medicines.”

Herbal medicines were viewed by some study participants to be effective in managing different conditions. Pat 6 affirmed:

“It is true that herbal medicines are in use and people use them, including my very close friends and they seem to get better after using them to treat various diseases.”

However, some of the respondents did not believe in the efficacy of herbal medicines in treating

HepB. Pat 5 said:

“I do not believe that the herbal medicines can help cure HepB. This is a very dangerous disease that needs medicines or drugs that are pure. I think the herbal medicines are not pure and not effective in treating HepB.”

Pat 6 also said:

“But for me, I do not believe in them and I do not use them because I am not sure about their purity and real effectiveness in treating diseases, especially a stubborn and serious one like HepB because they cannot also cure HIV/AIDS.”

Pat 1 stated:

“I personally do not believe in the use of herbal medicine to treat HepB. First of all, have these herbal medicines been tested, confirmed to be effective and authorized to treat HepB? Do they have the certificate from a recognized body indicating the presence of the healing component in these herbal medicines?”

Pat 2 also said:

“I personally, in my own thinking, I do not think those medicines can work and cure HepB without the use of modern medicine.”

After pPat 11g why Pat 2 thinks so, he said:

“Because HepB resembles HIV, then, local medicines for HIV should have already been found.”

4.4.2.6 Vaccination

Vaccination is an approved preventive measure for various diseases including HepB. Vaccination exercises are always organized by the government of Uganda to protect its citizens against different conditions including HepB. However, the HepB vaccination exercises were shunned and the cultural leaders who influence their subjects did not encourage them to go for vaccination against HepB. There was a perception that the government organized the mass vaccination with an intention of controlling reproduction and killing them. Pat 6 stated:

“People including the cultural leaders shun vaccinations especially those massive vaccinations that are organized by the government because of the belief that the government wants to make them docile to reduce the rate of reproduction, kill them or give them some new disease.”

Sometimes there may be someone who might want to go for HepB vaccination but the vaccines were not readily available at the health facilities. Pat 6 Stated:

“In most cases, these vaccines are also not available in health centre IIs and IIIs which are nearer to people than hospitals like this LRRH where everyone has to travel to receive any kind of HepB service.”

Pat 3 said:

“But now, nothing is said about it. Even vaccinations in the health centers are not there now because the vaccines are not there and people did not like it when it was brought in 2015 by the government.”

Upon inquiring why the mass vaccination was not liked by the communities, the reply was:

“It was not liked because of the fear of developing the disease from the vaccines. Some people used to say it was the plan of the government to kill people.”

Pat 2 similarly stated:

“In my village, they seem not to be talking much about vaccination because there are no vaccinations going on. It stopped a long time ago, now, you tell people to go for vaccination, where should they go? They do not talk about it.”

The fear of losing erection coupled with the long distance to the nearest health facility where vaccines were offered and the high cost in the private health facilities played a great role as well in discouraging the willing people from going for HepB vaccinations: Pat 6 noted:

“I saw in my village even up to now people still talk about it, very few people received the HepB vaccines because of the fear of losing an erection in men to control the rate of reproduction, the long distances to travel to the nearest health centre for the vaccine, the many doses (three times) that someone has to receive and the high cost of the vaccines in private facilities.”

It was after several deaths were registered that the cultural leaders and elders in the communities only talked about HepB vaccinations and encouraged their subjects to receive them. Pat 3 said:

“Ehh! I remember it was just once that my clan chief talked about HepB because it has killed many people from my village, over 30 people. He said people should

go and vaccinate because doctors said vaccination could help protect someone from catching the disease. That was the end of it.”

4.5 Determining the lived experiences of HepB patients receiving healthcare services at Lira Regional Referral Hospital before acquiring the disease

The data obtained on the lived experiences of HepB patients at LRRH before realizing that they had acquired HepB were categorized under the themes below.

4.5.1 Lack of knowledge

The lack of knowledge about HepB was evident among the study participants as they presented their first-hand experiences.

4.5.1.1 Awareness

Only two study participants were aware there existed a disease known as HepB before their diagnosis. Pat 8 said:

“I knew that HepB existed before I was told that I am suffering from it at the hospital. There was a health sensitization campaign at our school in 2008 when a nurse told us the students to test for it but it was expensive. It was at UGX80,000.”

Pat 12 stated:

“I lost a relative to HepB. So, by the time I was diagnosed, I was already aware of its existence.”

Most of the study participants expressed in their responses a high level of unawareness about the existence of HepB as a disease. It was mainly their first-time hearing about HepB as a disease after diagnosis from the health personnel. Pat 2 said:

“So, my first time of hearing about Hepatitis was in 2008 from medical personnel when I donated my blood.”

Pat 3 proclaimed:

“I was told I had swollen lungs and burnt liver. I was referred to the referral here where I was tested and told that I had HepB and that was my first time of hearing about it.”

Pat 7 decreed:

“I heard about HepB in 2016 from the health workers at where I work when they were talking about it amongst themselves.”

Pat 9 highlighted:

“I came to know about HepB existence when I came to the hospital”

Radio stations were one of the sources where some of the study participants knew about HepB’s existence as a disease. Pat 1 said:

“I got to know about HepB from the radio when an advert about HepB was being run.”

4.5.1.2 Cause, signs and symptoms

The cause of HepB as a disease was something that was not known to the study participants irrespective of the literacy level. The respondents could not tell whether it was a bacterial, protozoan or viral disease. Pat 1 stated:

“Hmmm, honestly, I am not sure about what causes it. I have no idea about it and I have never heard about it.”

Pat 6 said:

“HepB is a disease that I have not yet understood what really causes it and how it is transmitted from one person to another ever since it was found in me up to now.”

Pat 4 and Pat 12 avowed:

“I do not know what causes HepB in the human bodies, especially the form in which it attacks someone and exists. I do not understand about it at all.”

None of the study participants could tell that whatever they were experiencing were the signs and symptoms of HepB in their bodies. The disease presented itself with loss of energy, loss of appetite, very sharp pain in the upper part of the abdomen and spine, yellowing of eyes, developing pale skin, feeling cold and hot simultaneously, vomiting blood, body swellings, sweating and foaming

saliva in the mouth. These signs and symptoms might be easily mistaken to be some other diseases.

Pat 1 said:

“When you have not yet been told that you have HepB, you feel that you do not have energy and you are weightless, you feel you do not want to eat at all. It may be mistaken to be malaria because you also have joint pains similar to malaria.”

Pat 2 affirmed:

“It also does not make someone reduce in body size like HIV. If you have HepB in your blood, you feel some painful sharp sensation in your upper part of the abdomen and the spine.”

Pat 3 echoed:

“I started feeling a sharp pain in my stomach, swelling of my legs, vomiting blood and sometimes nose bleeding, sweating, alternating series of low and high temperatures. My desire for food disappeared and I would not feel like I needed to eat. I could not eat beans because my stomach would pain a lot whenever I ate beans.”

Pat 6 asserted:

“I had general body weakness, swellings on some body parts such as the stomach on the right-hand side and legs, yellowing of the skin, very sharp pain in the stomach especially the right-hand side, high and low temperatures almost at the same time and I would have foamy saliva in my mouth most of the time.”

Some respondents could not identify the signs and symptoms because they were diagnosed early before the virus could show itself. The virus only showed after dropping out of medication. Pat 7 said:

“I do not know exactly the signs because I was diagnosed early. But at some point, when I stopped my medication, I started feeling some sharp stomach pain on the right-hand side and general body weakness.”

4.5.1.3 Transmission

The means of transmission of the HBV from an infected person to a healthy person was one area that was so confusing to the study participants. HBV was closely associated with HIV by most study participants. Pat 1:

“Ahhhh, ..., it can maybe, be transmitted through unprotected sex and coming in to contact with sweat from an infected person. It can also be transmitted through sharing of beds with an infected person.”

Pat 7 echoed:

“HepB has very close resemblance with HIV in that it is transmitted through coming in to contact with bodily fluids like blood, saliva and sweat from an infected person, unprotected sex, body piercing like tattooing and body cuttings, sharing of unsterile sharp instruments with an infected person except that HIV may not be transmitted through saliva and sweat. For me, I got HepB from home when I slid and got pierced by the needle which had just been used to inject my aunt who had the disease.”

Pat 2 said:

“... through sexual intercourse, sharing of food utensils such as plates, cups and spoons”

Pat 4 acknowledged:

“HepB is very similar to HIV. So, I think it can be transmitted through unprotected sex with an infected person, sweat, touching the person who has died of HepB with unprotected hands and sharing beds with an infected person. It can also be through sharing plates, cups, spoons, forks, and basins can transmit HepB but I do not think so when you are treatment.”

Poor knowledge about transmission of HBV from an infected person to a healthy one existed among the study participants which can instead lead to the spread of the virus in the community through the right means of transmission. Pat 3 stated:

“HepB can be passed from one person to another through drinking dirty water, sharing items such as cups, plates, spoons, basins and towels.”

Pat 5 further echoed:

“The doctors have not yet told me how it is transmitted but I know it is only transmitted through cow dung because I used to handle cow dung a lot to smear and decorate the houses at home.”

4.5.1.4 Prevention

The study participants expressed different ways through which HBV prevention can be achieved which included practising non-risky behaviours both by infected individuals to safeguard the

uninfected persons from acquiring the virus and healthy individuals themselves and obtaining all the three doses of the HepB vaccines. Pat 1 identified:

“In order to avoid contracting HepB, one needs to abstain from sex or have only one sexual partner and remain faithful to that person or practice safe sex. Vaccination against HepB provides very good protection for any healthy person once all the three doses are finished.”

Pat 3 said:

“Sharing of eating apparatus should stop so that the healthy people cannot be infected by those who are already infected. The healthy people should stop sharing things with the infected people, like in my village up to now, some people still want to share with me my sugar-free soda because they want to feel how it tastes.”

Pat 6 stated with assurance:

“HepB vaccination is a very effective way of preventing someone from acquiring the disease and I always encourage people in my work as a VHT to go for any kind of vaccination that has been organized either by the government or any reputable organization.”

Pat 7 said:

“I think HepB can be prevented through taking the complete doses of the vaccination against the virus that causes it. I believe the HepB vaccines have no bad side effect as other people commonly say that they are used with the intention of controlling the reproduction rate or to kill people. Another way is not to share sharp instruments with other people because you may not know their HepB status.”

Screening for HBV before engaging in a relationship could be another way of preventing the HBV transmission as illustrated by Pat 7:

“Screening for the HepB virus, just like HIV or sickle cell, for people who may want to take their relationship to another level of settling together and also being open to your partner if you are positive before you going so far in the relationship.”

Some of the preventive means presented by the respondents expressed poor knowledge about the prevention of HBV transmission. Pat 2 said:

“You need to avoid sharing plates, cups, spoons, basins and clothes with uninfected people even when they are on medication.”

However, the use of HepB vaccination as a preventive measure was doubted by some of the study respondents. Pat 2 stated:

“I am doubtful about the effectiveness of the vaccination because even government hospitals have stopped vaccinating the adults against HepB.”

4.5.1.5 Treatment

Treatment of HBV was viewed differently by the study respondents depending on their belief. Pat 1 said:

“HepB can be treated only when it is still early”

Most of the study respondents doubted the treatment of the HepB to eliminate the virus from the body. Pat 9 said:

“HepB is a disease to live with just like HIV. Drugs are just to make you live a better life.”

Pat 11 stated:

“It is very hard to treat HepB. I have been in treatment for 6 years now but every time I come to the hospital; I am not told that I am getting healed. It is very likely that you live with the disease till death.”

4.5.2 Insufficient self-care

HepB requires self-principles to ensure that individuals live healthily and restrain from lifestyles that predispose them to acquiring HBV. Two sub-themes were generated as illustrated below:

4.5.2.1 High-risk behaviours

The study respondents confessed to living lives dominated by high-risk behaviours which could have predisposed them to contract HBV. The respondents shared sharp instruments, had multiple sexual partners, shared drinks and had unprotected sex among others. Pat 1 narrated:

“I lived a very happy life with people before my sickness; I could share whatever I had with them and also use their items such as basins, sewing needles because sometimes the uniforms could get torn, plates, cups, forks and bed among others.”

Pat 2 stated:

“I lived a very free life with people, we shared personal items like eating apparatus, beds, nail cutters and sometimes razor blades and sewing needles.”

Pat 3 narrated a string of lifestyles:

“Oh! Oh! Oh! Life was so free and sweet. We used to share like one straw among four people or even more when enjoying the “marwa”. Sharing cigarette was a very common thing. If you did not share one cigarette with your friends like even more than three or your friend did not give you, you would then be seen as a very bad person who is not social and does not want to share. It is still a common practice up to now in my village”.

The peer pressure exposed Pat 3 to various risky behaviours as he continued narrating:

“I pity young people of today. ... At our youthful days, life was so sweet not like your days now. Women were there, you could just choose. I had five ladies at a go when I was still a young man of 25 years old. Whoever had many ladies was considered a strong man. We also used to share soft drinks (sodas) among ourselves where one would sip and give to another person. Sometimes we would share among five of us.”

Pat 4 added:

“I had no problem with people, so, I could freely interact with them, enjoy outings with them and dancing. The truth is that I had girlfriends, at least more than one at some point.”

Pat 12 said:

“I one time had a boyfriend whom I realized he had five other ladies besides me. I trusted him so much and we started having sex without condoms. I think he could be the one who gave me the disease.”

4.5.2.2 Ineffective health-seeking behaviours

Insufficient health-seeking behaviours are decisions assumed by individuals who distinguish themselves to have a particular health issues with the aim of obtaining a remedy that is appropriate.

Most of the study respondents confessed to having gone to the health facility upon feeling some kind of discomfort. Pat 3 said:

“I was motivated to come to the hospital for testing because I really wanted to know what kind of disease I was suffering from because I had swellings on my legs,

very sharp pain in my stomach, vomiting of blood, having nose bleeding and alternating high and low fevers.”

The unbearable pain forced some respondents to go to the health facility for a check-up to find out what was wrong but not as a routine check-up. Pat 5 confirmed:

“I was motivated to go for the test because of the pain that I was going through.”

Pat 6 stated:

“I went to the hospital because I was always very sick and also the pain that I was going through was so much.”

Visiting the health facility for testing was done by one of the study participants following an accident involving a needle that was used on a HepB patient at home. Pat 7 noted:

“I got motivated to test for HepB because of the accidental piercing of my hand with the needle which had just been used on my aunt who was suffering from HepB disease.”

It was noted that some people instead of visiting health facilities whenever they were not feeling well especially when they were attacked by a strange condition, went to the shrines to seek healing.

Pat 7 said:

“There are shrines where people go to whenever they are sick or experiencing something strange to look for healing or solutions.”

The various expressions of the study participants described in the themes above showed great concern relating to the knowledge and perception about HepB and the kind of lifestyles the study participants lived. Most study participants portrayed poor knowledge about the disease and risky lifestyles which could have exposed them to contracting HBV.

4.6 Exploring the lived experiences of the HepB patients receiving healthcare services at Lira Regional Referral Hospital after acquiring the disease

The lived experiences of the HepB patients obtained from the field have been classified into two categorized as negatives and positives as the patients responded to their conditions. They are illustrated below.

4.6.1 The negative lived experiences of HepB patients receiving healthcare services at Lira Regional Referral Hospital after acquiring the disease

The study participants developed various negative effects of living with HepB ranging from stigmatization, failures in life, psychological consequences to spiritual struggling.

4.6.1.1 Stigmatization

The issues of stigmatization were mainly associated with socio-cultural aspect of dealing with the disease in the community. The themes below were generated that were deemed as stigmatizing:

4.6.1.1.1 Feeling rejected in the society

Many of the study participants identified that they had a feeling that they were rejected by those whom they considered as their close friends before their diagnosis with HBV. They were deserted by those who were close to them. Pat 5 stated:

“After the diagnosis, ah, ah, hmm, people got to know about my sickness after some time and some people whom I thought they were my friends feared me and deserted me up to now.”

The feeling of being rejected was also felt by students at schools which made their lives difficult since they could not be helped and therefore some were forced to change schools. Pat 1 hence narrated,

“I had a difficult life at school when my friends and others at school got to know my HepB status: I lost some of my close friends and my classmates could not help me whenever I consulted them on any subject.”

Pat 9 further corroborated with the narratives of Pat 1 which led to changing of schools:

“Two of them understood and encouraged me to continue taking my medicine but one of them abandoned me and started spreading my status in the school which made my life so difficult. Because I could not manage such kind of life, I had to change school.”

The feeling of rejection resulted into some study participants hating and blaming themselves for the kind of feeling they went through most especially after receiving such treatments from those whom they loved. Pat 7 narrated with grief:

“I hated myself and everyone around him and blamed myself for helping my dad that day. He told his friend who also told others and people got to know about my HepB status. Up to now, they walk away whenever they see me approaching them.”

The negative attitude of the communities of linking HepB to HIV affected the thinking and perception of the HepB patients when it came to the place of receiving their drugs. Pat 7 and Pat 11 stated similar concern that:

“Sometimes I even fear that someone else among my friends may see me getting the drugs and think that I am HIV positive.”

4.6.1.1.2 Negative attitude of the society towards the disease

The communities where the HepB patients lived had very negative attitude towards HepB in which people linked HepB to HIV alongside all the treatment given to HIV positive patients as being womanizers. Pat 3 noted with anguish:

“My life changed because people stated fearing me after they got to know that I was suffering from HepB. Majority of my friends began to say that I had already gotten HIV, so I would infect them. People labelled me a womanizer that is why you are suffering from HIV now but this was not true. I have now tested for HIV four times and I have been found negative throughout. Some people even told me it would just be so good if you died for our women and us to be safe.”

4.6.1.1.3 Fear

The study participants expressed fear of mistreatment and in their lives by the members of their communities if they ever had that they had HBV. This made some of them kept silent about their HepB status without disclosing it to others. Pat 2 confessed:

“I did not tell anyone that I was going to test for HepB because it did not want to be a laughing stock and people run away from me which would give me hard time.”

The experience of the HepB of some study participants with their relatives dictated their actions about disclosing instilling fear in them. Pat 7 said:

“I did not tell my friends because I feared they would run away from me just like some of my aunt’s friends ran away from her when she was still alive battling the disease. I also feared they could begin talking about me with others thus spreading my status to others.”

There was fear of transmitting the virus to healthy individuals to avoid living in self-conviction of infecting others. Pat 7 stated:

“HepB is a disease which can give me some hard time. I live in fear because of the self-conviction that everyone knows my status or I can easily transmit it to other people.”

However, some of the respondents did not have any fear in their lives at all since they did not look for the virus. Pat 6 said:

“I did not fear anyone because I did not look for it. I did not know how it came in to my body, so, it just came on its own. I just told my wife, siblings and very close friends about the test results that HepB was found in my blood but I was given drugs to take.”

4.6.1.2 Psychological impact

The study participants were affected psychologically mostly in the three areas below:

4.6.1.2.1 Depression

Depression was mostly presented in form of sadness among the study participants which affected their concentration in doing their daily activities. Pat 5 paused and stated:

“The disease really affected me mentally. I could not think well. It is hard to describe it but it was like I was about to run mad. I was always sad and scared and I could not concentrate in whatever I was doing.”

Depression affected the adherence to medication which resulted into worse situations that led to a sign of negative perception about HIV. Pat 7 narrated:

“Somehow, it has affected me because sometimes I feel so depressed and disappointed and fail to take my medicine which has led to increase in viral load. I have been admitted to the Intensive Adherence Care Unit twice together with HIV positive patients as if I was one of them.”

The thinking of death was a common phenomenon. The thinking of suicide and wishing for death was stated by Pat 7:

“Even thoughts of suicide sometimes come because of over thinking about my status and how I got it. I only wish I had not entered that room to help my dad work on my aunt.”

Pat 11 and Pat 12:

“Most of the times I wish death could come my way anytime soon. I would not be going through this pain.”

The thinking about HepB was an inevitable thing in the life of a HepB patient. Pat 2 stated:

“After testing for HepB, my life has changed a lot. At least every day, I had to think about something that concerns HepB however much I tried to make myself busy so that I stopped thinking about it. I could think about what really HepB is, how I got it, when it will kill me and so on.”

4.6.1.2.2 Fear of transmitting the virus to others

The study participants were so much afraid of transmitting HBV to the healthy individuals around or close to them. This was testified by Pat 7:

“I sometimes have this fear in me of infecting other people with HepB and also the constant thinking of my status and wishing I was like others who were free of HepB.”

The sharing of personal items was limited with the objective of preventing infecting others. Pat 2 stated:

“My things are my things like plates, cups, spoons and forks, basin, bathing soap, clothes among others because I do not want to infect other people and I keep on having that self-conviction that I infected someone.”

Staying away from people was noted as a way of protecting the healthy individuals from getting infected. Pat 10 noted:

“I could not fear anybody but now I have to stay away from large groups of people because I fear that maybe I will infect them and I fear being scolded in public because of my status.”

4.6.1.2.3 Anxiety

The feeling of fatigued, grinding of teeth and fast heart beat was registered which was a sign of anxiety among the study participants. Pat 5 stated:

I quite often feel fatigued, sometimes find myself grinding my teeth without my intention and fail to sleep. Sometimes I feel my heart is beating so fast.

4.6.1.3 Failures

There was a feeling of failures which was confessed by different respondents that resulted from living with HBV. The failures that were identified fell under the following sub-themes below:

4.6.1.3.1 Failure in performing personal responsibilities

There are responsibilities which are ought to be performed by an individual to be satisfied. However, some of the responsibilities, especially school fees, could not be performed due to living with HBV which affected the education of the children. Pat 4 highlighted:

“In many occasions I have failed to pay school fees for my children, which, greatly affects their education and makes me feel that I am failing to perform my duties as a father to educate them.”

Pat 11 further conquered with Pat 4:

“My children have in several occasions been sent back home from school because of school fees. The little money I have is for bringing me to the hospital and buying drugs. So, they sometimes stay at home for up to two weeks as other children are studying. This of course affects their performance but there is nothing I can do.”

Pat 3 said:

“My wish was to give each one of them a proper education but I have failed to do that.”

The failure to perform personal responsibilities resulted into the respondents prioritizing areas which could be financed, hence opportunity cost. Pat 1 said:

“My uncle incurs cost of my transport to and the hospital. This is my third time of coming to this hospital. I can see that he has reduced expenditures on certain things at home, like he used to buy meat every weekend to now buying it only once a month and he has also reduced on buying clothes for my cousins (his children) to meet my treatment expenses in terms of transport and buying of drugs when they are out of stock from the hospital.”

Pat 2 proclaimed:

“I cannot meet the needs for all the basic requirements right now because I have limited finance. So, I prioritize and use the money wisely. I think by now I should have already finished constructing my house.”

Pat 4 said:

“There are many things which I have foregone because I need to now prioritize the activities that require money.”

Pat 6 emphasized:

“The little money that I get is now used in buying only essential and basic items for the home. I cannot now buy other things which I see them as a want.”

He further added:

“I wanted to buy machines for making craft shoes after my training in craft shoes making but I failed because the little money that I got I needed to buy drugs, come to the hospital, carry out expensive scans at private hospitals.”

4.6.1.3.2 Failure in achieving personal goals

Living with HBV was a stumbling block in the achievement of personal goals as stated by some respondents. These included starting their homes, owning houses among others. Pat 7 stated:

“I thought I had gotten a boyfriend who would be my husband and I was getting ready to have a home but he dumped me because of my HepB status. That is why I am still single up to now.”

Pat 3 said:

“I became a laughing stock because I could not finish my very good house which I had started constructing at home.”

The statements of Pat 5 and Pat 9 were the same:

“But right now, I feel I have failed to achieve certain things in my life because I cannot do anything sensible now that can give me money.”

There were fears of engaging in big goals as confessed by Pat 7:

“I feel that I cannot commit myself to doing some big projects for myself like constructing a house because I may not finish it.”

4.6.1.3.3 Not achieving desired social status

The respondents highlighted that their HepB status facilitated their failures in achieving the social status that they desired in life. Pat 12 stated with grieve:

“Can you imagine I was an active member of a financial group but I was forced out just because I am positive of HepB? These people are so merciless.”

Pat 11 said:

“I have failed to complete my house because of this disease. The demand is too high for me to put money in the house. I should have also been like my friends who have permanent houses.”

4.6.1.3.4 Futility of the treatment

Most of the study participants indicated the long time that they have been in treatment but there is no sign of the disease getting healed. Some of them showed no content in the drug they received and wished for a change to another drug. Pat 3 said:

“I have lived with the disease for four years now, though there is some slight improvement, I still do not see myself getting healed very soon because it is the same drugs that I am always given from the hospital here every time I come here. I wish they could change to a better drug that can health me faster.”

Pat 11 said:

“Ah Hmmm. Sometimes I feel so disgusted with this treatment. I have been on treatment for six years now but I cannot remove this disease from my body.”

Pat 7 lamented:

“My aunt was on medication but she died, then, how about me. I lost hope immediately in life because at such a young age to acquire this serious killer

disease is not what I wished. I began imagining myself being lowered down in the coffin just as my aunt.”

4.6.1.4 Spiritual struggling

Most of the study participants showed that they suffered wondering about problems associated with HepB silently and privately. Most of the statements were related to spirituality as illustrated below.

4.6.1.4.1 A painful life

The study participants lived a life of pain that always stress them. The feeling of annoyance is what they live with. Pat 8 said:

“My condition is not good. I feel annoyed every time I think about this disease. If I could avoid it, I would avoid thinking about it but I cannot”

One study participant could not forget how his relative suffered in pain and finally succumbed to the virus. Pat 4 said:

“I remembered how my uncle suffered in pain and died in 2016 because I was told that he died of HepB. I actually saw death coming to me.”

4.6.1.4.2 The ‘why me?’

Most of study participants months after diagnosis asked themselves why they were the ones suffering from the disease because of what they experienced in their everyday lives. Pat 2 testified:

“Why and how did I get this very serious disease and how will I protect others? Inside me, I started asking myself but why me of all people to be going through this pain.”

Pat 8 said:

“Whose plan was this that I should suffer from this disease? Am I the cursed one among all?”

4.6.1.4.3 Feeling of atonement

Some study participants viewed HepB as a punishment by God for the wrong doings that they have done in their lives. Pat 2 said:

“Perhaps I am being punished for my sins. I am truly sorry for every bad thing that I have done.”

Pat 12 said:

“If I look back in life, it could also be the payment of all the wrong doings through which I got it. It makes me feel very low.”

4.6.1.4.4 The feeling of death

The feeling of death was identified as a common phenomenon among the respondents as a result of living with HepB. Pat 1 said:

“I always pray to God to forgive me of all the sins that I have committed and protect me whenever I am going to bed at night because anytime I can die any time. Even during day time when I am alone, I ask God for His healing powers upon me.”

Pat 2 emphasised:

“I saw death right in front of me and that feeling of dying like tomorrow remained in my life for long. Since this is a very deadly disease, it can be the one that I may not miss because you can die at any time.”

Pat 5 stressed:

“I, I, I saw death when I related my experiences with the eight people who died in my village.”

Pat 6 further highlighted:

“Sometimes I have this feeling that I have a short time to live but I have not done certain things in my life to have satisfaction and leave my family happy and secure.”

Pat 12 asserted:

“We struggled with a relative of mine who developed complication from HepB but unfortunately he died which really scares me and gives me the fear of death.”

4.6.1.5 Insufficient self-care

It is always good to develop self-principles to follow the guidelines given by the doctor in the administration of the prescribed drugs to circumvent the adverse effects of the condition or progression from the current state to the worse one. Proper self-care was therefore required of the respondents. The sub-theme identified is illustrated below.

4.6.1.5.1 Abandoning the prescribed drugs

Some of the study participants did not take the drugs as prescribed by the doctor which allowed their conditions to worsened. Pat 2 echoed:

“I forgot about this disease thinking that it was for a particular group of people just like HIV which is also for a particular group of people, this gave it a chance to intensify its effect in me to the extent of reaching and damaging my liver. I gave up on treatment for some time.”

Pat 7 said:

“I feel so depressed and disappointed and fail to take my medicine which has led to increase in viral load. I have been admitted to the Intensive Adherence Care Unit twice together with HIV positive patients as if I was one of them.”

4.6.1.6 Post traumatic pain

The effects of the response to the results of the diagnosis can last for a longer period of time which vary from one person to another. These effects can be negative or positive. The study participants exhibited negative traumatic growth which directly affected their quality of life as seen below.

4.6.1.6.1 Hopelessness

The general feeling of losing hope in life and surrendering one’s self to death was identified among the study participants especially those who had the past experience of a relative who suffered from HBV. Pat 7 stated:

“I lost hope immediately in life because at such a young age to acquire this serious killer disease is not what I wished. I began imagining myself being lowered down in the coffin just as my aunt.”

4.6.1.6.2 Frustrations and disappointments

Some study participants were frustrated with themselves that they acquired HBV considering the fact that they lived a responsible life. Pat 2 narrated:

“Basing on how I lived my live, I was puzzled and angry. I was disappointed when I learnt how the disease is transmitted.”

A study participant was frustrated with the way in which she acquired HBV from home as she offered help to the sick relative who had the virus. Her parents had always advised her not to share sharp instruments with others. Pat 7 stated

“I was very sad, disappointed and frustrated in that I got the HepB virus in a way which I have always been told to stay away from – sharing of sharp instruments.”

The study participants expressed frustrations and disappointments with the health workers when they were told from the health facility about their HepB status. They expected to receive information about HepB during the counselling sessions but these were not done.

Pat 6 said:

“I had the feeling that I should take my medication as the doctor was telling me. So, I got disappointed that the doctor did not tell me anything about how I should live.”

Pat 7 shared the frustration as:

“I am a bit frustrated that there was no thorough counselling session carried out after my diagnosis. If this is what is done to everyone who comes for HepB testing, that means people go back without knowing what really HepB is. I am talking about the basic knowledge about HepB like what it is, cause, transmission, signs and symptoms, prevent and treatment.”

Pat 10 lamented:

“How can the health workers fail to take the HepB patients through thorough counselling sessions just like it is done for HIV when someone goes for testing? It is very disappointing.”

The frustrations and disappointments were not only with the health workers, the interviewed respondents further expressed frustrations and disappointments with relatives and friends who deserted them when they learnt that they were HepB positive. Pat 3 said:

“I have not gotten any kind of help from the other relatives be it morally, socially, emotionally and financially. Out of the very many friends whom I had before I fell sick, it is just a handful of friends who have stood by me from the time of I was diagnosed up to now.”

Pat 8 stated:

“In this world, never lay your hope on anyone. Those whom I called them my friends ran away from me and I remained with just a handful of them. Most of my relatives have not yet even visited me in four years now.”

4.6.1.6.3 Financial burden

The feeling of being a burden to the relatives financially was identified among the respondents as they received support to manage their status. This came about as a result of the effects of HBV that weakens the body. Pat 3 narrated:

“Since 2016 I have been travelling to Lacho hospital every after 3 months for control while I am tested for viral load here, all funded by my brother who has lost so many things to support me. He has so far sold his two good pieces of land to finance my transport and buying of drugs. Sometimes I feel I am a very big burden to him.”

Pat 5 further avowed:

“I hate waking up in the morning and just sit like that without doing any work. This makes me sometimes feel that I am a burden to my family and the people around me. There is nothing harder than just eating, sitting and sleeping when you cannot do anything that brings money. Every time I am on the road to the hospital, money is needed which I have to just ask and be given. I feel I have become a child to my people.”

4.6.2 The positive lived experiences of HepB patients receiving healthcare services at Lira Regional Referral Hospital after acquiring the disease

The study participants developed various positive effects of living with HepB which are seen as post-traumatic growth after the diagnosis and coping up strategies. The positive effects helped the study respondents to have a better and improved quality of life with their status.

4.6.2.1 Post-traumatic growth and coping strategies

The study respondents developed different post-traumatic growth after being declared to them that they had the HBV as illustrated below:

4.6.2.1.1 The hope of getting healed

There was acknowledgement of hope of getting healed among the study respondents which gave them the strength to continue with their treatment. Pat 4 affirmed:

“But while still at the hospital, I slowly got the strength to say that no, this is just like having any other diseases which have medicines, I will take the medicines and get well. Diseases are meant to attack humans but can be treated and they disappear. I am positive that I will go through this and get cured.”

Pat 11 said:

“I am unwearingly waiting for that day when the doctor will tell me that you are now healed. I will be the happiest.”

It was also discovered among the study respondents that healing was also rested upon the supernatural existence of God with many of them placing their hopes of getting healed on God.

Pat 1, Pat 2 and Pat 3 stated their believes in that order:

“I told myself that God is the giver of life and He is the one who can take it. I believe in God the creator for the healing. I believe in God the creator for the healing and that one day, I will get out of this condition.”

Pat 5 also said:

“There is no other god, apart from the true God, who can heal anyone from HepB and I believe in one true God, the creator of heaven and earth is the only one who will heal me.”

4.6.2.1.2 Spiritual growth

The study respondents intimated their beliefs in God was hyperactive pertaining the occurrence of HepB as God’s plan in their lives. The believe was that God was the sole planner of their lives and whatever happened in their lives was planned by God and cannot be avoided. Their relationship with God greatly improved as they put their trust on Him for healing and protection. Pat 5 said:

“I believe that I have this disease because of God’s plan, not because I wanted it but it is for a purpose best known to Him. If He has planned something for you, you cannot avoid it by your own strength and He is the one who can cure any kind of disease in this world. And I believe God will cure me.”

Pat 6 reinforced Pat 5 that:

“Everything that happens is always for a reason and God has the answers to every kind of situations. If God has decided you will get cured, you will definitely get cured even at minimal costs and if He has decided that you will die of the condition you will definitely die even if you go the best hospital in the world. I place my hopes in God the Almighty for my healing.”

The feeling of being remorseful was witnessed among the study participants for their sins to be forgiven because of the feeling of dying at any time. Pat 2 said:

“I always pray to God to forgive me of all the sins that I have committed and protect me whenever I am going to bed at night because anytime I can die. Even during day time when I am alone, I ask God for His healing powers upon me.”

Spiritual growth made some study respondents not to worry in life in order to gain strength, avoid demoralization and thus live a life of better quality. Pat 6 itemized:

“Reading bible teaches me God’s word and lets me know what God wants, God does not want us to worry. If God can feed the birds in the air that do not have gardens, then why should a man worry? I do not always want to worry in life. It is not part of me because it demoralises and weakens me.”

Pat 12 said:

“I feel really supported spiritually and I rely on it because when I pray, I do not worry a lot because it makes me belief that God is in charge of my life.”

4.6.2.1.3 Changes in lifestyle

The lifestyles before and after diagnosis were not the same for almost all the study respondents. There were drifts in lifestyles from risky ones like smoking, drinking alcohol, sharing sharp instruments, having many sexual partners among others to the less risky ones in order to improve their quality of life and manage the disease. Pat 1 emphasised:

“I do not share any of my things with others, not even my bed because I want to protect them and I have learnt not to worry but to be happy and engage myself whenever I can in some activities that are not tedious.”

Pat 3 said:

“I no longer smoke; I do not even want to come in to contact with the smoke that come from someone. I now have only one wife whom I am so faithful to and love her so much because if I go out with other women and get another infection like HIV, I will end up dying very fast. I no longer share sharp equipment with others such as razor blades, nail cutters, sewing needles and safety pins among others because I should protect others.”

Pat 4 further noted with a tone of disappointment:

“Though I have fears in exactly what I should be eating because I have not been told from the hospital by the doctors what to eat and not to eat, I do not drink alcohol or smoke cigarette.”

Pat 5 said:

“I have left drinking alcohol ever since I fell sick up to now. I no longer do heavy work at home, not even cooking whenever soot is too much especially when cooking with firewood that is not well dried.”

Upon probing why did you leave taking alcohol? She said:

“I no longer drink alcohol because whenever I take alcohol, I get a lot of pain in my abdomen and I fear it may damage my liver beyond recovery.”

The health-seeking behaviour of the study participants improved greatly after diagnosis. They report to the hospital as scheduled and whenever they feel unwell instead of delaying at home or buying drugs from the local pharmacies and drug shops.

Pat 10 said:

“My visit to the health center has improved a lot. I used not to go to the nearest government health center but now, even when I get only headache, I am already at the center. I should be free of other diseases like malaria for example.”

4.6.2.1.4 Emotional relationship-strengthening

The actions of the relatives towards the patients greatly influenced the emotional strength among them. The acceptance of the disease by the relatives improved the relationship with the patients and gave them the courage and feeling that they were cared for.

Pat 2 asserted:

“I have not had any problem with my wife. In fact, my condition has again strengthened the relationship between me and my wife. She is always there for me.”

Pat 11 said:

“My wife takes very good care of me and ensures that I eat well cooked food prepared by herself. If she is not around, then she instructs my daughter to prepare the food very well and she calls me to find out whether I have eaten in time.”

Some study participants highlighted openness whenever entering in to a relationship with someone to in order to build trust. Pat 7 said:

“Hoh! I should be open to whoever approaches me for a relationship and tell him my HepB status and he also tests to protect him and he also gets to know his status. If he is okay with me then we move on, if he isn't, we don't go any further.”

4.6.2.1.5 Appreciating life

The quality of life of the study respondents greatly improved because they accepted their status and appreciated the kind of life they lived. Appreciating life was a very good coping up strategy that they used in order to live positively as they take their medication diligently. Pat 1 said:

“I accepted that I have this disease in my blood and I should take my drugs as prescribed by the doctor because I was told by the doctor that HepB is a disease which can get cured once you finish your medication. Since I am young and it was not my desire to contract HepB, I believe I still have a future and a life to live and I need to be positive.”

Pat 6 further said:

“I thank God for the life that He has given me. I have accepted that I have HepB and just like any other diseases, there is a cure. One time, I will get cured from this disease.”

Pat 7 reiterated:

“I have accepted my status now and my life is my life and if I lose it, it will be me and not anyone else. So, I must take good care of myself and take my medication.”

The statements of Pat 9 and Pat 12 were in agreement:

“I think HepB could be better than other diseases or eventualities that kill very quickly. You can stay alive for some time with it.”

4.6.2.1.6 Preparing for life after death

Some study participants sobbed when it came to expressing their coping up strategies upon coming in to agreement with their HepB status. Counselling sessions were carried out for those who could not control their emotions. The feeling of death was so immense that they had to begin preparing to leave their families behind when they die with where to live and have a better life.

Pat 2 noted with grieve:

“Right now, whatever I had not done in my life I should now do them. I should ensure I build some house, which I have already started, so that in case I day, my wife and children will have where to stay. I should buy some land for the two boys. You need to prepare your home so that when you are not there, those who remain behind can live a fairly good life. You need to see life of your family without you.”

Some of the study participants opted to comfort, strengthen and prepare their spouses to be ready for any eventuality that may arise. Pat 2 further noted:

“From time to time, I always advice my wife to be strong and be ready for anything because I may die anytime.”

Upon probing why he does what he stated above, he responded as:

“When something happens when you are prepared psychologically, you are not traumatized much and you do not feel the pain so much. You may feel that the deceased has just rested.”

Some of the study participants managed to acquire more assets for their loved ones to use in case they die. Pat 6 stated:

“I have sold another piece of land, out of the remaining two, and bought a bigger piece of land of 8 acres in another sub-county to prepare for my two boys so that in case I happen to die, they can use it.”

4.6.2.1.7 Support

The study respondents confessed to have received different kinds of support which are categorized as financial and non-financial. The non-financial support encompassed physical, spiritual, social, emotional and mental support. These supports changed their perceptions towards helping others. The study respondents were encouraged to adhere to their medication. Pat 4 compounded in his statement:

“People always help me in many ways, whether my relatives or my friends ranging from emotional, social, financial and spiritual support. Someone can come and gives me UGX500 or UGX1000 or just sits with me and we talk and laugh. My wife, brother and sister have always encouraged me to adhere to my treatment regime and they always follow me up to find out whether I am taking my drugs consistently. Some people come and give me very good ideas on how to invest money in small businesses and encourage me to join some groups which are beneficial in the village.”

Pat 7 stated:

“My family has always supported me physically, emotionally and spiritually. My friends gained courage to come to me and they always comfort me that I will get healed of this disease one day. Everyone tells me and encourages me to just take my medicines everyday as the doctor prescribed. They tell me I am not the first and will not be the last and it does not mean that I am going to die of it.”

Much as most of the study respondents received support from relatives and friends, some respondents confessed not to have received any kind of support. Pat 3 recited:

“I have not gotten any kind of help from the other relatives be it morally, socially, emotionally and financially. Out of the very many friends whom I had before I fell sick, it is just a handful of friends who have stood by me from the time of I was diagnosed up to now.”

CHAPTER FIVE: DISCUSSION OF RESULTS

5.1 Introduction

This chapter discusses the findings of the study in relation to other studies conducted by other researchers. Key issues which the study found are discussed in relation to other studies.

5.2 Discussion of the findings

5.2.1 Discovering the socio-cultural experiences of the HepB patients about the disease at Lira Regional Referral Hospital

The study found out that HBV was believed to be contagious due to the belief that it was very easy to be transmitted from an infected person to an uninfected person through sharing of domestic items, sharp instruments and casual handshake and therefore hard to avoid contracting it. This finding was in agreement with the study carried out in Ghana by Adjei and his friends (2019) where study participants described HepB as very contagious that could be easily transmitted through handshake and sharing of food from the same eating utensil. The study participants lived in fear of infecting others thus living isolated lives which in the long run led to self-stigmatization. The finding was further in agreement with a study carried out by Mugisha *et. al.* (2019) in South-Western Uganda which assessed the knowledge and practices with regards to HepB where the study participants considered HepB as easily transmitted through handshakes, and, sharing of eating utensils and public toilets or bathrooms.

The revelation of bad luck to have contracted HBV among the study participants is a belief that results from someone getting a bad ailment from among the many others who do not get it. In Islamabad, the study participants described that being diagnosed with hepatitis B and/ or C was a result of bad luck since they did not know the cause and ways through which HBV or HCV was transmitted (Ranani *et al.*, 2020). The belief of bad luck was registered in different studies in the

development of cancer in cancer patients, among pregnant women on pregnancy and HepB immunization and psychological consequences of chronic hepatitis C (Belizário, 2018; Malik and Hana, 2018; Al-obaid, Roediger and Lisker-melman, 2021).

Pat 5 and Pat 6 revealed that HepB was a very severe and serious disease since the signs and symptoms would not show early enough due to its asymptomatic nature, therefore, having adverse effects on the patients. The belief that HepB is very severe and serious was also registered in the USA in the study of the roles and attitudes of primary care physicians in HepB diagnosis and treatment (Upadhyaya *et al.*, 2015; Hamdiui *et al.*, 2018). The finding among the study participants that perhaps HepB was more severe and serious than HIV matched the findings in a study among the Moroccan-Dutch where other participants considered HepB to be more severe than HIV (Hamdiui *et al.*, 2018).

The belief that HepB was very severe and serious gave birth to another belief that HepB was very deadly which could always result in to the victim dying early even if the victim was put on the right medication. This finding matched the finding of other qualitative studies that were carried out on patients with chronic HepB in Korea, United States of America, Australia and Ghana that the study respondents acknowledged being diagnosed with HepB was more of a confirmation of a sentence to death (Lee *et al.*, 2010; Valizadeh *et al.*, 2016; Freeland *et al.*, 2021). However, much as most of the study respondents conquered with the findings of other scholars in having the belief of death, Pat 2 instead believed that death was a plan of God irrespective of the disease that one had which was not highlighted in any of the scholars' articles reviewed for this research project.

The use of herbal medicine in the treatment of HepB was registered among the study participants. There was a belief that herbal medicines would be able to work better and cheaper than the modern anti-HepB drugs administered at the health facilities which was also reported by Stickel and Schuppan (2007) in their study that most herbalists believed herbs could treat and prevent HepB

infections. Studies carried out in China found out in China that close to 80% of the Chinese who were infected with chronic HepB used herbal medicines either as a complement or as an alternative to the conventional anti-HBV drugs and Xiao Chai Hu Tang herbal medicine was used to reduce the HepB viral load in patients and the herbal medicines were cheaper than the modern drugs (Zheng, Wang and Yang, 2015; Liang *et al.*, 2019).

Additionally, herbal medicine uses also recognised in a study carried out in South Western Uganda on HepB knowledge, experience and beliefs of the community about HepB that herbal medicine was in use where the communities suggested herbal medicine in the management of HepB (Mugisha *et al.*, 2019). However, Pat 2, Pat 5 and Pat 6 expressed disbelief in herbal medicine use in treating HepB that it was not effective and would just worsen the conditions of the patients and lead. This could also contribute to poor health-seeking behaviour. Mugisha *et al.* (2019) found out in their study in Western Uganda that herbal medicine use led to delays seeking scientifically proven interventions from the health facilities.

The socio-cultural belief about HepB vaccination was very negative among the study respondents in that the mass HepB vaccination was meant to make the men docile and women infertile for the government to control the population of the public. This finding agreed with a study carried out in Pakistan which was found that the majority of the individuals in rural areas and urban centres in Pakistan recorded that vaccination programs was intended to make them infertile (Ali, Suhail and Ali, 2018). The authors further found out that the communities perceived that the vaccines meant to make them infertile as a benefit to the government were meant to be provided at no cost at the government owned health facilities.

The study respondents stated that the community believed that the vaccines were unsafe which coincided with the argument that the number of people worldwide who perceived vaccinations unsafe was on the increase which hindered the uptake of the vaccines (Dubé *et al.*, 2013). A study

carried out in Italy and Latin America revealed that study respondents believed that vaccinations were harmful (Cadeddu *et al.*, 2020; Guzman-Holst *et al.*, 2020), which was in line with the socio-cultural beliefs in LRRH about HepB vaccines. However, some of the study respondents had strong positive belief towards the HepB vaccination as Cadeddu *et al.*, (2020) found in their study that half of the study respondents considered the vaccines safe to humans. A section of the study respondents in influenza vaccination also considered the vaccines effective and treasured its benefits (Nagata *et al.*, 2011).

The belief associated with HepB that was linked with the acts of the gods was quite pronounced among the study respondents where some acknowledged actively practicing while some acknowledged witnessing others practicing. Those who actively practiced believed that some ailments were a punishment from the gods. Believing that HepB was a result of punishment from the gods among the study participants matched with the findings of the study carried out by Adjei *et al.* (2019) in Ghana where study participants believed that their sufferings from HepB were a result of the curses from the gods for their wrong doings.

The study further unearthed the belief that the swollen body parts were linked to witchcraft which needed the interventions of the gods where the victims visited the elders, commonly termed as witchdoctors. The finding was commensurate to the findings of Adjei and friends (2017; 2018) about HepB in Ghana that the swollen abdomens and feet because most patients in advanced stages of HepB present with oedema, ascites and jaundice was linked to curses from the gods.

There was a belief that the ancestors could seek for the forgiveness and healings of their descendants from the gods. This finding matched the finding of the study that was carried out among Hmong Americans indicated that the Hmongs made offerings and sought blessings for their families and protection through worshipping and paying respect to their ancestors (Jorgensen *et al.*, 2016). Additionally, communication was maintained by the Shamans between the spiritual

world and the living, and they also determined the cause of sickness and treated illnesses through the performance of ritual ceremonies.

An area of concern that was found in the current study was the cultural practices that were actualized by the communities as described by the study respondents. The study respondents acknowledged that skin cutting activities were carried out by the traditional people to provide cure to strange diseases including HepB where it involved bleeding. This finding was commensurate with the a study carried out in Vietnam which was revealed that 37.5% of the study respondents practiced skin cutting cures as a treatment option to HepB and C (Do *et al.*, 2015).

Communal drinking was found to be a common activity that surrounded cultural activities in the communities. This was done to show an act of sharing where a group of people shared the local brew as they entertained themselves. This cultural practice exposed the participants to acquisition of HBV thus leading to HepB disease. This finding matched the findings of other studies where the communal sharing of drinks was registered in the name of enjoyment and entertainment showing a sense of belonging and friendship which was considered a social problem that led to the spread of different diseases including hepatitis and the outbreak of Hepatitis A whose transmission was escalated by the sharing of KAVA dink using the communal drinking vessel in (Parker, Kurien and Huppatz, 2014; Yang *et al.*, 2016).

The study found out a common perception and belief among the study participants that sharing of bathing, eating and drinking utensils such as basins, towels, plates and cups among others would lead to transmission of HepB from an infected person to a healthy person. In other qualitative studies carried out on HepB, the findings were in agreement with this study's findings where the study participants acknowledged HepB transmission through sharing of such casual sharing of utensils (Mugisha *et al.*, 2019; Rajamoorthy, Mohd, *et al.*, 2019; Ranani *et al.*, 2020). However,

these kind of casual sharing of such utensils or meals do not lead to transmission of HepB from infected individuals to healthy individuals (Costa *et al.*, 2014).

5.2.2 Determining the lived experiences of HepB patients before acquiring the disease at Lira Regional Referral Hospital

This study exposed lack of proper knowledge about HepB in that the level of awareness was very poor because most study respondents only got to know about HepB at a later stage of their disease. This lack of proper knowledge put them at risk of developing Chronic HepB (Seremba *et al.*, 2017). This finding matched the findings of the studies carried out in Ghana and Iran confirmed lack of knowledge about HepB among the study participants where most patients were not aware of HepB as a disease not until they were diagnosed and many people had misperceptions about HepB and yet they were carriers (Adjei, Naab and Donkor, 2017; Ezbarami *et al.*, 2017).

The study revealed lack of knowledge of the cause, means of transmission, signs and symptoms of HepB among the study respondents in that the disease was attributed to using dirty water and coming in to contact with cow dung. A great deal in lack of knowledge on the cause, signs and symptoms was witnessed in Western Uganda, Nigeria and among the Asian-Americans where the study participants expressed that HepB was attributed dirty water or contaminated water from swamps and had no knowledge in the mode of transmission where study participants acknowledged HBV to be transmitted through hugging, handshakes, sharing food, playing in dirty water, sweat and feared using chopsticks (Preston-Thomas *et al.*, 2013; Maglalang *et al.*, 2015; Odimayo, Nwadioha and Utoo, 2015; Mugisha *et al.*, 2019;).

The study however, showed some good knowledge in the mode of transmission of HepB such as having unprotected sex with an infected person, sharing sharp instruments, mother-to-child transmission, coming into contact with body fluids of an infected person among others. This

finding of having good knowledge about mode of transmission of HepB which was commensurate in the findings of the study of the level of awareness of Hepatitis B viral infection among a subset of Makurdi Community in Benue State, Nigeria (Odimayo, Nwadioha and Utoo, 2015).

There were risks of transmitting HBV from infected mothers to healthy traditional birth attendants (TBA) and their newly born babies and TBA to mothers and their newly born children due to attending to the pregnant women giving birth without wearing proper protective gears such as gloves in addition to using unsterilized sharp instruments. Some study respondents confessed to having knowledge of such activities going on in their communities. In a study carried out on HepB and Hepatitis C virus infections among pregnant women in Arab and African countries found out that the infections were closely associated with coming in to contact with infected blood and its products, use of unsterile medical and dental processes, sharing of sharp instruments, intravenous drug abuse and use of traditional practices (Gasim, Murad and Adam, 2013). This route of infection was mainly linked to knowledge and socio-economic factors.

The study found out that majority of the study respondents had at least more than one sexual partner at any one time, shared sharp unsterilized instruments and straws in the local brew joints, body cuttings using unsterilized razor blades, and other practices that deprived their immunity such as sharing of cigarettes and liquor and eating less healthy foods like fatty foods. This indicated that the study respondents lived risky lifestyles which might have exposed them to contracting HBV. Jane *et al.*, (2016) and Oliveira *et al.*, (2016) found out in their different studies that HepB patients lived irresponsibly-risky lives before their diagnosis. Studies carried out in Malaysia, South-Western Uganda and Arak in Iran concurred with the findings where it were found out that the most common behaviours that increased the risk of individuals in acquiring HBV were sharing of nail cutters and syringes, body piercing, alcohol use, undergoing acupuncture and unsafe sexual activity and having multiple sexual partners also increase the risk of getting HepB (Ramezani *et al.*, 2014; Mugisha *et al.*, 2019; Rajamoorthy, Mohd, *et al.*, 2019).

The study revealed that the study participants abandoned treatment at some point in their course of life which was mainly caused by stigma and psychological effects of having HepB which worsened their conditions leading to admissions due to increased viral load and deterioration in the overall health of the patients. However, other studies showed that these were not the only reasons for abandoning treatment, others abandoned due to the adverse effects of mixing treatment with alcohol and marijuana (Vieira-castro, Carlos and Oliveira, 2017) while others abandoned because of financial constraints and deterioration in their conditions (Wang *et al.*, 2014), after obtaining immigration permits in to developed countries (Santilli, 2018), stigmatization (Treloar, Rance and Backmund, 2013) or reduction in drug concentration (Pros and Monfort, 2020).

The study participants confessed to not going to the health facility for a routine health check-up especially when they did feel healthy. They showed no signs of any ill-health even when they were positive of HepB. This could probably be because HepB is an asymptomatic disease that begins to show signs after it has begun damaging parts of the liver, or, there condition was not worrying. In studies carried on in Ghana among HepB positive people and healthcare workers, and, among the African Immigrants in the United States, it was discovered that the HepB positive people could not seek healthcare because of the absence of any clinical signs and symptoms of HepB and they looked well physically which meant their conditions were not severe (Adjei *et al.*, 2019; Freeland *et al.*, 2021;). Failure to visit health facilities for regular health check was a sign of inadequate self-care which could easily lead to chronic illness from HepB (Ezbarami *et al.*, 2017).

5.2.3 Exploring the lived experiences of the HepB patients in living with the disease at Lira Regional Referral Hospital

The lived experiences of the study respondents unearthed both negative and positive outcomes of living with HepB which are discussed in comparison with the outcomes of other studies carried out by other researchers.

5.2.3.1 The negative lived experiences of HepB patients in Lira Regional Referral Hospital, Lira district

The study revealed negative psychological consequences that the study participants faced due to negative attitude of the society towards HepB. The study participants considered living isolated lives due to the fact that HepB was considered as HIV/AIDS due to the fact that they share drugs (Ezbarami *et al.*, 2017). The finding matched the findings of a qualitative study carried out in Ghana on Chronic HepB stigma that there was negative attitude of the society towards HepB and the patients since people often consider HepB to be like HIV/AIDS (Adjei, *et al.*, 2019).

The study respondents further noted that they were removed from some of the social groups that they subscribed to upon disclosing their HepB and chose to live lonely lives. This finding was commensurate with the finding of a qualitative study carried out in Iran on the lived experiences of chronic HepB where some respondents stated that they were always left alone whenever they disclosed their statuses out and some of their friends abandoned them forever (Ezbarami *et al.*, 2017). The fears of transmitting HBV to their loved ones and victimization were so immense which made them to sometimes live lonely lives. A qualitative study carried out in Iran on patients with chronic HepB found out that they had the fear of transmitting HBV to their family members and friends therefore, they isolated themselves and created in them a sense of loneliness (Valizadeh *et al.*, 2016).

The HepB patients in Lira suffered anxiety and depression which manifested through feeling fatigued, grinding of teeth, fast heart beat and failure to sleep, felt sad most of the times, isolated, had constant thoughts about death as a consequence of HepB and sometimes committing suicide which affected their adherence to their medication and low quality of life leading to the feeling of hopelessness. The findings matched the findings of other studies where Hepatitis and HIV patients suffered forms of psychological consequences of carrying the disease such as victimization, fear

of transmitting the disease to others, anxiety and depression which led to disrupted psychological well-being and low quality of life (Hill *et al.*, 2014; Ezbarami *et al.*, 2017; Thi *et al.*, 2019) and attempts or thoughts of committing suicide or committing actual suicide (Sockalingam *et al.*, 2011; Dockry *et al.*, 2014; Lucaciu and Dumitrascu, 2015; Steel *et al.*, 2016; Himwaze *et al.*, 2020).

Some study participants reported feeling sad and disappointed as life went by because they wondered how they could have gotten HepB yet they lived non-risky lifestyles. Pat 2 lived a careful live which, to him, he could not have contracted HepB, which made him sad later on about his condition. These feelings of sadness were in line with the findings of a study carried out in Egypt where patients experienced sadness and disappointments after diagnosis (Metwally *et al.*, 2014).

There was manifestation of dejection in failure to get cured of HepB by the study participants. The failure to get cured from the disease considering the long period that some of them have been undergoing treatment resulted in to frustration and a general feeling that either the drugs were not working, they were not being given the right drugs or the disease does not cure giving a general feeling that it resembled HIV/AIDS that has no cure. A qualitative study in Iran found that some respondents with chronic HepB wondered of their possibilities of getting cured from the disease after their long period of treatment (Valizadeh *et al.*, 2016). A study carried out on “*emerging challenges in managing Hepatitis B in HIV patients*” coincided with the general feelings receiving of the study participants that whereas HepB can be prevented through vaccination, eradication is impossible once acquired making it resemble HIV (Soriano *et al.*, 2015).

Due to the negative attitude of discrimination and stigmatization, some study participants were forced out of the community groups such as the SACCOs because people did not want to sit near them and they were not pick to contribute any ideas to that could strengthen the groups. A study carried out among Vietnamese in Ho Chi Minh City and Chicago found out that social judgement resulted in to rejection, blame and exclusion hence impacting on a person’s self-esteem and socio-

economic status (Dam *et al.*, 2016). Additionally, other studies by Freeland *et al.* (2021) and Mokaya *et al.* (2018) also confirmed that HepB patients could not have health challenges only but also other life prospects that could define life such as interacting with a diverse cross-section of the society, employment, education and access to proper health care.

HepB resulted in to weakened bodies of some of the study participants rendering them incapable of performing certain tasks in their lives which gave them a general feeling of having failed to perform their personal responsibilities and achieve certain desired personal status in their communities thus only waiting for death. These feelings were synonymous with the findings of other studies were participants recorded failing to achieve personal responsibilities and goals and just waiting to die of HepB (Valizadeh *et al.*, 2016; Ezbarami *et al.*, 2017).

The study revealed that the study participants were offered intangible support in form of psychosocial, emotional and spiritual care as well as tangible support in form of food and finance so they could live a better and good quality of life, something which they appreciated so much. In a qualitative study on the lived experiences of HepB chronic patients, the study participants expressed having received support from their loved ones which improved their lives (Ezbarami *et al.*, 2017). However, the study participants expressed some kind of discomfort with the financial support that they always received which made them feel as though they were a financial burden to those who offered help. This finding seemed to be localized as other studies in Iran, Ghana and United States of America did not highlight this finding (Adjei, Naab and Donkor, 2017; Ezbarami *et al.*, 2017; Adjei *et al.*, 2019).

The study revealed a general frustration among the study participants where they felt the medical personnel were not willing to provide them with information about HepB which kept them unknowledgeable about the disease that they were suffering from which left them stigmatized because the medical personnel did not want to be close to them and interact with them. This finding

matched the finding of a study carried out in Pakistan on the experiences of stigma among HepB and C patients that some study respondents reported that the doctors avoided them and did not give them any additional information about their conditions (Rafique, Saqib and Siddiqui, 2014).

The study revealed that the study participants were subjected to stigmatization which made them feel rejected and discriminated within the communities. The study participants often felt their relatives and those whom they called friends did not want to come close to them or offer any kind of help which normally happened upon disclosing their status to others. A qualitative study carried out in Ghana on stigma among chronic HepB people and service providers found out the same scenario among the study respondents where they were avoided as soon as they disclosed their status (Adjei, *et al.*, 2019). Dam *et al.* (2016) carried out a study and found out that stigmatization of HepB patients led to rejection, blame, exclusion, and/or devaluation, which could damage a person's self-esteem thus impacting on socio-economic status.

The feeling of rejection was further witnessed by the study participants by being removed from the social groups like saving groups. Rita, who was an active member of a local financial group in her village, was removed from the organization due to her HepB status. The results of a review study carried out on confronting the stigma of HepB infection indicated that HepB patients were denied some life prospects such as interacting service providers with a diverse cross-section of the society, employment, education and access to proper health care (Mokaya *et al.*, 2018).

The study revealed that the study participants lost their close friends including potential spouses. A good example was Pat 7 who was chucked by her boyfriend whom she had made up her mind to get married to. This happened after disclosing their status to their loved ones due to the attitude that the communities had towards the disease. This finding was in agreement with the finding of a

study carried out in Iran where a study participant indicated that a friend whom he told of the result of the test told him straight that he had HIV and the friend left him forever (Ezbarami *et al.*, 2017).

There was spiritual struggling which was witnessed among the study participants as they struggled to come in to terms with God through remorsefulness and asking God to forgive them for their sins. There was a belief that they could have contracted HepB perhaps as a result of their bad acts before God. The respondents expressed that they were negatively affected by this feeling as they would feel sad and guilty most of the times. The study respondents confessed to be going through painful life everyday of their lives as a result of HepB. This finding was discovered in Iran by Ezbarami *et al.*, (2017) where study respondents felt sorry for their sins before God and negatively affected them.

Whereas positive spiritual beliefs were good for a patient's mental health, spiritual struggles ought to be controlled as negative spiritual beliefs may have an adverse effects on a patient's mental and physical spiritual health due to pain they are going through in their lives (Jones *et al.*, 2015). The spiritual struggling with sins in form of penitence or asking for forgiveness made the HepB patients felt they were being punished for their bad actions and had negative impacts on their well-being. A study carried out on understanding and addressing religious and spiritual struggles in health care found out that spiritual struggles in form of atonement led to poor life and health status of the patients (Abu-Raiya, Pargament and Exline, 2015).

Therefore, HepB patients had a wide range of negative experiences that ranged from stigma, discrimination, failures, spiritual struggling, feeling of hopelessness, feeling of being a burden, frustrations from the health facilities to psychological consequences. Much as they could have tried to live positive lives with the disease, the negative forces interfered with their initiatives and thus lived a life of loneliness, low adherence to treatment and low quality of life.

5.2.3.2 The positive lived experiences of HepB patients in Lira Regional Referral Hospital, Lira district

The study respondents exhibited positive post-traumatic and spiritual growth following their diagnosis with HepB which helped them gain courage to disclose their statuses to their partners hence improving their psychological stream of life. This finding was commensurate with studies among HIV positive patients who revealed their statuses to their partners in USA (Kamen *et al.*, 2016) and in Saudi Arabia on experiences of HIV patients where religiosity and spirituality was used as a way of coping up (Omer, Lovering and Shomrani, 2014).

The study revealed positive changes in the life styles of the study participants from risky before diagnosis to less or non-risky life styles by stopping smoking, drinking alcohol, having multiple sexual partners, practicing unsafe sex, sharing sharp instruments, consuming fatty foods, practiced positive and improved health-seeking behaviour, changed their nutrition and worked on stressful situations. These positive lifestyle changes helped the study participants to live a healthier life with improved quality of life and prohibited development of further complications. Other studies found out that it was very familiar for HepB patients to change from risky life styles to positive life styles which changed their conditions from worse to better (Abu-Raiya, Pargament and Exline, 2015; Adjei, Naab and Donkor, 2017; Adjei, Naab and Donkor, 2017; Ezbarami *et al.*, 2017).

The responses of the study participants intimated a great believe in God the creator which profoundly improved their spiritual growth thus improving their psychological sense about HepB. Pat 5, for example, believed that HepB was a disease which was brought by God and she had no control over it. Pat 6 affirmed that he entirely placed his healing from HepB on God according to his will. A study carried out in Ghana by Adjei and his friends (2017) found out that that most Ghanaians acknowledged God as the sole determinant of the destiny of a person and therefore, whatever came their way was in line with God's plans. The study respondents felt they were close

to God and their relationships with God had improved very well and they depended on Him. This finding was commensurate with other findings in other studies in that the study participants intimated that religiosity increased their closeness with their religious belief (Steel *et al.*, 2016).

The revelation from the study that some of the study participants resorted to reading the bible and preaching to others as a result of believing in God for healing and doing the work of God to improve their relationship corresponded with the findings of the study carried out among the HIV positive patients that spiritual activities such as reading the Qur'an, daily prayers and participating in the pilgrimage to Mecca became a way of getting back to their relationship with Allah (God), and also individuals with HIV/AIDS always reflected on their spirituality after being diagnosed with HIV/AIDS (Abu-Raiya, Pargament and Exline, 2015).

The acknowledgement of a strong hope of getting rid of HepB was very reflective among the study respondents such as Pat 4, Pat 11 gave them the strength and urge to continue with their treatment. God was the supernatural existence who could provide healing to whoever was willing to get healed by taking the right medication. A study carried out in Iran found out that the study participants who were HepB positive had the hope of getting cured which gave them the motivation of continuing with their medication (Ezbarami *et al.*, 2017).

The study respondents confessed to struggling and succeeding to accept their status and denied living a weakened life. They therefore lived a life of denial where they shifted their attention away from HepB to other important and developmental ventures thus helped them to cope with their conditions. In a qualitative study carried out in the Accra Metropolis, Ghana that explored the experiences of HepB people found out that the study respondents lived a life of denial which helped them shift their minds away from the disease to other important and developmental ventures (Adjei, Naab and Donkor, 2017). The study participants took life as normal and took their medicines as advised by the medical personnel and made themselves busy. This finding was in

agreement with the findings of a qualitative study carried out in Malaysia in uncovering the experiences and needs of patients with chronic HepB infection at diagnosis where the study respondents acknowledged keeping themselves busy and not thinking about their condition which helped them cope up very well (Ng *et al.*, 2013)

The study boldly showed the support that the study respondents received from their relatives and friends greatly influenced the emotional relationship among them. This was possible because the relatives and friends first accepted their statuses which gave them the courage and feeling that they were cared for. The spiritual, emotional, social, financial, psychological and mental support accorded to the patients improved their quality of life. A qualitative study carried out in Iran found out that the support offered by the relatives towards HepB patients greatly improved the emotional relationship among them and the study respondents confessed to living a better quality of life (Ezbarami *et al.*, 2017). Some of the study respondents were able to gain courage and disclosed their HepB status to their relatives and friends. This disclosure showed trust and earned them support which improved their quality of life as witnessed in the United States of America among persons living with HIV where emotional support greatly helped the HIV patients who disclosed their conditions to their relatives and friends (Kamen *et al.*, 2016).

Most of the study participants acknowledged and appreciated their lives as could be better than those who were suffering from other dangerous diseases and accepted to live with HepB as they waited for their recoveries. This gave them the strength and the courage to continue with taking their medication as instructed by the medical personnel. Ezbarami *et al.*, (2017) discovered a similar feeling among the study respondents who viewed HepB as a better disease compared to other adverse diseases or occurrences in life.

There was a feeling of remorsefulness to God for the sins committed as many of them thought contracting HepB could have been a form of punishment from God who was the sole giver of life

and healer of any kind of diseases. These feelings made them feel closer to God all the time. A study carried out in Ghana found out that most Ghanaians acknowledged that God was the sole determinant of the destiny of a person and therefore, whatever came their way was in line with God's plans, as, other participants depended on words of encouragement from their spiritual leaders (Adjei, Naab and Donkor, 2017). A study that was carried out among HIV positive patients in Pakistan found out that spiritual activities such as reading the Qur'an, daily prayers and participating in the pilgrimage to Mecca become a way of getting back to their relationship with Allah, and also individuals with HIV/AIDS always reflected on their spirituality after being diagnosed with HIV/AIDS (Abu-Raiya, Pargament and Exline, 2015; Adjei, Naab and Donkor, 2017).

This study identified that one study participant gained the courage and started speaking boldly about her HepB status in order to fight stigma and let the friends and colleagues know about HepB as a disease. This strategy was used in Uganda to fight stigma against HIV/AIDS where by the HIV positive youth came out and talked freely about their statuses and participated in beauty pageants (Aidsfonds, 2017; Mildmay Uganda, 2018; Voice Of America, 2019). However, this was a one peculiar finding as other studies carried out by other scholars in South Western Uganda, United States of America, Iran Ghana among others did not highlight in their work

In a nut shell, besides the negative experiences encountered by the patients, there were positive experiences encountered which ranged from spiritual growth to acceptances, hope of getting rid of the disease, emotional strengthening and self-denial among others. These experiences and strategies helped them cope up with the negative effects of the disease and thus improved their quality of life as they showed strength and resilience to live a positive life.

CHAPTER SIX: CONCLUSION, CONTRIBUTIONS AND RECOMMENDATIONS

6.1 Introduction

This chapter contains the conclusions, contributions to the body of knowledge and recommendations of the study.

6.2 Conclusion

The study also draws conclusion from objective one that the socio-cultural practices carried out in the communities seemed to be detrimental towards the prevention of the spread and treatment of HepB in the community. The practices had the potential to spread the disease and lead to progression of the disease to adverse conditions which would eventually lead to adverse health conditions of the HepB positive people. The socio-cultural practices realized from the study greatly influenced the actions of the patients with regard to prevention and treatment of HBV in the communities.

The study also draws conclusion from objective two that there was poor knowledge and lack of awareness about HepB among the study participants which communicated a bigger problem since they represented their communities. The highly risky behaviours lived before diagnosis as manifested through sharing of sharp instruments, alcoholism, communal drinking and multiple sexual partners among others could easily lead to contracting HBV. The poor health-seeking behaviours among the study respondents, which could have shown a true representation of their general communities where people visit health facilities only when they feel unwell. The combination of poor knowledge and poor health-seeking behaviours depicted a community that knew little or did not know the existence of HepB.

This study further draws conclusion for objective three that in the course of living with HepB, the patients experienced stigma, psychological difficulties and spiritual struggling to live with the

disease which lowered the quality of life and self-esteem of the patients in the communities. Much as the study participants experienced the negative impacts of HepB, their lives were as well positively influenced through post-traumatic growth and coping up with their conditions and support from family members, relatives and friends. The measures that they took played a big role in improving the quality of life and conditions of the patients, prevented progression of the disease to adverse conditions and improved their self-esteem in the community.

6.3 Contributions to the body of knowledge

The study reaffirmed that the lived experiences of HepB patients in Lira Regional Referral Hospital, Lira district were commensurate with the lived experiences documented by other scholars who carried out their lived experiences studies elsewhere. Stigmatization and psychological consequences of having HepB was paramount coupled with poor knowledge about the disease and socio-cultural beliefs about HepB were detrimental to the prevention and treatment of HepB. The positive effects of HepB where the patients looked positively at life and developed coping strategies were able to live better quality of life. However, the study discovered a new finding where some study participants expressed some kind of discomfort with the financial support that they always received which made them feel as though they were a financial burden to those who offered them help. This finding was not identified in the articles reviewed and cited in this research report.

6.3 Recommendations

To the Ministry of Health

The Ministry of health should ensure that the HepB services are brought closer to people. The drugs for HepB should be allocated to lower health facilities such as Health Centre IIIs to minimize the pain that the HepB patients experience on the road as they travel to LRRH to replenish their

drugs. Additionally, other services such as X-ray should be made available to HepB patients at the lower government health facilities to scan and assess the status of the liver and their response to the prescribed medication. Furthermore, the MoH should organise adult vaccination programmes against HepB at government health facilities where negative people in the communities can obtain vaccines and screening services for free and sensitise the public about the availability of the service.

MoH should work together with other agencies such as National Drug Authority to regulate and control the use of herbal medicines in treatment of various ailments including Hepatitis B. MoH should come up with community-based and culturally sensitive education programs to create awareness about HepB and encourage vaccination and good healthcare seeking behaviours. VHTs need to be equipped with good knowledge about HepB and facilitated to create awareness in the communities.

To the policy makers

Policy makers should formulate policies regarding the development, production and dissemination of IEC materials while involving HepB patients to enable passing out information that reflects and responds to the gaps that exists regarding knowledge about HepB and should be culture sensitive. Participatory inquiry activities that involve HepB patients, cultural leaders, immunization policy planners, policy implementers and supervisors and healthcare personnel will ensure that the IEC materials with precise and accurate information about HepB is prepared and distributed to the public.

To the healthcare workers and health promotion practitioners

Health caregivers, non-governmental organizations and other interested bodies should carry out community health education programmes to inform the general public about HepB. The education

programmes should be conducted using simple language for the lay person to comprehend. This can be carried out at worship places, market places, radios, house-to-house visits and use of megaphones. This can provide an avenue where counselling, screening and vaccination against HepB services may easily be brought closer to people. Disseminating knowledge to the public about HepB will not just increase awareness about HepB but also help in fighting stigmatization against HepB patients in their communities.

The health personnel should create enough time for the HepB patients and provide counselling services to HepB patients and whoever visits the health facility for HepB services. During the counselling period, good knowledge on HepB about its nature, cause, signs and symptoms, transmission, prevention, treatment, risk factors and how to live a positive and productive life with HepB can be passed on to the patients. This will ensure that the patients obtain credible and accurate information about HepB and live good quality life.

The health workers should be continuously trained on communication skills to improve on the way they interact with HepB patients and HepB management to equip them with up-to-date information about the disease. This will boost the dissemination of HepB information and ensure that the patients are equipped with the right information about their ailment.

To the religious leaders

There was a great spiritual influence on most of the study participants as confessed by them under spiritual growth. The religious leaders should provide counselling and spiritual nourishment to the HepB patients and encourage every member of their communities to always treat one another with love and visit health facilities for check-ups even when they are feeling well. Since religious leaders are always trusted and whatever they say is believed by their followers, they should encourage everyone to go for HepB screening and vaccinations to avert development of complications.

To the local leaders

The local leaders have the duties in their areas of jurisdiction when it comes to health matters and should ensure that every member of their communities live happily. They should liaise with health workers in organizing community outreaches to ensure that the members of their communities are provided with the right information about HepB. The local leaders should encourage members of their communities to appreciate and accept HepB vaccinations to prevent them from contracting HBV. Furthermore, they should fight discrimination against HepB in their communities by organizing social gatherings that promote unity and peace such as debates, dances, dramas and games where HepB can also be talked about.

Constant speaking about HepB will create more awareness about it. Therefore, local leaders should always talk about the disease whenever there is any gathering, if possible, call any health worker to participate in the gathering and speak about the disease and its preventive measures.

To the NGOs and other interested parties

Non-governmental organizations (COBs and CSOs) and well-wishers should form or organize forums where influential people, champions and HepB patients can come out and speak about the disease just like HIV to raise awareness, fight stigma, empower and build confidence among patients. Beauty pageants have been organized in Uganda where stigmatization is talked about and youths who are HIV positive showcase their talents and mention their successes in living with HIV and are empowered (Aidsfonds, 2017; Mildmay Uganda, 2018; Voice Of America, 2019). This can provide a good avenue for the patients who have successfully suppressed the HBV to come out and speak as champions to inspire others to do screening, vaccination and begin treatment if found positive and help in fighting stigma. The HepB positive people will also be inspired and empowered to visit health facilities as instructed by the healthcare personnel thus improving on their health-seeking behaviour and quality of life.

To the communities

The communities should provide conducive environment for the HepB patients by caring for them and providing them with all the necessary support. This will ensure that the HepB patients do not feel discriminated leading to stigmatization and psychological trauma. The communities should pay attention to seeking health care services from the health facilities near them. This will ensure that they have good health seeking behaviour and detection of any ailment which is still at its early stage.

6.4 Suggestions for further research

The study was carried out on the HepB patients who met the study inclusion criteria for participation. The data obtained from these successful study participants depicted what they experienced in their lives as active HepB patients still on treatment. The study therefore did not obtain data from those who once had the disease and recovered from it after receiving treatment due to their unavailability. The available data showed high rate of dropping out of medication either because the patients abandoned medication, died, moved to another area or changed health facility (LDHIS, 08 July 2019). This study therefore suggests that a study should be carried out to include those who will have recovered from HepB to obtain credible information on the experiences after recovery.

Another study can be carried out on those who were ones enrolled for treatment but dropped to provide detail information on the cause and come out with possible remedies to the factors that made them drop out of treatment.

A different study is further recommended to assess the failure of individuals to finish their three doses of HepB vaccines. This can help in bringing out the real reasons as to why HepB vaccines

uptake was low and the possible workable solutions to help fight the virus. Another study of importance could be assessing the access to treatment by the HepB chronic patients.

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Appendix I: Interview guide

- i. How did you come to know about Hepatitis B?
(Yin icako ngeyo ni ngo two Hepatitis B?)
- ii. What do you say Hepatitis B is? (PPat 11g questions on the perception about cause, means of transmission, signs and symptoms and severity)?
(Yin ikobo ni two Hepatitis B obedo ngo?)
- iii. What is your view on the ways of Hepatitis B prevention (pPat 11g questions on personal perception on vaccination)?
(Yin itami ni ngo i yore me ogengo kede two Hepatitis B? Aporere obedo agwera.)
- iv. What motivated you to go for Hepatitis B test?
(Ngo ame omi iwoto me pimere pi two Hepatitis B?)
- v. Did you tell anyone that you were going for HepB testing? (Probe for the fears of telling someone the intention of going for testing).
(Ibin ikobi ngatoro ni onwongo iwot me pimere pi two Hepatitis B)
- vi. What did the doctor/ nurse tell you when you went to the hospital for the test? (Probe for whether the counselling session was conducted or not, whether he/she was told about what HepB is, its cause, transmission, treatment, preventive measures, risky behaviours and lifestyle changes).
(Dakatal obin okobi ngo ikare ame i woto i ot yat adit me pimere pi two HepB?)
- vii. How did you use to interact with your friends and loved ones before diagnosis? How about now? (Probe for the risky lifestyles/behaviours and social life that could have led them to contracting HepB such as alcohol and drug abuse which led them in to unprotected sex, sharing of unsterilized sharp instruments, having many sexual partners among others. After diagnosis, probe for the positive and negative changes in lifestyle).

(Yin onwongo ibedo ni kede jo ni ngo ikare ame onwongo pwod pe ingeo ni itye ke kudi me HepB ikomi? Aman dong ibedo kede jo ni ngo iyo nge ngeyo ni itye kede kudi ni?)

- viii. What activities in your culture involve the use and sharing of sharp instruments like razor blades, needles, knives among others? Do you think these cultural activities contribute to the transmission of HepB in your community? (PPat 11g for the unsafe cultural practices with respect to HepB).

(Kodi kwera mene atye i te kaka wu ame mito jami abit acalo lyedi, picu kede pala, iyi akina jami okene abit dong? Yin itamo ni kodi kwera ni konyo a kobo atwo HepB iyi akino dano?)

- ix. May you describe what your cultural leaders say about HepB prevention. (Probe for cultural leaders' and their own opinion on vaccination and other preventive measures).

(Iromo kong tito ngo ame otela me tetwaro ni kobo ikom yore me gengo two HepB acalo agwera.)

- x. Do you think HepB can be treated and cured using other medicines apart from those given from the hospitals or other practices than visiting hospitals? Why do you think so? (Probe for the use of herbal medicines and superstitions).

(Yin itamo ni two HepB romo cangere iyore ame pat kede yore me dakatal? Acalo wot iot jok onyo tic kede yen me tetwaro.)

- xi. May you describe what your expectations were when you went to the hospital for HepB testing.

(Kong ikoba kong ngo ame onwongo itye igeno ame iwoto iot yat me pimere pi two HepB.)

- xii. May you please describe your feelings after the nurse/doctor declared the result of diagnosis to you. What came first in to your mind? (Probe for sadness, self-denial, hopelessness and frustration in life and the positive feelings after counselling session).

(Kong ikoba kong kit ame cwinyi owinyo kede iyonge dakatal ikobe adogi me apima ni.
Ngo ame obino iwi nama acel?)

- xiii. How did you disclose to anyone about your HepB status after testing and what were the reactions?

(Ibin ikobi jo ni ngo i yonge pimere ite nwongo ni itye kede kudi me HepB iremo ni?
Obin otimo gini ngo onyo okobo gini ngo?)

- xiv. May you please describe your social life and your marriage after diagnosis? (Probe for the negative and positive effects of being a patient of HepB).

(Kong ipora kong kite ame kwo ni kede jo tye kede medo kede iyi akino yin kede dako ni cakere iyonge pimere pi kwidi HepB?)

- xv. May you describe how HepB has impacted on your economic life? (Probe for the positive and negative changes in personal and family expenses: food, transport, treatment and basic requirements expenses)

(Kong ikob kong kit ame two HepB oloko kede kwo ni akwako kite me tic kede cente me yi cayo ni.)

- xvi. How have your friends and family supported you ever since you declared to them your HepB status?

(Yore mene ame owote ni kede jo odi ocung kedi cakere ikare ame ikobi gi ni itye kede two HepB?)

- xvii. How have you been able to cope with living with HepB? (Probe for all possible coping strategies in use by the participant)

(Yore ango ame ityo kede me ye me kwoyo kwo ame nwongo itye keded Kwidi two HepB?)

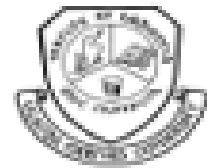
xviii. May you please describe the challenges which we have not talked about. (Probe for other challenges which have not been identified anywhere in the literature, but could be localised).

(Iromo kong kobo peko ame dano atye atwoyo two HepB tye kede ame wan pe oloko onyo okobo?)

xix. What do you think can be done to improve your life? (PPat 11g for individual's thoughts on ways through which the lives of HepB patients can be made better).

(Yin itamo ni ngo myero otim me miyo kwo adano atye kede two HepB bedo ayot?)

Appendix II: Introduction letter from Uganda Martyrs University – Rubaga Campus and Lira Regional Referral Hospital Approval



Making a difference

Faculty of Health Sciences
Email: health@unma.ac.ug

26th June, 2020

To Whom It May Concern

RE: INTRODUCING AKEJO DENIS SMITH

This is to introduce to you **MR. AKEJO DENIS SMITH, No. 2018-M282-20001**, a postgraduate student at the Faculty of Health Sciences, Uganda Martyrs University. He is pursuing a Masters of Public Health- Health Promotion degree. He is currently working on his research project;

"LIVED EXPERIENCES OF HEPATITIS B PATIENTS IN LIRA HOSPITAL, LIRA DISTRICT"

The topic and protocol have been approved by the relevant university authorities. Any assistance rendered to him in this respect will be highly appreciated by the university.

Yours sincerely,

A handwritten signature in blue ink, appearing to read 'Mathias Lwanga'.

Mr. Mathias ~~Lwanga~~

Associate Dean,

Faculty of Health Sciences,

Uganda Martyrs University

Appendix III: Approval by Lira Regional Referral Hospital to conduct the research



Uganda
CD&RT
University



Dr. Mark Okuni, PSE
handle.
15/07/2020



Making a difference

Faculty of Health Sciences
Email: health@umu.ac.ug

26th June, 2020

To Whom It May Concern

RE: INTRODUCING AKEJO DENIS SMITH

This is to introduce to you MR.AKEJO DENIS SMITH. No.2018-M282-20001, a postgraduate student at the Faculty of Health Sciences, Uganda Martyrs University. He is pursuing a Masters of Public Health- Health Promotion degree. He is currently working on his research project;

“LIVED EXPERIENCES OF HEPATITIS B PATIENTS IN LIRA HOSPITAL, LIRA DISTRICT”

The topic and protocol have been approved by the relevant university authorities. Any assistance rendered to him in this respect will be highly appreciated by the university.

Yours sincerely,

Mr. Mathias Lwenge
Associate Dean,
Faculty of Health Sciences,
Uganda Martyrs University



Approved
for data collection
at LIRA
Dr. Mark Okuni

Uganda Martyrs University P.O. Box 548 - Kampala - Uganda

Tel: (+256)011-10611 Fax: (+256)011-10100 Email: umu@umu.ac.ug

Appendix IV: Recruitment Material

Dear Madam/Sir,

My name is Akejo Denis Smith. I am a student of Uganda Martyrs University pursuing a Master's Degree in Public Health – Health Promotion. I am carrying out a qualitative research study on the lived experiences Hepatitis B patients in Lira Regional Referral Hospital, as part of the requirements for the award of the Master's degree.

Uganda has a high prevalence of Hepatitis B at 10%. Worse of all, 9 out of every 10 people do not know their Hepatitis B status which makes it a big burden both politically and socially. Northern Uganda is known to be endemic to Hepatitis B with the prevalence at 4.6%. The Ministry of Health earmarked Lango Sub-region for mass Hepatitis B vaccination in 2015 because it was one of the hardly hit districts in Northern Uganda. Lira district alone has a prevalence of 5.56%. Lira Regional Referral Hospital was identified as a treatment centre in the Mid North. Studies carried out in other countries have shown that Hepatitis B patients experience a lot of psychological and social treatments in their communities which somehow lower the quality of life of the patients. However, there is no study that has ever been carried out to understand the experiences the Hepatitis B patients in Lira district. This letter is therefore, addressed to you as the lead healthcare services provider in Lira district with respect to Hepatitis B.

The main objective of the study is therefore to understand better the lived experiences of the Hepatitis B patients attending care at Lira Regional Referral Hospital. There is therefore a need to carry out this research among the Hepatitis B patients to help design the health and social services that will best meet the unique needs of the Hepatitis B patients to improve their quality of life. This study will therefore be the first study focussing on the lived experiences of the Hepatitis B patients in Lira district.

I would like to recruit approximately 12 Hepatitis B patients who will be willing to participate in the study. There will be an in-depth interview; either in English or Luo, between me and the willing

participants where every participant's contribution and identity will be kept confidential. The participants' names will not be disclosed in the interviews, instead, each participant will be given a code to be used. Any participant who breaks down during the interview will be comforted by means of counselling. They will not be forced to answer any question that they may feel they do not want to answer. All information obtained will be treated confidential and any publication that will come after this study will have to protect the participant's confidentiality. I can organize for a meeting with you to explain to you more about this study.

I will be so grateful for the help that you will provide to accomplish this study to better understand the lived experiences of Hepatitis B patients attending healthcare at Lira Regional Referral Hospital in Lira district.

Thank you in advance.

Yours faithfully,

Akejo Denis Smith

Principal investigator

Uganda Martyrs University – Nkozi, Rubaga Campus.

denis.akejo@stud.umu.ac.ug/adenissmith@gmail.com

0774786801/0752786801

Margaret Joy Nalubega

The University Supervisor

Uganda Martyrs University – Nkozi, Rubaga Campus.

mjoynalubega@gmail.com

0772399605

Appendix V: Recruitment demographics and residential data

Study: A phenomenological study of the lived experiences of Hepatitis B patients at Lira Regional Referral Hospital in Lira district.

Name of Informant/Participant: _____

Participant's/informant's code: _____

Date Collected: _____

Age: _____

Gender: _____

Village/Cell/Zone/Ward: _____

Parish: _____

Sub-County/Division: _____

County/Municipality/City: _____

Marital Status: _____

Religion: _____

Education Level: _____

Occupation: _____

Any other information: _____

Appendix VI: Informed consent

Dear participant, my name is Akejo Denis Smith, a student of Uganda Martyrs University, pursuing a Master's degree of Public Health majoring in Health Promotion. I am conducting a research on Lived Experiences of Hepatitis B patients in Lira Regional Referral Hospital, Lira district. This letter is therefore, to invite you to participate in this study. You will be free to participate and withdraw from the without any penalty. Your identity will not be required and will not be used in the production of the report. At the course of the interview, feel free to ask any question that you may be having. You will not be forced to answer any question that will not be convenient to you. The interview will last for about 40 to 60 minutes.

For any inquiry about this study, feel free to contact my supervisor on 0772399605 or email mjoynalubega@gmail.com.

Study Title: Lived experiences of Hepatitis B patients at Lira Regional Referral Hospital in Lira district.

Declaration

I, _____ have read/ had the letter of information describing the study and I have understood the topic and objectives of the study and my role in it. The questions that I asked have been answered. I therefore consent to participate in this study.

Participant's name: _____ Code: _____

Signature: _____ Date: _____

Statement of principal investigator's responsibility

I have explained the purpose and the nature of the research study, the procedures and considerations to be under taken. I have offered to answer any questions that may be raised during the interviews. I believe the participants have understood the intent of the research and has offered to participate at free will.

Principal investigator's signature: _____ Date: _____

Appendix VII: Invitation letter

Dear sir/madam

Re: Invitation to the participate in the study of the Lived Experiences of Hepatitis B patients in Lira Regional Referral Hospital

Following your acceptance to participate in the above study, you are hereby invited for the interview which will take place on of 2020 at from am/pm.

Your presence will be very much appreciated.

Yours faithfully

Denis Smith Akejo

Principal investigator

Uganda Martyrs University – Nkozi, Rubaga Campus.

denis.akejo@stud.umu.ac.ug/adenissmith@gmail.com

0774786801/0752786801

Margaret Joy Nalubega

The University Supervisor

Uganda Martyrs University – Nkozi, Rubaga Campus.

mjoynalubega@gmail.com

0772399605

Appendix VIII: (A) Map of Uganda showing the location of Lira District where LRRH is situated, (B) the map showing the location of districts making up Lango Sub-region, and (C) the map showing the surrounding districts of Lango Sub-region



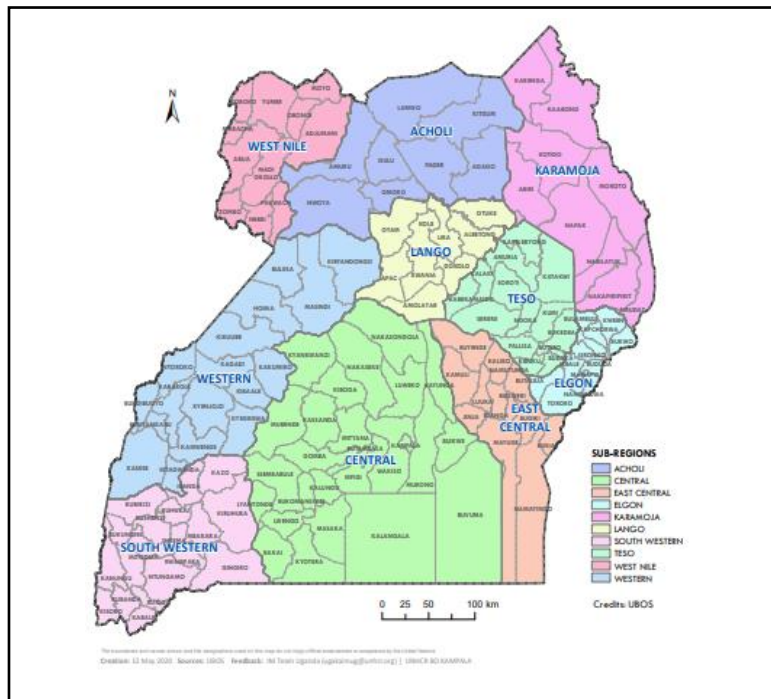
A. Source:

https://en.wikipedia.org/wiki/Lira_District



C. Source:

<https://reliefweb.int/sites/reliefweb.int/files/resources/76380.pdf>



B. Source:

<https://reliefweb.int/sites/reliefweb.int/files/resources/76380.pdf>

Appendix VIX: The budget

No	Particular	Quantity	Amount	Total Amount
1	Preparation			
	Site preliminary visit - Bus	2 trips	80,000	160,000
	Interview guide translation & proof reading	1 set	30,000	30,000
	Research tool pretest	3 tests	30,000	90,000
	Interview room reservation and preparation	1 room	10,000	10,000
	Audio tape recorder	1 pc	180,000	180,000
	Laptop (Acer)	1pc	1,350,000	1,350,000
	Memory card - 32 gigabytes	1pc	35,000	35,000
	Flash disk - 32 gigabytes	1pc	25,000	25,000
2	Transport			
	Bus	6 trips	80,000	480,000
	Boda boda	Block	50,000	50,000
3	Stationery			
	Printing papers	1 ream	20,000	20,000
	Pens	10 pcs	500	5,000
	Note book	1 pc	3,500	3,500
	Clip board	1 pc	4,500	4,500
4	Printing and photocopying			
	Attachments (Consent forms, research tool, recruitment materials and introductory letters)		33,200	33,200
5	Communication			
	Airtime		30,000	30,000
	Internet		15,000	15,000
6	Meals and refreshments			
	Breakfast	14 days	3,000	42,000
	Lunch	14 days	7,000	70,000
	Refreshment	12 people	3,000	36,000
7	Binding			
	Hard cover binding	4	15,000	60,000
8	Covid19			
	Nose mask	1 box	20,000	20,000
	Alcohol-based hand sanitizer	1 liter	45,000	45,000
9	Miscellaneous			
			100,000	100,000
	Grand Total			2,872,800

Justification of the budget

The prices of the different particulars were in Ugandan currency (Ugandan shillings). The cost of a two-way trip to Lira Regional Referral hospital was 40,000/=, there were a total of 8 trips. The were movements from my place of residence and of some study participants which was bargained at a block figure of 50,000/= for the entire period of data collection.

A realm of printing papers, 10 pens, one note book and one clip board were required for printing and taking field notes during data collection at 20,000/=, 500/=, 3,500/= and 4,500/= respectively.

The interview guide was translated and proof read at 30,000/= and 3 pretests were done at 10,000 each in a room which was hired at 10,000/= that included the data collection period too.

Printing each interview guide of four pages; introductory letter, approval letter, demographic data, informed consent form and invitation letter of one page each and recruitment material of two pages were at 300/= per page to be photocopied. The interview guide of four pages; introductory letter, approval letter, demographic data, informed consent form and invitation letter of one page each and recruitment material of two pages were photocopied at 200/= per page.

Breakfast and lunch for the PI were at 3000/= and 7000/= respectively for 14 days. Refreshment for all 12 eligible participants that finished the interview was 3,000/= per participant.

To comply with the standard operating procedures of the MoH against Covid19, 1 box of disposable nose mask made by Nityl and 1 liter of an alcohol-based hand sanitizer were procured at 30,000 and 40,000/= respectively.

Hard cover binding of four copies of reports for dissemination were budgeted at 15,000/= each.

Appendix X: The Gantt chart

Activity	Jun- Jul 2019	Aug -19	Sept. 2019	Nov. 2019	Dec. 2019 - Mar. 2020	Apr- 20	Aug - Nov 2020	Nov. 2020 - Mar. 2021	April - Oct. 2021	Mar. 2022
Selecting topic										
Literature reviewing and research gap(s) identification										
Presenting concept framework										
Establishing Research Supervision										
Proposal writing and handing in										
Obtain introduction letter for data collection										
Pre-test and data Collection										
Analysis of results										
Results writing										
Report drafting										
Writing final report and hand in										
Oral defence										
Handing in the final dissertation book.										