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Perceived Supportive Care Needs of Adolescents With Chronic Hepatitis B in a Resource-limited Setting

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Abstract

In Ghana, adolescents are disproportionately affected by hepatitis B. However, studies into adolescents' supportive care needs are lacking. The purpose of this exploratory qualitative study was to explore the supportive care needs of 18 adolescents with chronic hepatitis B who were receiving care at a tertiary hospital in Ghana. The data were processed using QSR Nvivo version 11.0 and analyzed using the Braun and Clarke procedure for thematic data analysis. According to the findings, adolescents with chronic hepatitis B have unmet supportive care needs ranging from information to financial need, psychological support, and social support. Explicitly, participants reportedly had a dilemma as to whether to keep or terminate their pregnancy to prevent transmission of the virus to their newborns. Physicians and nurses were perceived to be preoccupied with medication prescription and laboratory request writing rather than giving pretest and posttest counseling following diagnosis. This study highlights the need to have a tailor-made liver care for adolescents. Pretest and posttest counseling for adolescents with hepatitis B are also required.

Keywords

hepatitis B, adolescents, perceived supportive care need, Ghana

Introduction

Hepatitis B viral (HBV) infection is endemic in Ghana (1,–3). The distribution of HBV in Ghana is uneven in terms of age (2,3). Estimation from a recent review shows that about 14.3% of Ghanaian adolescents live with chronic hepatitis B (2). This is unsurprising considering that adolescence is marked by dangerous behaviors such as sexual exploitation, tattoos, and a reduced perception of illness (4).

People with hepatitis B (PWHB), including adolescents face enormous challenges in many locales, including Ghana (5,–10). For example, high cost of hepatitis B treatment, inadequate education from healthcare providers (HCPs), and unmet expectations of formal care were some of the challenges reported by PWHB in Ghana and Cameroon (11,12). Conceptually, supportive care need comprises emotional, social, practical, informational, physical, and spiritual needs (10). Although Valery and colleagues (10) review paper presents unmet supportive care needs of patients with liver diseases more broadly, it is unclear how these findings can be generalized to adolescents with hepatitis B in Ghana. According to the World Health Organization (13), effective intervention capable of addressing hepatitis B can best be realized when tailored to meet the needs of the target population. Although current therapies for chronic hepatitis B are focused on long-term medical care (14), we add to the discussion that adolescent supportive care may influence how successfully they manage their disease in adulthood (15,16).

In Ghana, studies on adolescents with hepatitis B perceived needs are lacking. Previous studies primarily focused on hepatitis B testing, serostatus disclosure, and barriers to treatment and care among adults with hepatitis B

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(11,17,18). Given the unique characteristics of adolescents, this study sought to document their supportive care needs to assist with program planning and policy formulation.

Methods

Study Design and Setting

An exploratory qualitative design was employed given that little is known about the phenomenon in Ghana. The study was conducted in the Ashanti region. The region has one of the largest teaching hospitals (ie, Komfo Anokye Teaching Hospital). The hospital runs a liver clinic and serves as a referral center as well.

Participants and Recruitment

Eighteen adolescents (10-19 years) with a documented diagnosis of chronic hepatitis B by a physician/liver specialist and hepatitis B profile results were included. Only 2 of the participants were below the age of 18 years and therefore parental consent and child assent were sought. The recruitment of the participant was supported by the nurses in the unit. In total, 25 participants were contacted but only 18 agreed to participate. For those who refused to participate cited reasons such as time constraints due to academic demand and examination. For others, their parents refused to allow them to participate, claiming that the children (under the age of 15 years) were too young to be discussing their health conditions.

Data Collection

We purposively selected participants who met the inclusion criteria. Data were collected through face-to-face interview using a semi-structured interview guide. The guide was developed based on literature (11,17). Questions asked included but were not limited to (1) how the diagnosis of hepatitis B has affected the participants' lives, (2) the kind of support and care they need and whether those needs are met, (3) difficulties they face in accessing care, and (4) what would make it easier for them to access formal healthcare. The guide was pilot tested using 2 adolescents with hepatitis B. Potential participants were either contacted directly or through their legal guardians by a nurse at the liver clinic. Those who agreed to participate were given specific information on the purpose of the study, confidentiality and privacy arrangements, and rights to withdraw as a participant. Two of the participants were interviewed in the presence of their parent/guardian. The first author (LK) who is experienced in qualitative interviewing facilitated all the interviews in an enclosed nurses' station in the hospital. Each interview lasted between 45 min and 1 h. Data were collected between May and June 2019.

Data Processing and Analyses

QSR Nvivo version 11.0 was used to process the data. Braun and Clarke (19) procedure for thematic analyses was followed. The flexibility associated with the use of thematic analyses in understanding broader constructs as well as peoples' experiences informed its adoption. The audio record interviews were transcribed verbatim. All the transcripts were coded by LA and CAA, followed by discussions of the codes and generation of major themes by the 2 authors. Discussion continued until consensus was reached. The transcripts were shared with 2 participants to establish whether the content reflected their views.

Results

Demographic Characteristics

Overall, 18 participants were recruited. Seven were males and 11 were females. Majority were aged between 18 and 19 years with the exception of 2 who were 16 and 17 years old. Almost all the participants were single except one. Fifteen out of the 18 participants were students. The participants had been diagnosed through one of the following means: physician-initiated testing, blood donation procedure, and outreach screening services.

Psychological Support Need

Participants indicated that being diagnosed with hepatitis B caused a variety of psychological problems, including sadness, worry, confusion about the source of infection, and potential complications. Although participants viewed pretest and posttest counseling as a key component of hepatitis B care, these services were reported to be either absent or insufficient in the hospital. They expected the HCPs to provide counseling based on their needs, but this did not occur.

> "Living with hepatitis B virus is very worrisome. I often feel so disturb because I cannot understand why a small girl like me would be burden with this deadly disease. I initially thought that the hospital could be a source of hope, but it seems to me that little support can be receive from here." (PWHB 18)

Others felt that a comprehensive counseling about the cause of hepatitis B, and available treatment are missing in the formal care.

> "Not much information on the cause, how to prevent our families from the disease, and treatment options are adequately shared with us here. So, we end up having a lot of unanswered questions in our mind regarding the disease." (PWHB11)

Words of encouragement from HCPs, according to the participants, will be beneficial in dealing with the emotional and psychological suffering they experience. Some participants ostensibly indicated that the attitude of the HCPs is equally essential. A therapeutic smile from the nurses, in particular, was a request that resonated with the majority of the participants.

> "Encouragement from the doctors and the nurses would do. At least tell me that there is still hope." (PWHB 3)

> "In the hospital, I think if they attend to my needs, counsel me and encourage me I will be okay. I will not think so much about the disease. Sadly, this is not happening" [R12]

> "I think that how you talk to the person can even yield positive result than the medicine given. Reassure the person that everything will be okay. For me, that's all I will like to hear to have peace of mind." (PWHB 11)

Hepatitis B Informational Need

The majority of the participants indicated that information on hepatitis B is very much needed. According to them, clinicians are frequently concerned with giving drugs, while other important hepatitis B information is largely overlooked. Some of the participants explicitly indicated their needs. They were particular about the effect of the medication and the expected outcome.

> "The only thing they (physician) will tell you is that take your drugs appropriately. Take your drugs on time, that's all they say. Apart from that they don't do anything." PWHB 15)

> "They should tell me if the medications are working. If my disease is resolving or not. When I go to conduct a new test, I should be told if the virus is reducing or going up. You should counsel me on the condition all the time so I can have a peace of mind." (PWHB 5)

One pregnant adolescent, in particular, stated that she was unsure whether to keep or abort her pregnancy due to a lack of information. According to her, she required information to inform her decision-making process, but none of the providers provided it. She narrates her dilemma,

> "I worry about the fact that the disease might affect my pregnancy. I always feel that if I have the baby, he or she might get infected or might fall sick easily. Right now, I don't even know what to do, either to keep the pregnancy or terminate it. I need information on that. The doctor didn't tell me how my baby will be affected, an information that I desperately need now." (PWHB 12)

Another worrying situation outlined by a Number of the participants is inconsistencies in hepatitis B related information. Some participants said there were multiple conflicting views about hepatitis B making it difficult to trust the sources.

> "Everyone has a different thing to say about hepatitis B. Some say there is treatment. Others say there is no treatment. You don't know what to believe." (PWHB 5)

> "When I found out I have the disease I googled on my phone. But then what the internet told me was not what the doctors told me. I thought I will take some antiviral drug but that is not what happened. I have been doing lab upon labs, yet no treatment." (PWHB 16)

Specialized Clinic for Adolescents With Hepatitis B

Having a specialized hepatitis clinic for adolescents with hepatitis B, according to all participants, can improve their care and possibly their quality of life. The majority indicated a preference for a separate clinic from their adult counterparts at the hospital.

> "I feel very uncomfortable when I visit the clinic. I don't like waiting for the doctor among the adults. Sometimes when we are waiting, I am always the only adolescent among them." (PWHB 7)

> "In fact, a special clinic for us would have been nicer and more resourceful since we can learn from others experiences anytime, we meet here together." (PWHB 11)

Others stated that the absence of specialized care for adolescents frequently keeps them in the clinic for an extended amount of time. In some instances, some of the adolescent forfeit classes in order to attend to liver clinic sessions. They said the considerable wait time interferes with their academic work because the clinic is held on a weekday while school is in session.

> "I mostly leave school a day to my review and return to school a day after my review due to the long waiting time at the clinic. I am sure that a separate day for only adolescents can reduce the time we spend at the clinic. Honestly, absenting myself three continuous days sometimes from school to attend clinic affect my learning and performance." (PWHB 6)

Some participants requested that online appointment schedules be implemented to ease the long queues that exist in the hospital to reduce the long wait times. Others suggested a follow-up system in which patients would be reminded of their appointment dates.

> "If they (management of the hospital) could do digitalization of services such as online appointment booking, it will cut off some of the issue we face here. Picking folders, moving around with it and so on will all ceased. They can also create a website, so you go there and book before you come to the hospital." (PWHB 17)

> "To me someone should call and find out anytime we are unable to come for check-up. There were times I did not go

> for check up for a long time, but no one contacted me to find out why I haven't been to the clinic for some time now." (PWHB 9)

Financial Sustenance

Several participants indicated the need for financial assistance. The cost of laboratory tests and drugs was stated to be extremely expensive for their parents and guardians. They said that the situation may be improved if the costs of drugs and laboratory tests were subsidized by the government or covered by the national health insurance program for subscribers.

> "Well for now it's the labs that is killing us. When you are going to run the test, they say NHIS (National Health Insurance Scheme) doesn't cover. The most expensive test is the viral load. Most people are unable to do it including myself. Government has to add it to the NHIS or subsidise the cost to make it easily affordable." (PWHB 1)

> "I think if the labs and medications go on the NHIS, it will be very helpful." (PWHB 5)

Because of the financial burden related to their HBV care and treatment, some participants stated that their parents are unable to satisfy other needs that they deem more important. Others stated that their parents frequently complain about the debts they have incurred as a result of their medical care whenever they want money for other essential items.

> "My parents have incurred a lot of debt. I sometime feel that they could have used that money for something else but because of this disease it's all gone into hospital visits. Sometimes because of the money she is spending, whenever I ask of money from her to do other things, she complains a lot and hardly gives it to me." (PWHB 6)

Given the significant expense of hepatitis B clinical monitoring and care, some participants proposed that the government cover the entire cost of treatment, as it does for those with other related conditions such as tuberculosis.

> "You see like it's done for the TB people where they get their drugs for free, same should be done for us. They are too expensive." (PWHB 8)

Hepatitis Support Group

A support group was highlighted as a critical need by several of the participants. Patient groups were viewed as a vital venue for PWHB to share their experiences, learn from one another, and create relationships.

> "For me meeting other people of my age with the disease will really be helpful. We will share experiences and build solid relationships and learn from each other experiences." (PWHB 3)

> "I think when we meet, we can share ideas and experiences. You will also be encouraged since you see people your age having the condition. You know you are not the only one." (PWHB 2)

Others further emphasized the importance of a support group by stating that it would act as a source of encouragement.

> "Yeah. I think it (support group) would help. At least you will have testimonies from other people to encourage you." (PWHB 8)

Discussion

This study provides insight into the supportive care needs of adolescents with chronic hepatitis B in Ghana. The findings show that adolescents with chronic hepatitis B have unmet supportive care needs ranging from information to financial need, psychological support, and social support.

We discovered that participants require informational support due to knowledge gaps regarding hepatitis B. Almost all participants expressed a desire for additional information regarding hepatitis B management and what to expect throughout treatment. Inadequate hepatitis B information has been documented in earlier research in Ghana and Cameroon, where patients with hepatitis B reported receiving little or no information regarding the disease prior to and following diagnosis (6,12). Similar findings have been reported in Canada, indicating that adolescents with chronic diseases require clear, straightforward information regarding their diagnosis and treatment (20).

Despite the fact that participants in this study had received medical support from clinicians, they felt that physicians and nurses were more concerned with prescribing drugs and writing laboratory requests than with offering pretest and posttest counseling following diagnosis. This same concern about physicians who attend to patients with hepatitis B has been noted in other jurisdictions (21). Further, nurses were seen not to play substantial roles in patient support in this study. The finding is, however, in contrast to research from other continents where there are different healthcare systems and greater investment in patient support (22,23). For example, Brunings et al. (22) reported that nurses in British Columbia give supportive care to patients with chronic liver disease. It is therefore important that Ghana invests in the additional nursing capacity as well as specialized hepatitis B patient care.

Furthermore, the study revealed that financial assistance is essential to properly manage chronic hepatitis B in adolescents. The most prominent sources of financial assistance cited by participants were NHIS coverage of the cost of hepatitis B medications and laboratory investigations. The study findings are consistent with those of Lemoine and Thursz (24), who concluded that the care of people with chronic hepatitis B in the African region is characterized by costly laboratory tests and medicines. As a result, it is proposed that the government of Ghana bear and/or subsidize the expense of hepatitis B diagnosis, treatment, and support.

The study's findings should be viewed with some strengths and limitations. This is the first study in Ghana and Africa to look into the supportive care needs of adolescents with chronic hepatitis B. However, due to the small sample size, generalization is not possible. The presence of some of the participants' parents during interview sessions limits the study, as this may have influenced some of the responses.

Conclusion

This study highlights the need to have a tailor-made liver care for adolescents taking into consideration their unique needs and expectations. Also, we recommend the integration of hepatitis B services into the HIV structures in the formal health care system such that pretest and posttest counseling can be a part of the routine care for PWHB.

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Ethical Approval

This study received ethical approval from the ethics review board of the Kwame Nkrumah University of Science and Technology (No. RD/CR19/060). Informed consent, anonymity, confidentiality, and freedom of participants to withdraw from the study were ensured.

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