

Information Behaviors of Patients with Sick Cell Disease in Sociocultural Context: A Fresh Perspective for Designing Sick Cell Disease Information Services and Communication Programs

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Abstract: *Sickle cell disease is a serious health problem globally. Despite efforts to reduce the burden of the disease, only a limited number of studies have examined SCD from a sociocultural perspective. This study aims at understanding information behavior of patients with sickle cell disease, using Chatman theory of information behavior as a theoretical framework to guide the investigation. This study adopted interpretative research paradigm and collected qualitative data using in-depth interview. Inductive analytical processes were used to analyze the data collected. Findings based on Chatman theory of information behavior revealed that sociocultural beliefs are the main reason for non-use of information communicated to patients with sickle cell disease. Therefore, this study recommended that for a sustained acceptance and use of information communicated to patients with sickle cell disease, there is the critical need for health policy makers and information professionals to design information program for patients with sickle cell disease based on the social and cultural Setting.*

Keywords: Information Behaviour, Sick Cell Disease, Sociocultural Context, Health Epistemology

Introduction

Patients' information behaviour regarding sickle cell disease is largely influenced by sociocultural beliefs and social norms. Applying Chatman's Theory of Normative Behaviour can inform the development of culturally appropriate information services and communication programs that improve the use of sickle cell disease information in Nigeria. This is because sickle cell diseases is a global health concern as nearly 100 million people suffer from sickle cell diseases worldwide, with over 300 000 children born every year with the condition (Kumar & Bhattacharya, 2024). Nigeria has the highest burden of Sick Cell Disease (SCD) and the top sickle cell endemic country in Africa, with an annual death of about 150,000 representing more than 8 per cent of mortality in the country (WHO 2017). In Nigeria Kaduna state has the

highest number of patients with sickle cell disease (KSRHK 2016). Sickle cell disease is a condition in which red blood cells are not shaped as they should be and when blood can't get to where it should, it can lead to pain and organ damage. It has consequences such as: polymerized hemoglobin (sickle hemoglobin, hemoglobin S), hemolytic anemia, painful vaso-occlusive events, vascular remodeling, and acute chronic organ injury (Olorynshola & Audu 2013). Most of patient's experience both acute and chronic pain, primary cause of hospitalization, which significantly impact the patients' health related quality of life. SCD is also associated with tissue ischemia and necrosis with organs injury as consequence. SCD increases susceptibility to infections, notably bacterial sepsis and malaria in children under five years. Respiratory infections can trigger the sickle-cell acute chest syndrome, with a high risk of death. A prompt diagnosis is the first step in improving outcomes of patients with SCD. Preventive diagnosis allows for parental education on pathophysiology of disease and recognition of specific signs to seek immediate medical care. Currently the only available treatments for SCD are hydroxycarbamide and L-glutamine. Additional therapy is blood transfusion to raise the haemoglobin for improved oxygenation in severe anaemia.

To reduce Sickle Cell Disease many scholars approach the problems from health perspectives and promote access to medical services for people affected by the disease (Kumar & Bhattacharya, 2024). While limited study exist in regard to sociocultural perspective or believes especially, from the patients with sickle cell diseases in Nigeria (Oscar and Marcelle 2022). Sociocultural perspective provides a lens for understanding individual everyday experiences and how individual construct knowledge about the reality of their health conditions within social context. To have a better understanding of this problem, save life and reduce the adverse consequences of sickle cell diseases there is the critical need to understand how patient with sickle cell disease get information, share information, and understand, use or avoid information on the illness within their sociocultural setting. Understanding the information behaviours of patients suffering from sickle cell anaemia will improve the design evidence based information programs on sickle cell disease to improve quality of life and wellbeing.

Health Epistemology

Health epistemology explores diseases and illness from subjective reality as against objective reality. Disease as subjective realty considers individuals as unique to groups and cannot be reduced to an object of science (Maraqah, 2014). However, a subjective reality related to disease allows individuals to understand reality in constructing knowledge in a consensual manner (Spancer, Phillips and Ogedegbe,

2005). Furthermore, the concept of epistemological perspective which adopts disease from subjective reality helps in understanding the condition of individuals, which makes room for community perceptions.

This is important against the background that community perceptions and reactions to disease and illness are entangled in the socio cultural domain ((Bientzle, Cress and Kimmerle 2014). For instance, in most indigenous communities of Africa, the perception about the causes of disease is usually ambiguous with an explanatory model different from a biomedical model. Therefore, understanding the sociocultural approach and using the appropriate research methods in health research can further enhance local understanding of the disease, (people's experience of disease) and health in Nigeria. Sick cell disease is devastating health problems that affect 60% of people in Kaduna State (Jejelola 2016).

Research Objectives

1. To explore experiences of patients with sickle Cell Anaemia in Kaduna North?
2. To understand the perceptions of patients with sickle Cell Anaemia about the information communicated to them in Kaduna North?
3. To analyze the acceptance or avoidance of health-related information among patients with Sick Cell Anaemia in Kaduna North using Chatman's (2000) Theory of Information Behaviour.
4. Lastly, the analysis will be used to develop a conceptual model for acceptance and use of sickle cell information in sociocultural context

Literature Review

Within the discipline of Library and Information Science (LIS), growing scholarly attention has been devoted to examining health information behavior within its broader sociocultural context, with particular emphasis on vulnerable populations such as individuals living with sickle cell disease (SCD). Contemporary literature consistently affirms that the access to, utilization of, avoidance of, and trust in health information are governed not solely by information availability but are equally conditioned by cultural belief systems, social norms, levels of health literacy, and the perceived credibility of various information sources. Chatman's Theory of Normative Behaviour remains a pivotal analytical framework within LIS scholarship, elucidating how individuals embedded within their "small worlds" selectively accept or reject health information on the basis of shared community values and prevailing social expectations. Recent empirical studies have established

that patients commonly rely on interpersonal networks, religious frameworks, and indigenous knowledge systems rather than formal health information channels particularly in contexts where distrust of healthcare providers and mass media is pronounced (Musa, 2015; Burnett, Jaeger, & Thompson, 2008). Furthermore, research on health information behavior has demonstrated that sociocultural perceptions substantially shape information-seeking patterns, treatment decisions, and health communication outcomes among patients managing chronic illnesses (Case & Given, 2016; Erdelez & Makri, 2020).

However, within the specific context of SCD, the literature indicates that misinformation, limited health literacy, and deeply entrenched cultural beliefs continue to impede the effective utilization of medical information and health services across numerous African communities (Anie et al., 2021; Olatosi et al., 2022). When the analytical focus is narrowed to Nigeria, these sociocultural impediments are rendered even more conspicuous. Patients with SCD in Nigeria navigate a complex and often contradictory health information environment, one in which formal medical guidance competes persistently with traditional and religious interpretations of the disease. A pervasive reliance on interpersonal networks and faith-based healing practices frequently results in treatment delays and poor adherence to established clinical management protocols.

Compounding these challenges, systemic inefficiencies and perceived stigmatization within formal healthcare institutions have engendered deep-seated distrust, further propelling patients toward informal information sources. In response to these realities, LIS scholars have increasingly advocated for culturally responsive information services, community-anchored health communication strategies, and user-centered information systems that meaningfully integrate local belief structures and trusted community networks. Such approaches are considered essential for enhancing health information acceptance and improving utilization outcomes among patients living with chronic conditions (Olatosi et al., 2022).

In Kaduna State and specifically within Kaduna North they lived experiences of SCD patients reflect both national and continental trends while simultaneously exhibiting distinct local dimensions. The sociocultural landscape of Kaduna North, characterized by pronounced ethnic and religious heterogeneity, profoundly conditions how patients access, interpret, and respond to health information. According to KSRHK (2016) preliminary evidence suggests that many patients in

this setting accord primacy to religious leaders, family elders, and traditional healers as their principal sources of health information, frequently marginalizing clinical guidance in the process. Exacerbating this dynamic are persistently low levels of health literacy and the circulation of pervasive myths surrounding SCD including beliefs that the condition is attributable to spiritual affliction or parental transgression factors that collectively contribute to suboptimal health-seeking behaviors and poor disease management outcomes. These findings collectively underscore the urgent imperative for targeted, community embedded health information interventions in Kaduna North interventions designed to honor local epistemological frameworks while simultaneously advancing evidence-based health practices. In the absence of such culturally congruent approaches, patients with SCD in this region will continue to encounter formidable barriers to effective disease management, including inadequate information utilization, delayed care-seeking, and substantially diminished quality of life.

Theoretical Framework

It is always important that a good research is linked to theory. This is because theory is used for choosing a methodological approach as well as for developing analytical tools for the research. There are a number of theories that can be used to explain the information seeking behaviour of patients with sickle cell disease. This study was grounded in Chatman (2000) theory of normative behaviour (TNB). The theory explains the common or routine events that characterize the everyday reality of people who share a similar cultural space. TNB attempts to address how social expectations and behaviour affect information behaviour (Burnett, Besant, & Chatman, 2001). The theory constitutes four constructs: social norms, worldview, social types and information behaviour. For this study three constructs were adopted to explain how patients with sickle cell disease get information, use information, share information and accept or avoid information within their sociocultural settings.

Social norms: refers to a sense of rightness and wrongness in social appearances within a small world. Small world can be seen as group of people that share the same idea and understanding.

Worldview: is a collective set of believe held by member who live in a small world. The value of having a worldview is that it gives a collective approach to the same value as they enter a person's awareness.

Social Types: can be seen as the ways in which individuals are perceived and well-defined within the society. The process of social type occurs within the boundaries of people living in the environment or society. That is why the theory

suggest that the most important members of the society are the insiders. That is why that information coming from the outsiders would not readily accepted or believed.

Previous Studies that adopted Chatman (2000) Theory of Normative Behaviour (TNB)

Several scholars from different fields of studies were conducted empirical inquiries and adopted Chatman (2000) theory of normative behaviour to study how people interact with the information in the small world. For instance, Musa (2013) conducted a study on resistance to polio immunization information in Kano. He adopted Chatman (2000) theory of normative behaviour to uncover the reason why people of Kano state are resistance to information on polio immunization.

The study adopted interpretative research paradigm and collected qualitative data using selective documents published on polio immunization. Qualitative content analysis was adopted to analyse the selected documents. Findings from the study revealed that people of Kano are resistance to polio immunization information due to the information communicated to them are not tally with their norms and behaviour.

Another study conducted by Muhammed (2016) adopted Chatman (2000) TNB to uncover how female suffering from dysmenorrhea share and access information to manage the illness. The study adopted qualitative methodology and case study research design, data from the study was collected using in-depth interview. The collected data were analyse using thematic analysis. Findings from the study revealed that females suffering from dysmenorrhea share the information on the illness within their small world and worldview despite the painful of the disease.

Using the four concepts from Chatman's (2000) TNB, Burnett and Nocasian (2008) examined a print-based virtual community that interacted in the pages of the Romanian magazine *Formula As*. The authors considered readers of *Formula As* to be a small-world group. The magazine published letters from its readers, who sought practical information on many aspects of life, including traditional Romanian medicine, Romanian cultural tradition, Romanians viewed from abroad, emigration, and so on. Findings indicate worldview of the Formula as Small World is, to some extent, a matter of editorial policy and choice; certainly the editors establish the basic categories into which the letters they publish are organized.

Research Methodology

This study adopted interpretative research paradigm. Researchers in this paradigm seek to understand and explain social phenomenon rather than predict (Burrell & Morgan). The assumption of using this paradigm in this study is to understand the information behaviour of patients with sickle cell disease in their sociocultural settings. In line with the research philosophical paradigm, interpretative research paradigm usually adopted qualitative research methodology. According to Musa (2013) qualitative research methodology refers to the method of inquiry employed to gather an in depth understanding of phenomenon and human behaviour especially feelings, perceptions or opinions, and the reason that governs behaviour. Qualitative research is seen to be appropriate for this study, this is because the purpose of this study is to explain the information behaviour of patients suffering with sickle cell disease, and how they access, share and use information on sickle cell disease within their sociocultural setting.

Research design adopted for this study is case study. According to Yin (2003) stated that, a case study method selects a small geographical area or a very limited number of individuals as the subjects of study. Case study research design is seen to be best suited for this study. The purpose of this study is to understand the information behaviour of patients with sickle cell disease in their sociocultural settings and select 16 participants who is currently suffering from sickle cell disease in Unguwan Rimi Village area of Kaduna North Local Government. Unguwan Rimi Village was selected because it has the highest member of patients with sickle cell disease in Kaduna North Local Government (KSRHK 2017). Participants from this study was recruited through purposive sampling technique particularly, criterion sampling. Therefore, respondents for this study must meet the following criteria: must be a sickle cell disease patient, aged 17-above, living in Unguwan Rimi Village and doesn't attend to any sickle cell clinic. This gave the researcher opportunity to understand where and how they got, shared and user or avoid information on sickle cell diseases and the reasons for not attending the sickle cell clinic.

Data Collection

The data from this study was collected using in-depth interview. In-depth interview seem to be a suitable for this study because they allow asking open ended questions to a small sample and exploring individual experiences, feelings, thoughts, opinions, attitudes or behaviours. Access to research participants was facilitated through the village head, who was formally approached and comprehensively briefed on the objectives and scope of the study. Upon receiving this information, the village head

invited the researcher to attend the mosque during the Maghrib prayer session. Following the conclusion of prayers, he introduced the researcher to parents of children diagnosed with sickle cell disease, whereupon the researcher provided a thorough explanation of the study, including its purpose, procedures, and the purposively defined participant selection criteria.

Recognizing the prevailing cultural and gender norms of the community, the village head arranged for two female research assistants to support the data collection process. This accommodation was necessitated by the researcher's gender, as it would have been culturally inappropriate for a male researcher to gain entry into the private domestic spaces of female participants. The involvement of female research assistants therefore ensured that data collection proceeded in a manner that was both culturally sensitive and ethically considerate of community norms. Through this community-gatekeeping approach, participants were successfully identified and engaged, and data collection was subsequently conducted within the bounds of the established cultural and ethical protocols of the setting. This is how it goes until primary data from sufficient amount of samples are collected.

In qualitative research there is no exact number of sample. Sample was based on data saturation that is when there is no new ideas or themes. Marshal (2006) explains data saturation as the point when there are no new categories, themes, or explanations emerging. Four research assistant were used. The research assistants was trained and retrained on how to collect the data. During the interviews the researchers used probing technique to solicit for in-depth information and/or to build on their responses. This provided the researchers with rich in-depth information. The data were transcribed for analysis.

Data Analysis

All interviews, with the consent of the participants, were audio taped and the recordings were transcribed verbatim. The transcribed data were analyzed using phenomenological method as described by Ricoeur (1981) and adopted in this study, the steps which includes. (a) *Transcribing the whole interview immediately after completion*: The voice-recorded interview were transcribed verbatim manually on plain sheet of papers. (b) *Reading the text to gather an overall understanding of its content*: To accomplish this task the researcher read and re-read interview transcripts while searching for similarities and differences in themes by underlined using pen (103 open codes), (c) *Determining meaning units and initial codes*: To accomplish this task, the 103 open codes were scrutinized and related open codes were identified

and grouped together to form 11 sub-categories, (d) *Classifying initial codes into more comprehensive categories*: To accomplish this task, the 11 sub-categories were condensed to 4 final categories.

The final categories were then narrowed into the three (3) themes of the theory. Following this steps, the researcher read and re-read focus group interview transcripts while searching for similarities and differences in themes and considered significant statements reported by respondents to develop meaningful themes and descriptions about the product packaging information as sources of information for sustainable consumption of youth and their sense of power to change lifestyles and promote sustainable consumption. The strategy for the data analysis is summarized in figure 1 below as adopted in this study from Ricoeur (1981).

Figure 1: Summary of data analysis adopted in this study

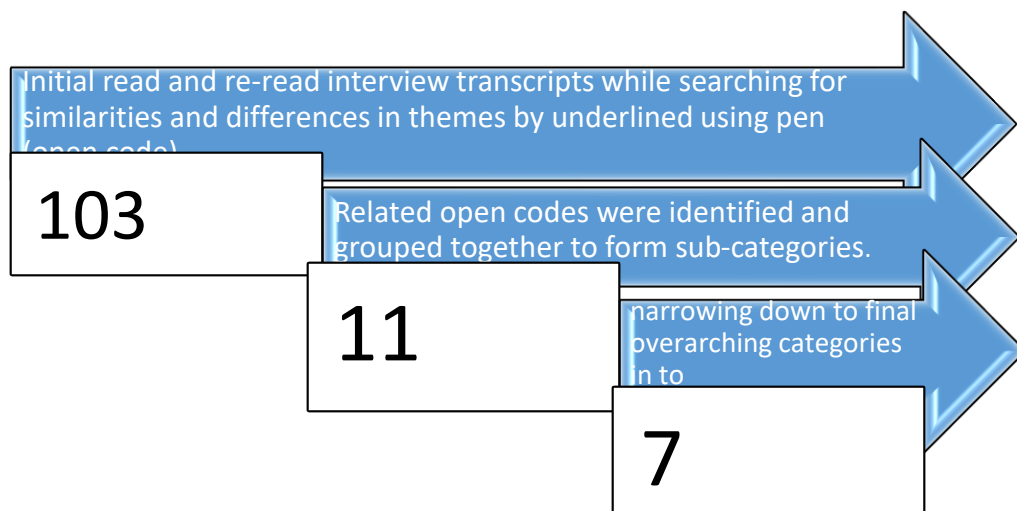


Table 1. Emergent Categories and Subcategories

Categories	Sub-categories
Disrupt academic performance	Unable to write a test due to SCD
	Unable to write an exams due to SCD
Social isolation	Isolation
Sickle Cell Disease Comes from God	SCD come from God
Sickle Cell Disease is gotten from Mosquito Bite	SCD come from mosquito bite
Marrying parent with same genotype	SCD come from person with the same genotype
Misinformation and Distrust in Mass media on Sickle Cell Disease	Distrust of radio
	Distrust of TV
	Misinformation
Suspicion of Health Care Providers on Sickle Cell Disease Information	Distrust of hospital workers
	Distrust of sensitization program

Findings

Findings from this study are presented in this style to allow the reader an opportunity to draw on the reflection of thought given to the participants’ responses.

Disrupt academic performance

This category presents excerpts from participants' responses describing the experiences of individuals living with sickle cell anaemia. One participant reported being *unable to take a test due to a sickle cell crisis*. Similarly, another participant explained that they *were unable to sit for examinations at school and were left behind academically because of illness*.

Social isolation

This category refers to narratives related to experience of patients with sickle cell anaemia. Participants explained that the pain of the sickness disallowed them to associate with their friends and relatives as explained by the following respondents: *“I preferred to be alone, can’t even play with my friends or participated in daily activities”* *“I feel isolated and take care of myself when am in pain”*.

“I don’t want to see anybody close to me because of the illness.....the respondent further said even my relative” Another respondent expressed that: *“I always want to be alone; I can’t even talk or play with anybody even my mother”*

Sickle Cell Disease Comes from God

This category comprises of responses from participants about their knowledge on sickle cell disease. The respondents believe that the illness or diseases only comes from God as expressed by these respondents: *“This disease the way I see it comes from God”* Another participant further beliefs that: *“it’s come from Allah only him can cause disease and also is the one can eliminate it”*

This respondent said: *“it’s comes from God, the respondent further said, I don’t know it causes, some are born with it, while some don’t notice it till they grown”*

Sickle Cell Disease is gotten from Mosquito Bite

This category explains narratives related to knowledge on causes of sickle cell anaemia. Respondents detailed that: *“At first someone contacts it through mosquito bite”* Another participant confirmed that: *“Mostly this disease is gotten from mosquitos when they bite you”*

Marrying parent with same genotype

The category showcases narratives related to marrying partner with the same genotype (person with AS genotype married with person with AS genotype) as knowledge cause sickle cell anaemia. As explained by theses respondents: *“Mostly through blood contacts between a man and a woman that are both AS positive will give birth to a sickle cell patient”* Furthermore, another respondent expressed that: *“it occurs when you got married with somebody with the same genotype”* in the same vein this respondent expressed that *“i was told from school that it is cause from the blood of Married people”*

Misinformation and Distrust in Mass media on Sickle Cell Disease

This category include narratives related to perceptions of patients with sickle Cell Anaemia about the information communicated to them. Participants explains that most of the information communicated to them is irrelevant as explained by these respondents: *“in radio I had that if you eat vegetables it will keep you healthily and I cannot eat only vegetables to satisfy”* in addition these respondents stated that: *“I saw them on T.V telling people the kind of drug to be taking and I can’t take that kind of medicine is not proper and unreliable, I preferred traditional medicine”*

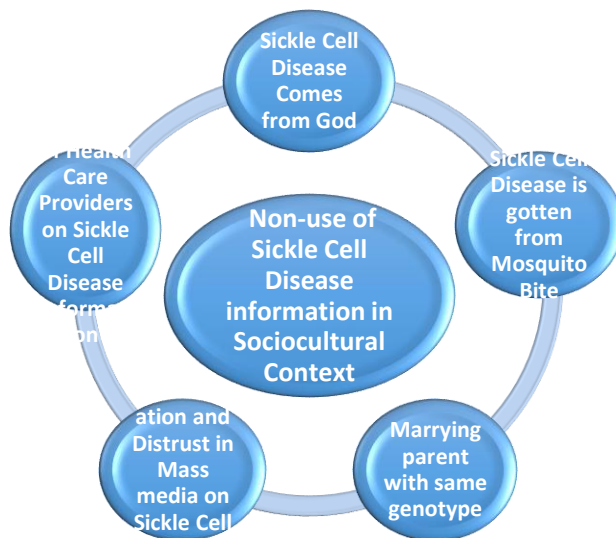
Another respondents stated that: *“I saw it on T.V I cannot eat the type of food they said, because it’s not healthy to me”*

Suspicion of Health Care Providers on Sickle Cell Disease Information

This category explained perceptions of patients with sickle Cell Anaemia about the information communicated to them by health care practitioners. Participants perceived health care providers unprofessional. As explained by these respondents: *“if you see the way this people communicated to us during sensitization programs you will surprise the don’t know how to talk”* Similarly, other respondents further explained that: *“they don’t even know the work because the way this people talk is not proper and clear, that is way I don’t even border myself to attend clinic in hospital”*

These respondents also stated their reason for not attending sickle Cell in the hospital: *“I don’t trust hospital workers and their medicine, I preferred traditional medicine”*

Figure 2: Non-use of Sickle Cell Disease Information in Sociocultural Context



Discussion of Findings

This section discussed the research findings. The findings were arranged in line with the research question asked from the study, in a convincing manner in order to archive the stated objectives of the study.

Experiences of patients with sickle Cell Anaemia in Kaduna North?

Findings from this study indicated that patient's experiences serious pain and as a result of that pain they were not been able to write a test or exams. In ability to write there continue assessment and exams also result to poor academic performance in school. Result from this study also revealed that many patients with sickle cell anaemia withdrawn from the school as a result of poor performance. The outcome from this study also shown they preferred to be alone, not participated in daily activities at, the pain of the sickness disallowed them to associate with their friends and relatives including their parents.

Findings from the study reveals that participants believes sickle cell diseases only come from god and only god can provide solution to the disease. However, the outcomes of this study also shown that patient's with sickle cell diseases don't know it causes, they believed some are born with it, while some don't notice it till they grown. Another findings from this study also discovered that participants believes that Sickle Cell Disease is gotten from Mosquito when they bite you. Furthermore, another finding also discovered that, sickle cell diseases happens when you got married with somebody with the same genotype. Mostly through blood contacts between a man and a woman that are both AS positive will give birth to a sickle cell patient.

Perceptions of patients with sickle Cell Anaemia about the information communicated to them in Kaduna North?

Result from this study also revealed that, patients with sickle cell disease perceived information on medicine and foods which communicated to them through mass media as a conflict with their norms and value, meanwhile the information is irrelevant to norms therefore the cannot use it. Finding also revealed that patients with sickle cell diseases preferred traditional medicine than any other medicine communicated to them through radio and T.V. Furthermore, findings from this study also indicated that, were not comfortable and dislike the way health care providers communicated to the most especially during sensitization revealing that they don't know how to talk to the and that is the reason why they don't really attend a clinic or went to hospital looking for a medicine. Findings also revealed that patients with sickle cell disease perceived and mistrust health care providers believing that it is a Western conspiracy, this is why they viewed health care providers as an agent of western nation with no credibility.

Explanation of acceptance or avoidance of information of patients with sickle Cell Anaemia in Kaduna North using Chatman (2000) theory of information behaviour

Chatman's (2000) theory of normative behaviour comprises four constructs, social norms, worldview, social types and information behaviour. For this study three constructs were adopted, (a) social norms (b) worldview and (c) social type.

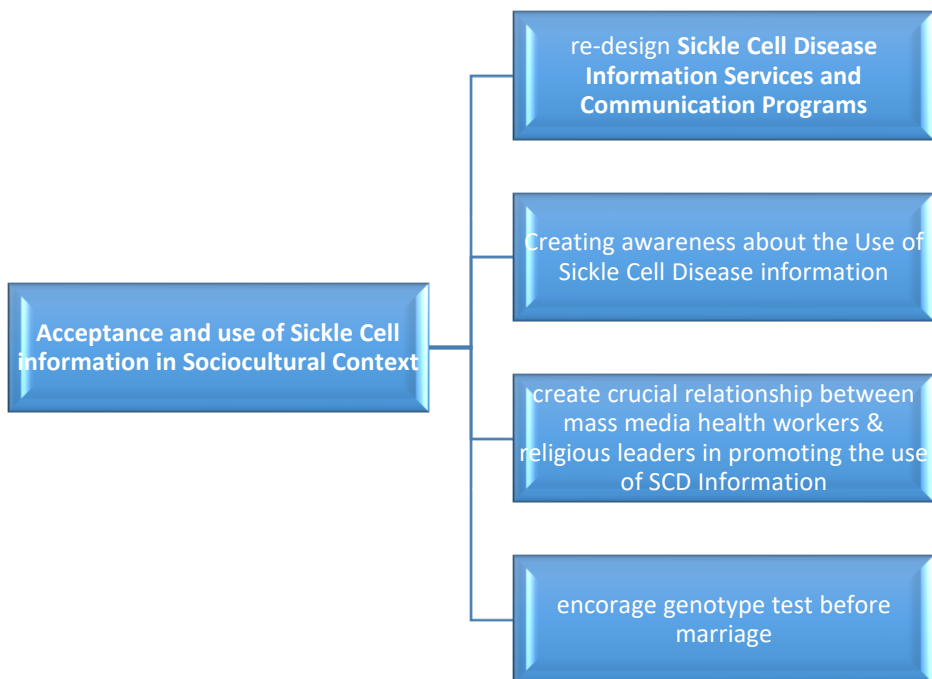
Social norms: is the group of people living in a particular environment or society and share the same understanding and information need. The findings in this study indicated that, patients with sickle cell disease are living in the same environment and share the same experience, understanding and information need that is why they were believed and perceived the sickle cell diseases only come from God, and also believed that sickle cell disease is gotten from mosquitos when they bite you. This confirms Chatman's (2000) assertion that the prominent role of the social norms is to hold the small world together.

Worldview: is "a collective set of beliefs held by members who live within or in the same environment. Findings from the study revealed that patients with sickle cell disease have a worldview deep-rooted in the collective understanding and believed in traditional medicine that any other medicine communicated to them, and also their understanding of information on drugs and foods communicated to them notify their worldview and they considered information communicated to them through radio and T.V as irrelevant to their need in everyday life information seeking behaviour. Chatman (1999) contended that members of a given small world would cross information boundaries only if "there is a collective expectation that the information is relevant".

Social Type: refer to the ways in which individuals are perceived and defined within the environment. Chatman's (2000) suggest that the most important members of the small world are the insiders. Finding from this study shown that, there are two main groups of social types identified in the study are insiders and outsiders. The insiders are the patients with sickle cell disease while the outsiders are the mass media and health care providers or public health workers. Patients with sickle cell disease do not accept information from health care providers and mass media because they perceived them as outsiders with 'undesirable behaviors'. They viewed health care providers and mass media as outside with suspicion and nothing good to expect from

them. As Chatman (1999) explained, the role of social types, i.e., that “most of us tend to reveal and exchange information among peers of our own type”.

Figure 3: Examples of Discourse Topics for Acceptance and Use of Sickle Cell Information in Sociocultural Context.



Conclusion

This study employed Chatman’s (2000) Theory of Normative Behavior to examine the information behavior of patients with sickle cell anaemia in Kaduna North. The findings revealed that patients' experiences are shaped by the physical, emotional, social, and educational challenges associated with the disease. The study further showed that many patients perceive information communicated through formal healthcare channels and mass media as irrelevant to their lived realities, leading to distrust and limited use of such information. Through the lens of Chatman’s concept of the "small world," the findings demonstrated that patients' information acceptance

and avoidance behaviors are strongly influenced by sociocultural beliefs, social norms, and trusted community networks. Consequently, beliefs such as attributing sickle cell disease to divine will or misconceptions about its causes continue to affect the use of health information among patients. The study concludes that understanding these sociocultural influences is essential for improving the effectiveness of sickle cell disease information services and communication programs.

Recommendations

Based on the findings and the three research questions, the study recommends the following:

1. Health policymakers, healthcare providers, and information professionals should design sickle cell disease information services that reflect the sociocultural realities, beliefs, and experiences of patients. Information on disease management, medication adherence, nutrition, and prevention should be communicated in ways that are meaningful and relevant to patients' everyday lives.
2. Religious leaders, traditional leaders, community leaders, and sickle cell support groups should be actively involved in disseminating accurate information about sickle cell disease. Their participation can help address misconceptions, increase trust in health information, and improve information acceptance among patients.
3. Healthcare institutions should promote patient-centered communication by training healthcare providers to understand the social and cultural contexts of patients with sickle cell anaemia. This approach can reduce patients' suspicion of formal information sources and encourage greater acceptance and use of healthcare information.

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