The Impact of the Information Use Environments (IUEs) and Information Behavior of People Living with Neglected Tropical Diseases (NTDs) on Participatory Diagnosis and Treatment Programming

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Article

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Abstract: This study examined how Information Use Environments (IUEs) influence the information behavior of people living with neglected tropical diseases (PLWNTDs) and how this affects their participation in diagnosis and treatment programs. The author demonstrated that local information use environments (IUEs) significantly impacted the information behavior of people living with neglected tropical diseases (PLWNTDs'), which can be harnessed to improve their involvement in diagnosis and treatment programs. The author compared user-centered and program-centered approaches within common IUEs in remote and impoverished areas, finding that NTDs persist due to a disconnect between program organizers and the affected individuals' information use environments (IUEs). Data was sourced from published papers, and OpenAI (ChatGPT) was used to generate list of local sources (IUEs) in affected remote communities. The findings indicated that understanding local IUEs can help program organizers enhance participation rates of individuals with NTDs in diagnosis and treatment initiatives. **Definition of Terms:** Neglected Tropical Disease's (NTDs), People Living with Neglected Tropical Disease's (PLWNTDs), Information Use Environments (IUEs)

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1. Introduction

This study investigates how information use environments (IUEs) influence the information behavior of individuals with neglected tropical diseases (PLWNTDs), potentially affecting their engagement in diagnosis and treatment programs. The focus of the study is particularly relevant given the significant role of contextual information-seeking processes in enabling affected individuals to access and utilize beneficial solutions, including specialized programs aimed at diagnosing and treating these diseases in areas where they are endemic. As noted by Hotez, Asojo, and Adesina (2012), neglected tropical diseases (NTDs) are among the most severe afflictions affecting millions of Nigerians living below the poverty line.

Therefore, by adopting a user-centered approach to information behavior, this study aims to examine how the information use environments (including primary information sources consulted) of individuals living with NTDs impact their participation in diagnosis and treatment programs. This approach represents a departure from the typical program-centered perspective, which often dictates what users require, towards a more patient-centered approach that prioritizes understanding the information environments used by affected individuals to fulfill their information needs.

1.1. Background

Neglected Tropical Diseases (NTD's) are a specific group of diverse diseases that have devastating effects on over one billion people globally. According to a post on the leprosy mission website, nearly two billion people globally are affected by neglected tropical diseases. Other reports including reports on WHO and similar websites such as Evidence Action, which claims that

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approximately 913 million children, predominantly from impoverished communities, face exposure to Neglected Tropical Diseases (NTDs) like parasitic worm infections (helminths) and schistosomiasis due to inadequate sanitation. Despite ongoing challenges posed by NTDs in many households across affected communities in sub-Saharan Africa, malaria remains one of the most widespread neglected tropical diseases in Nigeria.

Nwele and Nwaorgu (2017) noted that malaria alone has led to over 2.5 million deaths among young children in sub-Saharan Africa, making it the primary cause of illness and death due to its prevalence in nearly every household throughout the country. Publicly accessible information indicates that malaria is accountable for approximately 11% of maternal mortality and around 30% of child mortality in Nigeria. Moreover, it constitutes up to 30% of all malaria cases in Africa. Nigeria, with the continent's largest population at risk of malaria, holds the unfortunate distinction of being labeled the world's poverty capital. Given the established link between Neglected Tropical Diseases (NTDs) and poverty—where most Nigerians live below the poverty line—it suggests that malaria is likely to persist as the leading cause of NTD-related deaths in Africa for the foreseeable future.

2. Why “Neglected” Tropical Diseases?

These diseases, known as neglected tropical diseases (NTDs), are predominantly linked to poverty and are widespread in regions like Africa and other impoverished areas worldwide. The term "neglected" suggests that these diseases have been disregarded, overlooked, or insufficiently addressed. While stigma also plays a significant role in their neglect, the challenge remains that neglected tropical diseases (NTDs) receive inadequate attention and have sometimes been completely ignored for extended periods due to various factors such as political, economic, and financial considerations (Ochola, Karanji & Elliott, 2021).

According to Hotez et al. (2012), despite extensive intervention efforts by the Nigerian Government, the Federal Ministry of Health, numerous NGOs, collaborations with international bodies, and leading American universities, neglected tropical diseases (NTDs) remain prevalent in Nigeria. Ironically, NTDs cannot be deemed entirely neglected in the strictest sense of the term, considering the significant attention they receive through intervention programs conducted by local, national, and international agencies, including governmental and non-governmental organizations (NGOs), specifically aimed at addressing NTDs.

Research indicates a longstanding collaboration between the Nigerian Federal Ministry of Health and the Swiss Tropical and Public Health Institute, alongside various international agencies such as APOC, WHO, UNICEF, CBM, ITI, the Carter Center, Helen Keller International, Sightsavers International, Mission to Save the Helpless (MITOSATH), and other non-governmental development organizations (NGDOs) to expedite the mapping of neglected tropical diseases (NTDs) in Nigeria (Hotez, Asojo, & Adesina, 2012, p. 3). Despite these collective efforts and the dedicated budget allocations for projects specifically targeting NTDs in Nigeria, these diseases continue to prevail in most rural areas of the country.

One central argument of this study is the irony in the continued prevalence of these so-called neglected diseases despite significant attention received. For instance, the WHO prioritized eliminating NTD’s due to their global impact, specifically in regions of south-east Asia and sub-Saharan Africa, spending billions of dollars with anticipated hopes, yet neglected tropical disease still affect more than a billion people globally (Yajima, et al., 2023). What this suggests to the author, is that other factors may be playing hidden roles in their persistence. This suspicion underscores the timeliness of the study, as it shifts from traditional system-centered approaches to a people-centered focus.

Below, we would examine the different types of information use environments (both system-centered and people-centered) in comparison to their effects on the behaviors of affected individuals, while providing insights into potential contributors to the diseases' persistence. This analysis is important considering the insinuation that access to adequate quality information can undermine individuals' or groups' capacity to make informed decisions that can significantly impact their livelihoods (Oluwaseun, 2022).

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Table 1. Ranking of Nigeria by neglected tropical diseases cases and prevalence.

Disease	Estimated Number of cases in Nigeria	Ranking in Africa	Percentage of Global Disease Burden	Ranking Globally
Ascariasis	55 million	1	7%	5th behind India, Indonesia, China, and Bangladesh
Hookworm	38 million	1	7%	Tied for 4th with China behind India, Indonesia, and Bangladesh
Trichuriasis	34 million	1	6%	4th behind India, Indonesia, and Bangladesh
Schistosomiasis	29 million	1	14%	1
Lymphatic filariasis	25 million 80–121 million estimated at risk, requiring mass drug administration	1	21%	3rd
Onchocerciasis	30 million at risk, requiring mass drug administration	1	36%	1
Trachoma	18 million at risk	Not determined	Not determined	Not determined
Leprosy	4,531 registered prevalence	4	2%	7th

Figures obtained from Hotez, et. al., (2012) Nigeria: "Ground Zero" for the high prevalence neglected tropical diseases.

3. Information Use Environment: What is?

In the field of information science, it is crucial to grasp the concept of information use environments (IUEs) within the context of information behavior research (Capurro & Hjørland, 2005). According to Taylor (1991), information behavior encompasses a "set of elements that influence the flow and utilization of information messages and determines the standards by which the value of information messages is assessed." This definition hinges on two primary factors: (a) users and their surroundings, and (b) externally designed systems. Taylor further highlighted in his framework for studying information use environments that despite varying user dynamics, certain behaviors remain consistent, such as individuals seeking interpersonal sources or relying on each other for information.

The concept of information use environments centers around the distinctive characteristics of user groups. In essence, the study of IUEs revolves around the pivotal role of 'context' as the primary distinguishing factor and guiding principle for researchers interested in the field of information behavior. As highlighted by Khan (2018), information use environments are critical in the processes of information seeking, retrieval, and utilization. Given the focus of this study on Southeastern Nigeria, the notion of "context" pertains to how traditional values and cultural practices in African societies influence the information behavior of the people, especially their everyday information seeking process (Dankasa, 2016).

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4. The Role of Information Behavior

Wilson (2000) characterized information behavior as encompassing all human interactions with the attributes, origins, and pathways of information, involving processes such as identifying information needs, actively and passively seeking information, and utilizing information effectively. Moreover, given that individuals affected by neglected tropical diseases (NTDs) are predominantly affected by poverty, factors like "illiteracy, deeply rooted cultural norms, and practices" (Ochola, Karanji & Elliott, 2021) are likely to directly influence both their information use environments (IUEs) and their information behavior.

5. Information Needs

Defining information needs poses challenges due to its complex nature. Nevertheless, Weigts et al. (1993) propose useful categories that encompass both physical and cognitive aspects. Case (2012) explored the meaning behind people stating they "need" information, and Krikelas (1983) focused on the difficulty of defining a subsidiary concept. While Taylor (1968) identified four distinct levels of information needs and emphasized the quest to bridge gaps in knowledge or fulfill missing elements.

Information needs are often defined as the "missing something" or a lack of information that motivates individuals to search for something new. Grunig (1989) characterized it as an internal desire to obtain specific new information. Essentially, information need represents the inner drive that motivates people to seek out new information or ways of accomplishing tasks. It typically revolves around a sense of deficiency and can arise from various motivations such as curiosity, a sense of incompleteness, or the pursuit of intellectual satisfaction. Therefore, individuals affected by neglected tropical diseases (NTDs) need information relevant to their specific health needs and would actively seek such information albeit in familiar places.

6. Information Seeking

Ford (2015) defines information seeking as a fundamental component of information behavior, encompassing the stage where individuals actively search for new but specific information. This process, triggered by a gap in knowledge, drives people to seek relevant information to fulfill recognized needs. According to Kuhlthau (1991), information seeking involves the exploration of pertinent resources and engages various facets of one's existence, including physical, cognitive, and emotional aspects. In the initial stages of seeking, individuals often encounter uncertainty due to the abundance of available sources, yet as they progress, feelings of relief and satisfaction typically emerge (Ford, 2015). However, in the case of people living with NTDs and given their poverty levels and social stigma attached to their conditions, seeking information in unfamiliar places seems unlikely as they would rather turn to trusted familiar sources.

7. Information Use

The process of information use entails the utilization of newly acquired information, marking the final stage that begins with the recognition of a need or the awareness of a deficiency, which motivates individuals to seek and employ new information. Therefore, information use represents the phase where the process of need identification and information seeking culminates in the application of newly acquired knowledge. As noted by Capurro & Hjørland (2005), the concept of information use is fundamental to human communication and plays a central role in societal functions. However, using information is directly tied to information use environments, which needs to be carefully understood especially when addressing sick people living in poverty-stricken areas.

8. The Role of Information Use Environment's

Exploring neglected tropical diseases (NTDs) through the lens of information behavior research has shown promising advantages. Unlike system-based approaches such as government intervention programs designed for the affected populations, the information behavior approach focuses on users, in this case the affected people, offering solutions based on their experiences. Thus, understanding

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the information use environment (IUE) of people living with NTDs and their information-seeking or usage patterns is likely to encourage their participation in diagnostic and treatment programs, promoting increased community involvement in related activities. Interestingly, these assertions align with Dankasa's (2017) perspective on the pivotal role of context in information seeking for everyday survival.

People in remote communities often rely on various local sources for information. These sources compose their information use environments, and can vary depending on community's cultural, social, and economic contexts. Additionally, when asked to identify "local sources people consult in remote communities for information" the ChatGPT-generated response listed common local information sources predominant in remote communities, which the author breaks down into two representing both system-centered approach and people-centered approach, respectively.

Table 2. Common local information sources in remote communities (System-Centered).

Libraries & Resource Centers	Digital Sources	Extension Workers	Local Media	Local Government Officials	Educational Institutions	Public Notices
Community libraries	Mobile phone networks	Local advisors	Community radio stations	Village council members	Teachers & school staff	Posters & flyers
Mobile libraries	Internet access points	Cooperative societies	Bulletin boards	Government representatives	Community Edu programs	Public announcements
			Newspapers & newsletters			

As shown above, system-centered approaches do not terms from the people and lacks connectedness to the people, which is crucial to gaining the trust and cooperation of such a vulnerable group. Since these sources does not stem from the people, the gap between the mechanisms and the people (those living with the diseases) make them unsuited information use environments, and negatively impact the people's participation in preventive and curative programs. For example, nontraditional systems, especially the digital technology sources (e.g. local media, radio stations, newspapers) are unsuitable and likely would fail as relevant information use environments in remote areas, and among poverty-stricken people whom due to their conditions cannot afford or have any real need for technology (Onye & Du, 2016).

Table 3. Common local information sources in remote communities (People-Centered).

Community Elders & Leaders	Religious Institutions	Social Gatherings	Family & Friends	Traditional Storytellers
Village chiefs	Churches, mosques, & temples	Community meetings	Word of mouth	Oral history & folklore keepers
Religious leaders	Religious gatherings & sermons	Social events & festivals	Family discussions	Cultural heritage transmitters
Elders with extensive local knowledge				

These information sources listed above are credible information use environments and vital for disseminating information and ensuring community members stay informed about health, education, local news, and other important matters. Because they are people-centered, their impact would be more productive than the system-centered approaches listed on table two. Hence, a people-

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centered approach to programs (diagnosis and treatments) targeting vulnerable populations, such as people living with neglected tropical disease, would appeal better to the group including gaining their participation. This insight could prevent delays usually experienced by people living with neglected tropical diseases in accessing health care services (Godwin-Akpan, et al., 2023).

9. Discussion

The study throws insight on how primary information sources (IUEs) consulted by people living with NTDs could impact their engagement in diagnosis and treatment programs due to numerous reasons including information use environments adopted by program organizers like WHO.

While NTDs, such as parasitic worm infections and schistosomiasis, predominantly affect impoverished communities due to inadequate sanitation, malaria remains one of the most widespread NTDs in Nigeria responsible for significant morbidity and mortality due to poverty.

When examining the information behavior of people living with NTDs, it's important to note that different factors including poverty, illiteracy and cultural norms significantly influence their IUEs and information behavior. Hence, understanding these behaviors can enhance participation in diagnostic and treatment programs, which is why Chukwuocha et al (2024) emphasized the use a "Community Contact Persons" as direct link between program organizers and the affected people.

Information needs arise from a sense of deficiency or curiosity, motivating individuals to seek new information. Information seeking is a process triggered by these needs, involving the exploration of resources to satisfy recognized gaps. Effective information use is the culmination of identifying needs, seeking information, and applying newly acquired knowledge.

Therefore, understanding the concept of 'needs-in-context' of people living with NTDs can improve their participation in diagnosis and treatment programs. This is important because contextual factors like cultural practices and geographical location significantly shape the IUEs and information behavior of individuals. By adopting an information behavior perspective, the study demonstrated how user-centered solutions encourage community involvement and enhance the effectiveness of intervention programs for NTDs.

Furthermore, as table 3 reveals, local sources such as traditional and religious leaders including family and town unions, are important channels that control information flow in communities, possessing the capacity to impact the people's behavior. Therefore, programs organizers should recognize the important role local sources play as information use environment's and take full advantage of their influence to increase local participation in diagnosis and treatment programs.

10. Conclusions

This study shows that understanding the concept of 'needs-in-context', or the information needs of affected people and their information use environments are vital to addressing neglected tropical diseases (NTD's), especially since the stigma attached to their conditions makes them vulnerable and withdrawn from public spaces making it hard to engage with designated programs. It is hoped that since people-centered approaches are more effective than system-centered approach, it is advised to adopt the bottom-up approach as a response to achieve increased participation of the people in diagnosis and treatment programs.

The people-centered approach aligns with the global position on eradicating NTDs and demonstrates the usefulness of information behavior research as suitable to understanding how information flow in communities impacts group dynamics and the people's behavior towards outside sources.

Group dynamics, or contextual factors such as cultural practices, geographical location, and traditional systems significantly impact the choice of information use environments (IUEs) for any group of people. As the study suggests, the preferred IUEs of people affected by neglected tropical diseases can determine, prevent, encourage, or influence their response behavior towards proffered solutions to their plight. Finally, these factors play undeniable roles in shaping the information behavior of the people, particularly as they deal with their vulnerability and stigma attached to their

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conditions when searching for information or opening to relevant channels coming to address their conditions.

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