

A QUALITATIVE STUDY ON HEALTH INFORMATION NEEDS ON NON-COMMUNICABLE DISEASES AMONG RURAL COMMUNITIES IN SARAWAK, MALAYSIA

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Abstract

Individuals' increasing need for health information, as well as their inability to fully utilise health information, are driving health information-seeking importance. Because of the high prevalence of non-communicable diseases (NCDs) in the adult population, a lack of health facilities and services, and a distinct sociocultural context and healthcare system, it is crucial to investigate the health information needs of the Sarawak rural community. The purpose of this study was to explore the health information needs regarding NCD among adults in the rural communities in Sarawak, Malaysia. This is a qualitative study conducted between February and August 2021 and included twelve in-depth interviews as well as two focus group sessions. The study findings show that individuals with NCDs require more immediate information about medication, alternative treatments, treatment costs, and healthy eating tips. Most participants, whether NCD patients or healthy people, are interested in various NCD topics, indicating many unmet health information needs. These findings emphasise the importance of providing people in rural areas with timely, relevant, affordable, accurate and culturally sensitive health information. Suppose the health policymaker has a better understanding of rural people's information needs. In that case, they will be capable of developing a health information delivery system that takes the rural environment and the way rural people look for health information into account.

Keywords: Information need, non-communicable disease, qualitative, information- seeking, in-depth interview .

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INTRODUCTION

Individuals' increasing need for health information, as well as their inability to fully utilise health information, are driving the importance of health information-seeking. Patients and healthy individuals, for example, use health information to manage their health-threatening conditions, make health decisions, and change their behaviour (Tan et al., 2022). Patients may benefit from health information that can help them navigate the healthcare system, whether preventive or curative. As a result of the development of communication technologies, there has been a significant increase in the availability and accessibility of health information through healthcare providers, the media, printed materials, and the Internet, as well as the democratisation of information to ensure easy access to information (Hu & Hu, 2017). According to the Galen Centre for Health and Social Policy (GCHSP), the current situation in Malaysia is a "crisis" because more young people and children are suffering from non-communicable diseases (NCDs) (GCHSP, 2020).

Challenges and issues that have hindered the effectiveness of Malaysian health communication strategies have emerged during the last three decades. For example, concerns such as how policymakers need more insight into how to maximise social media's impact impede NCD prevention among Malaysia's young population (Ayub et al., 2019). However, regarding health information needs in addressing Malaysia's NCD problem, there needs to be more strategies in instilling awareness and disseminating health information. Exploring the health information needs of adults will thus assist in creating a better health communication strategy (Viswanath et al., 2020). Thus, this article aimed to explore the informational needs of adults regarding NCD, specifically among rural communities in Sarawak, East Malaysia.

LITERATURE REVIEW

Non-communicable diseases

The literature shows that NCDs such as diabetes, hypertension, and hyperlipidaemia complications lead to significant disability, morbidity, and mortality (Chatterjee et al., 2017). The findings of the NHMS 2019 show that one out of every five Malaysian adults has diabetes, three out of every ten adults have hypertension, and four in ten adults have raised total cholesterol levels (NHMS-Ministry of Health Malaysia [MOH], 2019). Because of the health disparity and distinctive sociocultural context and healthcare system between urban and rural Malaysia, it is essential to investigate the community's health information needs.

Health information needs

Individual information needs are part of a larger picture called health information-seeking behaviour (HISB). HISB is described by Mills Todorova (2016) as the process by which people discover and manage information about their health, threats, diseases, and health-protective behaviours. Numerous influential theories explain HISB, for instance, Daniel R. Longo's Expanded Model of Health Information Seeking Behaviours (Longo, 2005), health information seeking behaviour can be affected by both contextual variables such as health status and health care structure, as well as personal variables such as demographic and socioeconomic factors.

T. Wilson, in his Model of Information Behaviour (Wilson, 2000), states that information-seeking behaviour develops in response to a perceived information need. These theories assume that if an individual is an active information seeker, he or she will seek information to manage their health-threatening situation, to understand and get involved in health decision-making and to promote positive changes in their health-related behaviours (Zare-Farashbandi & Lalazaryan, 2014).

Therefore, an understanding of an individual's HISB characteristics and patterns allows the health professional to understand the elements critical to the people's adherence to health, mainly how the individual uses health information and makes informed health decision-making (Zimmerman & Shaw, 2020). This study provided some evidence-based recommendations for strengthening health prevention and promotive strategies tailored to Sarawak's multicultural populations, especially in reducing NCDs.

METHODS

Research approach

Qualitative approaches were used in this study. This approach aims to elicit information about the participants' experiences, perceptions, opinions, and perspectives on health information seeking. Qualitative research seeks to explore and explain the world through observation by appreciating the "subjective experiences of social actors and by unearthing data that are not easily accessed by quantitative means" (Power, 2002, p.87).

Research design

Specifically, this study utilises “phenomenological qualitative designs” (Creswell, 2014, p. 30) on how different people experience the same construct, such as information-seeking behaviour.

Study’s physical location

The location of this study is Lubuk Antu, a rural district in Sarawak of East Malaysia. Because of the district’s diversity of demographic characteristics, the Lubuk Antu district was chosen to represent rural areas for this study (Department of Statistics, Malaysia [DOSM], 2020).

Study’s population, sample and sampling technique

The inclusion criteria included Malaysian adults aged 18 years and above who resided in the district. This study assumes that individual above 18 years are mature enough to participate in the study on their willingness. For this study, the participants did not necessarily have any NCDs (like hypertension, diabetes, or heart disease).

The purposive sampling was applied in this study. The strength of purposeful sampling lies in selecting information-rich situations for in-depth understanding and giving insights about issues important to this study (Campbell et al., 2020). Purposive sampling procedures were employed in the qualitative phase; it also included a convenience aspect in which the chosen participants were expected to participate voluntarily.

The purposive sampling procedures used the maximum variation sampling approach (Collumbien et al., 2012), a strategy for determining the number of participants needed to identify or uncover distinct themes across a diverse sample. According to Palinkas et al. (2015) and Campbell et al. (2020), the strength of maximum variation approaches was to explore shared patterns that cut across various participants and minimise the possibility of bias in selecting potential participants.

Data gathering technique and procedures

Data are collected using in-depth interviews (IDI) and focus groups (FG). In general, IDI is based on semi-structured interviews in which the interviewer and interviewee engage in dialogue in response to predefined open-ended questions the procedures for selecting a potential participant for IDI participant using the maximum variation approach. The key participants are selected on purpose from three separate dimensions: community members, individuals who work in the private or government sector, and parents. Each variation has at least one participant who was chosen at random for that dimension. These selections are divided into four primary ethnic groups in the study area.

Prior to the interview, the selected participant must complete an informed consent form. Participants were informed that the sessions were being recorded and that their privacy would be protected. Due to travel limitations across districts in Sarawak in 2021, as well as to comply with the COVID-19 pandemic standard operating procedures, 4 out of 12 IDI sessions were held via video call. The rest were conducted in face-to-face interviews. The sessions were conducted between February and April of 2021. There was a total of 12 IDI and two FG sessions. Each FG session involved five participants.

Research instrument

The IDI and FG sessions used interview guides, which included semi-structured questions, to assist with the interview process. A set of questions for IDI and FG were developed based on the study's specific objectives, in which exploring informational needs is part of the specific objective. The questions included needs and reason search, information topics/type, information sources, information channels and usage, and capabilities in seeking health information. This interview guide was evaluated at the first session of IDI and FG to determine whether the questions were effective at capturing the topic and also to determine how culturally sensitive they were. The health communication specialist and public health specialist reviewed the interview guide's content.

Data analysis technique and procedures

Qualitative research is developed based on trustworthiness. The term refers to data collection and analysis procedures documented, systematised, and presented in sufficient detail to allow the reader to assess whether the process is reliable (Nowell et al., 2017). The management and analysis plan was developed using the seven-stage process proposed by Lester et al. 2020. Preparing and organising data, transcribing data, familiarising oneself with the described data, labelling data, coding data, creating themes from the underlying coded passages, and doing visual analysis are some of these phases. Among the initial vital steps were data preparation and organisation, which required it to be organised and consistent with the standard format for data analysis. This requires gathering all audio and transcribed files from IDI and FG interviews. The software program ATLAS. Ti version 22 is used to manage the data.

In total, 12 sets of IDI and two sets of FG's transcribe were produced. The criteria for determining the appropriate number of IDI and FG sessions are based on saturation, which occurs when the data collection and analysis process reaches a point at which no new categories or themes emerge (Guest et al., 2020). This study follows the recommendations of Francis et al. (2010), who recommended that the initial round of analysis contain a small number of participants and a stopping point. The first round

of analysis involves three interviews followed by another two rounds. It was found that after the third round of analysis (9th interviews), three subsequent interviews yielded no new themes. The final stage comprises ensuring that the analysis process is transparent. This is to ensure that the data collected is trustworthy. Through a procedure called member check or person triangulation, two research assistants independently coded the data to assure the study's validity by minimising researcher subjectivity, and three people (the researcher and two other research assistants) examined the final themes.

Research ethics

This study obtained ethical approval from the Medical Research Ethics Committee of the Ministry of Health Malaysia (Approval No. NMRR-20-2537-57272).

RESULTS

This study included 22 participants, 12 of whom were interviewed in person (IDI) and ten others in two FG sessions. Two sessions were conducted for the focus group (FG), each with five participants. The mean age was 46.6 ± 10.5 years (35–65 years). Participants represented Iban, Malay, Bidayuh, and Chinese ethnic groups. Even though this study did not include any NCDs, it was discovered that a substantial number of participants had hypertension (33.3 per cent) and a combination of hypertension with diabetes or heart disease (18 per cent). While for diabetes (12.5 per cent) and a combination with hypertension (8.3 per cent). Only 37.5 per cent of participants reported that they did not have any NCDs. Table 1 shows the characteristics of the participants.

Several themes regarding informational needs emerged based on the participant's health status. Most participants who have NCDs have immediate informational needs, such as the intent to seek more information on medication, alternative treatments, treatment costs, and healthy eating. Apart from that, some healthy participants need this information, but it is more for others, such as when they need information on medication and treatment costs. Healthy participants' informational needs are more focused on healthy lifestyles. However, they want to know more about disease severity, and they suggested that health information be tailored to Sarawak's sociocultural needs. Figure 1 depicts this interconnection.

Table 1 Characteristics of the In-depth Interview (IDI) and Focus Group (FG) Participants

Participant	Age	Gender	Ethnic	Level of education	Health status
IDI 1	53	Female	Iban	MCE	Hypertension
IDI 2	35	Female	Malay	SPM	None
IDI 3	45	Male	Iban	Bachelor Degree	Hypertension, Diabetes
IDI 4	40	Male	Bidayuh	Diploma	None
IDI 5	42	Female	Iban	Bachelor Degree	Hypertension
IDI 6	35	Male	Chinese	STPM	Hypertension
IDI 7	36	Male	Malay	STPM	None
IDI 8	36	Female	Bidayuh	SPM	None
IDI 9	37	Female	Malay	Bachelor Degree	None
IDI 10	50	Male	Iban	Primary school	Diabetes
IDI 11	55	Male	Chinese	SRP	Diabetes
IDI 12	60	Female	Iban	LCE	Diabetes, Hypertension, Heart disease
FG1	56	Female	Iban	Primary school	Hypertension
FG2	65	Male	Iban	LCE	Hypertension, heart disease
FG3	52	Male	Malay	SPM	Hypertension
FG4	45	Female	Malay	SPM	None
FG5	48	Male	Chinese	Primary school	None
FG6	40	Female	Iban	SPM	Hypertension
FG7	56	Female	Chinese	LCE	Hypertension, Diabetes
FG8	65	Male	Malay	Primary school	None
FG9	26	Male	Iban	SPM	None
FG10	48	Male	Iban	SRP	Hypertension

**Sijil Tinggi Persekolahan Malaysia (STPM)*

**Malaysia Certificate of Education (MCE)/ Sijil Pelajaran Malaysia (SPM)*

**Lower Certificate of Education (LCE)/ Sijil Rendah Pelajaran (SRP)*

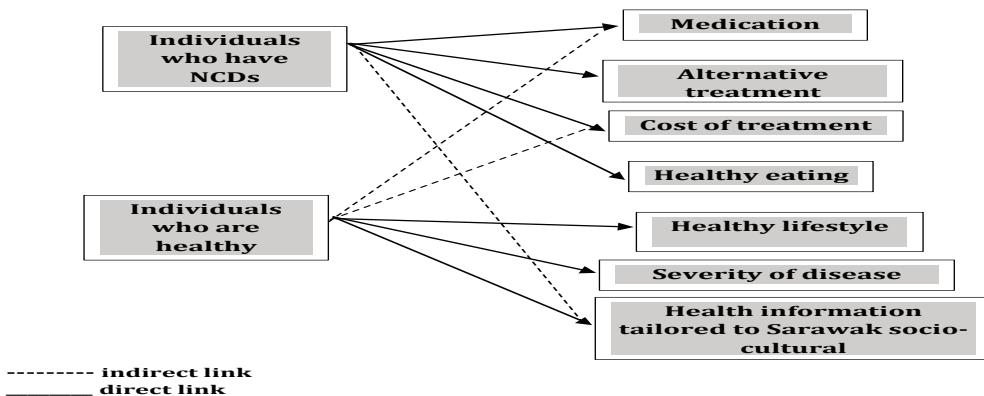


Figure 1: Emerging themes

Information needs on medication

Several hypertensive and diabetic participants preferred more medication information. Some of them want to know how to take hypertension and diabetes medications properly.

“I believe the doctor should provide us with more information on how to properly take diabetes medication.”

(IDI 3)

Another participant said:

“I have diabetes and high blood pressure at the same time. With so many medications to take, I sometimes worry that they will be more harmful to me. I believe that the pertinent information should be highlighted.”

(FG7)

Some participants have difficulty recalling the medication’s name. Medication information was part of the informational need because it was not provided during doctor-patient consultation.

“If you asked me what diabetes medication I was taking, I would say I didn’t know. I only know the medication as “diabetic medication.” The name is extremely complicated. I believe the doctor should provide more information about the medicine’s name. Don’t just hand out medications. Regrettably, detailed advice is not provided.”

(IDI 10)

Information needs on alternative treatment

Another piece of health information that was intended to be sought was about alternative treatment, even though they were being treated with modern drugs.

“Let’s say if we already know what modern medicine is, I think we should also search for other information on alternative medicine, such as homeopathy or herbal medicine.”

(IDI 5)

Regarding alternative treatment, some participants suggested more information that warned about the danger of relying on alternative treatment, for example, traditional herbs for medication.

“As for myself, because I have hypertension, I hope that more health campaigns will highlight the informational needs for the effects of taking modern medicine and relying too heavily on traditional medicines.”

(FG 3)

Information needs on the cost of treatment

Some participants were motivated to search about the cost of treatment because their family members were undergoing dialysis due to kidney failure caused by diabetes complications.

“It is vital to learn more about the cost of follow-up care. Everything is getting more expensive these days. You need to understand that not only for yourself, but also for our family. My parents have diabetes and are on dialysis.”

(IDI 17)

Participants require detailed information about medical check-ups or treatment at private clinics or hospitals to compare prices. This need arose due to their inability to access a government clinic due to a lengthy wait time.

“The cost of medications and health checks is rising. We hope they can tell us how much it will cost to get medical care at a private clinic. We are sometimes unable to visit the government clinic due to long waiting time. You understand that it’s not easy. It is simple for us to compare.”

(IDI 12)

The participant requires information regarding treatment costs in order to decide on their immediate health problem that requires immediate treatment.

“No, this does not imply that people in rural areas cannot afford private hospitals. My son works in town, and they can help me. If we want to receive treatment at a private hospital, we must compare prices. We really need the cost information.”

(FG 2)

Information needs on healthy eating

A sub-theme on healthy eating, explicitly controlling sugar and salt intake and cholesterol control, emerged. This is especially important for participants who are diabetics and hypertensive.

“It’s depended, if I was diagnosed with diabetes, of course my information needs will be various aspect of diabetes information.”

(IDI 10)

“I think we need to know or aware more on cholesterol, if you aware of the effect of cholesterol on our health we can take early preventive measures.”

(IDI 18)

One participant said:

“Yes, what important is information on controlling sugar intake...since I like to eat sweet drinks and food.”

(IDI 11)

Information needs on healthy lifestyle

One participant expressed a need for health information tips on how to stay healthy.

“For me, what important is that how to change behaviour towards healthy. That is the very the important thing.”

(IDI 4, None, 40 years old)

Another participants who did not have any NCDs stated:

“... some people seek information on heart disease, if they already aware of the disease, they might alert and more proactive in taking preventive measures in staying healthy, let say by adopting healthy behavior.”

(IDI 6)

One participant said:

“By doing medical check-up at least once a year will be good step in keeping your health, so that we will know that our own health.”

(IDI 9)

Information needs on the severity of disease

For some participants, even though they did not have the disease, they needed more information about its severity.

“Health information is important not only for the sick but also for healthy people, regardless you have diabetes or not, there a need for you to search information on the severity of disease.”

(FG 4)

Another participant stated:

“I think that health officials should now teach us that diabetes cannot be cured. To control it, we must take medication.”

(FG9)

Health information tailored to the socio-cultural needs of rural people

A theme that emerged was the need for information that is specific to the needs of the sociocultural Sarawak population. One participant said:

“My parents and relatives now and then adhere to traditional beliefs. Not that they are ignorant of modern medicine. Nonetheless, they wish to adhere to traditional beliefs. Their reasoning is that if we have followed it for thousands of years, why should we abandon it now? To address this misconception, I believe more information of the dangers of traditional practises to health are required.”

(FG10)

Another participant said:

“I don't really understand the language they use or the problem the minister (refer to Malaysia Health Minister) mentioned. They always talked about health issues in Peninsular Malaysia. Why not more balanced information from Sarawak also?”

(FG 1)

One participant raised concern about doctor-patient communication:

“The doctor was usually in a hurry when I went to the clinic for a medical check-up. They didn't have much time to give me sound advice.”

(FG8)

DISCUSSION

The purpose of this paper was to explore the informational needs of adults regarding NCDs, specifically among the rural communities in Sarawak. The findings of this study show that adults' information needs can be charted to their status, whether they were NCD patients (hypertension, diabetes, heart disease, or any combination of these diseases) or healthy individuals.

This study found that NCD patients required more direct and immediate information, such as medication, alternative treatment, and methods to control the illness, for example, healthy eating and diet. As for healthy individuals, these informational needs were also needed and reflected both for their benefit and the needs of others, especially for their family members. After being diagnosed with a disease, adults seek information primarily about the medication process, alternative treatments, and treatment costs.

Individuals suffering from any of the NCDs (hypertension, diabetes, heart disease, or any combination of these diseases) must undergo a lengthy follow-up treatment and medication process because the disease cannot be cured but can only be controlled by taking medication and practising healthy eating and other lifestyle modifications such as exercise, quitting smoking, and reducing stress (Budreviciute et al., 2020). For example, a recent systematic review and meta-analysis (Akhtar et al., 2022) shows that Malaysia has a high rate of pre-diabetes and diabetes.

Diabetes prevalence is associated with periods and increasing age. As a result, an individual with NCDs must seek information on a variety of topics in order to meet their informational needs, manage their health-threatening conditions, make health decisions, and change their behaviour. Each situation and stage of their disease necessitated further information. These can be explained theoretically using Wilson's Model of Information Behaviour (Wilson, 2000), which assumes that if an individual is an active information seeker, he or she will seek information to manage their health-threatening situation (Zare-Farashbandi & Lalazaryan, 2014).

According to the study's findings, people intend to seek and obtain a wide range of specific informational needs (See Figure 1). This is because people become more aware of NCDs when they have direct or indirect experience with them, such as being a diabetic or having diabetic parents. This may prompt them to seek or need more information on specific NCD topics or issues, such as diabetes self-care and hypertension medication. A qualitative study conducted in Indonesia (Pamungkas et al., 2021) found that a lack of problem-solving skills to manage poor diabetes management and a lack of affective responsiveness to encourage patient compliance influenced the adoption and maintenance of healthy behaviours among diabetic patients.

Our study found that dissatisfaction with current treatment at the government clinic, for example, appears to have prompted them to seek treatment at a private clinic/hospital in a significant city in Sarawak, such as Kuching, Miri or Sibiu. This encourages them to learn more and seek additional information, such as comparing the cost and price of treatment in the private hospital/clinic. According to our findings, the level of education may be related to a wide range of participants' informational needs and information-seeking in general. Participants generally have an average secondary education, considered an achieved basic education level. Only four of the participants completed primary school. Being in a rural community did not prevent the community from receiving a better education and accessibility to modern infrastructure on par with other urban areas in Sarawak.

This situation can be explained further in Longo's Expanded Model of Health Information-Seeking Behaviours (Longo, 2005), which assumes that health information-seeking behaviour can be influenced by contextual factors such as health status and health care structure, as well as personal variables such as demographic and socioeconomic factors. The findings of this study show that a substantial number of participants had hypertension (33.3 per cent) and a combination of hypertension with diabetes or heart disease (18 per cent). This leads to the question that more than awareness alone is needed to translate into better, healthy behaviour.

This issue could be related to health literacy, which is defined as the ability to obtain, read, comprehend, and apply information in order to make sound health decisions and follow treatment instructions (Sørensen et al., 2012). The findings of the NHMS 2019 (NHMS-MOH, 2019) revealed that approximately 93 per cent of Malaysian adults had limited health literacy, and 35.1 per cent had low health literacy. Previous studies have linked adequate health literacy skills to good health information-seeking practices and desirable preventative behaviours (Chen et al., 2018; Paige et al., 2017). Low health literacy was consistently linked to more hospitalisations, a lower ability to demonstrate proper medication administration, and a lower ability to interpret labels and health messages (Ren et al., 2019).

Another critical emerging theme is the need to tailor informational needs to the socio-cultural Sarawak population. Among the concerns raised were whether people still adhere to harmful traditional health beliefs, health information that is too focused on Peninsular Malaysian issues, and difficulty understanding the health message due to a lack of understanding in the Malay language. This could be because policymakers are unaware of the significance of considering socio-cultural values as essential factors in healthcare delivery that is too "top-down" and fails to meet the needs of Sarawak's diverse multi-ethnic populations (Khor & Shariff, 2019). Although the term NCDs refers to a wide range of diseases, this study focuses on hypertension, diabetes, and heart disease due to their high prevalence among Malaysian adults.

This qualitative study investigates the perspectives of several ethnicities in one rural district/province in Sarawak regarding NCD informational needs. As a result, it cannot be generalised to other communities in Sarawak or Malaysia in general.

CONCLUSION

In conclusion, the participants' information needs demonstrated that there is a continuing information challenging issue on the content of health information between what the health authority provides and what is needed by rural people at the community level. Our findings show individual with NCDs need more immediate information about medication, alternative treatments, treatment costs, and healthy eating tips. The fact that the majority of participants, whether NCD patients or healthy individual, are interested in a variety of NCD information suggests that there are many unmet needs for health information in rural Sarawak, Malaysia.

This study found that healthy individual needed to learn more about NCD prevention measures, such as living a healthy lifestyle and learning about disease severity. Furthermore, this health information is for their own benefit as well as the benefit of others, especially family members. These findings highlight the importance of providing people in rural areas with timely and relevant information in order to raise awareness and empower them to make timely and informed decisions about their health and well-being. In the dissemination of health information, various sources and communication channels that accommodate the socio-cultural aspect of the Sarawak population and individual level of health literacy should be considered.

Furthermore, with adequate health infrastructures and skilled health care personnel to bridge the rural-urban divide is utmost important to ensure that rural people have access to relevant, reliable, affordable and adequate health information about NCDs. If health policy maker has a better understanding of rural people's information needs, they will be capable of developing a health information delivery system that takes the rural environment and the way rural people look for health information-seeking into account.

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