Patients and Their Companion Perception about Disease and How to Communicate to Medical Practitioners

Persepsi Pasien dan Pendampingnya tentang Penyakit dan Bagaimana Mengkomunikasikan pada Tenaga Kesehatan

Leila Mona Ganiem[1], Euis Komalawati[2], Rosmawati Hilderiah Pandjaitan[3], Rafika Hani[4]

[1]Faculty of Communication Studies, Mercu Buana University, Jl. Meruya Selatan, Jakarta Barat*****
Email: leila.mona@mercubuana.ac.id
[2]Faculty of Social Sciences and Management, STIAMI Institute, Jl. Pangkalan Asem Raya No. 55, Jakarta Pusat
Email: euis.komalawati@stiami.ac.id
[3] Faculty of Communication Studies, Mercu Buana University, Jl. Meruya Selatan, Jakarta Barat
Email: bundarossa@mercubuana.ac.id
[4] Faculty of Communication Studies, Mercu Buana University, Jl. Meruya Selatan, Jakarta Barat
Email: Rafika.hani@mercubuana.ac.id

Masuk tanggal : 15-05-2022, revisi tanggal : 28-11-2022, diterima untuk diterbitkan tanggal : 30-11-2022

Abstract

Understanding the patient's and companion's perception of the patient's illness can improve the patient's compliance and overall satisfaction. Patients' understanding of their illness is essential for recovery. Doctors should understand the perceptions and interpretations about the illness, experience, knowledge and culture of patients and their companions. The disease is what happens to the patient. Arthur Kleinman's Explanatory Model of Illness provides a guide for understanding the patient's point of view. The purpose of this study was to explore the meaning of stroke experienced by patients, according to the point of view of the patient and his companion, and the treatment they had, second, to explore how the patient and the companion convey the condition to the doctor. The method uses a phenomenological approach through interviews, observations, and secondary patient data. There are two primary informants, namely two patients and two companions. This study's results indicate a gap regarding the meaning of the disease between the patient's conception and the health sciences. Patients' and their companion's perceptions denote the economic, social, and political background in terms of the patient's illness. The information that patient and companion convey to doctors, usually do not whole information about what they have done during the journey of treatment. Models for interaction that are mainly developed are between doctor and patient. For effective communication between doctor and companion to help the patient better, there is an important model for consultation that includes triadic communication: doctor-patient-companion which can be advantageous. Important also for the doctor to upgrade the knowledge about understanding not only biomedical information but also the socio, psycho, cultural, and religion of the patient.

Keywords: *companion perception, explanatory model of illness, patient perception, stroke*

Abstrak

Pemahaman tentang persepsi pasien dan pendamping tentang penyakit pasien dapat meningkatkan kepatuhan dan kepuasan pasien secara keseluruhan. Pemahaman pasien tentang penyakit mereka sangat penting untuk pemulihan. Dokter harus memahami persepsi dan interpretasi tentang penyakit, pengalaman, pengetahuan, dan budaya pasien dan pendampingnya. Penyakit adalah apa yang terjadi pada pasien. Model Penjelasan Penyakit Arthur Kleinman memberikan panduan untuk memahami sudut pandang pasien. Tujuan dari penelitian ini adalah untuk menggali makna stroke yang dialami oleh pasien, menurut sudut pandang pasien dan pendampingnya, serta pengobatan yang dijalaninya, kedua, untuk mengeksplorasi bagaimana pasien dan pendamping menyampaikan kondisinya kepada dokter. Metodenya menggunakan pendekatan fenomenologis melalui wawancara, observasi, dan data sekunder pasien. Ada dua informan utama yaitu dua pasien dan dua pendamping. Hasil penelitian menunjukkan bahwa terdapat kesenjangan makna penyakit antara konsepsi pasien dengan ilmu kesehatan. Persepsi pasien dan pendampingnya menunjukkan latar belakang ekonomi, sosial, dan politik dalam hal penyakit pasien. Informasi yang disampaikan pasien dan pendamping kepada dokter, biasanya tidak sepenuhnya menginformasikan apa yang telah mereka lakukan selama perjalanan pengobatan. Model interaksi yang banyak dikembangkan adalah antara dokter dan pasien. Untuk komunikasi yang efektif antara dokter dan pendamping untuk membantu pasien lebih baik, ada model penting untuk konsultasi yang mencakup komunikasi triadik: dokter-pasien-pendamping yang dapat menguntungkan. Penting juga bagi dokter untuk meningkatkan pengetahuan tentang pemahaman tidak hanya informasi biomedis, tetapi juga sosio, psiko, budaya, dan agama pasien.

Kata Kunci: *model penjelasan penyakit, persepsi pendamping, persepsi pasien, stroke*

Introduction

From a biomedical perspective, the disease may be defined as "a failure of the adaptive mechanisms of an organism to counteract adequately the stimuli and stresses to which it is subject; resulting in a disturbance in function or structure of some part of the body" (Plianbangchang, 2018). Besides that, the World Health Organization describes the definition of stroke as a clinical syndrome typified by "rapidly developing clinical signs of focal or global disturbance of cerebral function, lasting more than 24 hours or leading to death, with no apparent cause apart from that of vascular origin" (Puthenpurakal & Crussell, 2017). Stroke is a prevalent disease, especially in developing countries (Campbell et al., 2019; Kuriakose & Xiao, 2020; Liang et al., 2022).

The physician's knowledge can be different from patients' knowledge (Campos, 2019). Ideas and knowledge are social constructs that respond to different needs, interests, and values that have to do with our beliefs about things and how they are generated and shaped by social forces. In understanding disease, culture has its explanation because it can be used as a lens to understand and believe in disease. According to Kleinman, the definition of disease for a non-medical person can be very different. Illness can be interpreted as an innate human experience of symptoms and suffering that negatively impacts the patient and affects those closest

to them (Kleinman et al., 1978). A patient-centred approach is a way to involve patients in health care delivery, contribute to the quality of care, and strengthen health systems responsiveness (Waweru et al., 2020). Explanatory models of illness – the way people perceive, interpret, and respond to it – are mediated by the illness and cultural and social contexts (Dinos et al., 2017). It is crucial to understand the patient's experience with an interpersonal communication approach through fairy tales from patients and their companions.

Communication between doctors with patients and doctors with patient companions is the realm of interpersonal communication. Interpersonal communication is the exchange of ideas, information, opinions, and feelings related to a personal, social, organizational, family, national, and international event between two individuals (Budyatna & Ganiem, 2021; Pandjaitan, 2018). Understanding the meaning of disease from the patient's and companion's point of view is also part of understanding the communicator or communicant, according to the role taken in the interaction between health practitioners (including doctors) and patients. This understanding is essential, considering that disease is also a social construction of the patient that affects him in living life. There is a possibility that cultural and personal factors idiosyncratically influence the explanation from the patient and companion. Besides, we acknowledge three healthcare systems: biomedical, naturalistic, and personalistic (Mulyana et al., 2020).

Proficient doctors are expected to understand the patient's point of view to gain the patient's trust. When healthcare providers and patients listen and communicate, they can develop a shared understanding that may improve future decision-making and the quality-of-care patients receive (Kennedy et al., 2017). The philosophy of "going in from the patient's door, leaving the doctor's door" can be interpreted as a doctor's psychological maturity to accept the cultural context or the patient's personal experience first, then to direct the doctor's perspective, in this case, biomedically. Barriers to communication between doctors and patients/companions can be reduced with emotional and practical support. The problem is that emotional support for patients often gets less attention from doctors (Edgman-Levitan & Schoenbaum, 2021; Ganiem, 2018; Hyman, 2020; Mulyana & Ganiem, 2021; Nilsen & Malterud, 2017; Taber et al., 2015).

The role of the patient companion is also essential. A companion's presence to meet the doctor accompanying the patient is familiar. The companion is often seen as a family resource to improve the quality and safety of the patients (Turabián & B, 2016). Companions were present to provide accompanying 90% and emotional support 90% (Andrades et al., 2013). The patient's companion also preserves the doctor-patient interaction to maintain the patient as the most responsible and legitimate agent in the interaction and support the information during the consultation, such as history taking, problem presentation, and treatment recommendations (Fatigante et al., 2021; Troy et al., 2019). In the case of stroke, patients with a companion during a medical visit are about 1.7 times more likely to have than older adults without stroke (Price et al., 2019). Research from Ashkenazi et al. suggests that family members and other companions could facilitate faster and more effective emergency department (ED) management of stroke patients, possibly improving their outcomes (Ashkenazi et al., 2015). Besides, information

from companions can be used to assess the quality of life when patients are incapable of reporting their condition (Medea et al., 2021). For that, this research put the position of patient companions as vital to understanding their perspective.

Arthur Kleinman, a psychiatrist and anthropologist, created a theory of explanatory models (EMs). He proposed that individuals and groups can have vastly different notions of health and disease. The difference in point of view between doctor and patient can often be the reason behind misinterpretations or misunderstandings (Le Gautier et al., 2021; Shah & Kaltsounis, 2018); gender differences (Chen et al., 2021). The physician perceives the patient as a body experiencing symptoms; the patient usually perceives himself as experiencing illness.

To apply the explanatory model of illness, Kleinman suggests five elements of excavation: 1) etiology or cause of disease, 2) time and manner of symptoms, 3) pathophysiology or exploration of regular changes in mechanical, physiological, and biochemical functions either caused by disease or as a result of abnormal syndromes, 4) development of pain, and 5) treatment that is done.

This model emphasizes phenomena that patients demonstrate or interpret rather than those conceptualized by health science through exploring the "local moral world" from various aspects of patient disease. Explanatory models of illness – the way people perceive, interpret, and respond to it – are mediated not only by the illness itself but also by cultural and social contexts through their personal experiences (Dinos et al., 2017; Sayuti & Risnah, 2015). Understanding patients' perceptions of chronic illness are essential to designing effective strategies for helping patients manage these conditions (Habte et al., 2016). In this research, not all five elements of excavation are applied to this research.

Considering the patient's point of view regarding the disease is very likely to be different from the doctor's understanding. Besides, the healthcare reality comprises biomedical, naturalistic, and personalistic systems, which overlap (Mulyana & Ganiem, 2021; Rahmawati et al., 2019). Patients and companions are also not always willing to openly explain their thoughts and feelings. Doctors should explore the patient's condition in the interaction process, so it is interesting to study.

State-of-the-art research on illness explanation models relates to internalized stigma and disease behaviors, such as treatment preferences. The research use this model for people diagnosed with mental illness (Elliott, 2022) and patients with various health conditions, especially infectious ones such as COVID-19 (Al-Zamel et al., 2021). The second uses the Explanatory Model Interview Catalog (EMIC), a valid and reliable measure of stigma.

Internationally, there are many studies related to patient perception of their illness (Torain et al., 2021) for people with chronic diseases (Tran et al., 2019), people with pulmonary hypertension (McGoon et al., 2019), people with Parkinson's disease (Nijhuis et al., 2019), and stroke sufferers (Lamontagne et al., 2019). Likewise, research involving Kleinman's explanatory model of illness (Dinos et al., 2017) for people with HIV (Stonbraker et al., 2022) and stroke sufferers (Sanuade et al., 2021). In Indonesia, there are many studies on stroke (Agianto et al., 2022; Khariri & Saraswati, D, 2021; Thalib & Saleh, 2022);

however, those concerning the explanatory model of Kleinman's disease are still very limited. One of the studies conducted in Aceh in 2010 was regarding the patient's layman explanation of the stroke he had suffered, which included the definition of the disease and the things that caused it (Norris et al., 2010).

The purpose of this research is twofold. First, explore the meaning of stroke experienced by patients, according to the point of view of the patient and his companion and the treatment they had. Second, explore how the patient and the companion convey the condition to the doctor.

Interestingly, in this research approach, the perspective explored is only from the perspective of the patient and his companion, how they interpret the disease, what efforts are made and how they explain to medical personnel about their illness. This study does not explore how doctors react when interacting with patients and their companions. In addition, not all five elements of excavation are applied to this research. From Kleinman's concept, researchers will only explore the cause of the sickness, the impact on the patient, and the treatment the patient and their companion choose. The research may be valuable for improving doctor-patient communication, especially for stroke patients who need companion support, besides understanding the experience from the perspective of patients and their companions.

Research Method

This research uses a phenomenological approach, a study of consciousness for describing and ordering experience. Phenomenology is applied to the first-person subjective experience of illness to capture and acknowledge the primacy of varied and diverse perceptions. This qualitative research developed based on a thick understanding of the life world of patients and their families from the set of concepts taken from Merleau-Ponty, and how they communicate with health practitioners (Ratcliffe, 2020).

Some researchers use the terminology of a survivor instead of a patient. In this research, we choose the word patient instead of survivor; referring to the Cambridge dictionary, a patient is a person receiving medical care or getting care for by a particular doctor or dentist when necessary. The word survivor means a person who can continue living life successfully despite experiencing difficulties. As the research related to the elaboration of the experience of someone who got a stroke and how they communicate to the doctor, the word "patient" is appropriate.

The patient in this research is receiving medical care from a particular doctor due to a stroke disease. A companion in this research is someone who takes care of the patient and sits with the patient at the doctor, mainly while visiting the doctor. The roles of companions can be defined relative to four activities: 1) helping the participant onto the examination table; 2) reminding the participant about questions for their doctor; 3) talking to the doctor; 4) and helping to understand the doctor (Price et al., 2019), provide emotional support (Andrades et al., 2013). Those are the criteria of the selection for companion of this research. In this study, researchers interviewed two patients and one of their family from each patient. The total

informants are four people from Jakarta and Depok. The profile of the informants is shown in Table 1.

Table 1. Profile of the Informants

No.	Informant	Age	Sex	Education	Occupation	Residence	Note
1.	Patient-1	24	Male	University Student	Unemployed	Depok	--
2.	Patient-2	47	Male	Bachelor	Civil Servant	Depok	--
3.	Patient-1 Companion	48	Female	Senior high school	Employee	Jakarta	Patient's mother
4.	Patient-2 Companion	42	Female	Diploma	Employee	Jakarta	Patient's sister

Source: Primary Data Research

Researchers approached individuals and requested to participate in interviews about their experiences when they or their families got strokes. The interviews were semi-structured around the issues of interest of the research. Respondents were first asked about their health experience and the concept of stroke disease aetiology and prevention according to them and the family accompanying patients. The interview had done for around one hour for each informant. All the informants were those that researchers knew about their demographic questions, including marital status, education, occupation, and religion. The research was conducted from November 2021 to January 2022.

Firstly, researchers explore answers from patients and their companions regarding the meaning of the disease from their point of view. The researcher asked some related questions that Kleinman suggests to learn how the patient sees his or her illness: What do you think caused your problem? What is the chief problem the sickness has caused for the patient? What kind of treatment did the patient have? For the second objective, the researcher asked how the patients and their companions were informed about their health conditions and the treatments they had done to the health workers who provided services to them.

The research analysis is done by describing one by one in detail the findings of the development of the data obtained and made discussion. Complete data analysis refers to Miles, Huberman, and Saldana, which consists of four streams of activities that simultaneously occur, namely: 1) data collection; 2) data reduction, which is an activity to compile data abstraction; 3) data presentation, in the form of a presentation of the main points or an outline of the data whose validity is guaranteed; and 4) conclusions and verification, conclusions are drawn up tentatively to be verified during the study (Miles et al., 2014).

Result and Discussion

The disease of the patient in this research is stroke. Patients and their companions understand and agree that their doctors diagnosed the disease as a stroke. According to World Health Organization (WHO), stroke is considered as "rapidly developing clinical signs of focal (or global) disturbance of cerebral function, lasting more than 24 hours or leading to death, with no apparent cause other than that of vascular origin," (World Federation of Neurology, 2019). The

American definition of stroke includes silent infarctions (inclusive of cerebral, spinal and retinal) and silent hemorrhages (Coupland et al., 2017). Both patients had earlier diseases, such as cholesterol or high blood pressure. Both patients experience sudden pain, lose speech, rattle in their throat, urinate without awareness and are unresponsive. The confirmation about the diseases is used as the same perception and expectation about the symptom and treatment.

Perception of illness is a patient's cognitive appraisal and personal understanding of a medical condition and its potential consequences (Broadbent et al., 2015; Sawyer et al., 2019). The perception of individual experiences and mental frames living with a disease may relate to positive and negative beliefs. They can influence the ability to cope and manage the disease. Biomedically, the perception of the disease is the same: stroke. This perception is positive because it can lead to the same treatment effort, especially in the biomedical approach. The research result of the meaning exploration of stroke experienced by patients and their companions, as well as the treatment they had, is as follows:

The Cause of Health Problems

Table 2. The Cause of Health Problem

No.	Informant	What do you think caused your problem?
1.	Patient-1	• Patient-1 had high cholesterol then he got a stroke. His diet is not healthy. Patient-1 feels resentment at his father, who rarely returned home, was unable to be contacted and had rude behaviour - made him stressed and sick.
2.	Patient-2	• Patient-2 had high blood pressure, and then he got a stroke. • He had an unhealthy lifestyle and diet. • He got stressed due to the transfer of job position that was not as busy as before.
3.	Patient-1 Companion (mother)	• Her son did not have a healthy lifestyle. • The stress from her son was triggered by dissatisfaction with his father. • Her son is a perfectionist and likes things in order; if something is not what he wants, he will get angry. • At that time, her son did not have regular activities because her son was on leave from college. The lack of activities makes him get emotional faster. • The mother also felt suspicious of cultural factors that might occur in her son related to mysticism made by other people. Possible causes are: 1. The first possibility is from her husband, that is rude and irresponsible. He had affairs with several women. Perhaps one of them was disappointed in him and took revenge with mysticism. She questioned, "Why not the father? Why must it be her son?" 2. The second possibility is that because of her son. Before getting sick, he had many girlfriends. Maybe some people are hurt because of her son's behaviour, as she thinks her son is also rude.

		However, the mother thinks the first possibility is stronger than the second. • "I feel that maybe this disease was a warning from Allah to me. Maybe my son, as a young man, had done wrong according to religious belief; maybe he did prohibit things without my notice as a mother. Maybe Allah wants to show me, 'this is your son'."
4.	Patient-2 Companion (sister)	• Patient-2 had high blood pressure. His diet is not healthy, with high cholesterol and less exercise. • "He had a dream job that people expected of his position. Someone else might want his job position, so many are envious and might do some mysticism on him."

Source: Primary Data Research

Regarding the cause of the patient's problem, both Patient-1 and Patient-2 convey that they had an earlier trigger that caused the disease. Patient-1 had high cholesterol, and Patient-2 had high blood pressure.

"I like to eat noodles, cheese, spaghetti, and other high cholesterol foods. I also rarely eat fruits and vegetables, and I do not exercise because I am busy with my college." (Patient-1)

"Because I had high blood pressure since I was 30, I have taken a pill for lowering blood pressure every day. My doctor gave me the prescription, then I repurchase the pill at the pharmacy." (Patient-2)

They both did not have a healthy lifestyle (unhealthy diet, less exercise) and experienced stress in the family or office. Both patient companions believed that the patient had a previous disease, unhealthy lifestyle, stressful situation, negative thinking or emotions, and suspicious that other people did the mysticism to the patient. The perception of mysticism in both patients tends to come from the companion. One companion, the patient's mother, also thinks that her son's disease is perhaps a punishment from God.

"I feel that maybe this disease was a warning from Allah to me. As a young man, maybe my son had done wrong according to religious beliefs; maybe he did prohibit things without my notice as a mother. Maybe Allah wants to show me, 'this is your son'." (Patient-1 Companion)

The companion explained the perception about the possibility of having mysticism and God's punishment. Here we can understand the importance of a companion in influencing the patient's medication process. As the representative of the patients, the companions see the cause of the health problem as not only biomedical but also stress, and they are suspicious that there is a power outside of themselves.

It is important to understand perceptions and beliefs of the causation of ill health either from patients or their families. They are linked to a socio-cultural perspective. In Indonesia, people combine indigenous medical systems as an alternative healthcare service with biomedical health services. Kleinman's explanatory model of illness is quite similar to Murdock's ill-health theoretical model. Murdock suggests that we must distinguish between beliefs about the natural and supernatural causes of illness and disease. Both Kleinman and Murdock

perceive illness as having a combination of 1) supernatural causes include: theories of mystic causation (i.e., fate, ominous sensation, contagion, and mystical retribution); theories of animistic causation (i.e., soul loss and spirit aggression); and theories of magical causation (i.e., sorcery and witchcraft); 2) natural environment such as biological and psychological factors natural causes include beliefs that the impairment of health is a physiological consequence of some experience of the victim that is consistent with Western biomedicine. The other causes are social causes such as social trust, experiences of family support and harmony (Kahissay et al., 2017).

In Indonesia, alternative healing practices based on the personalistic system are known and widespread throughout Indonesia. The three healthcare systems, namely biomedical, naturalistic, and personalistic, can be found throughout Indonesia. Geographically, the biomedical system is more applied in big cities. In remote areas, naturalistic and personalistic systems are more commonplace than in cities. (Mulyana et al., 2020). Education and sociological background can also influence perception (Mulyana & Ganiem, 2021).

The Chief Problems the Sickness has Caused for the Patient

Table 3. The Chief Problems the Sickness has Caused for the Patient

No.	Informant	What are the chief problems the sickness has caused for the patient?
1.	Patient-1	He cannot continue studying, making it difficult to find a job, not easy to build a personal relationship or get married, losing many potential opportunities, and needs more help from others.
2.	Patient-2	He cannot continue working, has difficulties in personal and professional relationships, loses many potential opportunities, worries about the future, and is dependent on others.
3.	Patient-1 Companion	He cannot continue to study, and the disease is more significant and irreversible. He has difficulty finding a job to help himself and his family. He has difficulty finding a candidate to be his wife. He is emotionally fragile and a financial burden, losing many potential opportunities.
4.	Patient-2 Companion	He cannot continue working to fulfil his family, has difficulties in his personal and professional relationships, is losing many potential opportunities, is financially tricky, more dependent on others, and has more sickness.

Source: Primary Data Research

The sickness has caused both the patient.

"I cannot do my normal activities such as completing my colleague; I cannot get the job I dream of; I have difficulty meeting my friends or having a girlfriend, and many more problems such as needing more help from others." (Patient-1)

"My brother was very active and had extensive networking. He initiated many cultural programs in his community on a national and international scope. He could not work after the stroke. He had difficulties financing his family; besides, the disease was getting more and more pervasive." (Patient-2 Companion)

Both patients have suffered due to the disease. They said they could not continue their everyday life, could not continue to college or work, and had difficulties in relationships, financial burdens and many potential job opportunities or others. Both companions also have the same opinion about the loss of the patients. The disease is getting pervasive and irreversible.

Research from Tiwari et al. regarding stroke survivors in India concluded that themes emerged regarding the impacts for the stroke survivor are: 1) pervasive and irreversible; 2) multifunction loss and dependency; 3) holistic impact on the health of the person and family; 4) money and matter; 5) nonaccommodative cost and baffled belief; 6) professional paralysis, social crisis; and 8) slow and obscured progress (Tiwari et al., 2021). The caregivers should also adjust their lifestyle with financial apprehensions, worry about the future, prolonged hours of care, and stress are significant factors that increase the caregivers' burden. Wassenius et al. integrating consequences of the stroke into everyday life from those who experience a long-term stroke, conclude that "it takes time" to engage in occupational (Wassenius et al., 2022).

The Kind of Treatment, the Patient Had

Table 4. The Kind of Treatment, the Patient Had

No.	Informant	What kind of treatment did the patient have?
1.	Patient-1	• The necessary treatment is to use medicine from a doctor; eat; use a balm that wears off within two days, or therapeutically with warm water and alternative remedies for any treatment done at home. • Alternative medicine by reading certain verses from Al Quran, praying, taking rest, and positive thinking. • Physical therapy and alternative medicine are needed.
2.	Patient-2	• Medication from the doctor is necessary. • Eat healthy food and physical therapy. • Praying.
3.	Patient-1 Companion	• Therapy is the primary treatment because it directly impacts her son. • The doctor's treatment is secondary, significantly after long two years of sickness and no good recovery progress. • Praying to God and asking for prayer from a religious person. • Meet the healer or shaman (religious approach). • Using herbal. • Healing through a family approach. She asked her husband to pay more attention, go home regularly, give her a salary, communicate with his children, and encourage him. If this is done, it is hoped that his son will be less stressed. • She expected his son to think more positive thinking, not bother with trivial things, did not overthink, which causes stress.
4.	Patient-2 Companion	• The doctor's treatment is essential. • Therapy for self-independence is also vital. • Traditional medicine such as herbal is also consumed. • Praying to God, ask for prayer from family and religious people.

	• Healing through a family approach like encouragement from wife, son and families. • Ruqyah, religious chant and prayer. • Meet healer or shaman (religious approach).

Source: Primary Data Research

What kind of treatment did the patient have? Both patients believed the necessary treatment was medication from the doctor, physical therapy, eating healthy food and using particular external medicine such as balm when needed. Both patients believe that praying and positive thinking are also essential.

Both patient companions support the medication treatment from the doctor for the patients, even though they are the ones who mostly accompany the patients. Both patient companions believe the therapy is more priority for patients to be more independent and have self-help. Besides, always taking bio medication is quite expensive.

> *"We have economic considerations. We meet alternative therapies and treatments because they are less expensive than surgery or hospitalization. We also believe that herbal is a kind of natural healing; we hope that the human body has a self-healing mechanism. Alternative medicine is also safer because it tends not to react. The use of therapy also tends to exercise physically or provide a safe touch from chemical substances. Alternative medicine is more personal, less general. The same disease in a person will have a different approach." (Patient-1 Companion).*

Referring to the three healthcare systems, both patients have used the biomedical, naturalistic, and personalistic. It means that even though those three healthcare systems go separately, to some extent, they are overlapped (Mulyana et al., 2020). We can differentiate the treatments for both patients into three healthcare systems: 1) Biomedical systems include meeting several doctors, mostly visiting more than three hospitals; 2) A naturalistic system is an impersonal approach that tends to be nonmechanistic. It considers illness due to natural conditions of cold, heat, winds, dampness and the upset in an imbalance of body elements. Naturalistic may come, such as using herbal medicine and water therapy; 3) A personalistic system that sees the disease as the result of the intervention of a supernatural being (God, deity), a nonhuman being (ghost or evil spirit) or a human (witch or sorcerer). It is probably a feeling of being punished. Some activities in this treatment include meeting religious leaders, chanting, rubbing, and reciting prayers. Patients get energy like an electric shock when the healer touches it; they meet another healer that predicts there is someone who feels hurt by the patient for various reasons (this is for both patients with a different healer). Usually, the healer gives prayed water.

Both companions said that they considered praying to God and requesting prayer from religious people significant. Family and companions of Patient-2 even regularly held prayers with families and colleagues. Traditional medicine, such as herbal, was consumed by both patients, by buying themselves or getting from other families or friends. Emotional healing from families. Meet the healer or shaman to get rid of bad luck or witchcraft.

Kahissay et al. argue that illness's perception is linked to supernatural, natural, or societal causes (Kahissay et al., 2017). Therefore, health practitioners should include strategies for supporting patients' needs in all three domains. There are associations between favorable illness perception with better health outcomes for patients, while unfavorable illness perception has been associated with worse outcomes. For that, a doctor or health practitioner should use a multifaceted approach including behavioral, clinical, educational, and psychosocial components to improve one's illness perception through educative, cognitive-behavioral, or psychodynamic counselling (Sawyer et al., 2019).

How Patients and Their Companions Communicate to Their Doctor

Table 5. How Patients and Their Companions Communicate to Their Doctor

No.	Informant	How patients and their companions communicate to their doctor
1.	Patient-1	• The patient informs the condition according to the question from the doctor regarding the physical condition. • The patient did not express concern about his perception because the doctor did not ask a more profound question. • The doctor suggested therapy and taking medicine.
2.	Patient-2	• The patient informs the condition according to the question from the doctor regarding the physical condition. • The patient did not express concern about his perception because the doctor did not ask a more profound question. • The doctor suggested therapy and taking medicine.
3.	Patient-1 Companion	• The patient's mother only informs the patient's physical and mental conditions.
4.	Patient-2 Companion	• Sister of Patient-2 accompanies the patient, replies to the doctor's question, or shares their concern regarding the patient's physical health and mental condition.

Source: Primary Data Research

How do patients and their companions communicate to their doctor about their health and treatment? Both patients had informed of the condition according to the question from the doctor regarding the physical condition. They did not inform any concern about his perception because the doctor did not ask a more profound question, and they had communication difficulties.

"As usual, the doctor asks about my condition. My mom and I explain what we know and feel. I never tell my feeling or my worried also. There is no time; there are a lot of other patients." (Patient-1)

The patient informs of the condition according to the question from the doctor regarding the physical condition. The patient did not express concern about his perception because the doctor did not ask a more profound question. The doctor suggested therapy and taking medicine.

The companions stated that they informed the doctor about the patient's mental condition but did not inform the doctor about the cultural treatment they had done.

"Besides medicine, I add honey or traditional medicine that family had given. I inform regarding healthy food taken, but not the traditional or herbal." (Patient-1 Companion)
"I inform the doctor regarding his health condition and his mood. I hope the doctor can add motivation to my brother." (Patient-2 Companion.
"We have limited time to meet the doctor, and sometimes we still have many questions, but we see the body movement or feeling of, sorry I need to meet another patient, so we ask more to the herbalist or people who understand about stroke." (Patient-1 Companion)

Here we can see the importance of a companion for the patient. Stroke survivors with more significant physical impairment and dementia were likelier to have a care companion. Communication problems are also common after someone gets a stroke, such as speaking, reading, writing and understanding what other people say to them. Around one-third of stroke survivors have problems with these communication skills because if a stroke damages some parts of the brain responsible for a particular task, this can cause problems with communication. However, it does not affect their intelligence (Stroke Association, 2022). The other person also has difficulties understanding the patient.

The companion in this research is the one who can help the patient on the examination table; talk to the doctor and registration officer; add certain important information about the condition of the patient that the patient or doctor has not raised; help to understand the doctor; facilitating patient-doctor communication and providing contextual information; provide emotional support. That companion may also influence the consultation. According to Price et al. (2019), stroke survivors are about 1.7 times more likely to have a medical visit companion than older adults without stroke. According to Andrades et al., the companion played a supportive role in 62% of the consultations (Andrades et al., 2013).

There is a gap in information during the communication between the doctor-patient-companion. Patients and their companions do not share all information about the patient. There is little discussion regarding the treatment that patients have done. The doctor should have the cultural capability or skills to enable clinicians to work effectively with patients from diverse cultural backgrounds and enhance clinical outcomes (Dinos et al., 2017). The explanatory models should become part of the routine mental health assessment through the "cultural formulation", given its importance for diagnostic accuracy. The model does not always consist of a concrete, fixed set of beliefs, but can be construed as multiple explanations, held simultaneously, some transient in nature.

Conclusion

According to the point of view of the patient and their companions, some aspects of stroke are expressed: the cause, the impact, the treatment, and the religious help. They both did not have a healthy lifestyle (unhealthy diet, less exercise), experienced stress in the family or office, had negative thinking or emotions and got others' suspicious mysticism or God's punishment. They both suffered from the disease and had many difficulties continuing their life. They both believed the necessary treatment was medication from the doctor, physical therapy,

eating healthy food, using particular external medicine, praying, and positive thinking. Both companions support the medication treatment; the therapy is more priority for patients to be more independent and have self-help. Both companions said they considered praying to God and requesting prayer from religious people significant. They have used three healthcare systems: biomedical, naturalistic, and personalistic.

According to conveying doctor about the conditions, the patients and their companions had informed to answer the doctor's questions regarding their physical condition. They did not inform any concern about his perception because the doctor did not ask a more profound question, and they had communication difficulties.

Explanatory models of illness should be included in clinical use. Medical practitioners should include routine assessments regarding cultural formulations and interviews in their daily clinical practice. Also critical for the doctor to upgrade the knowledge about understanding biomedical information and the patient's socio, psycho, cultural, and religion. This knowledge is the way to place the patient's autonomy rights in decision-making, beneficence, and non-maleficence.

To enrich knowledge about patient perceptions of disease, we propose the following research suggestions: 1) The most developed models of interaction are only between doctor and patient. Because the companions helped the patient in many tasks, from accompanying them at the examination table to providing emotional support, they might also influence the consultation. For effective communication between doctor and companion to help patients better, there is an essential model for consultation that includes triadic communication: doctor-patient-companion, which can be advantageous. 2) It is necessary to do more research related to layman perceptions of the disease because it is still rare, especially in Indonesia, which has a variety of cultures in its society. 3) This research is limited to the patient's and companion's perspective on the disease, for this reason it is necessary to do research using the doctor-patient and patient-doctor method so that margins are obtained from two different sociological information points of view.

All the findings are contextual to the research. However, as differences exist depending on the individual medical, cultural, and psychological setting, caution should be asserted in generalising findings.

Acknowledgement

The authors express profound gratitude to Mercu Buana University and STIAMI Institute for their support and assistance in this research. Sincere gratitude also goes to all the informants in the study for their insights, experiences, and comments shared.

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