Unraveling communication between child patients’ family members and healthcare staff

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ABSTRACT

Health Communication in general and therapeutic communication in particular as relatively new communication fields are getting more important at the present, let alone in Indonesia with a population of over 270 million people. They come from hundreds of ethnic groups that may have different assumptions about the causes of and the solutions to various diseases and illnesses. Many health problems are related to communication problems between health providers and patients who may come from different cultures. These communication problems occasionally lead to medical malpractice. It is based on this reason that effective communication between healthcare staff (doctors and nurses) and patients (and their families) is deemed critical in bringing about satisfying results for both parties. This study aims to unravel therapeutic communication between healthcare staff and family members of patients. It used a phenomenological qualitative research method. The sample of the study were family members of child patients hospitalized in two hospitals in Jakarta who accompanied the child patients during their hospitalization from 2015 to 2017 and in 2019. The sample consisted of 30 participants; they all were interviewed and observed in the study. Without aiming to make generalizations, the research findings showed that in essence the research participants were satisfied with the communication conducted by the healthcare staff and the BPJS (Badan Penyelenggara Jaminan Sosial or Social Security Administrator) program provided by the Government. But some of them had their unspoken dissatisfaction with the overall treatment process related to doctors’ communication and the deficiency of the BPJS program.

Keywords: Therapeutic communication; patients’ family members; healthcare staff; BPJS; phenomenological method

Mengungkap komunikasi antara anggota keluarga pasien anak-anak dan tenaga kesehatan

ABSTRACT


Kata-Kata Kunci: Komunikasi terapeutik; anggota keluarga pasien; staf perawatan kesehatan; BPJS; metode fenomenologis

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INTRODUCTION

People communicate all the time; the nature and process of their communication change, depending on the context of space and time (Khairil et al., 2020; Mulyana, 2018). The meaning of a message is subject to various factors, be it biological, environmental, or socio-cultural. The communication practices in medical encounters comprise two modes: first, methods using soft skills such as emotional communication, sympathy, respect, and supportive attitude. Second, the instrumental mode such as body language, listening skills, nonverbal practices (Bleave, 2012; Del Piccolo & Goss, 2012; Khalfan et al., 2015; Oliveira et al., 2014; Shahid et al., 2013).

Effective communication between healthcare staff and patients will bring favorable experiences such as emotional comfort and favorable technical details of treatment such as information acceptance, compliance with treatment, and overcoming the therapy obstacles (Bleave, 2012; Manganelli, 2016; Mulyana, 2016; Nona et al., 2015).

Long before we were aware of the role of healthcare staff’s effective communication to cure patients’ illness, Hippocrates pointed out the connection between doctors’ effective communication and the greater probability of the patient’s recovery. He stated in 400 BC, “The patient, though conscious that his condition is perilous, may recover his health simply through his contentment with the goodness of the physician.” This was also reinforced by Michael Balint over a half century ago that the most effective drug in medical practice was the doctor himself (Bensing & Verhaak, 2004).

A lot of research has indicated that healthcare staff’s empathy toward and effective communication with patients reduce their worries, pain and blood pressure and enhance their general health. Essentially the studies conclude that the healthcare staff’s more effective communication adds significantly to the patients’ wellness. In this context, communication is considered effective if the effect of communication fits the purpose of the communication participants, whether to inform, to educate, to entertain, to persuade, to induce action, or to settle a problem. Communication among people involved in healthcare is effective if it fulfills the expectation of the communication participants (doctors, nurses, patients), or more specifically, the full recovery of the patients (Mulyana, 2016).

Based on the above contention, from the perspective of patients and their families, positive communication practiced by healthcare staff can have good effect on patients’ and their families’ perception of the medical treatment given by the healthcare staff in the hospital. Access to quality healthcare services is pivotal in countries like Indonesia, where many people are not able to receive or have access to proper medical facilities. Indonesia now has a national healthcare insurance program managed by Badan Penyelenggara Jaminan Sosial (BPJS) or the Social Security Administrator.

Indonesia is a country embracing a collectivistic culture that encourages people to maintain social harmony (Mulyana, 2019). The collectivistic culture refers to societies whose members have been socialized into strong cohesive groups which cultivate the members’ loyalty throughout lifetime, in contrast with the individualistic culture which refers to societies where the ties between people are loose; thus, everyone is expected to take care of oneself and one’s immediate family (Hofstede, 1996).

Because members of the collectivistic culture have strong commitment to foster harmony, they avoid direct confrontation. Typically, the third party is expected to mediate the two parties in disagreement to save their faces. So, members of collectivistic cultures are not accustomed to settling conflicts. To avoid conflicts, when these cultural members must be examined by medical doctors, they often seek the consent from their elders, and in some cases, the family spiritual healer with whom they have had long contact. People who embrace a collectivistic culture consider illness as a social problem rather than a personal one. People suffering from illness usually ask for help from their family members. Other members of the family or even the community are engaged in eradicating the illness, by accompanying the patients to the health providers, watching them at night in the hospital, and by visiting them as often as possible (Mulyana, 2016).

As Indonesians generally belong to the collectivistic culture, the way Indonesian people exchange information is distinct and different from other peoples of the Western individualistic countries. Indonesians are not
accustomed to talking about sensitive issues such as negative communication modes with other people, especially high-ranking ones which may include people with higher social status such as medical doctors, as they are worried that such a discussion will undermine the social harmony that should be maintained.

While pondering over the Indonesians’ cultural values in their communication with each other, this research aims to unravel communication between families of patients and healthcare staff in two hospitals in Jakarta. More specifically, this research aims to explore the extent to which the family members of the child patients are satisfied with the services given by the Indonesian health insurance program administered by BPJS and with the healthcare provided by the healthcare staff (doctors and nurses). Additionally, this research also aims to explore the challenges of communication between the family members of the child patients and the healthcare staff and the way the family members overcome their dissatisfaction and get over cultural obstacles and how they find ways to manage their anxieties.

METHOD

This study is based on an interpretive paradigm assuming the subjects of the study have consciousness to construct the meaning of their experiences. They are not merely inanimate entities that can be quantified and predicted like in objective, deductive and positivist research. Simply put, this research takes an inductive model resulting in significant themes and descriptions.

In a phenomenological study, the number of research participants is not a critical issue, as the study can highlight a few subjects, as Duke recommends, from three to ten subjects (Creswell, 2013). Even three to six interviews are considered adequate to carry out phenomenological research aiming to unravel the subjects’ personal perceptions and understandings of their experiences (Braun & Clarke, 2013). The number of the research subjects in this study exceeds far beyond the number of research subjects recommended above, that is, 30 family members of the patients treated in a public hospital and a private hospital in Jakarta. The relatively vast number of the research participants enabled the researchers to analyze the data to the maximum degree, although this study is not aimed to make generalizations.

The whole study lasted from February 2015 to May 2019, with the purposive sample of this study consisting of 11 males and 19 females aged 32 - 55 years at the time of the field research. Most of them are parents of the child patients who came from rural and urban areas in Indonesia, the rest being their relatives such as grandmothers, aunts, and uncles. Most of the child patients were suffering from several kinds of illness such as dengue fever, typhus, and especially cancer. Ethics consent was given to the researchers by the Health Research Ethics Committee of the participating hospitals. The patients’ family members signed the forms of agreement (informed consent) to participate in this study.

This research employed a phenomenological method or strategy involving semi-structured in-depth interviews with the research participants and observation (Creswell, 2013; Mulyana, 2018). The researchers needed more time to gain trust from patients’ families prior to interviews with them and endeavored hard to enable the patients’ family members to feel comfortable in answering the researchers’ questions. The research endeavor was hampered by the anxieties of the research participants who found their beloved children in uncertain situations as patients, with a few in critical conditions. The researchers needed to be steadfast to find the most suitable time to talk with the patients’ family members, because they also had to have a focus to take care of the patients. The researchers met with every research subject four until five times, including developing rapport with each of them, this resulting in a relatively long duration of research. While having discussion with the family members, the researchers did alleviate some of the family tasks such as feeding the child patients and carrying their luggage.

All the 30 family members of the 30 patients were inclined to become the sources of detailed information about themselves and the medical treatment given by the healthcare staff to the patients, although a few of them were initially reluctant or doubtful to do so.

A qualitative study like the present one is useful for generating hypotheses which later can be tested by objective-quantitative research.
From the results of this investigation, the main themes were developed, which were used as a basis for developing alternate themes (Chittem & Butow, 2015). In this paper, the researchers have used some of the research participants’ quotes without revealing their names in order to protect their actual identities, privacy and confidentiality. The names of the two participating hospitals are also undisclosed to protect their reputation.

RESEARCH FINDINGS AND DISCUSSION

From the phenomenological data collected, the researchers have developed some important findings as delineated and discussed in this part of the paper.

All of the research participants indicated their dissatisfaction with part of the service of BPJS as the state operated health insurance facility. Although BPJS gave the patients an economic and health benefit in the form of receiving the same medicinal treatment facilities, from another perspective the BPJS was perceived by the research participants as undesirable and a burden to patients. This induced negative emotional reactions, anxiety, and loss of hope. BPJS only covered part of their financial burden. They had to spend expenses for necessities such as food, accommodation, transportation, laundry, pampers and medicine for patients.

Still from another perspective, all research participants agreed that the BPJS implementation in the field was unfair to them who had a different (lower) economic status. From the moment they wanted to get the facilities and prescriptions, they had to wait and feel frustrated with the process. The following are the problems they encountered:

“With the emergence of BPJS health insurance I feel I have gained great support and it’s hard to imagine what it would be like without it. The doctor’s communication with me is good and in fact it was the doctor that recommended BPJS to me. The nurses are good and patient too. In spite of this I am still stressed by the long queues which begin from waiting to register for examination, collecting medicine, chemotherapy and getting a room. The extreme level of my child’s condition is due to delays in receiving chemotherapy”

“What can I do? Sometimes I wonder why my fate is like this. I have tried to accept it. However, sometimes I still feel upset. I feel sorry for my child. If it is me who have to queue until the midnight, then I am okay with it. But seeing my kid anxious, crying,

Relative Dissatisfaction with part of the BPJS Service

Source: Authors’ Research Findings, 2021

Figure 1 Factors Contributing to Dissatisfaction
saying: ‘Mama, it hurts. I cannot take it any longer,’ how can anyone not be upset?”

“I know that I should wait in a long queue. That is why I usually come at dawn, before the hospital’s opening hour. [Meanwhile] My wife is watching our kids. I usually skip work to queue. Even though the medical bill is free, it is not my only expense. If I am frequently absent from work, I am afraid that I will get fired. I feel guilty to my colleagues from work. Fortunately, my friends and boss are very kind. They understand my situation.”

In fact, this finding is not surprising. Many cases from casual talks with BPJS patients in some hospitals and clinics in Indonesia, media reports, and some research results indicated that some of BPJS patients feel discriminated against or neglected by the healthcare staff where they are examined and/or hospitalized. They feel that the healthcare staff tend to prioritize other general (non-BPJS) patients, let alone patients who have better (private) health insurance. For instance, one of the researchers was told by his brother in-law who had experienced such unfair treatment in a private hospital in Bandung. He had to wait for a long time to meet the doctor who then said harsh words to him, including ‘You are luckier to have a less terrible ailment.’ As another illustration, there were differences of service in the Public Hospital in Surakarta as experienced by the BPJS patients as the subjects of the study. The BPJS patients felt less satisfaction compared to the general patients, because the service given to the BPJS patients was not effective and was not efficient (Pertiwi, 2017).

Another weakness of the BPJS service according to the majority of the research participants pertains to incomplete information. Some research participants obtained the information about BPJS from other patients, not from a trusted source. Those family members then relied on the rumors in order to obtain the best and most relevant information for their needs. There were two kinds of rumors. First, information about the disease and the procedure to get the medical treatment in the hospital and also the available choices of medication. Second, the information about the infrastructure facilities such as a place to stay in the vicinity of the hospital, and possible donations from generous individuals or charity organizations that carry out philanthropic programs to support child patients and their families. In reality, there were always generous people who came to the hospital to donate light meals, pampers, pillows, and toys for their children. Some volunteers even helped them to get new fresh blood from places outside of the hospital.

Interestingly, rumors helped the family members to overcome the emotional turmoil on the daily basis. The information exchanged between them, regardless of its reliability, helped them to reduce their anxieties and displeasure.

“It’s not possible to maintain close relations. This is a big hospital with a lot of patients. The doctors and nurses are understanding. None of them are pushy or annoying, but they only turn up when it’s time to come. There is no in-depth contact. We only see them and get a response when we ask about our child’s condition or when a situation occurs. We can’t feel close to the nurses, let alone to the doctors.”

“The checkup, operation, and hospitalization expense is—thank God—free. I am delighted. But before I came to this hospital, I did not know that free healthcare such as BPJS existed. My mind was blank, quite for a long time. I was confused. There were so many people in the hospital. So I took a seat on the edge of the road, while buying some snacks for my kid. I was talking to some people there. From them, I know about the BPJS. I almost cannot believe it. But then, I saw that one of the men [whom I was talking to] also had a very sick kid. I feel like I can trust him. So I follow several steps that he explained to me.”

“Fortunately, I have friends who are also poor. We often share information on doctors, nurses, cheap medicine, housing, and many other things. Many pieces of the information are true, although some are not. Nevertheless, [the information sharing is] actually quite helpful. For example, I know which doctor that will kindly answer my questions regarding the medical procedure. Even though some doctors and nurses are nice, many of them are unfriendly. I know
In general, the research participants were satisfied with the time management handled by the healthcare staff who could fulfill their technical needs and enlighten their emotional burden as well. But some of these healthcare people did not show empathy to them through their statements, such as depicted by the following research participant:

“I can feel which one [of hospital staff] is sincere and which one is not when they are talking to us. When we are in a difficult situation, we will be very happy if, at least, the doctor is friendly. It will even be better if he or she sometimes tells a joke to melt the situation. When doctors are like that, children [patients] usually become very happy, they laugh. Because we have been in the hospital for quite a long time, sometimes we get bored and run out of activities to do with our children.”

The majority of the research participants said that they were happy with the medical service. However, based on the researchers’ observations, some of their verbal statements were not consistent with their actual feelings, some of which were expressed through their body language such as facial expression and intonation, pitch, and speed of speaking. In a high-context culture such as Indonesia, it is common for people to not say what they mean and to not mean what they say. Put differently, the actual or closest meaning of a message is often embedded in the context of communication, in the body language of the communication participants, and sometimes in their silence. Only when a person keeps asking or interrogating his or her communication partner, the latter will give an honest answer. In this research the researchers did such a thing carefully when interviewing some of the research participants until the researchers were satisfied with their answers.

The tendency of Indonesian people to give ‘proper’ answers may also be due to the fact that in Indonesia there is a higher power distance between common people and people who have a high prestigious profession like medical doctors (Geert Hofstede, 2010; Geertz Hofstede, 1996). A medical doctor is one of the top figures in social hierarchy in Indonesia, especially based on social status parameters. In an Eastern culture like Indonesia, subordinates or people from the lower class also look up to and show their obedience to their superiors or people from the higher class by not criticizing them.

A larger proportion of the research participants had favorable views of doctors’ and nurses’ communication with them. A
cultural aspect that encouraged the research participants to say that the doctors’ and nurses’ communication was positive is their spiritual background. As spiritual human beings, they thought that they had to surrender themselves to God who has created whatever situations they faced and whatever afflictions they had.

“I feel that everything has been preordained. My child is ill. My family and I are having difficulties but we have come into contact with nice people - patient doctors and nurses who are understanding - especially when I was told by the hospital administration that the total cost reached 1.3 billion rupiah. Try imagining where we could find that much money. Thank God for the BPJS … We have already received financial assistance and patience was fitting.”

“Even though one of my kid’s eyes cannot see anymore, when I see there are many worse cases [than hers], I am thankful of what is left. God is still protecting my kid. Even though sometimes I feel tired when I am queueing, I still withstand it. I feel luckier than those parents who have sicker kids.”

The tension to deal with the uncertainty of the patients’ ailments, made the family members feel sad. When they were trying to obtain the assurance of their kids’ fate from the healthcare staff, they felt that all those people in charge did not strive the best they could to respond to their worries, and consequently they became more anxious. This problematic situation made them doubt the medical treatment provided by the hospital. When the anxious feeling grew more frequently, they sought information about alternative medicine to cure their kids’ illness. They were keen on having the conversation with family members of other patients about alternative treatment for their ill children. They felt that such a conversation gave them a possible way out.

Some research participants suffered from more extreme anxieties since they came from rural areas far from a big city. They had a sort of culture shock. A big city like Jakarta was too expensive, unkind and noisy for them. They felt alienated in Jakarta. They had to financially support not only their children as hospitalized patients, but they also had to financially support themselves in the big city, especially for food and accommodation, and other family members such as siblings of the child patients, who still lived in the village where they came from.

Some of the research participants felt a little relief when they met family members of other patients who came from similar social backgrounds, especially those who came from the same ethnic group, the same religious group, or the same place of origin. By mingling with others who were socially and culturally similar to them, they were able to exchange information on the nature of their children’s ailments, the place to stay near the hospital, and even the approximate amount of money they had to spend for their children’s medical treatment. It was found out, for example, that parents whose children were suffering from cancer had to accompany their children longer. But it was impossible for them to stay in the hospital, so they had to seek a humble place to stay which they could afford financially.

From the observation, the researchers could figure out that the patients’ family members did not really ponder over other treatments beyond the biomedical treatment suggested by the healthcare staff, when they felt satisfied enough with the healthcare staff’s medical service. They used the discussion on the alternative treatments or alternative medicine as a catalyst to overcome their anxiety.

“Even though the check up is free and the medicines seem sophisticated, when the doctor diagnosed that our kid’s condition was uncertain, my husband and I were confused. Therefore, we were looking for another ointment that can help the effect of prescribed medicine. What can we do? The doctor seemed like he already gave up, but still gave my kid medicine. Maybe because it is free. The situation was very stressful. I hope traditional medicine can help. I listened to every advice, and will try to obtain any ointment that can cure my kid’s disease.”

“Frankly I was very disappointed when the doctor said that our kid’s case was hopeless. I felt weak. Even though I did not have to pay or think about payment I was still sad. As a parent I had to find...
another way. I went looking for all kinds of medicine without telling the doctor. The doctor learnt about this from another patient and I received a warning. He said it would cause a conflict of medicines. I said nothing. Who knew whether the alternative medicine would help or not.”

This study found that most of the research participants were more comfortable with nurses. Nurses helped them to get through their difficult time, in contrast with doctors, who did not have ample time to accompany them when they were in need of technical and emotional backups while assisting their children.

**Discussing Factors Contributing to Relative Satisfaction.** The research participants’ satisfaction was partially due to not only the nurses’ collaboration but also due to the research participants’ cultural backgrounds, especially their spirituality. Those who are religious in particular all have similar views that they may not complain about anything if they want something good for their kids. Religions taught them to have a positive mind and behavior if they want God to help them. Put differently, they tend to be fatalistic, irrespective of the actual interpretation of their religions they embrace. That is why they appeared fine during the treatment process. This condition fits the notion that people’s personal backgrounds can give patients or their family members a strength in critical situations (Bartz, 1986).

However, there is a factor that affected the research participants’ less satisfaction, namely, the technical aspect such as the insurance services. There was not adequate information on how to get the best options in using the insurance. Besides, they had bad experiences while queuing to get the room or prescriptions, this giving them some negative experience. Based on this study the researchers realize that this technical constraint (long queue time) has contributed to the whole sense of satisfaction. This finding approximates the research finding (Mathews et al., 2015) that the waiting time adds to the satisfaction degree.

The third factor that affects the relatively low level of satisfaction of some participants is the limited communication of healthcare practitioners, especially doctors. This is related to the contention (Jacobalis, 1989) that communication is one of the main factors that affect patients’ satisfaction with the whole medical treatment. The researchers found that the lack of communication between doctors and family members of the patients made the family members feel neglected. The research participants became more anxious because of this problem.

From the observation, it turned out that the research participants needed a companionship from an authoritative figure like a doctor. In an Eastern culture like Indonesia, people tend to rely on the decisions made by patrons, superiors, or elders (Mulyana & Ganiem, 2021). In this case, when the doctor, as a patron, gives a direction or information which is limited in terms of its duration and frequency, the research participants lost their confidence in the treatment. When the family members were listening and smiling to the healthcare staff, the smile did not mean that they felt satisfied. They tried to send a positive cue to the doctor or the nurse, because they were worried if they showed their dissatisfaction, the doctor would not take care of the patient any longer. So, they displayed a positive manner to the healthcare team, as an effort to obtain a better treatment.

The fourth factor that affects the research participants’ relative satisfaction is the social communication between patients’ family members and other non-medical persons (other patients and their family members) in the hospital. The moments of sharing their favorable and unfavorable experiences, provided the family members with alternative ways to cope with their anxious feelings. The researchers found that some of the research participants learned about the alternative treatment because of their helpless feelings due to the lack of communication with the healthcare staff, notably the doctors. People sharing the information about the alternative medicine felt that they received new energy to get through the hard times. Most of the research participants, specifically 26 participants, said that it had never occurred to them before to use the alternative treatment. They used to believe in the modern treatment, therefore they chose to go to the hospital. But later in the treatment journey, they felt frustrated especially because they could not get the proper time to discuss their anxiety with the doctors. This situation led them to find the discussion on the alternative treatment with other family members of the
patients as another way to cope with their problem.

It is common for patients to choose a hybrid approach for a medical treatment. It is noted, even for cancer, the alternative treatment can be combined with modern treatment (Tabatabaei et al., 2016). However, in this research, the use of alternative treatment (traditional method) did not get any support from the healthcare staff. When doctors or nurses discovered that patients were using alternative medicines, the healthcare staff were more likely to give pressure to the patients’ family members. So, the warning given by the healthcare staff about the alternative treatment contributed to the level of stress of the research participants.

This research indicates that when the family members of the patients and the healthcare staff were in good relationships, the former always indicated positive behavioral signals to the latter. The discomfort and dissatisfaction felt by the research participants did not lead them to ask for better treatment or even complain to the medical staff. This tendency, to reiterate, is due to the collectivistic nature of Indonesian community who tends to maintain social harmony and avoid conflicts, especially when facing authoritative figures like doctors. In return, the doctors, being used to engage in a paternalistic mode of communication, tend to control all the information and treatment decision for the patients (Mulyana, 2015; Mulyana & Ganiem, 2021; Mulyana & Verity, 2016). In a paternalistic culture like Indonesia, the family members of the patients, like the patients themselves (both as the clients), are more likely to comply with the advice of the doctors as their patrons.

CONCLUSION

This study found that the research participants’ overall impression of the medical treatment given by the healthcare staff to child patients through the service given by BPJS program in the two hospitals in Jakarta was relatively favorable. All the family members of the patients indicated that they were relatively satisfied with the medical treatment given by healthcare staff. However, based on some observation and intensive communication with the family members, some of them revealed that they were dissatisfied with the healthcare staff, especially the doctors who indicated a lack of communication with them, although this dissatisfaction was unspoken due to their reluctance to criticize them.

It was revealed that to some extent they were grateful for the existence of the BPJS program that could support the medication and the hospitalization of the patients such as their children, while hoping that the program would be better in the future to serve the patients, especially those from lower-class families. More specifically, they suggested, the time of the service and treatment should be faster, and the additional cost should be lower in the near future.

From the researchers’ point of view, further research can be conducted to explore the issues above, which should involve longer and more intimate interaction with research participants so that more unsaid and hidden meaning of their communication messages can be revealed. For instance, it is interesting to find out how the healthcare staff and the patients and their families communicate nonverbally and what meaning can be attributed to the nonverbal behavior displayed by the parties involved. It should be remembered that the majority of Indonesians belong to ethnic groups, such as the Javanese and the Sundanese, who are engaged in high-context communication in which meaning is often ambiguous and indirect. Since members of a few ethnic groups such as the Batak, the Macassarese and the Betawi tend to practice low-context communication, there is a question about the way these members communicate with members of the high-context culture in the healthcare context. In this case, participant observation is deemed inevitable to corroborate the data taken from in-depth interviews with the subjects of the study, especially to ascertain the closest meaning of the ambiguous verbal messages.

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