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Subjective Illness Experiences of Open-heart Surgery Patients in the Thai Cultural Context

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This qualitative case study investigates the illness experiences of patients who underwent open-heart surgery in the Thai cultural context. The study site was a central hospital in the Eastern region of Thailand. Data were primarily collected by narrative interviews with seven patients who had open-heart surgery under varied circumstances. Narrative analysis was used to analyze the data. The key findings are: 1) the subjective illness experiences of the patients before and during the open-heart surgery includes being on the edge between life and death, feeling like coming back from death, and attributing their surgery to misfortune; 2) the subjective illness experiences of the patients following the open-heart surgery includes increasing dependence on medical technology and feeling like a cyborg, a non-human or an animal. The patients' subjective illness experiences reflect their perspectives on medical technology in open-heart surgery. The findings could contribute to medical personnel's more holistic understanding of the lives of patients from scientific as well as cultural viewpoints and to the improvement of the mental and emotional health care for open-heart surgery patients.

Keywords: *medical technology, subjective illness experience, open-heart surgery, culture*

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Introduction

Narratives of collective experiences of patients are vital to the delivery of health services because they reflect human spiritual needs, ideology and the relationship between humans and their surroundings (Kleinman, 1988). Patients with myocardial infarction, also known as angina pectoris, often describe chest pain and discomfort that include pressure, heaviness and squeezing in the chest, difficult breathing, and sometimes pain in the left arm, the neck or the armpit (Lhojaya, Phongpanich, & Sakhonphan, 1993). In doctors' opinion, open-heart surgery with medical technology is the only means to fix the problem and rid the patients of the pains and suffering. But the patients themselves rely on cultural beliefs in describing their experiences of an open-heart surgery. They often experience the feeling of being at the threshold between life and death. In the process leading up to the operation, they experience anxiety from the fear that they would cross that threshold and never revive.

Patients' experiences with medical technology are often filled with imagination stirred up by doubts and worries about its harm to the human body at one end, and its miracle as a cure at the other. Patients have to deal with the uncertainty of the outcome of the application of medical technology, whether it is death, disability, disfigurement, blood loss or grief; they have to encounter with the prospect of their lives being controlled mechanically and electronically (Biehl, Good & Kleinman, 2007). These experiences reflect the patients' positive and negative views of medical technology and its impact on their post-operation identity. Consequently, the reactions of patients with cardiovascular diseases to medical technology vary from enthusiasm and disappointment to denial as when encountering the failure of treatment (Lapum, Angus & Watt-Watson, 2010). Although there have been many studies on the health outcome of open-heart surgery regarding mortality, morbidity and economic costs (Rujirawat et al., 2008), the study of patients' subjective illness experiences with medical technology has been neglected.

Gabe, Kelleher, and Williams (1994) suggests that surgery destroys religious faith, morality and physical health and reduces the worth of human to that of machine-like organisms. Applying this concept to open-heart surgery, Portor (2006) argues that the dissection of the chest in such an operation put the body in crisis. According to Johnson (1991), since inside the chest is where the heart, the most important organ in the body, is located, when it is cut open, for the patients, it signifies the approach of death, suffering and worry about the caring of their children and family members

in the future. These feelings and emotions are termed as the patients' subjective illness experience with open-heart surgery.

No studies have been conducted in Thailand so far on the subjective illness experiences of open-heart surgery patients, whether in the periods before, during or after the operation. In Canada, a study by Lapum, Angus, and Watt-Watson (2010) concluded that the feelings or subjective illness experiences affected the patients' recovery after open-heart surgery. Those who were distrustful or fearful of the medical technology in open-heart surgery were found to have difficulty to adjust when entering the recovery process. A study by Vila, Rossi, and Costa (2008) found that patients who have coronary artery bypass grafting surgery believed that the heart means life, and life would end if it stops beating. Thus medical staffs need to assist the patients' transition to the rehabilitation process by informing them of facts about medical technology and give them encouragement in order to change their passive attitude into satisfaction.

This study is intended to obtain the patients' perspectives on medical technology which may be useful for those who are responsible for providing health care to open-heart surgery patients in the context of contemporary Thai society. It draws upon a broad perspective of critical medical anthropology to understand the patients' thoughts, emotions, feelings and practices under the context of socio-economic, political and cultural changes at local and national levels. The concept of cyborg anthropology is also applied to explain the relationship between machine, viewed as an artifact to maintain health, and human in a cultural context. Critical medical anthropology perspective analyzes individual illness experience within a context shaped by the structure of society, culture, political factors, the capitalist economy, the medical establishment, and unequal patient-medical personnel relationships. Medical technology is a new form of power which affects human body in today's society (Bear, Singer & Susser, 1997). On the other hand, cyborg anthropology is the post-modern perspective which poses a serious challenge to the human-centered foundations of anthropological discourse. Within these perspectives, the main purpose of this study is to understand the patients' subjective illness experiences before, during and after open-heart surgery and its effects on their day-to-day practice.

Methods and Data

This study used qualitative data from narrative interviews with patients and in-depth interviews with medical personnel supplemented by documentary data. A central hospital in the Eastern region of Thailand was purposively chosen as the study site. With approval of responsible personnel of the hospital's Surgical OPD Department the primary researcher of this study was able to access to data of patients who had underwent an open-heart surgery at various timing ranging from six months to nine years prior to the study.

For narrative interviews, the patients who participated in the study were informed about the study purpose and that their views and the data obtained from them will be kept confidential. With permission, participants were asked to choose a place of their preference where they felt comfortable during the interview. After the interview and where necessary, the researcher would exchange with the participants about medical knowledge that might be useful to them.

The data collection took place from December 2011 to March 2012. The validity of data was triangulated by: 1) a study of the patients' illness experiences of medical technology in open-heart surgery using narrative interviews and participatory observation of follow-up treatment; 2) a study of related documents; and 3) in-depth interviews with medical personnel who implemented policies, regulations and guidelines for the application of medical technology in open-heart surgery at the hospital.

Seven participants were included for interview. These were open-heart surgery patients who had a specific case history and co-morbidity with other chronic illnesses, such as one involving emergency surgery, myocardial infarction, or infection of the surgical wound. These seven participants were selected purposively out of 75 patients in the record of the study hospital who had undergone open-heart surgery at various timing prior to this study. Most of the participants (six cases) are male; their ages range from 50–79 years. Five out of seven participants had operation at hospitals in Bangkok or elsewhere; only two had it at the central hospital that was the study site. Four participants still continued working after the operation while three participants stopped working. Five participants had their medical costs covered by the government Universal Coverage Health Care scheme while two participants were under the Civil Servant Health Care scheme. Open-heart surgery of these seven participants took place at various times, ranging from six months to nine years before the study. Background information of the study participants is given in Table 1 below.

Table 1 Selected characteristics of participants in the study

Participant#	Sex	Age (years)	Working status	Time since operation	Other illness	Health care scheme
1	male	79	Continued working after operation (as a Buddhist monk)	7 years	Cerebral thrombosis, diabetes, hepatitis	Universal coverage scheme
2	female	64	Stopped working after operation	3 years	Diabetes, osteoporosis	Universal coverage scheme
3	male	51	Continued working after operation	6 months	Herniated intervertebral disk	Universal coverage scheme
4	male	67	Continued working after operation	1 year	Diabetes	Civil servant health care scheme
5	male	65	Stopped working after operation	2 years	Diabetes	Universal coverage scheme
6	male	50	Continued working after operation	4 years	Gout	Civil servant health care scheme
7	male	69	Stopped working after operation	9 years	Cerebral thrombosis, gout	Universal coverage scheme

Ethical Considerations

This study was undertaken after it had been scrutinized and approved by Mahidol University's Human Research Ethics Committee for Social Sciences under license No. 2011/220.0612 and had obtained permission from the administrators of the studied hospital. After the selected participants had agreed to take part in the study, the primary researcher arranged a meeting with them to introduce her and explain the purpose of the study and the data collection process. The participants were informed that they were free to withdraw from the study at any time if they choose to, that doing so would in no way affect their medical treatment and their relationships

with the medical staff, that the information given in the interviews would be kept confidential, and that the finding would be publicly disseminated for the benefit of medical education and the development of appropriate forms of treatment. The informants were then asked to sign a consent form for participation in the study.

Data Analysis

The narratives were analyzed chronologically, emphasizing critical events that led to changes to the individual (Elliot, 2005) and using his or her open-heart surgery as the focal point of interest and for identifying the main points for analysis. The analysis of data went through the following steps: transcribing the audio-taped interviews, data processing, data verification, indexing, concluding the result and presenting. The findings were presented in a way that clearly convey ideas, views, and diverse attitudes among the research participants and illustrate interesting points with quotes from interview data. Where appropriate, passages from the original interview are quoted in a way that the meanings of the words given by participants are not altered (Creswell, 1994; Miles & Huberman, 1994).

Findings

The analysis of the patients' narratives of the events before, during and after the open-heart surgery produced the following findings:

Experiences before and during surgery

When informed by the doctor of the need for open-heart surgery, the participants were in a state of shock and gripped with fear of death, unsuccessful treatment, suffering and dependence on others. This tremendous anxiety affected their mind and identity. It also worried their relatives and those close to them who know something about open-heart surgery from the media. The participants who were going to have an open-heart surgery were generally perceived as a person standing between life and death, and their identity was one of those who, in the face of death, were physically weak and mentally vulnerable. They described their feelings as being on the edge between life and death, coming back from death and being in misfortune. These feelings are illustrated below.

Being on the edge between life and death: In emergency for heart surgery, when some patients were about to lose consciousness or in a critical condition, they prayed to ease their fear asking for blessings from sacred beings for a successful outcome. A 64-year-old woman described her experience as follows:

> *When I was carried out of the car on arrival at the hospital, doctors swarmed around me. A doctor asked for my consent to an operation. I asked him if it would cure me. He replied: 'There is no guarantee; it could be either life or death. Your condition is critical. With the operation you may still die. No operation, you surely will die. Will you take a chance?' I had never had such pain, unbearable pain that left me with no strength to be on my feet. It made me lose my senses. I felt so choked that I could not speak or breathe. I told him to go ahead with it. I couldn't bear it any more. The pain was overpowering. I prayed to the Buddha for his protection. Just as I was about to faint, I heard the doctor saying: 'Is she up to it?' (Case 2)*

The patients usually had a very vulnerable state of mind, feeling depressed, sad and lonely. In their unconsciousness and being sustained by medical technologies, some let out these suppressed feelings.

> *While I lied unconscious for 20 days up to the heart surgery, the doctor injected me with a heart stimulant drug. A nurse later told me that while in coma I, at the age of 50, talked unconsciously about my father. 'Dad, do you love me? Why did you leave me here alone? When you will come to get me?' Then I yanked the dripping tube from my arm and bled all over the bed. A doctor had to give me a shot to stop the bleeding. I was a child when my dad and my mom separated. He never sent her any money. So I could afford for only Prathom 4 education. (Case 3)*

Being under anaesthesia, some patients dreamed about a journey to the afterlife, reflecting their vulnerability and fear of death and entrust their life to fate. To cope with this emotion, they relied on beliefs in merit and karma in anticipation of the outcome of the heart surgery, which may result in either disability or death. A 67-year-old male participant recounted a dream he had after having been anesthetized for the operation as follows:

> *I saw the Yommatood (guardian of the underworld in traditional Thai beliefs) in my dream, but he didn't come for me because I was not fated to die yet. Because I have done good deeds all my life and never did evil things, I believed I would*

> *come out of the operation without being paralyzed. So my children needed not to take care of me, and that would free both of us from furthering the bonds of karma. (Case 4)*

Another participant saw open-heart surgery as a chance for escaping death and believed that the supernatural would bring about a favourable outcome. A 69-year-old male participant recalled his experience:

> *I lied in the ICU for 15 days, but my condition barely improved. So I prayed to the Lord Buddha to bless me with a good, kind doctor who could cure me and save my life. When the doctor told me I needed a heart surgery, I readily consented. No operation would only mean death. An operation would give me a chance to survive. (Case 7)*

Coming back from death: Some participants experienced a cardiac arrest and their hearts stopped. Doctors had to use a defibrillator to shock their hearts back to normal rhythm. One participant, a 51-year-old male, described his feeling as coming back from death.

> *From the first night in the hospital, I was sent straight to the ICU. I thought my heart stopped beating for a while, twice actually. A nurse shook me hard twice before I felt myself being woken up and wondered why. When I opened my eyes, I saw doctors and nurses swarming around my bed. It was OK, go on sleeping, they said. It happened like this twice.* (Case 3)

Another participant underwent an emergency open-heart surgery after being defibrillated following a cardiac arrested. He felt like coming back from death.

> *I went to see the doctor in the examination room. He asked what was wrong. I said I was drilling when I felt this sensation gripped my heart, choking and making me breathless. At this point I just stopped breathing. The doctor and the nurse pulled me up and laid me on the bed. They pushed down on my chest three times. On the third my heart started beating again, but I was still unconscious. So the doctor sent me for an emergency heart operation. (Case 5)*

Misfortune: Some patients attributed their life-threatening experiences of cardiac arrest to bad luck. They felt vulnerable as they were fighting against death and facing uncertain future. One participant recalled this:

> *I had never fallen ill before. It was bad luck that I was so gravely ill that I needed heart surgery. When my heart stopped beating, the nurse in the ICU told me later that she thought I was going to die. (Case 3)*

Two participants believed that bad luck caused them to have a cardiac arrest and subsequently an emergency open-heart surgery. They said:

> *It is my fate not to die yet. But I had to lose a lot of money to drive off the bad luck. I went to three hospitals in one day. The doctors referred me from one to another and at the end I had a heart surgery and survived. (Case 5)*

> *My wife wanted to build shop houses for rent in the market area. So she had her fortune told. The fortune teller said she must get it done quickly. If she waited for another two months, he said, it would fall through because a very bad luck would strike our family. Two months later the doctor told me I needed a heart operation. (Case 6)*

Experiences after surgery

Patients who underwent open-heart surgery have developed subjective illness experiences as dependent on medical technology and perceived themselves as a cyborg.

Dependence: Some patients have become increasingly dependent on medical technology, seeing it as instruments to soothe their bodies. They felt that they could not live without it, and that it has become part of their bodies. This attitude has led to the patients' increasing dependence on medical technology including medications for various chronic diseases. This is clearly reflected in the experiences of three participants quoted below:

> *Since the heart operation, my condition has hardly improved. If I miss the medications a couple of times, I would feel choked. So I have to take the drugs regularly. I got diabetes five months after the operation. I've just had an operation to remove cataract. I have osteoporosis too. Even without meal the medications alone can make me full. (Case 2)*

> *I have taken many kinds of medicines for heart disease, high blood pressure, anti-coagulant drugs for almost 10 years, even before the operation. Altogether 22 tablets every day. (Case 3)*

> *I need a bag to carry all the medicines along. Seeing me carrying a large bag, people think I'm rich having lots of money. Open it and you find a whole bunch of medicines for a number of diseases that I have. If a thief steals it, he would kill me, taking away the medicines I need. (Case 7)*

A cyborg: The patients looked at themselves or their bodies as a cyborg, a non-human or an animal, despairing and feeling deprived of their own abilities. Some felt that after going through the operation, their bodies hindered their daily life activities. The old Buddhist monk, 79, described this as follows:

> *Heart arteries are like a water pipe. After a while dregs build up inside and clog them. Nothing can rid them completely unless they are replaced with a new pipe. Balloon angioplasty is like forcing something through the pipe to unclog it. In this case an artificial blood vessel is passed into the arteries to widen them. Even balloon will not make the problem go away for good. There is a good chance that they would clog again and you need another balloon. It's unlike coronary artery bypass surgery, in which blood vessels taken from other parts of the body are used for grafting. (Case 1)*

The participants described workings of an organ (in this case, heart) of human body as if it was a part in a robot. This reflects their view of surgery as a means to fix parts of the body which are afflicted with a disease, injured, out of order, or defected from birth. Surgery removes the disease or replaces the defected parts with a new one in order to bring the body back to its function. Surgery, therefore, is like repairing, rebuilding or reassembling a machine, a robot. In an open-heart surgery in which the surgeon uses a surgical knife to cut the breastbone of a patient and push the cut wide open to reach down to the heart. These procedures stirred some patients' images of themselves being like an animal, which affected their emotion and feeling towards medical technology in heart surgery and degraded their humanness.

> *After the heart operation, I felt pains on both sides of the surgical wound in the middle of my chest for as long as six months. I asked my doctor why the pain in my chest muscles lasted much longer than others. I heard from some of those who had heart surgery that theirs last only one month. The doctor said my chest was cut in half and pushed wide open just like pigs for eight hours. So the chest muscles were much bruised. (Case 3)*

When one participant was told by his doctor that the operation partially unclogged some of the blocked vessels, he felt hopeless because he had no choice but to

continue to take the medicines. He tried to understand the doctor's explanation of his illness experience with the best of his reasoning.

> *After the operation my condition has hardly changed. Just like before I have to take medicines for heart disease, high blood pressure and diabetes. When I feel choked or tightness in my chest, I need to take the sublingual medication. The doctor told me some of the blocked vessels could not be bypassed in the operation because the vessels were small and grafting had high risk of rupturing them, and that would be fatal. (Case 4)*

The need to take loads of medicines, one of the most common medical technologies, has caused despair in these participants and convinced them that they might not live for long.

> *My heart doctor told me to walk for exercise. My orthopaedist told me not to. They contradict each other. Once back from walking for exercise, I couldn't pull myself up on my feet. One of my children had to carry me to see the orthopaedist. He advised against walking too much, but I told him the heart doctor said I needed to exercise by walking. I don't know if I'd still be alive five years from now. Taking so many medications makes me feel choked. It's too much for the body. (Case 2)*

Moreover, most participants found that after the operation they were unable to take care of themselves and had to depend on others around them. Some lost the abilities they had previously possessed or gave up their work.

> *The doctor told me not to worry too much. Don't do heavy work. Don't carry things over three kgs. And that's for the rest of my life. Before the operation I had done all kinds of work. Since the operation I have stopped gardening and do only housework such as doing laundry with the washing machine, cooking and house chores. (Case 2)*

> *I used to drive. But I can't do it any more after the operation because when I tried, I had this sudden memory loss, forgetting that I was driving. (Case 3)*

> *After the operation I can't walk up the stairs. A bed room had to be made for me downstairs. The doctor told me not to force a bowel movement. I need to take a laxative, and now my bowels have got used to it. Without it, I can't get my bowels moving. (Case 4)*

Conclusion, Discussion, and Recommendation

Before and during open-heart surgery, all the participant, except the Buddhist monk, had subjective illness experiences associated with Buddhist beliefs such as karma, fate and merit. After surgery, all participants had to live with medical technology (medication), their survival depended on it. Participants in this study viewed medical technology as having both positive and negative effects on their bodies but they tended to give less positive meanings to it. Before having open-heart surgery all were in a vulnerable state of mind as they were fighting against death and facing uncertain future. Although an open-heart surgery could save their lives, some participants showed distrust of medical technologies in a heart operation. Body-invasive medical technology aroused the patients' fear of death and doubts about its safety. They compensated this loss of confidence by embracing religious and cultural interpretations and concepts such as fate, Buddha's blessing, luck, merit and karma. These interpretations enabled them to view life, death, illness and suffering as inevitable. This cultural thinking runs counter to scientific reasoning.

Haraway (2008), an expert on cyborg anthropology, proposed that human and technology co-exist in a cultural context. Technology affects and controls social relationships, body and subjective experiences. In the case of open-heart surgery patients and medical technology, their co-existence has been mediated by cultural meanings ranging from the begging for blessings from sacred beings, luck, fate, dream about a journey to after-death worlds, illusions or sighting of things invisible to others. The open-heart surgery patients lost consciousness from being anesthetized or, in the case of an emergency surgery, from a cardiac arrest together with intense pain. Being under life-threatening circumstances and tremendous anxiety, they tried to fill the gap of memory loss while being unconscious with dreams and accounts from people who were present at the critical moment to understand their own illnesses. After open-heart surgery, patients exist on the blurred line between science and culture, body and machine, human and non-human/animal, self and other.

The participants also had to dispel the anxiety resulting from the open-heart surgery context that they had to entrust their lives with the medical personnel and accept the consequences. They had to find ways to adjust to these conditions and help themselves the best they could. Cultural beliefs help the patients deal with the unpredictability of the outcome and effectiveness of heart surgery technology by entrusting their lives to fate, sacred beings, merit and karma—these forces will decide whether their bodies agree with the medical technology or not. In this sense, the

patients' views reflect not only a predominant moral philosophy in Thai society that is linked to supernatural powers or sacred beings but also reflect people's lack of understanding of the production of medical technology and what accounts for failure or success of its application in heart surgery.

The findings of this study are consistent with those suggested by Scheper-Hughes (2000) and Lock (2001) which demonstrate that the meanings of illness experience of people in non-western society are influenced by their culture and religious beliefs. The scientific medicine is a sub-culture that has recently been introduced to non-western societies and has yet to gain complete dominance over them.

The findings in this study may be useful for health practitioners and providers. More specifically, they point to the fact that subjective illness experience of patients and their perspectives of treatment and medical technology are important and hence should be taken into account in providing them treatment. Another point is the need for providing a holistic care for the heart patient. Numerous evidences have indicated that patients who suffer from heart disease often have other morbidities especially diabetes and hypertension. Thus it is important to pay attention to all types of illnesses and deliver treatment to these patients holistically.

This study was conducted on limited number of patients under specific context of the Thai culture. As such, the findings may well be applicable in the context within which it was carried out, while in other contexts it should be taken with caution.

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