

Waiting for a heart transplant: the lived experience of Hong Kong Chinese patients



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SUMMARY

- ❖ Heart disease is the second leading cause of death in Hong Kong following malignant neoplasm. Heart transplant has become an established method of treatment for patients with terminal heart failure.
- ❖ Research has demonstrated that waiting for heart transplant surgery can lead to physical and psychosocial deterioration.
- ❖ Using a phenomenological approach informed by the ideas of Husserl, this study explored the lived experience of Hong Kong Chinese male adult heart transplant candidates. Six informants were interviewed either at home or in the hospital.
- ❖ The results revealed four themes: enduring the wait; preserving self while waiting; making sense of waiting; and believing in yuen (fate or superpower). The themes were closely interwoven into one tapestry of enduring the waiting.
- ❖ Patients employed the internal forces of enduring the wait, preserving self and making sense of waiting, while employing the external force that pushed the patients to believe in yuen.

INTRODUCTION

Heart disease is the second leading cause of death in Hong Kong following malignant neoplasm (Chan, 1998). During the 1997 census, 15% of the total number of deaths (4,896 cases) in Hong Kong was related to heart disease (CSD, 1998). There is also growing evidence that the prevalence of cardiac disease in Hong Kong and in mainland China is increasing (Sanderson et al., 1995). Compared with the total of 4,909 deaths in 1994, heart disease has been increasing to 5,220 in 1999 and 5,537 in 2000 (Department of Health, 1994/95; Hospital Authority, 1999; 2002).

Over the last decade, heart transplant has become an established method of treatment for patients with terminal heart failure particularly in North American and Western European countries (Hosenpud et al., 2000). Without transplant, the prognosis for people with terminal heart failure is limited to between 6-12 months survival (Delahaye, 1996). Heart transplantation in Hong

Kong began in 1995, but since that time only a small number of transplants have been done. The latest records showed that there were 20 heart transplant candidates on the waiting list at that time (HKMA, 1999). In Hong Kong, the age range of patients on the confirmed waiting list is between 19 and 60 years of age. The ratio of male to female candidates is 10:1, owing to the larger male population suffering from heart disease. Once patients are on the waiting list, they undergo periodic physical assessment at weekly to six weekly intervals, depending on each patient's physical condition. These follow-ups are important to detect any deterioration in the patient's physical health, as evidence shows that heart transplant candidates often show physiological deterioration associated with multiple organ failure – about 15% to 20% die while waiting for surgery (Leier et al., 1997).

Waiting periods for these patients range from between 6-18 months, sometimes more, depending on the availability of donors. Prolonged waiting times for patients in Hong Kong are attributed mainly to the low donor rate of only three patients per million population per year, compared with Australia which has a donor rate of 19 per million population, Europe with 18 per million population, and Spain with 22 per million population (HKMA, 1999). The reason for this low donor rate is because Hong Kong people usually want to preserve a 'complete body' after death and the relatives do not like to cause any more 'pain' to the dead body (Mok, 1994).

Studies have shown that patients waiting for organ transplant suffer from physiological as well as psychological deterioration (Zipfel et al., 1998) and that waiting for a heart transplant could be a long and tedious process for most candidates. These studies were mainly conducted in western countries and most of the literature addressed all organ transplantation. Very few studies addressed heart transplantation in particular, and no studies were found among the Chinese population. As the number of patients awaiting heart transplantation is steadily increasing in Hong Kong, it is therefore timely to conduct a study such as this to explore, describe and explain the meaning of 'waiting' from the lived experience of Hong Kong Chinese patients. As the majority of heart transplant candidates in Hong Kong are male, the focus of this study was on the experiences of adult males.

LITERATURE REVIEW

From the literature search, 'waiting' has also been associated with the term 'waiting list' or as a condition of 'watchful waiting' (Shavers et al., 2004). Most of these articles related to patients with serious diseases undergoing treatment, or patients with unstable conditions expecting something to happen (Clarke-Steffen, 1993; Plowfield, 1993). Watchful waiting is also now used as a new intervention to monitor patients while waiting for treatment that may take up to six months or longer. During this period of waiting, the patient knows that he or she is more likely to die from complications associated with the health problem.

Different authors found that physical disorders such as shortness of breath, fatigue, palpitations, sleep disturbance, pain and fluid retention were found to be highly correlated with the length of waiting (Naylor et al., 1995; Bengtson et al., 1996; Jonsdottir & Baldursdottir, 1998). Lofaso et al. (1994) also revealed the prevalence of sleep-disorder breathing in 20 outpatient candidates awaiting heart transplant. This was illustrated by poor quality sleep caused by sleep disruption associated by increasing hypoxemia, which could lead to further cardiac dysfunction during end-stage heart disease. Physical discomfort like insomnia and restlessness at night were also noted. Progressive physical deterioration could also lead to death for candidates on the waiting list. D'Armini et al. (1998) explored the survival rates and risk factors causing early death. Of the 278 patients on the waiting list for heart-lung and lung transplantation, 28.8% patients received transplants, 36.0% died while waiting and 35.3% were still awaiting transplantation. However, the impact on the physical condition of heart transplant candidates was not studied as much as its impact on the psychosocial aspects affecting the patients' lives. This might be related to the difficulties of investigating the symptoms and the regular check-ups required by these candidates. On the other hand, candidates with significantly improved clinical status may be taken off the waiting list (Leier et al., 1997).

The longer the patients had to wait for surgery, the higher their nervous reactions were. Jalowiec et al. (1994) studied transplant-related stressors for 175 patients waiting for a new heart from two medical centres in the Midwest and South Chicago, USA. The authors identify 39 common preoperative stressors. The ten worst stressors were finding out about the need for a transplant, having end-stage heart disease, family worrying, illness symptoms, waiting for a donor, uncertainty about the future, no energy for leisure activities, constantly feeling worn out, less control over life and dependency on others. They found that one factor was particularly stressful for those waiting longer than the median time of one month, while 16 factors were particularly stressful for those waiting less than one month. Waiting for a new heart and recognising that they needed a heart transplant were found to be the worst stressors.

The results of this study concur with the qualitative study conducted by Porter et al. (1994). Thirty-nine candidates on the active list for heart transplantation from four mid-East Coast transplantation centres in the USA reported three most common stressors, including requiring a heart transplant, having terminal heart disease, and worrying family members. The three most common coping strategies were thinking positively, using humour and trying to keep life as normal as possible. The findings also reported the presence of hope or the patient's desire to spare family members from worry. However, the authors stated that transplant recipients

may have underreported their stress and suggested that the transplantation team should support positive coping strategies when possible, and closely monitor both patient and family stress and coping throughout the waiting period.

Cupples et al. (1998) also examined heart transplant candidates' level of stressors from the time of placement on the waiting list and on the following 3rd, 6th, 9th and 12th month. It was concluded that feelings of relief and euphoria may subside after initial placement on the list. However, patients reported that the good news of being placed on the waiting list resulted in stress, especially after waiting for a certain period of time. The study by Bunzel et al. (1992) reported that 66% of Swiss patients stated that waiting for surgery was frustrating, 63% of patients were worried about what might happen during the waiting period, while 30% of patients felt that they should not have to wait for surgery. Other patients were afraid to miss the telephone call that would inform them that an organ had become available and they were to have surgery very shortly. Therefore, heart transplant candidates tended to limit any social activity outside their home. However, they also reported that support from their spouse was one of the most important factors in predicting the success of heart transplantation.

The importance of social support and relationships with friends and family members were also reported in the literature. However, family members of heart transplant candidates also suffer from psychological stress during the waiting period (Hirth & Stewart, 1994). The patients' families often expressed concern about survival, success of the operation and how to support the patient during the pre- and post-operation stages (Lindsay et al., 1997). Collins et al. (1996) reported that the five most stressful factors for the spouse during the waiting period were:

- ❖ Fear that the patient might die;
- ❖ Not knowing when the transplantation would take place;
- ❖ Not knowing if the transplantation would take place;
- ❖ Not knowing if a donor heart would become available;
- ❖ Waiting for transplantation.

Fear that the patient might die before a heart could become available was the worst stressor for the spouse. Working spouses perceived more stressors related to responsibility, socio-economic activities, and their own self.

In summary, a prolonged or unknown waiting period for patients and their families awaiting organ transplantation is not a desirable or pleasant experience. It is particularly true for patients waiting for organs such as the heart. Unlike a kidney or liver, living people cannot donate a heart. Thus, exploring and describing the experiences of patients waiting for a heart transplant will be valuable evidence for nurses to increase understanding and awareness of this situation, and to provide information on which to base nursing practice. This in turn may lead to improvements in the care of these patients. Moreover, since the literature that was reviewed generally related to either kidney, liver, lung or heart transplantation from the context of western countries, the findings and recommendations for practice may not be applicable to Hong Kong Chinese, and in particular to heart transplantation candidates. To understand patients' interpretations of their illness, experience from a cultural perspective is important to ensure culturally appropriate care. It is therefore both timely and significant to conduct a study of Chinese adult heart transplant candidates' experiences and feelings of waiting for a transplant. This study aims to answer the research

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question: 'What is the meaning of waiting for a heart transplant as experienced by the Chinese adult heart transplant candidates in Hong Kong?'

METHODOLOGY

Research design

A phenomenological approach informed by the ideas of Edmund Husserl was used to explore the 'lived experience of waiting', because this particular approach can provide very rich and detailed accounts of people's experiences in a range of health care settings (Stewart & Micunas, 1990). A phenomenological approach is composed of both finding the essence (elements of the ideal or true meaning of something) that gives a common understanding of the phenomenon, and intuiting (accurate interpretation) of what is meant in the description of the phenomenon under investigation (Struebert & Carpenter, 1995). To avoid imposing the researcher's preconceptions, 'bracketing' was used, which requires the researcher to remain neutral regarding their belief or disbelief in the existence of the phenomenon being studied. The researcher sets aside previous knowledge or personal beliefs to prevent this information from interfering with the discovery of the participants' descriptions of their lived experiences (Crotty, 1996). The notion of bracketing is consistent with the philosophical ideas of Husserl.

Participants and setting

Purposive sampling was used in this phenomenological study and participants were referred to as informants. The criteria for inclusion in this study were cardiac patients who were:

- ❖ On the waiting list for heart transplant;
- ❖ Orientated to time, place and person with no mental illness;
- ❖ Able to communicate and willing to express their own feelings and experiences through an interview.

The informants came from the heart transplant register list of one hospital in the New Territories, Hong Kong. Possible informants were nominated by the nurse heart transplant co-ordinator and were contacted by telephone to explain the purpose of study, ask if they were willing to participate, and to set a time, day and place for the interview that would be most convenient for them.

In this study, only six male heart transplant candidates consented to be interviewed. However, this is an acceptable number for phenomenological research. After obtaining the patient's written consent, interviews were conducted either in the patient's home or in the outpatient department during a routine check-up. Approval to conduct the study was given by The Chinese University of Hong Kong Ethics Committee and the hospital ethics committee. The purpose and nature of the study, including possible risks and/or benefits, were explained and a written consent form obtained. The transplant co-ordinator was also contacted after each interview to report any emotional upset or stress shown by the informants, so that appropriate support and care could be given. In this study, no informants suffered from any untoward consequences.

Data collection procedure

The term 'conversation' rather than interview was chosen to describe fully the data collection process used (Bergum, 1991) as it implies an interactive discussion between the informant and the researchers. Initially, informants were asked by the researcher about basic demographic and related physical data. Then, unstruc-

ured, interactive conversations were conducted, which lasted between 45-60 minutes. All interviews were conducted in the Chinese language. The following open-ended questions were used to initiate or prompt the conversation:

- ❖ What does it mean for you to wait for a heart transplant?
- ❖ Tell me all about your experiences and your feelings while waiting for a heart transplant.
- ❖ What were the reactions, feelings or thoughts of your family when you were placed on the waiting list?
- ❖ How did you utilise your time while waiting for a heart transplant?
- ❖ How did you cope with the idea of a possible long waiting time?

To gather rich and in-depth data from the informants, repeated interviews were carried out until the researchers considered that as full an account as possible of the informants' experiences had been achieved, indicated by no new information being obtained during the interviews. All interviews were audio tape-recorded.

Data analysis

Colaizzi's (1978) phenomenological method was used to analyse the verbatim transcripts. This particular method of data analysis reflects the tenets (essence and intuiting) of Husserlian phenomenology as the researcher is required to become immersed in the data and it also incorporates the notion of bracketing. The method included the following seven steps:

- ❖ All tape-recorded interviews were transcribed verbatim into Chinese transcripts;
- ❖ The transcriptions were read line by line, which allowed the researchers to grasp what the informants were saying;
- ❖ Significant statements relating directly to the subject matter were extracted;
- ❖ Formulated meanings were taken from these significant statements;
- ❖ These meanings were then organised into clusters of themes;
- ❖ The themes and their meanings were synthesised into an exhaustive description of waiting for a heart transplant as experienced by the male Hong Kong informants;
- ❖ This description was validated with the informants to evaluate the trustworthiness of the study findings.

Quality and credibility of research

As suggested by Lincoln and Guba (1985), credibility, auditability, fittingness and confirmability were addressed to evaluate the trustworthiness of this phenomenological study. Numerous quotes from the informants' descriptions of their experiences of waiting were included in reporting the findings. Patients' experiences were constantly compared with the other informants. The researchers made sure that the process of data analysis was meticulously and clearly described and recorded so that other researchers could follow the researcher's trail of inquiry in conducting this study. Informants were asked to reconfirm and validate what was said from the previous interview to make sure that the meanings were not lost, as some may be embedded in the informants' description of their experiences of waiting.

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Themes	Formulated meanings
Enduring the wait	<ul style="list-style-type: none"> ❖ Patients accepted the physiological and psychological consequences of waiting. ❖ Patients got through the period of waiting by 'living day by day'. ❖ Patients coped with the possibility of a long wait by either thinking or not thinking about the time.
Preserving self while waiting	<ul style="list-style-type: none"> ❖ Patients modified their work schedules and lifestyle. ❖ Patients distanced themselves from others to hide their suffering. ❖ Patients resumed work and household responsibilities to a minimum. ❖ Patients learned to self-evaluate the seriousness of their symptomatology and adhered to strict follow-up regimens.
Making sense of waiting	<ul style="list-style-type: none"> ❖ Patients adopted strategies to lower their self-awareness of the condition. ❖ Patients pretended to accept their condition to spare family from worrying. ❖ Patients reduced their uncertainties by relating their own experiences with others for a predictable reference. ❖ Patients endeavoured to build self-confidence and self-determination.
Believing in yuan (external forces)	<ul style="list-style-type: none"> ❖ Patients accepted their vulnerability. ❖ Patients sought relief by believing in yuan. ❖ Patients admitted that fate and luck played an important role in their prognosis.

STUDY FINDINGS AND DISCUSSION

The focus of this study was the experience of waiting for a heart transplant by six Hong Kong Chinese adult male heart transplant candidates. From the analysis of the transcribed data, four main themes were revealed. These themes were: (1) enduring the wait; (2) preserving self while waiting; (3) making sense of waiting; (4) believing in yuan (external forces). Table 1 below gives a brief summary of these themes and their formulated meanings.

Enduring the wait

Enduring meant 'getting through' the events that happened once patients were placed on the heart transplant waiting list. These patients, who were already physiologically compromised because of their heart condition, expected that they would encounter some problems throughout this waiting period. Patients complained that they experienced physical discomfort, for example fatigue and shortness of breath. This was mainly attributed to the patho-physiological effects of the cardiac disease, as described by one informant: 'When doing some physical work, after only 15 seconds, I felt short of breath.' However, they also believed that they had to continue with their normal life activities to a minimum and had to endure any physiological effects once in a while. Informants described their experiences relating to enduring as: 'I know it myself. For example, I walk, walk up slope for some distance, I know I am deteriorating, I feel the shortness of breath, and feel very difficult!'

The physiological consequences of prolonged waiting varied from patient to patient. Some needed to be admitted to hospital for stabilisation of their condition or for treatment of severe deterioration in their cardiovascular functioning. Learning to bear the consequences involves accepting that the presence of illness is unchangeable and may even mean deterioration and additional problems (Dewar & Morse, 1995). Fatigue, shortness of breath and chest pain were the most common problems experienced by the Chinese patients waiting for surgery. These symptoms were also similar to those experienced by patients in previous studies conducted with western patients (Jonsdottir & Baldursdottir, 1998; Naylor et al., 1995). Sleep disruption was another common symptom experienced by the Chinese patients, which was thought to be caused by cardiac dysfunction and hypoxemia. Patients expressed

that if they did not get enough sleep, they felt tired during the day and were unable to work. This problem was similar to those found by Lofaso et al. (1994) among 20 heart transplant candidates in the USA.

Enduring the wait not only involved the physiological problems associated with the heart condition but also the psychological effects of waiting. Feelings of uncertainty were brought about for many reasons. Firstly, patients were uncertain when their time for surgery would come. Secondly, nobody could tell them when the waiting would end because this depends mostly on when a compatible organ heart can be found. For example, one informant expressed: 'Nothing is in my head...nothing...hoping to keep physically healthy before the transplant...can walk again...until that day...That day is far away, you don't know when it will come. Or is there such a day? You don't know. It's a question mark!'

To manage this uncertainty, patients reported that the best way was to 'live day by day' and not to think about it. One informant expressed how he managed with the uncertainty: 'I have put all the problems behind, throw it to the back of my mind. Just wait and see what happens day by day. This made me feel better, more relaxed...just sitting there...not doing anything.' Patients revealed that by thinking positively about the whole thing or by ignoring and not thinking at all about their condition, they were able to cope much better with the psychological stressors associated with waiting. The findings from this Chinese study concur with studies by Porter et al. (1994) and Cupples et al. (1998), where heart transplant candidates tried to think positively and keep life as normal as possible, including the use of humour. However, in this study, the Chinese patients never indicated using humour as a coping mechanism to overcome their stress. This may be associated with the cultural practices of when humour is used within Chinese people's interactions (Leung, 1996). In addition, Chinese patients did not want to think about the waiting time, as one informant explained: 'I haven't set a time [for waiting]; if you have set it and it wouldn't come [as expected], you would feel unhappy. That is, you would feel lost of hope. In other words, without setting a time limit, you can continue to have hope.'

The informants in this study came to a point when they had to think about the seriousness of their condition. Their only alternative was to have a heart transplant, and as one informant stated:

'...have a heart, transplant will then be possible; without a heart there won't be any other method.' They knew that being on the waiting list was a good sign that gave them hope, 'something to look forward to'. However, in the literature, the concept of hope and the experience of hoping were not clearly understood (Jevne, 1990) and also how these concepts influenced clinical outcomes (Morse & Doberneck, 1995). The Chinese study seemed to define hope more clearly from the lived experiences of the informants, but may need to be explored further in future research. The fact that the Chinese patients expressed that they had to live with their condition and bear the consequences of waiting seemed to give them hope while trying to preserve self.

Preserving self while waiting

Preserving self included methods to maintain both physical and psychological integrity. Physical restrictions resulted in informants being unable to maintain their present level and type of work or occupation, which led to suspension of certain family roles and responsibilities. Some, who had left their job, declared that they had 'nothing to do' and therefore felt worthless and bored, as one informant explained: *'Only eat, drink and play...nothing to do the whole day...that is doing nothing. The person is worthless.'* To overcome this feeling of worthlessness, some patients did volunteer work, while others continued to do their usual occupation, although only with a minimum degree of effort. Other patients gave up work completely but found it hard to be in a reversed role; to care for the household while the wife earned a living to support the family. To maintain some sort of self-worth, patients learned to adjust to their new roles. This was often quite difficult because, in Chinese society, males are the breadwinner of the family (Leung, 1996). The informants in this study were quite young and of a work productive age. Therefore, being laid off from work meant that they also had to give up the breadwinner role within their family. They had to accept financial support from their family and friends.

Another way of preserving self was to modify their lifestyle. Patients on the waiting list needed to follow strict guidelines, such as eating non-salty food, decreasing their social activities and doing regular exercise. They also were required to adhere to the follow-up regimens recommended at the out-patient clinic. Preserving self has been seen to require deliberate action, focused energy and tremendous effort and will power (Morse & O'Brien, 1995). Informants explained the changes in their lifestyle: *'I try hard not to eat stimulating food, and food high in cholesterol, that means eating a balanced diet.'* In addition, to preserve self, they also distanced themselves from their friends so that they could lessen their psychological burden, as they declared that they could not pay their friends back, which meant to recover and be healthy again as their friends expected. Preventing close relationships with their friends while in this condition was very difficult, however it did help to maintain their inner self-peacefulness. They also distanced themselves from any social activities because they wanted to maintain their healthy lifestyle. They explained that going out meant that they might eat something that would not comply with their regime, or that they might lose the chance for a heart transplant because the hospital could not contact them, as two informants explained: *'In the past, my friends and I went out together for dinner and we were very happy. But now, I can't! It is because I can't eat salty food and I can't drink too much water. I*

don't want to miss the call, so I stay home most of the time. I don't want to miss my chance.'

The informants all attempted to seek a lifestyle that they could tolerate and maintain to favour their health. King and Jensen (1994) also explained that the major mechanism for preserving self was managing role transitions and interpersonal relationships. Knowing and accepting that they were sick required the patients to make sense of what was happening.

Making sense of waiting

The shock of the initial experience of being placed on the waiting list forced the patients to make sense of what was expected of them throughout this period. They reflected on their past, their roles and responsibilities within their social world and within their present health condition. Deciding to be placed on the waiting list for a heart transplant was a decision that needed to be thought through very carefully with the advice of their physician and their family. Being placed on the waiting list gave them a sense of hope and that they still had a future to look forward to. However, these patients were also aware of the possibility of a long wait, as a compatible organ heart is limited and often difficult to find. But accepting this option was something that they felt they could not reject and, as one informant expressed: *'In reality you can't reject...you can't always be blaming yourselves.'*

Making sense often necessitates making adjustments to develop some perspective on what they were enduring (King & Jensen, 1994). Some patients tried to make sense of waiting by lowering their self-awareness of their condition; not totally ignoring their health, but trying to avoid knowing everything about the disease, treatment, surgery and prognosis. By not knowing, they felt less afraid, less stressed, and they coped better living day by day, as commented by this informant: *'As what I understand, thinking about these things [matter of heart transplantation] will introduce myself a lot of stress. That's why I dare not think.'* Some patients tried to make sense of what was happening by relating their own experiences with other patients. They looked for predictable reference points, as one informant described: *'During watching TV, you can see other people having [all sorts of] physical disabilities, maybe, I feel that they are worse than you [me]...at least I am physically perfect and can walk here and there...by comparison, I know that I am quite alright.'*

If patients were successful in making sense of their situation, they felt that they were in control, which tended to increase their self-esteem, coping abilities and hope for getting better (Benzein & Saveman, 1998). For some patients who were unable to make objective sense of what was happening, they resorted to some external forces, or *yuan* in Chinese terminology.

Believing in yuan (fate or supernatural powers)

Over time, when patients were no longer able to endure the wait, they resorted to believing in some spiritual being. Chen (1996) related this to the Chinese way of conforming with nature in order to cope: *'Listen to heaven and follow fate'* (p25). As one informant described: *'At this moment, being human, it is simple: just neglect them [the bad feelings and uncertainty] and follow what may happen, just like this.'* On explaining what he meant by follow what may happen, he stated: *'With [heart] or without, both are good. Have or have not the chance of transplant are both good.'* All informants claimed to have no religious belief. However, in real-

ity they accepted that some external forces controlled the world in certain patterns and logic. This strategy was useful for protecting patients from feeling guilty of being idle and not having the power to change the situation. Powerlessness was expressed as a negative feeling for these patients, and to balance their minds and rationalise, patients developed strategies to maintain inner self (Morse, 1997). Uncontrollable environmental forces challenged patients who were more accustomed to controlling their lives and rationalised that they were just unlucky. As one informant expressed: *'I'm so dark [unlucky]...Just as my wife said, the future depends on 'Tien' [heaven or supernatural forces].'* Seeking relief from believing in luck or fate helped the informants to cope with their illness experiences, as one informant explained: *'Because I am not thinking too much, I believe in 'Ming' [fate] and that's all...I mean accepting what is happening and living with it.'*

Yuan refers to the belief that outcomes are determined by fate or supernatural forces. As Yang (1982) argued, those who believe in yuan will be protected and will have a favourable outcome. Yuan also functions as a defence mechanism that can shield the individual from negative emotions and outcomes (Leung, 1996). Patients in this study claimed that waiting requires strategies that are both internal and external to the self. When patients are unable to cope with the physiological and psychological consequences of heart disease and the uncertainty of waiting, they were forced to resort to some external forces order to preserve self, make sense and maintain their endurance. Internal forces refer to those who believe that reinforcements are under the control of the patient; external forces refer to fate, luck or chance (Rotter, 1996). It is widely agreed in the literature that, because of the Confucianist, Buddhist and Taoist traditions of the Chinese people, they tend to possess a stronger belief in external forces when all other remedies or strategies of endurance fail (Bond, 1986).

Exhaustive description of waiting

From the four themes revealed in the analysis of the data, it appears that waiting for a heart transplant as experienced by the Chinese adult heart transplant candidates revolves around the concept of enduring. For these patients, getting through the period of waiting is a long and tedious process that seemed to test their capacity to endure both the physical and psychological consequences of the disease process. Patients learned to manage their ability to endure in order to cope with the unpredictable length of waiting for an organ heart. Patients employed two types of control to endure the wait. The first type involved internal forces where patients themselves had the ability to control, such as enduring the wait, preserving self and making sense of waiting. The other type involved external forces that pushed the patients to believe in yuan. These participants employed both these internal and external forces to help them remain as physiologically healthy as possible, and to keep their place on the waiting list. Being on the waiting list gave them a sense of hope and something to look forward to. Living day by day was a philosophical stance that these patients adopted to help endure the waiting time for surgery and transplantation of a donor heart. Waiting was manifested by unknowns, uncertainties and in-between time where life was suspended. Sometimes patients were unable to make sense of the illness events, especially when the illness outcomes were unpredictable. Mishel (1990) proposed that positive growth and change may evolve over time

and factors influencing this change may include physiological status. Uncertainty of the waiting period and physical deterioration are particularly traumatic and often frightening for the patients to endure. Patients learned to tolerate and accept their limitations. For some patients, this required confronting and regrouping (Morse, 1997) their emotions and their ability to endure the wait.

CONCLUSION

Of the six informants that were interviewed, there was a wide variation in the waiting period; from a few weeks to one year. In this study, only male heart transplant candidates were interviewed because the number of females on the waiting list was too small (two out of ten), and all refused to be interviewed. Therefore, a limitation of the study is that by only interviewing male heart transplant candidates, the findings may not be generalised to female candidates. Therefore, this study was unable to reveal the conditions and needs of female candidates waiting for heart transplants in Hong Kong.

However, the findings from this study do provide valuable evidence for Hong Kong nurses in understanding how male adult Chinese heart transplant candidates feel and experience this period of waiting for surgery. This will help nurses to interact with these patients more effectively, and plan for and provide more specific and useful information and support during this critical period. Furthermore, the interview enabled self-reflection for the patients. The transplant candidates were able to review and accept their own situation, which helped them to be aware of the value of recognising and understanding the necessity to wait for an organ heart, as well as to prepare themselves physiologically and psychologically for the possibility of a long waiting period.

To improve the care of candidates waiting for heart transplantation, more studies should be conducted especially within the Hong Kong context. Longitudinal studies could be conducted from the pre-operation to post-operation stages of heart transplant to explore the candidates' experiences at different stages of adaptation to the waiting period. A study directed towards the patient's family or spouse could also be conducted to reflect a more complete picture of the impact of waiting.

This phenomenological research study sought to explore the experiences of a particular group of candidates on the waiting list for heart transplant in Hong Kong. The study revealed themes that were similar to patients from western countries awaiting transplant of other organs (kidney, liver, lung, heart). However, one theme that may be distinct within the Chinese population is belief in yuan, in which everything that happens is determined by fate, luck, chance or supernatural forces. Waiting for a heart transplant has been integrated into the life of these Chinese candidates. The deteriorating effects that might impact on the candidates' endurance, tolerance and optimistic point of view must be considered in order to maintain a life of normality among these individuals.

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REFERENCES

- Bengtson A, Herlitz J, Karlsson T & Hjalmarson A. (1996) Distress correlates with the degree of chest pain: a description of patients awaiting revascularisation. *Heart* 75 (3), 257-260.
- Benzein, E. & Saveman, B.I. (1998) Nurses' perception of hope in patients with cancer: A palliative care perspective. *Cancer Nursing*. 21(1): 10-16.
- Bergum V. (1991) Being a phenomenological researcher In: Morse, JM. (Ed.) *Qualitative Nursing Research: A Contemporary Dialogue*. Newbury: Sage Publications, pp51-71.
- Bond, MH. (Ed) (1986) *The Psychology of the Chinese People*. Hong Kong: Oxford University Press.
- Bunzel B, Wollenek G & Grundbock A. (1992) Psychosocial problems of donor heart recipients adversely affecting quality of life. *Quality of Life Research* 1 (5), 307-313.
- Census and Statistics Department (CSD). (1998) *Population By-Census. Summary Results*. Hong Kong: Government Printer.
- Chan MJP. (1998) *Annual Departmental Report for the Financial Year 1997-1998*. Hong Kong: Government Printer.
- Chen YD. (1996) Conformity with nature: a theory of Chinese American elders' health promotion and illness prevention process. *Advances in Nursing Science* 19 (2), 17-26.
- Clarke-Steffen L. (1993) Waiting and not knowing: the diagnosis of cancer in a child. *Journal of Pediatric Oncology Nursing* 10 (4), 146-153.
- Colaizzi PF. (1978) Psychological research as the phenomenologist views it. In: Valle R & King M. (Eds) *Existential Phenomenological Alternative for Psychology*. New York: Oxford University Press.
- Collins EG, White-Williams C & Jalowiec A. (1996) Spouse stressors while awaiting heart transplantation. *Heart & Lung: Journal of Acute & Critical Care* 25 (1), 4-13.
- Crotty M. (1996) *Phenomenology and Nursing Research*. Melbourne: Churchill Livingstone, pp20-27.
- Cupples SA, Nolan MT, Augustine SM & Kynoch D. (1998) Perceived stressors and coping strategies among heart transplant candidates. *Journal of Transplant Coordination* 8 (3), 179-187.
- D'Armini AM, Callegari G, Vitulo P, Klersy C, Rinaldi M, Pederzoli C, Grande AM, Fracchia C & Vigano M. (1998) Risk factors for early death in patients awaiting heart-lung or lung transplantation: experience at a single European center. *Transplantation* 66 (1), 123-127.
- Delahaye JP. (1996) Preoperative assessment and indications for heart transplantation. In: Herve J. (Ed) *Organ Transplantation and Tissue Grafting*. London: John Wiley & Company Ltd, pp755-760.
- Department of Health. (1994/95) *Annual Report*. Hong Kong: Government Printing.
- Dewar A & Morse JM. (1995) Unbearable incidents: Failure to endure the experience of illness. *Journal of Advanced Nursing* 22 (5), 957-964.
- Hirth AM & Stewart MJ. (1994) Hope and social support as coping resources for adults waiting for cardiac transplantation. *Canadian Journal of Nursing Research* 26 (3), 31-48.
- Hong Kong Medical Association (HKMA). (1999) *Hong Kong Medical Association*. [Online] Available at: <http://www.hkma.com.hk/eindex.htm> [accessed 27 November 2004].
- Hosenpud JD, Bennett LE, Keck BM, Boucek MM & Novick RJ. (2000) The registry of the International Society for Heart and Lung Transplantation: seventeenth official report – 2000. *Journal of Heart and Lung Transplantation* 19 (10), 909-931.
- Hospital Authority (HA). (1999) *Hospital Authority*. [Online] Available at: <http://www.ha.org.hk/hesd/nsapi/> [accessed 27 November 2004].
- Hospital Authority. (2002) *Hospital Authority Statistical Report*. Hong Kong: Government Printing.
- Jalowiec A, Grady KL & White-Williams C. (1994) Stressors in patients awaiting a heart transplant. *Behavioral Medicine* 19 (4), 145-153.
- Jevne R. (1990) It all begins with hope: Who said what about hope? *Alberta Psychology* 19 (3), 26-31.
- Jonsdottir H & Baldursdottir L. (1998) Experience of people awaiting coronary artery bypass graft surgery: the Icelandic experience. *Journal of Advanced Nursing* 27 (1), 68-74.
- King KM & Jensen L. (1994) Preserving the self: women having cardiac surgery. *Heart & Lung: Journal of Critical Care* 23 (2), 99-105.
- Leier CV, Whitby G, Kennedy RA & Binkley PF. (1997) Removal from the 'waiting list' for heart transplantation: a risk factor for sudden death? *Journal of Cardiac Failure* 3 (2), 105-111; Discussion: 113-116.
- Leung K. (1996) The role of beliefs in Chinese culture. In: Bond MH. (Ed) *The Handbook of Chinese Psychology*. Hong Kong: Oxford University Press, pp247-262.
- Lincoln YS & Guba EG. (Eds) (1985) *Nationalistic Inquiry*. California: Sage Publications.
- Lindsay P, Sherrard H, Bickerton L, Doucette P, Harkness C & Morin J. (1997) Educational and support needs of patients and their families awaiting cardiac surgery. *Heart & Lung: Journal of Acute & Critical Care* 26 (6), 458-465.
- Lofaso F, Verschuere P, Rande JLD, Harf A & Goldenberg F. (1994) Prevalence of sleep-disordered breathing in patients on a heart transplant waiting list. *Chest: The Cardiopulmonary Journal* 106 (6), 1689-1694.
- Mishel MH. (1990) Reconceptualization of the uncertainty in illness theory. *Image: The Journal of Nursing Scholarship* 22 (4), 256-262.
- Mok CY. (1994) *Organ donation in Hong Kong*. *Public Health & Epidemiology Bulletin* 3 (1), 1-3.
- Morse JM. (1997) Responding to threats to integrity of self. *Advances in Nursing Science* 19 (4), 21-36.
- Morse JM & Doberneck B. (1995) Delineating the concept of hope. *Image: The Journal of Nursing Scholarship* 27 (4), 277-285.
- Morse JM & O'Brien B. (1995) Preserving self: from victim, to patient, to disabled person. *Journal of Advanced Nursing* 21 (5), 886-896.
- Naylor CD, Sykora K, Jaglal SB & Jefferson S. (1995) Waiting for coronary artery bypass surgery: population-based study of 8517 consecutive patients in Ontario, Canada. *The Lancet* 346 (8990), 1605-1609.
- Plowfield LA. (1993) *Experiences of family waiting following neurological crisis* (PhD thesis), University of Virginia Dissertation Abstracts 54-07B, 3554.
- Porter RR, Krout L, Parks V, Gibbs S, Luers ES, Nolan MT, Cupples SA, Lopley D, Givan DA, Ohler L & Nunes N. (1994) Perceived stress and coping strategies among candidates for heart transplantation during the organ waiting period. *Journal of Heart Lung Transplantation* 13 (1, Pt 1), 102-107.
- Rotter JB. (1996) Generalized expectancies for internal versus external control of reinforcement. *Psychological Monographs* 80 (1), 1-28.
- Sanderson JE, Chan SK, Chan WW, Hung YT & Woo KS. (1995) The aetiology of heart failure in the Chinese population of Hong Kong – a prospective study of 730 consecutive patients. *International Journal of Cardiology* 51 (1), 29-35.
- Shavers VL, Brown M, Klabunde CN, Potosky AL, Davis W, Moul J & Fahey A. (2004) Race/ethnicity and the intensity of medical monitoring under 'watchful waiting' for prostate cancer. *Medical Care* 42 (3), 239-250.
- Stewart D & Micunas A. (1990) *Exploring Phenomenology*. (2nd ed.)

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Athens: Ohio University Press.

Struebert HJ & Carpenter DR. (1995) *Qualitative Research in Nursing*. Philadelphia: Lippincott.

Yang KS. (1982) Yuan and its functions in modern Chinese life (in Chinese). Proceedings of the conference on: Traditional culture and modern life. Taipei: *Committee on the Renaissance of*

Chinese Culture, pp103-128.

Zipfel S, Loewe B, Paschke T, Immel B, Lange R, Zimmerman R, Herzog W & Bergmann G. (1998) Psychological distress in patients awaiting heart transplantation. *Journal of Psychosomatic Research* 45 (5), 465-470.

