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**Exploring the Health Care Experiences
of Rural Thai People Living with
Acquired Valvular Heart Disease**

**A thesis presented in partial fulfilment of the requirements
for the degree of
Doctor of Philosophy
in
Nursing
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New Zealand**

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ABSTRACT

Valvular heart disease (VHD) is a preventable disease but it is one of the major causes of chronic illness in developing countries. As this disease is curable by surgery, access to appropriate and effective health care is necessary to prevent people from developing this disease and to treat people with VHD. The voices of people living with this condition will provide direction for health professionals in the development of better health care services for those living with VHD. This qualitative narrative study aimed to explore the experiences of individuals living with VHD.

Thirty individuals diagnosed with VHD participated in this study drawn from a population of individuals attending a Thailand provincial hospital. They participated in การคุยแบบเปิดออก (open and honest conversation) which was supported by a Thai cultural stance to build the trust necessary for the conversations. Conversations aimed at eliciting information about personal health care experiences were undertaken and lasted from 30 to 90 minutes, all were audio-taped and transcribed verbatim. Multistage narrative analysis methodology was used to identify emerging themes and three major themes emerged: autonomy and life with VHD, the effort of learning for life with VHD, and the maximisation of resources for the management of life with VHD. All of these themes indicated difficulty of access of acceptable and affordable care and difficulty in involvement in health care and illness management. These findings suggest that health care structures, resource distribution and the way professionals interact and communicate are important factors in the health care experiences of individuals living with VHD.

Health care services that are based on the principles of equity and balance of power between institutions and clients may support the development of appropriate health care services for all individuals. Culturally-based narrative research is recommended to increase the possibility of expanding ways of knowing with the inclusion of a range of points of views for understanding health care provision. This knowledge is necessary for the development of client-centred and community-based health care services to improve health care outcomes for the rural population in Thailand.

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GLOSSARY

A

อนามัย -Aa-Nha-Mai	Primary health care units
อัมพาต -Aum-Ma-Bhat	Paralysis

B

บาท –Baht	Thai currency with the exchange rate (between 2006-2007) as follow: 25 Baht = 1 NZ\$ 30 Baht = 1 AU\$ 35 Baht = 1 US\$
บาปกรรม-Bhab-Krum	A sin caused by doing bad things
พยาบาล-Bha-Ya-Ban	Nurse
เบื่อ-Bhieu	Feeling bored
บ่เฮ็ดนำที่เพิ่นบอก-Boh-Hed-Num-Pien-Bok	Refusing to comply
บุญกรรม-Boon-Krum	The good things or bad things which were done in the past life (karma)

D

ดีใจ-Dee-Jai	Feeling cheerful and happy
ดำนา-Dum-Na	Growing rice in a mud farm

H

หัวใจอ่อน-Hua-Jai-Oon	A weak heart
หัวใจรั่ว-Hua-Jai-Rhieu	Valvular regurgitation
หัวใจตีบ-Hua-Jai-Teeb	Valvular stenosis
หัวใจโต-Hua-Jai-To	Cardiomegaly
หัวใจวาย-Hua-Jai-Vay	Heart failure

J

เจ้าหน้าที่-Jao-Nha-Thee	A pronoun indicating government health
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ใจใหญ่-Jai-Yai	care worker
จำใจ-Jum-Jai	Confidence
จำเลือด-Jum-Leaud	Have to force one's self to do something
จำศีล-Jum-Sil	Echymosis
	Staying in the temples and practicing religious rituals
K	
กาลามสูตร- Ka-Lam-Ma-Sood	Buddhism philosophy states that knowledge needs to be interpretative rather than recalled and believed without being carefully examined
กาลเทศะ-Ka-La-Te-Sa	Time and place
ความเป็นกันเอง-Kam-Pen-Kun-Eang	Treating people with respect
ความไว้เนื้อเชื่อใจ-Kam-Wai-Neou-Cheiu-Jai	Trust that what they say is valid and that they will not be named
บุญกรรม-Boon-Krum	Karma
การคุยแบบเปิดอก-Karn-Keoy-Bab-Pead-Ok	Open and honest conversation
ถือศักดิ์ถือเนแท้-Keou-Kuk-Keou-Nhie-Thae	Behaving in the way that as assertive as people who have expertise, privilege, or high status
ขี้คร้าน-Khi-Kharn	Not having motivation to do thing
เกี่ยวข้าว- Kiew-Khao	Harvesting rice by hand using a curved knife
เกรงใจ- Kreing-Jai	Behaving in a way that avoids annoying others
ความเกรงใจ-Kuam-Kreing-Jai	Being thoughtful
กำลังใจ-Kum-Lung-Jai	Feeling empowered which may be from oneself or others
L	
ลิ้นหัวใจร้าว-Lin-Hau-Jai-Rhieu	Vulvular regurgitation

ลำบาก-Lum-Bak

Hardship

ลำบากใจ-Lum-Bak-Jai

Feeling frustrated and stressful

M

ไม่ทำตาม-Mai-Thum-Tam

Non-compliance

เมื่อย-Mhiey

Weary

หมดหวัง-Mhod-Wang

Hopeless

หมอ-Moh

A pronoun used to describe both
Indigenous and professional health care
Providers

หมอพื้นบ้าน-Moh-Bheun-Bhan

Indigenous healers

หมอดู-Moh-Doo

Fortune teller

หมอผีฟ้า- Moh-Lum-Phee-Pha

Indigenous healer who performs a ritual
Dance for spiritual healing

หมอพระ-Moh-Pra

Monk who acts as indigenous healer

หมอเส้น-Moh-Sen

Indigenous healer who uses massage
Techniques as the main form of treatment

หมอชา-Moh-Ya

Indigenous healer who uses herbs as the
main form of treatment

N

น้อยใจ-Noi-Jai

Feeling unhappy and pettiness

หงุดหงิด-Ngud-Ngid

Feeling irritated and annoyed

นวด-Nheud

Massage

นำท่วมปอด-Num-Theum-Pod

Pulmonary edema

O

เอาใจใส่-Ooa-Jai-Sai

Attentiveness

อบสมุนไพร-Oph-Sa-Moon-Phai

Warm steam prepared by boiling herbs
and applied to the weak parts to heal them

P

เป่า-Pao	The action of blowing the air out from the mouth of indigenous healers to treat a defect
ปาทองโก้-Pa-Thong-Ko	Food made from flour and deep fried
เปิดอกคุยกัน-Pead-Ok-Keoy-Kun	Prepared to tell all
ภาษาหมอ-Pha-Sha-Moh	Medical language
ภาษาอีสาน-Pha-Sa-Ei-San	Issan language
ผีตายโหง-Phee-Tay-Hong	Spirits of people dying from an unnatural Cause
ฝน-Phon	To prepare Ya-Phon, a herb is crushed by stone and the resulting powder diluted in water by Moh-Ya
ผงชูรส-Phong-Choo-Rod	Monosodium glutamate
ปลง-Pong	Absolutely accepts whatever happens
ผักชี-Phuk-Chee	A vegetable similar to dill
เพื่อน-Pien	This is the pronoun that is used for persons of higher status. In this study, the participants used it to refer to both indigenous and professional health care providers, it is a sign of respect
ประถม-Pra-Thom	Primary schools

R

รถเด็กเตี้ย-Rod-Tak-Tak	Modified two wheeled tractors similar to a truck used by the farmer
โรคลิ้นหัวใจ-Rok-Lin-Hua-Jai	Valvular heart disease

S

สบายใจ-Sa-Bay-Jai	The state of feeling mellow, cheerful, and comfortable
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สบายใจขึ้น-Sa-Bay-Jai-Kheun	Gain better stage of mind
สามสิบบาทรักษาทุกโรค-Sam-Sib-Baht-Rak-Sa-Took-Rok	30 bahts for all diseases
ศิษย์คิดล้างครู-Sid-Kid-Lang-Kroo	Students threatening the teachers and knowledge
สาวใส่ให้กากิน-Soa-Sai-Hai-Ka-Kin	Tell a secret to an enemy
T	
ตายโหง-Tay-Hong	Dying from an unnatural cause
ถ่างลิ้นหัวใจ-Thang-Lin-Hua-Jai	Valvular dilatation
ท้อแท้-Tho-Thae	Feeling unwilling to do things, similar to depression and regression
ต่อว่า-Tho-Wa	Criticized
ทำใจ-Thum-Jai	Trying to have positive thoughts about a negative situation and accepting the effects of that situation that eventually lead to Pong
ตับโต-Tub-To	Enlarged liver
U	
อึดอัด-Uod-Ud or อึดอัดใจ-Uod-Ud-Jai	Feeling under pressure
W	
ไหว้ครู-Wai-Kroo	Ceremony to mark students' respect of Teachers
Y	
ยาแก้ไอ-Ya-Kae-Ai	Anti-cough drugs
ยาแก้ไข้-Ya-Kae-Kai	Anti-pyrogen drugs
ยาแก้อักเสบ-Ya-Kae-Uak-Seb	Anti-biotic or anti-inflammatory drugs
ยาละลายลิ่มเลือด-Ya-Lha-Lhay-Lhim-Lheud	Anti-clotting drugs

ยานอนหลับ-Ya-Non-Lub

Anti-insomnia drugs

ยาฝน-Ya-Phon

Herbs which are crushed and diluted in
Water and used as drugs

ยาต้ม-Ya-Thom

Boiled herbs

ยาวันโรค-Ya-Wan-Na-Rok

Anti-tuberculosis drugs

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CHAPTER 1

INTRODUCING THE RESEARCH

The scope and dimensions of nursing practices, and the ways in which patients deal with their experiences of health and illness, are often communicated in stories. (Parker & Wiltshire, 2003, p. 97)

Introduction

Valvular heart disease (VHD) is a progressive deterioration of one or more heart valves that can be stenosis or regurgitation. The deformity of valve (valves) leads to inadequate blood supply as cardiac output decreases. Rheumatic fever is often the leading cause of acquired VHD and access to health care is necessary to prevent recurrent rheumatic fever caused by streptococcal infection (Carapetis, Mayosi, & Kaplan, 2006). The incidence of the disease is still high in the developing nations with limited health care development to ensure access to prevent the disease development (Schaffer, et al., 2003). Valvular heart disease is still a cause of chronic illness globally according to Carapetis, Steer, Mulholland, and Weber (2005) estimate the global burden include existing cases of rheumatic heart disease at 15.6 million and 233,000 deaths per year. They also predict that there 282,000 new cases will be diagnosed annually. Rheumatic heart disease is the main cause of acquired cardiovascular disease during the first five decades of life (Veasy & Tani, 2005), particularly in developing countries (Olivier, 2000; Saxena, 2002). In developing countries, rheumatic fever accounts for 25-45% of cases of cardiovascular disease (Olivier, 2000).

In Thailand, VHD is a cause of chronic illness. Prevalence of rheumatic heart disease is 1.2 to 2.1 per 1000 children (Olivier, 2000). Rheumatic heart disease is one of ten leading causes of mortality in Thailand with an incidence rate of 88 per 100,000 of population in 2002 (Department of Disease Control, Bureau of Epidemiology, 2002). VHD is also a cause of the high burden of cardiovascular disease in terms of prevalence of cases and adult deaths (The Thai Working Group on Burden of Disease and Injuries, 2002). In fact, VHD is preventable and curable. Why is this disease still a health problem? This question has inspired my interest in exploring health care stories of people with VHD with the aim to gain better understanding about health care provision for people with VHD. The focus of this thesis is to explore and understand the health

care experiences of people in rural Thailand diagnosed with VHD using a narrative research approach. This research will contribute to the development of more effective ways of working with people with VHD in rural areas in Thailand. This introductory chapter briefly introduces the research and provides an overview of the thesis.

Research Significance

People living with long-term illness face increased health care demands due to the complexity of their conditions, therefore, support from health professionals is essential for the well-being of people living with long-term illness (Bixby, Konick-McMahon & McKenna, 2000). Support is necessary both in health care settings and in communities (Walblay, 2004). Encouraging people with chronic disease to access and use health care services is crucial for them to gain and maintain their well-being. Access to appropriate health care impacts positively on the health of people who are prone to VHD and those diagnosed with this disease. Using health care services is crucial for the prevention of VHD (Bonow, et al., 2008; Eisenberg, 1993; Günther, Asmera & Parry, 2006; Michel, Hayden & Owen, 1995; Saxena, 2002) and disease progression (Saxena, 2002). People with VHD who experience disease complications have a significantly increased higher death rate than people with VHD without the disease complications (Petty, et al., 2000; 2005). Surgery can provide a cure for people with VHD when the disease has progressed. It can be concluded that access to appropriate health care services is the key for people with VHD to achieve maximum level of well-being and also increase the possibility of living a normal life with chronic illness.

Narrative research can provide essential information for health care provision. Using clients' narratives to identify their health care requirements can contribute to the improvement of chronic illness management (Cayton, 2006; Kennedy & Rogers, 2002; Redman, 2005). Health care provision which is based on clients' needs and expectations can improve client engagement in health care, access to health care, and integrated and comprehensive team care (Davis, Schoenbaum & Audet, 2005). Narrative is the most common form of communication used for organising and recording social and personal experience (Robinson & Hawpe, 1986) because a range of views about issues of concerns provided by individuals in community is essential to extend understandings of situations and possibilities for problem solving by constructing new notions based on complexities, depth, and various views (Lambart, et al., 1995). Narrative research is

described as a research method for understanding people's experiences through their story-telling (Denzin & Lincoln, 2005; Josselson & Lieblich, 2001; McAdams, 1993; Robinson & Hawpe, 1986). Narratives influence appropriate actions for managing current challenges and in the future by understanding the current and the past of social situations through individuals' stories in society (Cooper, 1995; Murray, 2004; Robinson & Hawpe, 1986). Sharing clients' narratives is a strategy aimed at creating love, healing, growth, and solidarity within health care (Miller & Crabtree, 2005). Cooper (1995, p.124) states that "through sharing stories, we create healing communities and guard against the kind of detachment that allows people to slip away unnoticed". Ignoring clients' stories can lead to increased suffering and the deaths of clients because of the limitation of health care provision which focuses on clients' concerns, in addition clients may have limited participation and access to health care services (Bruner, 2002).

Narrative meaning is dynamic. The meaning is reflected, recollected, and constructed by the interaction of a person's cognition with internal and external environments. Narrative meaning is an open system in which "new forms of organisation can emerge and new meaning can be developed" (Polkinghorne, 1988, pp.15-16). I agree with this statement and believe that, through the mutual exploration process of narrative research, participants are encouraged to critically consider their narratives and connect the narratives to wider beliefs and values (Duffy, 2007). Narrative meaning relies on the plot (Bernstein, 1990; Bruner, 2002; McAdams, 1988; Murray, 2003; Polkinghorne, 1988). The storage of plot lines is used by people in each society to organise the series of events. The plot lines are embedded in each society in terms of culture, social norms, beliefs, and values (Polkinghorne, 1988). The plot of a story is used by people in society to make a meaning of events. Therefore the meaning of similar situations can be interpreted differently based on the plot of a story for each social context. Narratives are fundamental for understanding specific meaning of events in each community. Also, this understanding would provide appropriate direction of actions to manage the issues of concern in the community as these actions are supported by the knowledge that closely relate to concern of the people in the community and may encourage cooperation and participation in managing the social problems.

Limited participation in health care by people with chronic disease, their families, and the community is a common phenomenon in current health care practice. Clients are often alleged to be non-compliant with care regimens and this non-compliance can be blamed by health professionals for negative health outcomes (Todd & Laden, 1998). This accusation is likely to widen the gap between clients and care providers by limiting the means to encourage client participation in health care and seeking help from health care professionals. Also, if based health care practice on understanding clients' needs and expectations by listening to their stories, this practice may increase the opportunities of working in partnership between clients and health professionals. I believe that by using clients' narratives to inform health care providers, they would provide better care for clients. Understanding the importance of the clients' points of view about health care raised a potential research question which would enable me to explore the gaps in health care provision for people with VHD in Thailand.

Research Inspiration

Clients' life-stories are the significant inspiration throughout this study. My willingness to learn from clients' life-stories about their health care experiences is a key for starting this research project. Their stories encouraged me to explore more stories to gain data for analysis and interpretation by narrative methodology to achieve a better understanding about health care provision for people who live with VHD.

Although I was trained to focus on both scientific knowledge and development aesthetic of nursing which refers to the art and beauty of caring with mutual understanding of clients' life world. However, when I was working as a registered nurse in a care setting which was focused on disease I had limited means to develop aesthetic knowledge which focuses on understanding people as individual within a wider social context. This kind of knowing can improve the development of empathetic and client-centred care. At the time I was trained, the main focus of care was informed by medical knowledge of people's bodies and diseases to support my clinical practices. The concerns and aims of caring were to manage clients' distress caused by the disease with the main focus of relieving the signs and symptoms of the diseases. As the main focus of care was mainly on the disease when I worked in the hospital, the main nursing focus included assessment, care plans and evaluation to relieve and eliminate signs and symptoms which are the consequence of the diseases. I had limited opportunities to provide and

develop empathetic and client-centred cares which demands a range of knowledge informed by understanding people in their wider social context to expand knowing for the improvement of appropriate health care provision. The ways of knowledge people in their contexts require listening to clients' life-stories rather than a focus only on disease-orientated care. After nine years working as hospital-based registered nurse, I have now moved to work in rural areas. Now that I am working with people in these communities, I found that I was struggling and realised that I had limited knowledge to support people with chronic disease in the community.

This research focuses on the development of mutual sharing of health care information for managing illness between the participants and me. Mutual listening was a prerequisite for this cooperation. Through this experience, I realised that in the past, I have only worked for and never worked with people living with disease. Assessment, care plan, intervention, and outcome evaluation for clients are initiated and delivered based on my concerns about their health problems. Is this enough to support people with chronic disease? In fact, I found that I had limited practical knowledge to care for such people. Understanding how to work with clients enriches my knowledge and provides effective ways to encourage these people to manage their illness and gain better health outcomes. I believe that understanding clients' health care experiences is necessary to work effectively and provide client-centred care for people with VHD. What and how people with VHD perceive and understand health care services was my objective for the research outlined in this thesis. Therefore, participants' narratives which are the outcomes of this study can be used to support health care providers to work with clients aiming at effective illness management. This cooperation should enable people with VHD to achieve maximum well-being because health care provision is informed by clients' needs and expectations.

It is important to clarify the way I approach and understand research and to define myself as a researcher. To do this, I must address the influences that have led me to understand and interpret the topic and my approach to narrative research. Clients' narratives help me to gain better understanding of their world of health care. This insight is achieved by listening to or reading clients' stories to develop aesthetic clinical practice. This interpretation process is essential for understanding the narratives of others, their actions, and "how they are living their very lives" (Freeman, 1993, pp. 2-

4). Narrative meaning is constructed using reflexivity as a central component of narrative interpretation (Lieblich, Tuval-Mashiach & Zilber, 1998). “It is in reflecting on experience that we construct stories” (Robinson & Hawpe, 1986, p. 111) and reflexivity is required to find the meaning within the data (Hunter, Lusardi, Zucker, Jacelon & Chandler, 2002).

Reflexivity is a central component of narrative research (Elliot, 2005). Reflexivity is essential because it is a tool to understand the deeper meaning of the phenomenon by the participants’ lens and the researchers’ lens (Freshwater, 2004; Sword, 1999) important for the provision of empathetic care which is a central concern of my nursing practice. Reflexivity also involves the realisation that researchers are part of the social world that they study (Askeland & Bradley, 2009; Frank, 1997). Reflexivity is the property of self as relational (Linde, 1993). I consider that I am a part of this research process because I am a member of a health care society and also brought up and lived in a rural area in Thailand. I have been involved in this research from the beginning by reviewing the literature and thinking about my clinical experience and carefully thinking about how health care services for people with VHD influences the development of this research question. I have my own beliefs and values which are informed by practice contexts, and reflection on clients’ stories brings those beliefs and values into greater focus by interaction with experiences that are different from mine. The analysis of participants’ stories demands critical reflection from the researcher who is the instrument for generating evidence, revealing the researcher’s creative processes in conveying the complex phenomenon, and interpreting the analysis findings to the context (Freshwater, 2004). Reflexivity of the researcher is essential for this study where as Chase (2005) states, narrative researchers construct participants’ voices and realities that are enabled or constrained by their social conditions. In this study, understanding participants’ health care experiences is supported through reflection on participants’ stories, my own personal beliefs, values and experiences, and also the broader social contexts.

Research Contexts

Living with chronic illness needs appropriate support from health professionals to manage illness and live a normal life. Health care services are necessary for people diagnosed with VHD to achieve maximum well-being. Limited health care resources in

rural Thailand for those who live with VHD create difficulties from both VHD and the access to health care services.

Thai health care

The Thai health care structure is based on a centralised system. In Thailand, under the Ministry of Public Health, health care services are categorised into three levels: primary health care with 9,715 primary health centres in each community (Tambol); secondary health care with 723 community hospitals in each district (Amphur) which provide from 10 to 100 beds for in-patients and 70 general hospitals in each province; tertiary health care with 25 regional hospitals which provide both general health services and specialist services (Ministry of Public Health [MoPH], 2005). In addition, there are five university (research) hospitals under the Ministry of Education. In Bangkok, there are seven general hospitals and 61 health care centres under the management of Bangkok Metropolitan administration (MoPH, 1998). There are around 298 private hospitals in Thailand (MoPH, 2005). Advanced medical technology and delivery by specialists are at secondary and mainly at tertiary hospitals which are located in urban areas. Consequently, people who live some distance from health care settings, for example in rural and remote areas, experience difficulties and increased burdens such as travel to health care services.

Rural areas in Thailand have limited health care resources for supporting people to live a normal life with VHD. This limitation can be represented by the number of health care resources, the number of physicians, nurses, and beds per number of clients in rural areas are lower than urban areas (MoPH, 2005, 2007). This means the rural population in Thailand has limited access to health care services, especially client-centred health care provision. People with this disease in rural areas face difficulties both from having VHD and access to health care provision to manage VHD. This limited access to health care is likely to be influenced by the disease-orientated health care provision and the failure to integrate the points of view of those who live with chronic conditions in rural Thailand. Health care provision based mainly on disease is likely to have a limited focus on individuals' needs and expectations which can lead people with VHD to decline to seek help. Declining of care may be caused by different point of views about disease and health care, the goal of illness management, and desirable health outcomes between health care providers and clients. Consequently, in Thailand, even when advanced

medical technology for people with VHD is available, people with this disease still experience limited access to effective health care services. People in rural areas are prone to develop VHD as a consequence of limited access to preventive VHD health care services. People living in rural Thailand diagnosed with VHD are also prone to VHD complications due to limited access to appropriate illness management at the right time caused by poor health care accessibility. This situation is supported by the higher number of people with VHD in rural areas than in urban areas (MoPH, 2005; 2007).

Nursing and health care

Nursing should focus on the development of a client-centred care model aiming to positively impact on health care outcomes. By addressing the needs of clients, health care for people with chronic conditions is improved (Boltz, et al., 2008; Fulmer, et al., 2002; Guthrie, Edinger & Schumacher, 2002; Pfaff, 2002). The success of nursing input in improving health care provision is used as a health care model for people with chronic disease (Fulmer, et al., 2002). Examples of the positive impact of nursing on health care outcomes include reducing the incidence of confusion for hospitalised older persons (Guthrie, Edinger & Schumacher, 2002) and provision of a better quality of aged care (Boltz, et al., 2008).

In Thailand support from health authorities as influenced by disease-orientated health care provision for nurses to develop care for people with chronic disease in rural areas is limited. People with chronic diseases in rural areas have particular challenges related to the limited numbers of health professionals and the distance from health care settings, and these contributing factors often lead them to experience an exacerbation of the disease and a readmission to hospital because of worsened health status (Scott, 2000). Nurses who work in rural health care settings also experience limited support from peer networks for delivering care to people with chronic disease (Lindeke, Jukkala & Tanner, 2005). Nurse practitioners who work in primary health care settings have particular challenges because of the high numbers of clients, the need to rotate to other health care settings, inadequate medications and instruments to support effective health care provision, and the lack of a peer network (Boonthong, Athaseri & Sirikul, 2007). Because of these limitations, people with VHD who live in rural and remote areas have limited access to health care delivered by nurses.

Research Focus

This research has developed from my interests and experience as a nurse. Having worked as a registered nurse to provide care for people with chronic illness, both in hospitals and communities, I found that listening to clients is missing from clinical practice. This omission is basic to access to health care and limits cooperation of clients in health care. Encouraging clients' cooperation is essential in health care provision, in particular in relation to VHD which is a preventable and curable disease.

Research aim

The aim of the research was to explore and understand the experiences of people with VHD to inform and support improvement in health care provision. Narrative inquiry is the methodology and method chosen to explore the experiences of individuals living with VHD. The health care experiences of individuals living with VHD are explored through individuals describing their understanding of health care. The aim is to gain a better understanding of the experiences of individuals diagnosed with VHD. It is believed that listening to and reflecting on clients' narratives can support consensus between clients and care providers in health care which is essential for accessible and acceptable health care provision.

Research objective

I started this exploration with the question: What are the health care experiences of individuals with VHD? Through this study participants' narratives may enrich care providers' understanding about current health care provision. This information has the potential to be used to develop more relevant and empathetic health care which can encourage clients to use health care services. Participants' stories can increase nurses' awareness and improve care for people with VHD because of knowledge of health care issues from the client points of view. Through increased understanding, health care provision should become more client-centered which can increase access to health care. People with VHD may gain well-being through appropriate health care provision which is based on the perspectives of those who live with this disease.

Thesis Overview

This thesis is organised into nine chapters and both Western and Thai concepts are introduced and discussed throughout the thesis, the Thai alphabet appears to be slightly

smaller than the English alphabet but both are 12 front size. In Chapter two, I discuss the literature under four main areas: VHD and a profile of people with VHD describes the nature of VHD and the characteristics of people with VHD; Thai health care focuses on structure, resources, services, insurance, and policy for managing heart disease; factors influencing accessibility to health care, health care seeking, and participation in health care includes social conditions, cultural diversity, self-management, and family and community; and finally, the contribution of nurses to health care for people with chronic disease is discussed, with focus on information providing, self management, cooperation in health care, continuing health care, and opportunities for nurses to provide and develop health care services for people with chronic illness.

Chapter Three describes the theoretical basis and reasons for selecting narrative inquiry, and narrative methodology. The chapter starts with a history of narrative inquiry and addresses development, definition and the characteristics of narrative inquiry. Narrative in a Thai context is discussed in terms of ways of knowing and story-telling. The relationship between narrative and health care is also explored.

In Chapter Four a detailed description of the method of data collection is presented focusing on the narrative interviews with participants. The narrative analysis technique is also discussed and ethical issues and trustworthiness of the data are addressed.

The findings from the study are presented in Chapter Five to Seven. Chapter Five describes participants' autonomy and living with VHD. The analysis finds that participants manage to overcome a number of challenges as the assertion to access health care services includes assertive decision-making to seek help directed by their expectations and life circumstance, and a strong determination to access health care services by overcoming traveling difficulties, the challenges of health care services, bearing the difficulties and accepting life with loss.

The focus in Chapter Six is on the analyses of the participants' efforts by learning to manage life with long-term illness in rural areas. As the heart is the most important organ, participants seek and value health care information from health professionals, lay persons with relevant experience and stories related to living with illness and its management. Opportunities to learn from health professionals appear to be limited by

rural people with VHD being hesitant to raise their concerns, cultural differences between care providers and clients such as the difference of client and health professional language and by the complex bureaucratic delivery of health care services.

Chapter Seven considers how participants maximise health care resources to manage living with VHD. Living with long-term illness demands continuing support from a variety of sources. Participants access enough health care services while they are hospitalised and having follow-ups at heart clinics. In order to gain continuing care when they are in a community distant from health care settings, participants seek help from local indigenous healers for alternative support, their family member is also a significant resource to achieve the aim of living a normal life with VHD. Participants have limited understanding about the disease, treatment and means of illness management. However, as the willingness to achieve well-being, they base the management on own self and lay understanding about disease and health care to develop illness management.

A discussion of the findings from the study and the focus on the cultural and health care service barriers is discussed in Chapter Eight. Cultural barriers indicate that the different meanings given to health and disease, and the language difference between care providers and clients, widens the gap and increases inaccessibility to health care. Health care services which are based on values underpinning the biomedical models aggravate the inaccessibility to health care because inequity of health care resource distribution leads to limited health care options in rural areas. Therefore, rural people manage to overcome the challenge of limitations of health care services with the support of lay persons and indigenous healers. In addition, people who access health care services experience challenges managing life with chronic conditions because of the limited client-centred health care services caused by disease-orientated health care provision.

Chapter Nine considers what the findings from the study might mean for those, such as nurses, who work in a practice area of health care for individuals living with VHD. These clients' experiences are presented to inform health care educational programmes and educational delivery for health professionals to support those diagnosed with VHD. This data may be used to develop and implement policy that may support individuals achieve greater well-being through the delivery of more effective health care services.

Health care and illness management services which are appropriate, for example by having nurses with an understanding of client-centred care as managers, may facilitate accessibility to health care. Narrative approaches can provide a range of point of views of people with VHD about health care provision. The knowledge from clients can support health professionals to gain a better understanding to develop acceptable and accessible health care services.

CHAPTER 2

VALVULAR HEART DISEASE AND HEALTH CARE CONTEXTS

Introduction

The literature review about issues related with valvular heart disease (VHD) and health care is based on local, national, and international databases. These literatures were searched in two Thai databases including (i) ฐานข้อมูลวิทยานิพนธ์ไทย (Thai Thesis Database) from Burapha University, ChaingMai University, KhonKaen University, Chulalongkorn University, Mahidol University, Songkhroa University, Mahasarakham University and Naresorn University where programmes for graduate nursing are available, nine titles related to VHD were found and (ii) ฐานข้อมูลวิจัยไทย (Thai Research Database) with key words ไข้รูห์มาติก, โรคหัวใจรูห์มาติก, โรคลิ้นหัวใจพิการ, rheumatic fever, rheumatic heart disease, valvular heart disease (VHD), where no articles were found. Almost all of the literature reviewed in this study is available from three databases including Health Databases on EBSCO host from 1966 to 2009, CINAHL from 1981 to 2009, and MEDLINE via PubMed from 1964 to 2009. The key words included VHD, rheumatic heart disease, heart disease, heart valve disease, chronic disease, chronic illness, health services, health care management, social support, indigenous, socioeconomic, developing countries, nursing, advanced nursing practice, rural nursing, continuing care, self-management, client-centred care, continuing education of rural nurses, and rural health. Some articles were searched for on Scopus by author names such as Carapetis, McDonald, Harrington, and Cass. Some articles available as hard copies with and without publication are also included in the literature review.

From the literature it can conclude that VHD is still a cause of chronic illness within developing and developed countries. Valvular heart disease impacts on physical and psychological health of people with VHD, their families and community. Related literature focuses on the incidence and prevalence of VHD, found that limited access to health care services was an attributing factor increasing the prevalence and people with limited access to health care are highly affected by this disease (Carapetis, 2007; Carapetis & Currie, 1999; Carapetis, Mayosi & Kaplan, 2006). Access to health care, seeking help from health professionals, and collaboration between clients and health care providers are necessary to prevent or manage VHD. Social conditions and cultural

diversity impact on the perception of people with VHD and their families effecting cooperation and participation in health care. Nursing practice focusing on client-centred and continuing care impacts positively on the management of illness, for example the improvement of dyspnea management of clients with VHD (Buatee, 2002) and results in improved health care outcomes (Ward, 1997). Rural nursing practice has positively effected chronic illness management and the improvement of health of rural populations as a consequence of appropriate illness management (Marek, Popejoy, Petroski & Rantz, 2006). Description about health care and rural health practice in Thailand will be further discussed in this chapter later.

Definition of VHD

Valvular heart disease is caused by one or more valve defects, either stenosis or regurgitation, or both, which lead to an inadequate blood supply to the body (Bonow, et al., 2008; Shipton & Wahba, 2001). Rheumatic heart disease is often the precursor to VHD (Carapetis, Mayosi & Kaplan, 2006) and 40% to 60% of people with rheumatic mitral valve disease usually have a history of rheumatic fever during childhood (Segal, 2003). Rheumatic fever occurs when a person contracts a haemolytic streptococcus group A infection. The incidence of this infection has remained high in both developed and developing countries (WHO, 2004). The streptococcus infection results in rheumatic fever and if infected persons do not receive effective care and treatment to prevent recurrence of rheumatic fever, their heart valves are damaged (McLaren, Markowitz & Gerber, 1994).

People with valve deformities experience both physical and psychological signs and symptoms. Individuals with this disease may experience shortness of breath, dyspnea on exertion, fatigue, edema, syncope, and palpitations (Bonow, et al., 2008). Left untreated, the cardiac valves will be further damaged and the sequelae of this are that individuals may develop more life threatening consequences. Possibilities of VHD complications correlate with the deterioration of the valve (valves) and the heart such as enlargement of the left atrium. People with a longer duration of the illness are likely to have more life threatening complications such as atrial fibrillation which causes more complex problems including ischemia and stroke (Carabello, 2004; Diker, et al., 1996). The important objective in caring for people with VHD is proper management aimed at preventing the development of more serious complications. People with longer duration

of illness face more severe disease symptoms and disease complications and are likely to have higher levels of distress.

Distress from these symptoms can lead to other health problems such as poor nutrition, lack of rest, less activity, and psychological problems (Segal, 2003). Living with a chronic disease impacts on daily life and causes a high level of stress which impacts on emotional health (Maneesilp, 1999). However, the effects of stress on emotional is difference depending on each clients' coping mechanisms. Clients with difficulty coping may experience more suffering than other clients who can cope better. Gustavsson and Bränholm (2003) reported that clients with heart failure with a higher degree of coping resources were more satisfied with life as a whole. Health care provision for people with chronic disease is needed to expand the focus of care to support clients to cope with long term life with chronic disease. Supporting people with chronic disease to cope and live in positive ways such as the development of self-management and social-network resources can help clients to achieve maximum well-being as a result of less suffering from disease symptoms.

Incidence and Prevalence

Acquired VHD, which is often caused by rheumatic fever, is still a cause of chronic disease worldwide with a high incidence among people living in poverty. Socioeconomic factors attribute to the distribution of the affected population where the possibility of haemolytic streptococcus group A infection from over-crowded housing, malnutrition, bad hygiene, or limited access to health care is high.

Worldwide

Although VHD is preventable, it is still a cause of chronic illness for people who live in both developing countries and developed countries. The reduction of this disease in developed countries correlates with the improvement of living conditions such as less overcrowding, better hygiene, good nutrition, and better health care access (Carapetis, 2007; Carapetis, McDonald & Wilson, 2005). However, the prevalence of this disease has remained high in developing countries and is also a health problem in developed countries (Schaffer, et al., 2003). This disease remains an obvious public health burden across the developing world causing more than 200,000 deaths a year (Carapetis, Steer, Mulholland & Weber, 2005).

People who live with limited resources are more likely to get VHD in particular caused by rheumatic fever. The incidence of rheumatic heart disease is related poverty, malnutrition, overcrowding and poor housing (Nordet, Lopez, Duenñas & Sarmiento, 2008; Shaper, 1972). McLaren, Markowitz and Gerber (1994) reported that people who live in remote areas account for a large proportion of individuals with this disease. It is also found that people who are poor and have limited education are particularly prone to VHD (Carapetis, Mayosi & Kaplan, 2006). The higher incidence of VHD among people with a range of disadvantages is likely to be influenced by the nature of the disease caused by streptococcus infection. Factors which contribute to the infection include malnutrition, poor hygiene, overcrowding, and a lack of access to health care (WHO, 2004). Rural areas in both developing countries and developed countries have more factors related to increase in streptococcal infection. When more of these factors are present the infection rate is likely to be much higher. People who live with disadvantages such as living with poverty and living with some distance also have limited access to health care services for a range of reasons such as the living distance from health care settings. It can be concluded that people with poverty are likely to be affected by VHD.

Indigenous populations have a higher incidence of rheumatic heart disease as compared to the overall population (Carapetis, 2007; Carapetis & Currie, 1999; Jaine, Baker & Venugopal, 2008). For example, indigenous people in Fiji die from rheumatic heart disease in greater numbers than the overall population (Singh, Carapetis, Buadromo, Samberkar & Steer, 2008) and indigenous Australians' morbidity and mortality from acute rheumatic and chronic rheumatic disease is 19 times greater than other Australians (Indigenous heart disease worse, 2004). In New Zealand there is also a higher rate of acute rheumatic fever in Māori and Pacific peoples (Jaine, Baker & Venugopal, 2008). The high incidence of the disease and death rate from rheumatic heart disease of indigenous people are likely to be caused by living with poverty and having limited access to health care services.

Valvular heart disease can impact on wider society because women are prone to get VHD. Valvular heart disease is found in both men and women, however women are at a much higher risk than men of developing VHD. This difference in incidence is similar both in developed and developing countries. In 2003, the Strong Heart Study in USA

found the prevalence of female: male was 5.5:3 per 1000 (Schaffer, et al., 2003). Sadiq, et al. (2009) reported the prevalence of rheumatic heart disease in Pakistan of female: male ratio was 1.6:1. Women also account for the higher mortality rate of people with VHD. In the United States in 2004, 3,248 people died from rheumatic fever and rheumatic heart disease and female deaths from this disease was higher than the male rate (American Heart Association, n.d.). The reasons suggested for the higher number of women with VHD include women usually being overburdened with work and providing support for their families (Sindhu, 1992). Because of this situation they have limited time to think about their health. Consequently, they are less likely to access health care and, therefore, may have a greater tendency to develop rheumatic heart disease. As women are the main family member who care for others, VHD is likely to have more impact on family and wider community because the reducing of caring support from women with VHD.

Valvular heart disease can have a high impact on social productivity because the disease affects young adults and is a cause of death at an early age. The WHO (2005) reported that people aged between 15-35 years account for the highest proportion of people with VHD, with 27.5-52.9 per 1000 of people with this disease. This disease can cause premature death at a time when young people reach the time of their greatest productivity in society (Carapetis & Currie, 1999; Carapetis, Mayosi & Kaplan, 2006). Singh, Carapetis, Buadromo, Samberkar and Steer (2008) reported the mean age of people with rheumatic heart disease in Fiji who died from rheumatic heart disease was 38 years. The mortality rate of clients with rheumatic disease in rural Ethiopia was 125.3 per 1000 persons and the mean age at death was 22 years (Günther, Asmera & Parry, 2006).

Thailand

Acute rheumatic fever and rheumatic heart disease are high in incidence but less researched in developing countries (Carapetis, McDonald & Wilson, 2005). Steer, Carapetis, Nolan and Shann (2002) concluded in a systematic review that the prevalence of rheumatic heart disease in developing countries is needed to be researched as environmental factors such as socioeconomic status, overcrowded housing, nutrition status, and limited access to health care are closely related to the prevalence of the disease. Establishing the incidence of acute rheumatic fever and rheumatic heart disease

in Thailand is based on few articles with one very dated. In Thailand, rheumatic heart disease is still a leading cause of chronic illness and large numbers of people are diagnosed with this disease. Mori, Okuda, Nishioka, Ueda and Phornphvtkul (1979) reported that the incidence of rheumatic heart disease in Thailand was one hundred times greater than that in Japan. The prevalence rate of rheumatic fever and rheumatic heart disease is still high in Thailand. The incident of rheumatic fever was 1.2-2.1 per 1,000 school children (Ibrahim & Rahman, 2002) and the rates of rheumatic heart disease was 31.82 per 100 000 population (MoPH, 2007). The rate is higher in rural areas as compared to people who live in urban areas (MoPH, 2007). More detailed incidence and prevalence rate of VHD in Thailand are needed.

Management and Treatment

Effective health care for the prevention and treatment for VHD is well developed. Antimicrobial treatment is effective in preventing people from contracting recurrent rheumatic fever which is a leading cause of VHD. Heart valve surgical techniques can replace and repair deformity of valves to restore normal heart function. The main challenge of health care for people with VHD is equity of access to health care which is the key factor for both the prevention of VHD and the treatment of this disease.

Preventive management of rheumatic heart disease including: primary prevention entails adequate diagnosis and treatment of streptococcal sore throat and secondary prevention with continuous antimicrobial prophylaxis for streptococcal infection of client with acute rheumatic fever (Worldwide control of rheumatic fever, 1979) and this preventive management is still recommended as the effective strategy for rheumatic heart disease prevention (Carapetis, McDonald & Wilson, 2005). The beta haemolytic streptococci group A are the common cause of children and young adult pharyngitis and can cause acute rheumatic fever which is a leading cause of rheumatic heart disease (Roberts, et al., 2001). Antibiotic therapy at the onset of pharyngitis symptoms can prevent acute rheumatic fever and recurrence of rheumatic fever and finally, rheumatic heart disease. Therefore, antibiotic treatment is necessary to prevent the development of VHD (Bonow, et al., 2008; McDonald, Brown, Noonan & Carapetis, 2005; McLaren, Markowitz & Gerber, 1994). Access to treatment is the key to preventing people from contracting VHD. Primary health care that ensures regular penicillin administration for people after the first acute rheumatic fever episode is an effective way to prevent

recurrence rheumatic heart disease (Günther, Asmera & Parry, 2006; McDonald, Brown, Noonan & Carapetis, 2005; McLaren, Markowitz, & Gerber, 1994). According to the WHO (1992) report on a programme for preventing VHD the recurrence of rheumatic fever only at 0.4% of schoolchildren with rheumatic fever. Because of the effectiveness of preventive management in 1972, WHO launched a register based project to control acute rheumatic fever and rheumatic heart disease and increase access to antibiotic prophylaxis (McDonald, Brown, Noonan & Carapetis, 2005; WHO, 2001). A registered based programme for the control of acute rheumatic fever reduced the incidence and severity of rheumatic fever, the recurrence of rheumatic fever and the prevalence of rheumatic heart disease in Cuba where a comprehensive prevention and control of rheumatic fever and rheumatic heart disease programme was carried out to test the strategies for prevention of the disease (Nordet, Lopez, Dueñas & Sarmiento, 2008).

However, encouraging greater cooperation of clients with the treatment is needed due to requirements of regular treatment over a long period. People diagnosed with acute rheumatic fever have monthly intramuscular benzathine penicillin, or take sulfosamides, penicillin, or erythromycin daily to prevent the recurrence of streptococcus infection (Worldwide control of rheumatic fever, 1979). The treatment is highly demanding, for example monthly penicillin injections in children after a first episode of acute rheumatic fever and follow-up until the third decade of life (Marijon, et al., 2008). The need for commitment to regular and long-term treatment to prevent future complications leads to poor treatment adherence of clients where there is a lack of appropriate health care provision to support client participation in health care. Stewart, McDonald and Currie (2007) reported that 56% of people with acute rheumatic fever adhered to prophylaxis treatment and concluded that this management is inadequate to prevent the recurrent of rheumatic fever in indigenous clients. Saxena, et al. (n.d.) reported that only 48% of children with rheumatic heart disease were taking penicillin prophylaxis regularly. This preventive treatment is also less practical in developing countries as a result of a lack of sustainable policy of rheumatic heart disease (McLaren, Markowitz & Gerber, 1994; WHO, 1995). The inadequate preventive practice can be attributed to the high incidence of rheumatic heart disease worldwide and especially in developing countries. Consequently, this disease is still a cause of chronic illness.

Preventive health care provision for VHD is needed with and support from local, national, and international levels. Primary health care professionals are also required who are interested in preventing this disease. According to Carapetis, Mayosi and Kaplan (2006, p. 165) the success of preventing rheumatic heart disease demands “political will, local and international understanding and interest, and a long-term commitment to maintaining rheumatic fever control programmes”. The clients’ perspectives about health care services are needed to understand issues around adherence with rheumatic fever prophylaxis, for example in the Aboriginal community, clients expected health care providers to visit people at home, to talk to families, to encourage clients and care for them emotionally and spiritually in a manner similar to their family members (Harrington, Thomas, Currie & Bulkanhawuy, 2006). Encouraging and supporting primary health care providers such as nurses who focus their care on client orientation may increase the possibility of successful preventive health care services for VHD. For example, Grayson, Horsburgh and Lennon (2006) reported a study of a rheumatic fever register, managed by community-based nurse-led clinics in New Zealand and found the compliance rates were from 79.9 to 100%.

Clients with significant symptoms due to valvular deterioration from both stenosis and regurgitation need intervention both to relieve symptoms and to prolong life. The intervention to correct valve damage is necessary to prevent VHD complications such as atrial fibrillation (Diker, et al., 1996). Shipton and Wahba (2001) found that appropriate surgical techniques and undergoing the heart operation at the appropriate time can help clients live longer with less immobility. Providing effective health care management for VHD requires monitoring including physical examination and specific investigations such as echocardiography or cardiac catheterization which is a key for disease evaluation and for decision making about appropriate treatments (Shahbudin & Rahimtoola, 1982; Shipton & Wahba, 2001; Veasy & Tani, 2005). Operation techniques vary depending on the valve affected. For example, valve replacement is necessary for aortic stenosis (Bonow, et al., 2008) which is different from the treatment for mitral stenosis where mitral balloon valvotomy can provide relief of the symptoms with long-term benefits (Carabello & Crawford, 1997). Mitral valve replacement is only used in cases where valvotomy and commissary (repaired valve technique) are not suitable (Bonow, et al, 2008). As the appropriate treatment correlates to the health outcomes of people with VHD, access to appropriate health care is necessary for people affected by

VHD for preventing life threatening complications and ensuring a stable health status by the proper treatment at the appropriate time.

Systemic embolism is a life threatening condition caused by VHD complications in rheumatic mitral valve disease. Antithrombotic drugs can reduce the incidence of this complication. Therefore, medications are also necessary for the VHD management for clients with and without the heart surgery. The seventh conference of the American College of Chest Physicians on Antithrombotic and thrombolytic therapy recommend that: for clients with rheumatic mitral valve disease who experience atrial fibrillation or a history of systemic embolism, the medications are an oral anticoagulant, aspirin, and dipyridamole or clopidogrel; for clients with mechanical prosthetic heart valves, medications are vitamin K antagonists, and aspirin; for clients with bioprosthetic valves medication is aspirin (Salem, et al., 2004). All of these medications can reduce forming of blood clot which is a cause of systemic embolism. The adverse effects include the life threatening risk of bleeding, and close monitoring of international normalised ratio (INR) is required (Salem, et al., 2004). Health care provision for people with VHD who take antithrombotic therapy includes close monitoring from health professionals and along with self-monitoring skills and knowledge and understanding about the treatment and its effects.

Health Care for People with VHD in Rural Thailand

Health care for people with VHD has not been well established in rural areas, in Thailand. Rural populations face difficulties accessing health care which leads people in rural areas to be prone to get VHD and the ensuing impact of the disease. There are inadequate numbers of health professionals in rural areas which means there are limited health care options for people living with a chronic disease. The provision of good health care resources increases health care usage. An inequity of health care resource distribution exists in Thailand with health care resources being more available in urban areas when compared to rural areas. An example is in 2004 the ratio of people per bed for general services, between the Bangkok metropolis and other provinces was 224 and 527 respectively (MoPH, 2005). In 2004 the ratio of people per physician in Bangkok compared to other provinces in was 879: 4,582. Similarly, the number of people per nurse was 289 in Bangkok and 747 in other provinces (MoPH, 2005).

Health care resource distribution is based on disease-orientated results in people in rural areas in Thailand with limited access to health care for VHD. Primary health care units which are the nearest health care resources have limited preparation to deliver care focusing on VHD prevention and VHD management. Health professionals in primary health care settings also have limited support to deliver preventive VHD programmes. This limitation is likely to be caused by disease-oriented health care provision which leads primary health professionals to focus on referring clients to secondary or tertiary health care settings rather than focusing on finding and supporting people they care for. In addition, health care guidelines for people with VHD in Thailand are disease-orientated. A guideline for physicians for the management of VHD focuses mainly on the relief and elimination of signs and symptoms of VHD (Physician Office, MoPH, n.d.). Based on this guideline, doctors in provincial hospitals and other tertiary hospitals are able to diagnose and provide specific treatment for heart disease. Treatments which require advanced medical technology such as open heart surgery are provided at central hospitals or university hospitals. In this guideline, primary health professionals are not informed to focus their practice on preventing people they care for from the development of VHD.

National health care insurance contributes to the challenge of health care access of people in rural areas in Thailand. In 2001 the Thai government launched a scheme for universal health care coverage. This policy, called the “thirty baht for all disease treatment” is aimed at ensuring equity of access to health care (National Healthcare Insurance Office [NHSO], 2003). In order to get the coverage Thai residences are registered with a particular health care setting decided by the health care authority. After that, they get health care services from the health care setting where they are registered, except in the case of emergency or when referred by a registered health care setting to access services from other health care settings (NHSO, 2003). Referral by a registered health care provider is needed to access other health care settings where they are not registered. If clients want to get health care services from hospitals where they are not registered, they have to go to a registered hospital for a referring note before going to other hospitals. Without a referral document from the registered hospital, health coverage is not provided and clients have to pay their health care expenses. People in rural areas are commonly registered with the health care settings near their homes such as community hospitals. At community hospitals or primary health care units cardio

specialists are not available, therefore, people with VHD which require care from cardiologists are referred to the hospitals where the specialists are available. People with VHD in rural areas are likely to have more difficulties accessing appropriate health care services for VHD than people in urban areas where health care facilities for appropriate care for the disease are available.

Health care provision for heart disease focuses mainly on the prevention of myocardial infarction. In Thailand, heart disease is a focus for best practice which was launched by the Ministry of Public Health. Three excellent health care projects funded by the Ministry of Public Health in Thailand are the centres for accident, for cancer, and for heart disease. Health care settings which are audited as centres of excellence have to meet certain evaluation criteria. The criteria for centres of excellence for heart disease are focused on the prevention of myocardial infarction. People who are admitted with chest pain are closely monitored and gold standard practice guidelines are used to prevent blood clots in the coronary arteries. If the EKG shows ST elevation streptokinase is administered within six hours and clients are referred for a coronary bypass operation. This project has had a positive impact in the prevention of myocardial infarction for Thai people. However, people diagnosed with VHD still access conservative treatment, an example is symptomatic treatment. This project may reduce accessibility to health care services for people with VHD because health professionals focus on providing services for people with ischemic heart disease and myocardial infarction to meet the criteria of the Heart Excellent Centre. Health professionals may mainly focus on the development of health care services creating disparities for other heart diseases such as VHD. Consequently, this could lead to limited possibilities for improvement in the care of VHD. People with VHD cannot access the benefits of the Excellent Heart Centres at the level of gold standard which are available already at some provincial hospitals in Thailand at the same standard for people with ischemic heart disease and myocardial infarction.

Nursing and Health Care for Chronic Illness

Advanced nursing practice has impacted positively on health care for people with chronic illness. Advanced practice is based on client-centred orientation supporting the development of self-management of clients and strengthening continuing care in the

community. However, Thai nurses who work in rural areas have limited support to develop advanced nursing practice for chronic illness such as VHD.

Client-centred care is highly recommended to provide appropriate care for people living with chronic illness to achieve a maximum level of well-being. The important aim of client-centred care is to support clients to develop self-management skills and knowledge (Wagner, et al., 2005). Self-management is the means by which people with chronic disease integrate their daily life with the illness. It is a process by which people create a sense of order, discipline and control in their lives (Tullett, 2008). Self-management encourages people to achieve well being through providing a sense of dignity and self-respect (Delmar, et al., 2006), as well as a sense of control (Hertz & Anschutz, 2002). Self-management enables people living with chronic illness to live successfully with the disease, for example, with less psychological and physiological symptoms (Efraimsson, Hillervik & Ehrenberg, 2008; Tezzel & Gözü, 2006). Nurses need to be aware about the importance of client's self-management and create services to encourage self-management (Efraimsson, Hillervick & Ehrenberg, 2008; Gerson, Dorsey, Berg & Rose, 2004; Miller, 2004; Tezzel & Gözü, 2006). Advanced nurse practitioners can help people with chronic disease to attain and maintain their self-management of the disease. For example, nurse-led care managed by nurse practitioners in health clinics support people with chronic illness to develop self-management ability (Macdonald, Rogers, Blakeman & Bower, 2008). This success is through care focused on the wider concerns of clients unlike the disease-orientated health care.

Continuing care to ensure coordination of illness management between health professionals in hospitals and care providers include health professionals, local healers and clients' family members in community is necessary both for the prevention of VHD and for people with chronic VHD in communities. The cooperation of people, family, community, health care professionals is essential for continuing care (Smeenck, de Witte, Nooyen & Crebolder, 2000). Nurses are the health professionals who can facilitate continuing health care (Marek, Popejoy, Petroski & Rantz, 2006; Obman-Strickland, et al., 2008; Van Achterberg, Stevens, Crebolder, de Witte & Philipsen, 1996; Ward, 1997). Continuing care helps people with chronic disease to gain better functional ability and have fewer symptoms (Marek, Popejoy, Petroski & Rantz, 2006; Reynolds, et al., 2008), to achieve their health care needs (Ward, 1997), and also reduce

rehospitalisation costs (Smeenk, Ament, Van Haastregt, de Witte & Crebolder, 1998; Ward, 1997). The development of continuing care in advanced nursing practices for people with chronic disease through using models of care such as the transitional care model which provides continuing care by encouraging peer support groups and health care professionals in the community (Forchuk, Jewell, Schofield, Sircelj & Valledor, 1998; Reynolds, et al., 2008). Another model was for providing home visits by nurses (Marek, Popejoy, Petroski & Rantz, 2006; Obman-strickland, et al., 2008; Price, 2007; Ward, 1997).

However, nurses who provide continuing care face a range of challenges and need appropriate support for the development of advanced nursing practices. Developing advanced competencies is essential to support nurses to provide ongoing client-centred care as the focus of health care provision. For example, providing continuing care requires the nurse to anticipate and prevent potential problems, therefore the nurse needs to develop the habits of anticipated thought about health care challenges and take reasonable clinical practice to manage health and health care problems (Benner, Hooper-Kyriakidis & Stannard, 1999). According to Benner (1984, p. 46) advanced nursing practice requires the development of seven domains of competency including:

The helping role, the teaching-coaching function, the diagnostic and patient-monitoring function, effective management and rapidly changing situations, administering and monitoring therapeutic, interventions and regimens, monitoring and ensuring the quality of health care practices, organisational and work-role competencies.

Therefore, formal education and continuing support from health care institutions are important for nurses to develop and maintain advanced practice for continuing nursing care with the requirements of advanced competencies to provide continuing care independently. Hardwick and Jordan (2002) found that nurses who graduated with post-registered bachelor studies and master studies in nursing and midwifery in the United Kingdom reported that they used knowledge informed by formal education for the improvement of practice by the influence of their studies on their research skills.

Rural nursing practice can improve health care for people with chronic conditions in rural areas. People with chronic illness in rural areas face challenges of living with diseases created by limited access to health care services (Huttlinger, Schaller-Ayers & Lawson, 2004). The challenges of shortage of health care providers in rural areas has fostered innovation in health care services led by nurses in both developing and developed countries (Bowden, Shaul & Bennett, 2004; Edin, 2004; Naumann, et al., 2004; Uys, Minnaar, Simpson & Reid, 2005). Nurse-led health care provision in rural areas has improved clients' illness management. This is supported by clients' views that nurse-led clinics are important for the community as it is a health care resource to support changing of health risk behaviors (Bowden, Shaul & Bennett, 2004). Rural nursing also supported clients with chronic illness to improve self-management (Weinert, Cudney & Spring, 2008). Nursing innovation for people with chronic illness in rural areas has improved clients' health outcomes. Gensichen, et al. (2009) reported health care services by nurses improved clients' health status such as having less severity symptoms and improved quality of life.

A major challenge for health care provision in rural areas is staff turnover (Pastel, Liu, Homa, Bradley & Batalden, 2009). The turnover rate of nurses who work in rural areas is higher than in other areas in Australia according to the findings of the Queensland Health Ministerial workforce as cited by Hegney, McCarthy, Rogers-Clark and Gorman (2002). A high turnover rate of rural nurses can effect the quality of rural health care provision. Health care in rural areas requires nurse practitioners who are continuing interested in rural health and work with understanding each rural community. Reducing the turnover of health professionals could improve rural health care provision. In contrast, turnover of staff may deter effective health care services in rural areas because of the difference of providers' points of view and expertise. As turnover rates of health professionals in rural areas is still high, supporting rural care providers requires appropriate guidelines for consistency and adaptation alongside standard competencies of rural practitioners.

Nurses who work in rural areas have specific competency requirements because nurses working in isolated areas have limited resources. Rural nurses have expanded nurses' roles, for example, in New Zealand, advanced nursing roles in: a primary nursing role include accident and emergency and health promotion, giving telephone advice and

consultation and management of health conditions; and additional services such as pregnancy care, family planning, cervical smear, breast-self examination, palliative care, public health and other responsibilities including receptionist work, practice organiser, social worker, and counsellor (Ross, 1999). Adequate preparation and continuing support such as continuing education, are required to support nurse practitioners to deliver a safe, appropriate and effective health care service in rural areas. Kosteniuk, D'Aroy, Stewart and Smith (2006) reported that rural and remote registered nurses viewed support for continuing education as necessary for the ongoing development of nursing practice in rural and remote areas. However, it is difficult to ensure continuing education for nurses in rural and remote areas, an important challenge for advanced nursing practice in rural areas (Offredy, 2000). Ireland, et al. (2007) suggested that in order to provide sustainable remote and rural care, the barriers to professional education to support the development of competencies and skills of rural practitioners are needed to be addressed. Continuing educational difficulties of nurses in rural areas because of a limitation in educational resources can influence the views of nurses about effects of further education in their practice. Nurses in rural areas may also have fewer concerns about their further study than urban nurses because a greater workload relates to a shortage of staff. This limitation can effect the quality of care for rural populations because rural nurses are required to develop a range of competencies to manage the challenge existing of working in deprivation of health care resources and isolation.

In rural Thailand the possibility of developing advanced nursing practice is limited. Boontong (2000) reported that registered nurses were rarely available in the primary health care settings in rural areas. Primary health care units which are located in rural and remote areas and provide essential health care for rural people, are mainly serviced by technical nurses who were trained for 2 years instead of the 4 years required for registered nurses. The health care workers are trained for two years and can deliver basic health care services including hygiene advice, immunisation programmes, and community sanitary information such as advising about waste management. Primary health care providers can also provide primary treatment for disease symptoms but have limited resources and support for providing definitive diagnosis such as heart disease.

Currently, the Nursing Council in Thailand is making an effort to support rural practitioners, in particular technical nurses for ongoing education by encouraging and supporting nursing schools to provide study programmes and enrol more rural nurses. Some nursing schools also provide educational programmes for other health workers to be educated as registered nurses. The Nursing Council also provides support for registered nurses to develop as advanced practitioners with four months training at primary practitioners for 10,000 registered nurses between 2002 and 2012 (Terathongkum, Hanucharunkul & Suvisit, 2009). However, resource administration is under the management of Ministry of Public Health, Thailand. As a centralised health care system, after graduation, registered nurses are rotated to work at health care settings available at district and provincial hospitals. There are few primary health care positions for registered nurses. Therefore, almost all nurses after completing further study have to move away from rural and remote communities to district or provincial hospitals.

Opportunities for nurses to develop care for people with chronic illness are likely to be limited by the focus of care based on disease-orientated. This focus leads to limitation of integration clients' context to be a part of illness management. Therefore the cares may not meet the needs and expectation of clients. Nurses in rural areas in Thailand have limited opportunities to deliver and develop care for people with chronic diseases because of many factors. One of these limitations can be attributed to hospital-based practice which is informed by way of the nursing education of Thai nurses. Most Thai training courses for registered nurses are based on hospital-based care. Four years of nursing study is divided into eight semesters and generally nursing students take most of their practice time (5 from 6 semesters of practice) at hospitals with limited time to gain nursing practice in the community (1 from 6 semesters of practice). Thai registered nurses who graduate from these training programmes largely focus on providing and developing health care services for people who are admitted to hospitals. Therefore, registered nurses have limited experience delivering services to people with chronic illness in rural communities. This limitation may be because the meaning of healthy is interpreted to be the total elimination of disease. According to this interpretation of health, nurses in Thailand aim to provide health care in order to reduce the effects of disease, such as signs and symptoms and to help people to be cured of their disease.

Thai rural nurses have limited opportunities for the development of nursing practice with high workloads and limited ongoing education opportunities. Nurses in rural areas face high workloads and often take on the roles of other health professionals because the shortage of health professionals in rural Thailand. For example, at some primary health care units, physicians are not available and nurses have to take the physicians' roles. Nurses in health care settings, particularly in primary health care, often provide health care that would normally be done by doctors and pharmacists (Boonthong, 2000), and Terathongkum, Hanucharurnkul and Suvisit (2009) reported that primary nurse practitioners perceived that they had to take physician's role.

Nurses in rural areas also face higher workloads than urban nurses because there are a reduced number of nurses and other health professionals in this area. This shortage of staff can lead rural nurses to have limited opportunities for further education. It is rare for nurses who work in rural areas to gain further formal education which is necessary for nurses to develop advanced practice competencies. In some primary health care settings there are only one or two health workers and it is impossible for the primary health care workers to leave for additional formal education. Educational limitations leave nurses in rural areas to provide care with the limited opportunity of advanced nursing practice development.

Social and Cultural Contexts

Social and cultural environments strongly relate to the incidence and prevalence of VHD. Because of illness management is the key for people with chronic illness to live a normal life, therefore the level wellness of those living with chronic illness depends on the quality of illness management. It is widely accepted that social and cultural factors contribute to illness management, therefore it is necessary for health professionals to gain an understanding about clients' social and cultural contexts especially in case of VHD.

Social environments are an important influencing factor on health and relate to both morbidity and mortality rates (Mohan, Twigg, Barnard & Jones, 2005; Roux, 2001). Social capital such as social welfare, level of political participation, quality of relationships with people in the community, the social norms or human values about health outcomes and geographical deprivation affect the health of people with chronic

illness and their access to health care (Mohan, Twigg, Barnard & Jones, 2005). Limited social capital, both material and geography, that represent social wealth such as education level, employment status, housing, and car ownership related with the self report of illness, material deprivation and geographic isolation relates to a high self reported morbidity (Boyle, Gatrell & Duke-Williams, 2001; Haynes, Bentham, Lovett & Eimermann, 1997). In contrast, people who have high social resources have a low mortality rate from health problems related to their behaviors such as smoking, alcohol consumption, exercise, and eating behavior (Mohan, Twigg, Barnard & Jones, 2005).

People who live in rural areas have a higher rate of long-term illness (Barnett, Roderick, Martin & Diamond, 2001). In Thailand people who live in rural areas have less material wealth, for example, they earn less than people living in urban areas (National Statistical Office, 2008). Rural people also live in geographic isolation and are distant from social welfare facilities and supporting networks from government which is located in towns or the cities. Health care resources are also limited in rural and remote areas in Thailand. Rural people who live with limited social resources are prone to preventable diseases and also those diseases which are caused by inappropriate health behaviour and chronic illness. There is a growing trend of health problems among Thai people who live in rural areas and statistics show the increasing incidence of diabetes mellitus, hypertension, and rheumatic heart disease among the rural population between 2005 and 2007 (MoPH, 2005; 2007).

Cultural diversity affects the entire health care process for people with chronic illness. There are a range of studies reporting that cultural differences attribute to understandings of disease, for example, people with less awareness of disease because of limited understanding of care providers' language (Dubard, Garrett & Gizlice, 2006). Cultural beliefs also relate to access to health care because the influence of culture on decision making in health care. An example is people refused medical treatment because of their cultural and religious beliefs without considering basic human and health care needs (Linnard-Palmer & Kools, 2004; 2005). Understanding the correlation of culture and health care use is needed to develop acceptable health care. Enhancing the recognition of cultural diversity among health care providers can improve adherence to treatment by people from diverse cultures by the positive perception of care which is acceptable and suitable with their ways of living (Hilderley, Iwamoto & Knobf, 2000).

Saha, Komaromy, Koepsell and Bindman, (1999) reported that ethnic clients who are cared for by physicians with the same ethnic group, for example Hispanics cared for by Hispanic physicians, were satisfied with health care and reported that they had access to both preventive and all needed medical cares. Cultural sensitivity and cultural awareness of care providers is essential to support access to health care services and clients' participation in illness management.

In Thailand, cultural belief is one of the important factors that influence access to health care. The specific cultural beliefs of Thai people affect health care for VHD. For example, beliefs about death can make people with VHD reluctant to have heart surgery. Generally, dying is perceived to be a consequence of surgery by Thai people. As a result a high number of people refuse surgery and, in particular, heart surgery, which people with VHD often need for the replacement of heart valves. The heart is perceived by people as the most important organ, therefore undergoing heart surgery risks death because the operational procedure interferes with the normal function of the heart. During and after surgery, people worry that the heart may stop working and never regain its normal function.

Specific and general beliefs relating to dying by people living in the North-eastern part of Thailand also influence access to appropriate health services for VHD. Isaan people believe that if they get a permanent scar by surgery and then die, this scar will exist in the next life. They will have this scar and will experience the same disease again. Dying during the operation is an unnatural cause of death and they call this ตายโหง-Tay-Hong (dying from an unnatural cause). ตายโหง-Tay-Hong (dying from an unnatural cause) is considered as an evil event, and people who die like this could face an un-peaceful life after death. They may never be reborn because their family and community cannot prepare for the funeral and future life and the spirits do not realise they are dead. The spirits do not know where to go and are lost. Their family can also face negative effects if a family member dies from an unnatural cause. Some people avoid contact with those families during the funeral because this may cause a chain of death events of oneself and family. Other families in the communities may perform some ritual activities to prevent spirits of ผีตายโหง-Phee-Tay-Hong (spirits of people who dying from an unnatural cause) entering their families.

Family and community are an important support for people with chronic disease. People with chronic disease often rely on family members' opinions and others in the community about illness and its care, treatment and management. Support networks in the community have a positive influence on health and health care (Klassen & Washington, 2008; Kyngäs, 2004). Seeking help from care providers is strongly influenced by family and others in the community. This is because attitudes towards illness are strongly influenced by social network members (Eng & Smith, 1995; Klassen & Washington, 2008). Moreover, adhering to illness management needs family and community support. Family members are significant persons who encourage retaining self-care activities for managing life with long-term illness (Saito, Sagawa & Kanagawa, 2005) and support people with chronic disease to maintain healthy behaviours (Clark, Whelan, Barbour & MacIntyre, 2005). Social support is attributed to the better health of people living with illness, both physical and psychological health. Support from family helped people with chronic conditions to gain better mental health (Griffiths, et al., 2007; Klassen & Washington, 2008) and physical well-being (Klassen & Washington, 2008).

There is a correlation between social support and psychological response, and people with chronic disease have fewer psychological problems if social support is available as social support can protect people from stress (Israel, Farquhar, Schulz, James & Parker, 2002). Social support is an important resource that enables better coping by those living with chronic disease. Support from the family and the community help people with chronic disease to cope with the illness. Friedland, Renwick and McColl (1996) reported that support from close friends encouraged people with chronic illness to develop more problem-orientated coping styles. Family and community are the important resources of emotional support. This kind of support is highly needed among people with chronic disease. Emotional support helps people to reduce fear and face health problems (Klassen & Washington, 2008) and reduce stress (Israel, Farquhar, Schulz, James & Parker, 2002; Wolff & Ratner, 1999). The reduction of stress by a better coping style and good emotional support can lead to a decrease in psychological problems. Consequently, those who live with chronic disease are more motivated to develop self-management knowledge and skills to maintain health and achieve an optimum level of quality of life. Social support is important to help people living with

chronic illness to achieve better health, both physical and psychological. Therefore, strengthening social support in the community through building networks and social capital to develop resilience would enhance health and well-being (Griffiths, et al., 2007).

Nursing Literature and Research on VHD

Literature related to nursing care for rheumatic fever, rheumatic heart disease, and VHD is limited both of number of the articles and the range of topics. A search through the databases related to medical and health sciences were used key words, nursing and rheumatic fever, rheumatic heart disease, and heart valve disease, raring from 4-38 articles within the period of 28-45 years, with the average of 0.14 to 1.35 articles annually. Available literature revealed the limited range of issues discussed about nursing care for people with rheumatic fever, rheumatic heart disease, and VHD. The focus was mainly on the development of services based on disease-orientated health care provision. For example, from the CINAHL Database and Health Databases on EBSCOhost, most focus for these diseases was on the concerns of health professionals. Many studies were around the development and outcomes of nursing interventions to support surgical outcomes and drug administration.

There was limited research conducted by nurses. A few recent articles aimed to understand people with rheumatic heart disease and the people who care for those with rheumatic heart disease. One research study focused on the perspective of mothers of children with acute rheumatic fever using a questionnaire to determine knowledge about treatment, epidemiology, symptoms, route of infection, and complications of the disease (Kasmaei, Atrkar-Roushan, Majlesi & Joker, 2008). Another study used a case study approach to examine the development of continuing care to support a person with VHD based on Orem's nursing theory (Chang, 2003). However, there was no study focusing on exploring the needs and expectations of people with rheumatic fever, rheumatic heart disease, and VHD. It could be argued that a limited variety of research topics and a lack of research concern about the perspectives of those with VHD leads to limited information to support appropriate and effective development of health care provision to support appropriate illness management and the prevention of VHD, therefore, the incidence and prevalence of the disease has remained high. Increasing the number of research studies by nursing scholars may contribute to a wide range of information to

support understanding for the appropriate development of health care for prevention and care for people with VHD. Research conducted by nurses on VHD employed a variety of quantitative methodologies, for example a structured interview with a questionnaire (Davies, 2000; Kasmaei, Atrkar-Roushan, Majlesi & Joker, 2008). One research employed qualitative methodology using a case study approach (Chang, 2003).

In Thailand, research articles related with rheumatic fever, rheumatic heart disease, and VHD which were conducted by nurses who submitted the thesis for a Master and Doctoral degree that were available on ฐานข้อมูลวิทยานิพนธ์ไทย (Thai Thesis Database) were also limited of number with a total of nine articles and two available hard copies. The participants in the studies represented were drawn from clients who attended care at tertiary hospitals in Bangkok and big cities such as KhonKaen and ChaingMai where tertiary and university hospitals are located (Atthaphon, 2000; Boonyia, 1994; Buatee, 2002; Kaewkulpat, 1998; Maneesilp, 1999; Piyawattanapong, 1995; Rerkluenri, 1997; Samranbua, 2001; Suparasie, 1995; Trirongchitmoah, 1996). It was one thesis that was submitted for a doctoral degree that was also based on clients who access tertiary hospital (Sindhu, 1992). None of the research was drawn from participants of the rural-based population.

Research by nurses in Thailand focused on the clients' perspectives about health care and mainly on the issues surrounding the quality of care for supporting clients who underwent valve replacement (Atthaphon, 2000; Boonyia, 1994; Piyawattanapong, 1995; Samranbua, 2001; Suparasie, 1995; Trirongchitmoah, 1996). Researchers have also explored the perception of VHD, clients' role performance, and clients' role clarity (Sindhu, 1992), health perception and clients adaptation (Kaewkulpat, 1998), clients' symptom experiences and their symptom management (Maneesilp, 1999), nursing intervention to support the development of clients' self- management for reducing their dyspnea (Buatee, 2002), and health seeking behaviour of women diagnosed with VHD (Rerkluenri, 1997). There were no research focused on preventive health care, for example there was no research on rheumatic fever or prophylaxis of rheumatic heart disease. Thai nurse researchers have employed both quantitative and qualitative research methodologies. However, qualitative research relating to the disease is limited. Qualitative approaches included content analysis (Buatee, 2002; Maneesilp, 1999;

Rerkluenri, 1997) and Grounded theory as the method for analysing interview data (Sindhu, 1992).

This research project is likely to add different ways to understand health care provision for people with VHD because the participants of this study were drawn from a rural-based population, with the use of narrative methodology to explore clients' health care experience. Participants in this study live in rural Thailand and may provide expanded ways of knowing about what can increase understanding about health care provision for VHD. Expanding understanding informed by clients' perspectives about health care is useful for the development of appropriate health care for people with VHD in rural Thailand. According to Carapetis (2007) states that the development of health care provision for prevention and care for VHD in developing countries needs "applied research relevant to developing countries should take place in developing countries" (p.3).

Conclusion

This chapter has discussed how disease-orientated health care can contribute to the poor access and limited participation in health care for clients with VHD. This difficulty adds to the burden of this disease on vulnerable people, both in developing and developed countries. The individual, family and community participation in health care can impact positively on the care of people with chronic illness. Currently, a number of Thai nurses are aware of and make an effort to focus on fostering client-centred health care provision. However, rural Thai nurses are still faced with a range of challenges. One the challenges is the requirement that health professionals listen to clients' health care experiences. It can be assumed that the limited opportunities for nurses to provide care for people with VHD in rural areas in Thailand contributes to limited continuing and client-centred health care provision. This research will examine the understanding of people with VHD and about their health care. This can provide fundamental information for the development of health care to reduce the gap between clients and care providers to ensure access to and participation in health care services. Health care provision based on the perspectives of those who live with this disease may improve accessibility and facilitate the participation in health care for people diagnosed with VHD.

CHAPTER 3

RESEARCH METHODOLOGY

It is because we all live out narratives in our lives and because we understand our own lives in terms of the narratives that we live out that form of narrative is appropriate for understanding the actions of others. Stories are lived before they are told – except in the case of fiction. (MacIntyre, 1981, p.197 cited in Sarbin, 1986)

Introduction

This chapter explores narrative research in term of its history, movement, development, definition, and characteristics which inform the design of this research. Despite the many interpretations of narrative research there are consistent themes that inform its development. These ideas include the view that narrative research allows the readers or researchers to participate in the lives and worlds of the participants and co-construct the meaning of the events. This means that there can be different interpretations by people who read or listen to the narratives. Narrative research has a potential to expand ways of knowing in Thai culture because story-telling is commonly used to deal with daily life challenges. Conducting narrative research in Thailand can encourage participants to participate in the study as story-telling is widely accepted as a means of living a life of the people in Thailand. Narrative research enables me to move into the world of the health care experience of individuals living with VHD. I assert that narrative research is a suitable choice for understanding health care for people with VHD because of the constructivist-interpretive intent in this research which is “relativism-local and specific, constructed and co-constructed realities” (Guba & Lincoln, 2005, p. 193).

Narrative Research: History and Movement

Narrative inquiry has been defined by interdisciplinary qualitative researchers as the study of individuals in their social and historical context such as in ethno-methodological methodology, explorations of women’s journals, life histories, and autobiography (Chase, 2005). Narrative research is shaped and informed by interdisciplinary scholars who value narrative as a means of giving meaning and making sense of one’s own and others’ experiences (Polkinghorne, 1988). Narrative researchers also share respect for the value of context, especially time and place (Kramp, 2004).

Narrative research has been employed during the 1920s and 1960s by the human disciplines such as psychology with the focus on cognitive science (Polkinghorne, 1988) with Freud considered as a primary psychologist who used secondary life narrative documents for applying psychoanalytic theory (Atkinson, 1998, 2002). The Chicago School sociologists are considered the “predecessors of today’s narrative researchers” (Chase, 2005, p. 653) with the idea of telling a participant’s story (Riessman, 1993; Rosenwald & Ochberg, 1992). During the 1920s and 1930s, Chicago social researchers conducted this kind of research with the aim of understanding social issues through personal life record (Chase, 2005; Riessman, 1993). This is considered practically difficult because it is time consuming to detail the whole life-story of the participant, for example, the social life record of one Polish immigrant was nearly 800 pages (Chase, 2005).

The narrative turn has arisen from the postmodern (Denzin & Lincoln, 2005; Richardson & St. Pierre, 2005; Smith & Hodkinson, 2005) and the postexperimental movements (Denzin & Lincoln, 2005). The growing use of narrative study during the 1990s marks a narrative turn which has been influenced by the intellectual, social, and cultural change, the crisis in representation, better access to people at the margins, and a willingness by scholars to use research to make a difference (Bochner, 2002). The momentum of using narrative approach has been marked by beginning the publication of narrative studies such as, narrative and life history (now published as narrative inquiry) in the United States since 1991, the Narrative Study of Lives, a series of edited collection by Josselson and Lieblich (1995) started in 1993 and published regularly, and Riessman’s (1993) text on narrative analysis in 1993 (Elliot, 2005). The turn to narrative is marked by movement in how people value ways of knowledge changing from idealism to relativism. Clandinin (2007) identifies movement toward narrative inquiry with the four shifts in ways of thinking of researchers including: the relationship between the researcher and the researched from distance to mutual relationship; a move from the use of numbers toward the use of words as data; a change from a focus on the general and universal toward the local and specific; and a widening in acceptance of alternative epistemologies or ways of knowing instead of only valuing objective knowledge. Interest in narrative accounts has also been influenced by the call for the rights of people who are oppressed such as minorities, third world cultures (Personal Narratives Group, 1989; Rosenwarld & Ochberg, 1992) and research aimed at social

movements (Davis, 2002), as it is believed that the narratives of people who are oppressed can raise awareness of demands for social change (Riessman, 2008). Davis (2002, p.4) says

...social movements are dominated by stories and story-telling, and narrative goes to the heart of the very cultural and ideational processes these scholars have been addressing, including frames, rhetoric, interpretation, public discourse, movement culture, and collective identity.

Employing narrative research which allows the voices of people from non-dominant groups such as women, racially or ethnically oppressed people, or lower-class people, to be heard in public is essential for social change because the dominant objective view is balanced by different life experiences (Personal Narratives Group, 1989). Stories reveal truths about human experiences which enable more acceptable and useful human sciences (Riessman, 2008), therefore, narrative methodology has become increasingly used in research in human science disciplines (Chase, 2005; Davis, 2002; Hinchman & Hinchman, 1997; Murray, 2004).

Narrative research has been employed by many disciplines within the social sciences in anthropology, feminist, psychology, and sociolinguist studies to explore issues of concern about individuals in their social and historical context (Atkinson, 1998; Chase, 2005; Murray, 2004). Narrative scholars aim to gain relevant and practical knowledge to deal with social issues because the objective view gained from quantitative studies is too limited for understanding of human experiences (Personal Narratives Group, 1989; Pokinghorne, 1988; Riessman, 1993). Narrative research methodologies are “particular rich sources” which encourage better understanding of individuals’ lives and “have the potential to undermine or perpetuate the conditions and relationships in which the life evolved” (Personal Narratives Group, 1989, p. 6). Because of the need to hear the participants’ voices, narrative research has been considered useful by humanities and social sciences scholars (Chase, 2005). For example, narrative research has been widely used among psychologists in response to the need for a means of understanding of individuals’ points of views. This understanding is considered fundamental for psychology according to Sarbin (1986, p.3) who claimed that narrative is “a root metaphor for psychology”. The outcomes of narrative studies provide a means to

develop practical knowledge for psychologists because participants' narratives are essential for psychologists to understand more about the human condition. Consequently, narrative methodology becomes more using in psychology (Murray, 2003).

To provide care, nurses need to understand about the lives of others knowledge which can be provided by a narrative study (Clandinin & Connelly, 2000; Holloway & Wheeler, 1996). Narrative research is a powerful tool for knowing about ourselves and others (Witherell & Noddings, 1991) and the focus of inquiry on an emphatic understanding about others can expand knowing about others by carefully listening to the stories (Chase, 1995; Josselson, 1995). Therefore, nursing researchers turn to narrative to understand clients' experiences about illness and engaging with health care in their social contexts because this understanding is necessary for nursing practice with the focus on providing client-centred care. It is widely believed that providing client-centred care can help clients to achieve holistic well-being. Providing care with knowing clients needs, thoughts, and feelings also encourage more caring health care provision. Caring is considered as a fundamental aspect of health care delivery and nursing practice (Brykczyńska, 1997; Frank, 2000; Newman, 2005; Spitzer, 1998). Narrative research can be described as person-centred in that it attempts to bring the experience of an individual to the centre of inquiry and is humanistic and holistic in its approach to client care (Holloway & Freshwater, 2007), therefore, nursing scholars turn to narrative approach with the aim of developing caring approach based on a client-centred philosophy.

Narrative inquiry has spread through the sociology of health with a focus on lay perspectives on disease and their experiences of ill health, in particular people with chronic illness (Elliot, 2005), as narrative research has the potential to contribute to the understanding of chronic illness because telling a story is a "major way that individuals make sense of disruptive events in their lives" (Riessman, 1990, p. 1199). Riessman also points out that the narrative method can describe how individuals make sense of difficult experiences (Riessman, 1989). Narrative research is considered an approach which can increase the understanding of illness (Elliot, 2005; Murray, 2004) and has been employed to conduct research in areas such as illness experiences (Haidet, Kroll & Sharf, 2006), their illness management (Kralik, Koch, Price & Howard, 2004), health

care experience (Eldh, Ehnfors & Ekman, 2004; Stevens, 1992) and the impact of chronic illness on individuals' sense of identity (Kleinman, 1988). The narrative approach can provide the possibility of deep and complex understanding about chronic illness because its focus is on subjectivity.

Narrative research is used to develop and reform healthcare education to meet the requirements of rapid change in health care provision to meet the needs and expectations of clients. Dynamics in health care provision are needed for the development of acceptable and effective health care services which require the preparation of health professionals to focus on providing health care services to fit with clients' context. Therefore, it is important for health institutions of education to shift to community-based rather than hospital-based care (Diekelmann, Ironside & Harlow, 2003). The change of focus influenced narrative inquiry where the participants' stories are a core concern foster better opportunities to discover essential stories which may be used to develop suitable curriculum to educate healthcare professionals. The shift of focus of care is to client and community concerns instead of focusing only on medical concerns. Narrative research has also been conducted to explicate the lived experiences of nursing teachers, students, and clinicians and highlight the common experiences and shared meaning of nursing education (Dahlberg, Ekebergh & Ironside, 2003). Swenson and Sims (2003) reported that narrative-centred curriculum for clinical nursing education can encourage nursing students to develop their practice to meet with future challenges by preparing to learn by listening which is necessary for gaining understanding about health care issues for the improvement of clinical practice. Chase (2005) argues that using the principles of narrative research is the best way of preparing people to develop strong listening skills.

Narrative Research: Development, Definition, and Characteristics

The word narrative derives from "the Indo-European root 'gna' which means both 'to know' and 'to tell'" (Hinchman & Hinchman, 1997, p.1). Narrative is a basic human activity, a way of thinking and being (Currie, 1998) and is a means for constructing past events and actions to claim identities and construct personal lives (McAdams, 1993; Mishler, 1999; Riessman, 2002; 2008). To perform daily activities, human beings rely on memories in narrative form about the series of actions of each activity which are stored in storied form and recalled as the guideline for appropriate and suitable

actions and also used as a means to justify other actions. Narrative is a mode of thinking because experience and memory are mainly organised in the form of narratives, stories, excuses, myths and reasons for doing and not doing (Polkinghorne, 1988). People also claim their identities and construct their lives by using narratives to construct their past events and actions (Riessman, 1993) and to support claims that their actions are acceptable and reasonable for clarifying their lives in society (Rosenwald, 1992). Narrative is widely used for different purposes and is a part of being human as Atkinson (2002) states that stories are the centre of community life and story-telling “gives us direction, validates our own experience, restores value to living, and strengthens community bonds” (p. 122). Therefore, it can be concluded that narrative is everywhere in everyday life (Holstein & Gubrium, 2000; Riessman, 1993) and people reconstruct life-stories to help deal with various issues and different aims in complex social environments (Holstein & Gubrium, 2000).

The terms ‘narrative’ and ‘story’ are used interchangeably by researchers (Holloway & Freshwater, 2007; Polkinghorne, 1988; Riessman & Quinney, 2005; Riessman & Speedy, 2007; Sarbin, 1986). Narrative is used flexibly to mean a story about “particular event” and “specific character”, an “extended story” about an aspect of life, or a narrative of life from birth to the present (Chase, 2005, p. 652). Riessman (2008, p.3) provides a brief definition of narrative as follows:

In everyday oral story telling, a speaker connects events into a sequence that is consequential for later action and for the meanings that the speaker wants listeners to take away from the story. Events perceived by the speaker as important are selected, organized, connected, and evaluated as meaningful for a particular audience.

A careful examination of the definitions of narrative and story find that story and narrative are often given a similar meaning. However, the terms narrative and story are slightly different, story is a part of narrative and narrative provides the whole series of stories. Narrative is used to tell a story and the story is the account of events. Clandinin and Connelly (1994) suggest that story refers to phenomena and narrative stands for inquiry and a story is one type of narrative (Riessman, 2002; 2008). Holloway and Freshwater (2007) conclude the difference between narrative and story is that story is

the “what” of the narrative and narrative is the “how” of the narration, which consists of how the story is told and presented and how the characters are represented (p. 10). As there are slight distinctions between narrative and story, in this study narrative and story are used interchangeably. The stories which were told by participants represented both what was the point of stories and how the story point should be told. In the research report, I was the co-narrator and also re-constructed narratives in the same way as the participants using a story. In this research project, the term narrative represents the strategies and the methods of the study and the term story mainly stands for the health care accounts of individuals living with VHD. In conclusion narrative is used both to illustrate the methodology and as the methods of this study. Stories stand for the events occurring in the health care of the participants throughout this thesis. Narrative will be both the process and results of the research, as Clandinin (2007) says “narrative inquiry embraces narrative as both the method and phenomena of study’ (p. 5) and Elliot also suggests that a personal story is an evidence for analysis of narrative methodology (Elliot, 2005).

A story has a basic structure such as a “setting” which locates time and place and involves “human or humanlike characters” and also is about life events (Coles, 1989). Narrative also share some similarities to story structure, as Riessman (2002) concludes narrative structure is based on structural narrative properties which proposed by Labov (1972) include six parts: a summary of the substance of the narrative, the time, place and situation; participants; sequence of events; significance and meaning of action; attitude of the narrator; what finally happened, and a return of the perspective to the present. Through the structure of the narrative, listeners and readers not only know what the story is about but they can also relate the story to time and place. Riessman (2002) argues that narrative structure can expand understanding about social events and human subjectivity is a central concern for the interpretation, the meaning of human lived experience and its physical, political, and historical context (Ellis & Flaherty, 1992). The listeners and readers would also have better understanding about thoughts and feelings of the narrators which can enable the listeners to have a sense of sympathy towards the story-teller. Consequently, subjectivity is a central concern of narrative inquiry informed by the structure of narrative, story-telling is considered as a powerful method that enables people to understand others. The components of the story provide a subjective stance to the data because the thoughts and feelings of the narrators can be

observed through the stories. As Ellis and Flaherty (1992) say, an attempt to understand subjectivity is “to convey lived experience of thoughts and feeling” (p. 5) which can be communicated more clearly through personal stories. It can be concluded that subjective lived experience is closely related with personal stories (Davies, 1992). Therefore, people gain a close relationship to the narrators because of a better understanding of the listeners through learning by listening to the personal truths of others (McAdams, 1993). The subjective intention of narrative inquiry supports the aim of this research project to explore the personal health care experiences of people with VHD focusing on participants’ thinking and feelings related to the social context in which they live.

The ‘plot’ frames the meaning of the series of events in a story and holds events together (Atkinson, 2002; McAdams, 1993; Sarbin, 1986). Sabin (1986) suggests that the core of the plot structure “is human predicaments and attempted resolutions” (p. 3) and a plot has been described as a causal link within narrative (Elliot, 2005). The plot is necessary for giving meaning to events as human beings usually recognise the significance of events by organising and connecting a series of events within a specific framework which forms the plot. Giving meaning to the same event is different in each community because traditional stories in each community are the “blueprint” which form the plot of a narrative (Atkinson, 1998, p.2). Therefore, the same events can be interpreted differently in each society. People in each community can interpret, understand, and construct narratives based on the local offering of plot lines by their societies. The plot provides the cultural context for narratives including social norms, beliefs and values which encourage readers and listeners to clearly and deeply understand others. It is the plot that enables cultural sensitivity for interpreting the specific meaning of a similar story which is told by people in different contexts. Therefore, narrative research can be considered as a cultural sensitive methodology, as Chase (1995) argues that narrative can provide both evidence about individuals and a means to understand more about the broader culture shared by a community of individuals. Analysing of a narrative addresses cultural aspects of research which “can be related to narrative and illuminated by its study” (Davis, 2002, p. 10).

Narrative’s function is for understanding one’s own life and other people’s lives (Bruner, 1990; Coles, 1989; Linde, 1993; Polkinghorne, 1988). The fundamental interest of all forms of narrative is the focus on making sense of experience,

constructing and communicating meaning (Chase, 1995), and narrative structures organise and give meaning to experience (Bruner, 1997). The function of narratives may

...give meaning to and make sense of experience and emotions..., segment and organise experience, actions and events..., provide a coherent whole of experience and thoughts..., confirm group membership or group consciousness...(Holloway & Freshwater, 2007, p.21).

Atkinson (1998; 2002) concludes stories of each community is used by its people to relate to each other including psychological functions. People also use story to gain understanding about themselves and social functions which can bring people together to be a part of society as they gain a sense of belonging to the community by clearly knowing oneself and others. The functions of narrative allow both narrators and listeners or readers to understand the meaning of events and themselves. Narrative also provides the possibility to understand phenomena as a whole. By listening to and reading personal narrative, people may also be empathic toward the narrators as they gain a deeper understanding of the narrators through the thoughts and feelings that are conveyed through parts of the stories. Because of the way narrative functions in terms of providing a means for understanding others through life-story, narrative inquiry is suitable for interpreting and constructing the stories about the health care experiences of individuals living with VHD.

The definition of narrative research is framed by the function of narrative and has a variety of meanings. Narrative research is a subset of qualitative research designs which are employed by researchers to explore stories for better understanding of the events through participants' stories (Polkinghorne, 1995). Lieblich, Tuval-Mashiach, and Zilber (1998) defined narrative study as research that uses or analyses narrative materials. Clandinin (2007) distinguishes narrative research from other qualitative research stating that narrative research includes the study of stories or narratives or descriptions of a series of events with the assumption that the story is the fundamental unit that recounts human experiences. Chase (2005) outlines the distinctive features of narrative inquiry from other qualitative methodologies which are seen through "analytic lenses" (p. 656). First, both oral and written narratives are used to describe the past experiences of the narrators. Narratives provide a point of view, emotions, and thoughts,

which are interpreted by the researcher. Second, narratives are shaped, constructed, and experienced by the narrators. This means the participants' stories are important in narrative study. Third, narratives are influenced by social context. Fourth, narratives are shaped by social interaction. Different social conditions mean that different narrators may tell the same story in different ways. Fifth, narrative researchers view themselves as narrators (Chase, 2005).

Narrative research focuses on discovery and fosters "more exhaustive quests for explanation" rather than confirmation of hypotheses (Josselson, 1995, p. 30). In this approach, empathy with participants is a requirement of narrative research because empathy allows for a clearer perception of others and better understanding (Josselson, 1995). As narrative researchers are concerned with exploring subjective experiences where there is a need to develop mutual relationships with participants. Narrative researchers focus on sharing participants' stories which can encourage and invite further discussion and interpretation by listeners and readers rather than providing concrete immutable meaning of the stories. Narrative researchers are not concerned about one simple truth but are conscious of the multiple truths within the data, as Josselson and Lieblich (2001) say "the narrative research approach is oriented toward subjectivity, intentionality, pluralism, relativism, holism and contextuality" (p. 280). A research approach which focuses on the meaning generated through participants' narratives has the potential to encourage the researcher to listen and read participants' stories carefully because it stimulates the audience to recognise and empathise towards the storyteller (Davis, 2002). This recognition and empathy is because in stories human character is one of the components of narrative enabling the researcher to relate the meaning of events to the context of the participants' lives. Therefore, the meaning of an event is likely to focus more closely with the story-tellers' lives by mutual listening to participants' stories. Narrative is a means which allows others to know personal experience of narrators, as Josselson (1995) says "to understand another within the emphatic stance means being able to understand their stories" (p. 32). Therefore, narrative research provides the possibility for attaining participants' thoughts and feelings about their life events with the stance of sharing stories for co-creation of narrative meaning. In sum, "stories appeal to the intellect to be sure, but also to emotion and imagination, to moral and aesthetic intuition, as well as logical reasons" (Davis, 2002, p. 19).

Narrative research provides reflexive possibilities because “interacting with narrative is an emotional, precognitive apprehending that is sublime, unstructured, and nonverbal in nature” (Ronai, 1992, p.123) and is also encouraged by the discontinuous unit of the story which can revise and change the narrative meanings in different times, occasions, and audiences (Linde, 1993). The narrative is a social act, the narrators selecting and organising to tell stories to fit with a particular occasion, intention, audience and context (Mishler, 1999). Reflection by narrators and listeners is important for understanding narrative meanings of individuals and groups (Riessman, 2008). The reflecting process encourages both narrators to discover deeper meaning of their lives which is important for interpreting and understanding experiences through life-stories (Atkinson, 1998) because narrative reflexivity allows the narrator to observe, reflect, and correct their personal narratives (Linde, 1993). Narrative interpretation involves comparing and contrasting the narrative meanings taking into account the social contexts, and reflexivity is a part of the process. People who read the outcomes of narrative research have the opportunity to reflect on the meaning of participants’ experiences which have been constructed by the researcher because both participant and researcher voices are provided in narrative report. Denzin (1997, p. 217) says that:

The poetic or narrative text is reflexive, not only in its use of language but also in how it positions the writer in the text and uses the writer’s experiences as both the topic of inquiry and a resource for uncovering problematic experience.

Narrative research allows a flexible approach to qualitative study in order for understanding of people lives in context. Riessman (2008) says narrative study has been employed as a qualitative methodology approach internationally, entered many disciplines, and energized many study topics. The flexibility of narrative approach relates to the plot of narrative which provides a contextualised and deep narrative meaning and provides the possibility of cooperation between the researcher and the participants through the research process. Multiple, flexible, and open ways of approaching narrative can enable research outcomes to be more specific practical knowledge which is suitable and acceptable within each culture and discipline. Narrative research is interdisciplinary as narrative “does not fit neatly within the boundary of any single scholarly field” (Riessmann, 2002, p. 217) and it could be

argued that the growing use of the narrative approach is fostered by the flexible approach of narrative study. Consequently, different approaches, strategies, and methods have been employed by narrative researchers to answer questions of concern (Lieblich, Tuval-Mashiach & Zilber, 1998). Lieblich, et al. (1998) conclude that there are two main types of narrative approach which focus on content or form of a story. The content of narrative study focuses on the details, meaning, motive, images or the structure/form, coherence, style, voices and timing in the study. The form of the narrative is structure of the plot, the sequence of events, and the style of the narratives. Narrative research can be approached as holistic or categorical and this is dependent on whether the focus is on a part or the whole of the narrative (Lieblich, et al. 1998). This study focuses on content of participants' narratives about their health care experiences in order to describe a part of their lives.

Life-story narrative research is the methodology of this study. The forms of personal narrative include biography, autobiography, life history, and life story which illuminates a life over time in its historical and cultural contexts (Personal Narratives Group, 1989). Narrative research is described as interdisciplinary (Riessman, 2002) and the term "narrative umbrella" covers the researchers who work from a variety of interpretive stances (Josselson & Lieblich, 2001, p. 277). Hatch and Wisniewski (1995) conclude that narrative research includes

...autobiography, biography, interpretive biography, autobiographical narrative, life history narrative, oral narrative, life narrative, personal narrative, stories, life stories, self stories, personal experiences stories, auto-ethnography, ethnographic fiction, personal history, oral history, case history, and case study (p. 124).

Life-story narrative is considered to be both methodology and method (Atkinson, 1998; Linde, 1993; McEldowney, 2003a; Riessman, 1993) which is an interdisciplinary approach to study lives, to understand "one life across time" and "how individuals' lives interact with the whole" (Atkinson, 1998, p.4). To achieve the aim of the study which is the understanding of participants' lives when interacting with health care services, life-story narrative is used as the methodology and method of this study. Life stories are used for describing "turning-point moments" in narrators' lives (Denzin, 1989, p. 7) and is a suitable means for understanding the meaning of periods of change in human lives

because the experience of life transition is narratively constructed and conveyed through stories (McAdams, Josselson & Lieblich, 2001). Life-story focuses on what happened, how a story is told and the construction of meaning (Hatch & Wisniewski, 1995) and Atkinson (1998) also claims that life-story is the best way to enable an understanding of the whole or parts of participants' lives. This study is concerned with one aspect of life and aims to understand the meaning of the participants' narratives of health care experiences. Therefore, life-story narrative is suitable as a methodology for conducting this study. Cross sectional life-story is used to collect stories about part of participants' lifetime and is the method for the collection of data in this study. Linde (1993) asserts that obtaining part of a lifetime narrative is sufficient when it contains a large enough number of narratives and the relations of each narrative. Linde (1993) also points out that data which is collected by this method is manageable, permitting the researcher to consider a number of participants, allowing a comparing of narratives, and creating coherence in the chain of events. In this study, interviews (open and honest conversations) which invite participants to tell a part of their life-story focused on their health care experiences provides sufficient data to interpret, create, and construct narrative about an important part of participants' health care experiences from their life-stories.

Narrative is a basic meaning-making device for organising and understanding the relation of human beings, human actions, and events transforming them into an understandable composite (Gubrium & Holstein, 1997; Polkinghorne, 1988; Riessman, 2002). Davis (2002) argues that narrative is a unique and powerful form of meaning-making tool. Interpretation of people's experiences through a meaning-making device such as narrative can enable a culturally and contextually constructed narrative meaning to an event as a whole. Gubrium and Holstein (1997) suggest that patterns of narrative linkage convey "horizons of meaning" providing culturally specific experience meanings, in another word, the same experience can be interpreted differently in different contexts (p. 148). In addition, as narratives are socially constructed, the interpersonal and social contexts are necessary in narrative analysis (Denzin, 1989; Mishler, 1986b; Robinson & Hawpe, 1986), and this is the responsibility of the narrative researcher to preserve and respect while analysing and interpreting participants' life-stories (Riessman, 2002). Cooper (1995) claims that the character of narrative is fluid as narratives can be reinterpreted, changed, retold, and reframed.

Narrative approaches emphasise the person's experiences with the analysis focusing on both individual and sociocultural components (Flick, 2002; Josselson & Lieblich, 2001; Murray, 2003). Context is necessary for narrative analysis and interpretation as narrative researchers say "neglecting the context from which a life is narrated invites the risk of misunderstanding and misinterpretation" (Personal Narratives Group, 1989, p. 19) and Goodson (1995) also says that "stories need to be closely interrogated and analysed in their social context" (p. 95). Therefore, this study focuses on both the analysis of participants' narratives and the social context of the stories and the story-tellers' approach to interpret, co-construct, and co-create narratives in health care of individuals living with VHD.

The Thai Context

Generally, culture closely influences narrative inquiry, in particular life-story, as Linde (1993) says life-story is an account of event that is "the product of a particular culture" (p. 11). Culture influences how people tell a story which is informed by the models held in each community (Rosenwald, 1992) that give meaning to narrative accounts. Culture strongly relates to narrative meanings, as Bruner (2002) says

Breaches of the ordinary, once domesticated in narrative, bear the stamp of the culture, not a seal of approval from *Good Housekeeping* [sic] but one in the form of "Oh, *that* [sic] old story again." (p. 90)

Resulting from the correlation of culture and narrative, culture is underlying assumptions of narrative inquiry, as McEldowney (2003a) states in her doctoral research that "narrative inquiry are contextually bound historically, culturally, politically and socially" (p. 36). Culture is an essential part of the story which is needed to be understood when interpreting its meaning, as Rosenwald and Ochberg (1992) says "all stories are told and that all self-understanding is realised within the narrative frames each culture provides its members" (p.2). It is also through narrative that cultures are known and understood, and Rosenwald and Ochberg (1992) conclude that "the culture 'speaks itself' through each individual's story" (p.7). In particular, narrative research focuses on personal experience stories that are never detached from social, cultural, and historical contexts (Denzin, 1989), in other words, story-telling is a key cultural expression (Crites, 1997).

Culture also influences how Thai people use story-telling to negotiate everyday life. Thai people tell stories to balance the events in their lives and the listeners gain an understanding of those events. As culture strongly influences narrative, it is important for considering Thai cultural issues relevant to narrative which closely relates how Thai people use stories and story-telling. The positions of knowledge are informed by how Thai people value in knowing objectivity or relativity paradigms will also be addressed.

Ways of knowing

Knowledge occupies a high status in Thai culture. This status can be observed by the ways in which Thai people pay high respect to both materials such as texts and knowledgeable persons, for example how teachers are treated by students as a means for students to gain knowledge. Thai students also respect and treat the teachers as holy symbols. This can be observed at the commencement of study programmes with the ritual ceremony which is called ไหว้ครู-Wai-Kroo (Ceremony to mark students' respect of teachers). This ceremony is considered an important event at every education level from kindergarten to university. In this ceremony, students prepare flowers, candles and incense and give these to the teachers to show their respect and to represent their willingness to learn from the teachers. During the ceremony students also commit to being obedient and studying hard. The strategies of this ceremony also convince students that teachers are to be respected because they are committed to working hard for students. As can be observed through the poem that is used in the ceremony that ข้าขอประณตน์อมสัการ (I would like to pay absolutely respect to [the teachers]) บูรพคณาจารย์ ผู้ประสิทธิ์ประสาทวิชา (The teachers who hand on knowledge) ขอเดชกตเวทิตา (ask for the reward which is influenced by respect, appreciation, and a willingness to reciprocate to the teachers who work so hard [to support the development of student wisdom]) อีกริวิพาปัญญาให้เกิดแตกฉาน (and also the patience and ambition [of the students] to achieve wisdom). Thai students usually believe that teachers are persons who know the most. Therefore, knowledge from the teachers or texts that are written by the teachers are always seen as ideal and as needing to be respected. It is uncommon among Thai students to critique or criticise what teachers and text books have said. Some students who criticise teachers or respected books may be accused as ศิษย์คิดล้างครู-Sid-Kid-Lang-Kroo (students threatening the teachers and knowledge).

This status of knowledge in Thai culture encourages an approach to knowledge by Thai academic scholars which is based on positivism. Positivist epistemology supports the position of knowledge in Thai culture based on the fundamental idea that the world has a real existence outside human beings. Objectivity is a central concern of positivist reality in that the researchers have to distance themselves from the respondents to ensure the objectivity of knowledge. “Positivist-based quantitative researchers employ the language of objectivity, distance, and control because they believe these are the keys to conduct real social science.”(Greenwood & Levin, 2000, p. 92). Consequently, this encourages Thai scholars to employ research methods which are based on positivism even if using qualitative research such as grounded theory which provides specific approaches which can be replicated for data analysis, because its development complies with objectivity requirements of positivism (Charmaz, 2008). The growth of positivistic view points in research approaches by Thai researchers is also influenced by the education system which focuses on ideal and verifiable knowledge. Ideal and verified knowledge is accepted because it is considered to be scientific and logical knowing how to deal with issue of concerns. Because of the educational focus, students are encouraged to memorise and recall knowledge. The Thai curriculum rarely encourages learners to develop interpretative skills and because of this the researcher may feel more confident with a positivist research methodology through which truth can be confirmed.

Narrative research can increase the possibility of horizontal knowledge development. The horizontal knowledge is informed by a variety of points of view of specific understandings about events of people in communities. Narrative inquiry sits in the constructivist paradigm which is interested in subjective and inter-subjective social knowledge and the active construction and co-creation of knowledge by human consciousness (Guba & Lincoln, 2005; Schwandth, 1994). Guba and Lincoln (2004) point out that constructivism has moved from ontological realism to ontological relativism. Realities are comprehensible in the form of multiple, intangible mental constructions, socially and experientially based, local and specific in nature, and dependent for their form and content on the individual persons or groups holding the constructions (Guba & Lincoln, 2004)). In Thai society การามสูตร-Ka-Lam-Ma-Sood (Buddhism philosophy which states that knowledge needs to be interpretative rather

than recalled and believed without being carefully examined) is considered as a necessary strategy to develop horizontal knowledge. Currently, a number of Thai people strongly recommend กาลามสูตร-Ka-Lam-Ma-Sood as the means to deal with the limited education that is informed by a vertical knowledge point of view values knowledge which is informed by validity resources and is immutably ideal. I contend that employing narrative inquiry that values plural reality is a means to growing an interpretive knowledge base to balance vertical knowledge which is dominant in Thai society.

Narrative research encourages participants to be more vocal about their experiences in their stories. Narrative is a methodology which values the participants' stories as the core of its inquiry and increases public space for people to have their voices heard. Consequently people in society have a greater opportunity to speak out through narrative research strategies. The outcome of narrative study provides the opportunities to understand social issues from a variety of point of views which are provided by the storytellers. Thai people may have a variety of knowledge sources to use for understanding the social issues and also different means to deal with the problems, rather than relying on only objective and ideal knowledge that may provide limited information and limited means to solve complex social problems. In addition, shifting to a relativist reality may also encourage Thai participants to contribute their knowing about their concerns through stories with the expectation that the researchers' analysis would speak for them.

Increasing of narrative outcomes can balance and move society with better understanding by its people. Bruner (2002) says "through narrative, we construct, reconstruct, in some ways reinvent yesterday and tomorrow" (p.93). Narrative increases the range of understanding about issues of concerns because of the multiple points of views of a number of people interpreting stories and giving story meanings in their own ways. Narrative research outcomes may also encourage more people to tell their stories or reflect on the narratives because they may compare and contrast accounts to ones own experiences. The use of narratives in this way provides increasing possibilities for social development and influences the openness of listening to others because other narratives increase the possibility for understanding. The participants' stories not only

can be used as data for analysis but also move society forward because the needs and expectations of the participants may be taken more seriously to inform both practice and policy level decision making. I contend that because of this, narrative research should be supported to encourage people to share their experiences and value the knowledge developed from participants' stories to balance the dominant voices in Thai society.

Narrative and story-telling

Story-telling is an essential function of human beings for thinking, speaking, giving a meaning and providing a narrative account of an event. Telling a story enables people to gain understanding about their lives, as Atkinson (1998) says, "we discover deeper meaning in our lives through the process of reflecting and putting the events, experiences, and feelings that we have lived into oral expression" (p.1). Story-telling is necessary through out the process of narrative study as it is the tool for gaining participants' stories and reporting the research findings. Understanding how people in each culture view and use story-telling is a key of the development of appropriate narrative research in each community.

Narrative is an important means to support Thai people to live a normal life as stories are told to others to smooth over events in everyday life. This is a practical method that Thai people use to understand the events and solve problems in their lives. Thai people use storytelling in everyday life to educate children, discuss their issues and concerns, and as a way to deal with their problems. Stories about confidential personal issues are shared with family members or close friends. By sharing stories, both story-tellers and listeners understand the problems and may also discover ways to address them. It can be concluded that narrative is necessary for Thai people to approach their everyday problems. However, using narrative as a strategy of problem solving is more commonly used to handle individual problems rather than community level problems. This may be because knowledge which is developed by Thai people through sharing stories is not valued in a society where the dominant knowledge is informed by positivism.

Story-telling is common and valuable in everyday life of Thai people because Thai people share stories to understand and deal with everyday problems in their lives. This is different from engaging in an interview process which is the usual method for collecting qualitative data and is mainly initiated by the researcher. As story-telling is a

method which Thai people commonly use to solve the problems, employing narrative methodology may provide the Thai participants with more opportunity to cooperate in the research process. Consequently, participants may be keen to cooperate in the research project because of the possibilities provided by story-telling to encourage action around the understanding of, and solutions to, concerns according to their everyday experiences. The findings resulting from better engagement with participants should also provide full stories that facilitate deep understanding about the participants' lives. As Thai people use story-telling in common in everyday life, narrative methodology is strongly recommended because this approach can improve research outcomes from the more sensible and subjective point of view of participants' narratives.

Narrative and ways of knowing

Narrative methodology in a Thai context has been informed by valuing story-telling as a method which is commonly used to deal with daily living issues. Thai people share life-stories as part of negotiation with others that their actions are reasonable and are acceptable. Story-telling is a strategy to foster multiple points of view and also to invite others to reflect on the stories, therefore, the events in the stories are interpreted and reconstructed in different ways which enables a better understanding about the events. This strategy may also increase ways of dealing with the problems within those events. Goodson (1995) asserts that storytelling is a means of expanding horizontal ways of knowing and is a starting point that allows others to learn about the storyteller's world. Through the notion of storytelling in Thai culture, narrative inquiry has the potential to develop relevant knowledge which can be used to change and develop Thai society, particularly in regard to health care provision. Thai participants and Thai researchers may have a better opportunity to share responsibility for solving issues of concern as participants are encouraged to share their stories in their own way without focusing on, or taking responsibility, for providing correct answers to help the researcher solve the problems. Researchers work with the participants' stories to gain practical knowledge which may be the means to solve the problems. The participants' life-stories are constructed and re-constructed and shared with various audiences which increases various ways for understanding the problems. Retelling stories has the possibility for wider reflection on the meaning of the events which is interpreted by different readers or listeners, and focusing on multiple points of views of the events. This retelling can

expand ways of understanding about, and provide a range of means, to deal with the problems. It may also increase the possibility for consensus about practical and appropriate actions towards solving problems.

Narrative inquiry can support Thai researchers to develop their research expertise from the stance of Thai culture. Distance from participants is not a requirement of narrative research and because this approach demands a mutual relationship between participants and researchers, Thai researchers have the potential to develop culturally aware research methods. Because of the principles of narrative research, the characteristics of Thai culture which facilitate mutual relationship, such as attentiveness, need not be overlooked while conducting the research. Thai researchers have limited opportunities to develop research methods which are appropriate for supporting Thai participants to fully participate in the research process. The requirement for mutual relationship is different from the requirement for objectivity where researchers have to distance themselves from the participants which may fail to empower and support participants to participate in the study. This failure is likely to be led by the participants' view of the researchers as strangers because of the rigid characteristics required by an objective stance. This characteristic may widen the gap between the participants and researchers as it is considered unfriendly behavior in Thai culture. Therefore, narrative methodology can support and encourage Thai researchers to include cultural sensitivity as part of developing sensitive knowledge for Thai society as they learn to understand the topic of concern through participants' narratives which are told with open and honest intent as the result of the mutual relationship enabled by culturally appropriate research methodology.

However, appropriate encouragement for Thai researcher to employ narrative approach is necessary as stories are widely used as the unit of analysis by qualitative researchers for example in grounded theory, ethnography, or phenomenology and in Thailand, stories are often employed as the data for qualitative research. Narrative inquiry is still limited in use as the study approach in Thailand which may be influenced by storytelling being thought of as lay information by the researchers. Because narrative inquiry is rarely employed by researchers in Thailand, the accounts of research using this methodology which may inspire qualitative researchers are limited. This limitation may

lead researchers who are interested in and respect participants' stories, employing other qualitative methods rather than narrative methodology to conduct research.

Another factor that may deter Thai researchers from employing narrative research is that personal issues are not a public matter. Personal problems are usually handled by individuals, and people in communities are rarely involved with one another's personal lives. It is an important challenge for Thai researchers to convince others that narrative inquiry is a reasonable and worthwhile research approach with useful outcomes. Overcoming this resistance by pointing out that narrative research is focused on using life-stories as a meaning-making device to gain better understanding about others lives to ensure clearer understanding about social issues rather than involving the participants' personal lives, may foster the movement toward narrative methodology among qualitative researchers in Thailand.

In my experience, the impact of clients' stories on my understanding about health care provision has developed my clinical practices in ways which are more empathetic toward clients. Clients' stories not only give me better understanding about health care but also enable others to gain an understanding about health care, for example, through telling clients stories to nursing students. However, at the beginning of this research project, I still hesitated to use a narrative approach to conduct the study. What was the cause of this hesitation? This caution was informed by my academic experience where story-telling has been viewed as lay information rather than operating at a professional and academic level. Stories are viewed by academic scholars as less scientific. This point of view may reflect both the preference for positivism and the status of knowledge in Thai culture.

Narrative and Health Care

Employing narrative research encourages the participants to answer the research questions about their health care experiences in their own way, rather than supplying a correct answer. The multiple events in life-stories are from understanding of people who encounter health care services and can expand knowledge of what health care may look like. The ways of knowing is provided by the participants by employing narrative research can increase the possibility for the researchers and listeners to work through health care provision problems and develop appropriate and acceptable health care

services. This kind of knowledge can be used to balance biomedical knowledge which is dominant in the health care system.

Participants' narratives encourage the researcher to gain a better understanding of the participants' perspectives on issues of concern. Listening to, reading and interpreting their stories leads the listener or the reader into the narrators' worlds and promotes mutual understanding of their worlds which provide greater understanding about any issues of concern (Cooper, 1995; Denzin & Lincoln, 2005; Josselson & Lieblich, 2001; McAdams, 1993; Robinson & Hawpe, 1986). Multiple points of view about health care provision explicated through the participants' narratives increase the possibility of clarifying issues about health care provision. This enables health professionals to balance their knowledge in order to work with, not only work for, vulnerable people. Knowing how to work with clients should be a consequence of health professionals' understanding about health care provision through expansion of horizontal ways of knowing from the participants' stories and valuing the participants' voices.

Participants' narratives provide a diverse range of information which balances dominant points of view and reduces the gap in understanding between researchers and participants. This is a contribution to knowing and understanding about health care provision informed by participants' life stories to balance with the biomedical knowledge of the researchers which is dominant in health care systems. Narrative research provides life-stories which illustrate the variety of points of view about the specific event. Narratives carry information with powerful emotions, an understanding of human beings, a sense of connection, and the tacit knowledge gained through experience. The range of information encourages the listeners and the readers to construct new, sensible and reasonable notions (Lambart, et al., 1995). Conducting narrative research into the health care experiences of people living with VHD should increase the possibility for understanding about health care issues of people with VHD. Employing this approach can also highlight the voices of underrepresented groups such as those living in rural areas.

Witherell and Noddings (1991) suggest that "understanding the narrative and contextual dimensions of human actors can lead to new insights, compassionate judgment, and the creation of shared knowledge and meanings that can inform professional practice" (p.8).

Consequently, narrative study is applied to many fields for the development of effective practice. These include psychiatric practice (Coles, 1989), health care practice (Estefan, McAllister & Rowe 2004; Severtsen, 2004), and nursing education (Diekelmann, 2001; Hartrick, 2000; Nehls, 1995; Hillocks, 1999).

Miller and Crabtree (2005) suggest if participants' voices are absent, this prevents the development of acceptable and accessible health care. The voices that speak through narrative can foster the development of health care services. Participants' narratives also have potential to encourage a consensus on events, as this is influenced by understanding each others points of view through narratives. Ben-Ari (1995) concludes that stories are used when people want to get closer which is a key factor in the development of comprehension of events. A focus of narrative research is on encouraging reflexivity on events which increases the possibility of clarifying meaning from a variety of points of view supporting consensus about health care provision. Understanding about health care events which is based on consensus meanings is necessary for acceptable, accessible and better quality of health care. Narratives have the potential to develop consensus by mutual understanding between narrators and listeners, as listening to other narratives can build trusting relationships and the appreciation of other ideas (Cooper, 1995).

Narratives can support the development of trusting relationships and the appreciation of individual ideas between clients and care providers which is a key to health care provision being more client-centred. McEldowney (2003b) argues that, without these voices, oppression will persist because people who are oppressed are isolated and ignored by society. McEldowney (2003b) also points out that giving voice, or listening to stories of oppression, may encourage others to share their own stories and encourage participation in the transformation of oppression.

Narratives are necessary to make changes in health care services. Social change, according to Murray (2004), is based on and facilitated by bringing the oppressed voice into a place where it can be heard. Murray (2003) claims that "through narrative we not only shape the world and ourselves but they are shaped for us through narrative." (p. 95). Listening to and interpreting participants' narratives of health care experiences of individuals living with VHD may be foundational in the development of appropriate

health care delivery for these individuals and may also increase accessibility to health care services because it is likely to be acceptable to clients. Cooper (1995) who observes that narratives are very powerful for teaching and guiding an individual to think, imagine, and make moral choices. It is believed by using narrative research as the approach of this research on the health care experience of people with VHD can provide participants' points of view about health care provision for VHD and may inform health professionals about the current health care services and encourage planning of further acceptable health care services for those who live with VHD.

I assert that using narrative as methodology and method to understand participants' health care experiences through the participants' life-stories may foster the development of acceptable health care provision for people with VHD in rural areas, Thailand. As narrative research provides the possibility of pluralism of knowledge this should encourage the creation of a variety of ways to understand and handle health care delivery problems. The outcomes of narrative research can provide diverse health care information and may encourage involvement in giving help for individuals living with VHD. Health care services development based on clients' points of view should ensure better access to health care services because health care delivery focuses on the concerns of the participants narrated through participants' health care stories. Therefore, participants' narratives in this research are essential for the development of appropriate and acceptable health care, such as nursing care delivery or nursing education.

Nursing care and education which are based on horizontal knowledge from the outcomes of narrative research should provide essential knowledge informed by knowing more about clients' lives to contribute to the caring stance of nursing practice which is different from the care based only on medical knowledge that cannot support clients to achieve the maximum level of well-being. Understanding clients' from their life-stories support nurses to gain more sympathy toward clients which is informed by the thoughts and feelings of clients through their stories. The focus of care may shift to be client-centred care because the care is informed by clients' concerns rather than current health care provision which is mainly informed by disease-orientated health care services. This focus of care is as essential as knowledge related to illness and illness management from health professionals is required in order to support people with VHD to achieve holistic well-being. In addition, using narrative approaches for preparing

professional nurses and the development of clinical practices supports strong listening skills which is necessary for provide health care in a more caring way. These are the reasons underpinning my use of narrative methodology for conducting this research.

Conclusion

Narrative inquiry which is an interdisciplinary qualitative research methodology has been gradually employed by qualitative researchers because of the need for practical knowledge which values subjective data and a relativist reality for understanding human sciences. Narrative research has been informed by the function of stories which provides the researcher with an understanding about participants' experiences. Even though narrative research has a range of approaches, the core of inquiry is a story and a focus on empathy towards participants which encourages the narrative researchers to be more open and keen to learn through participant points of view. Understanding and recognising subjectivity is a valid part of the research. Narrative research is conducted with the focus on collaboration of participants and researchers in order to construct and create narratives and also to reflect on the context of the narratives. Collaboration, construction, creativity, and reflexivity are influential to conducting a narrative research project. Narrative methodology is a suitable methodology to conduct research in the Thai context because stories are commonly used as a method to understand others and as a strategy for seeking the means to reach a consensus in problem solving. This methodology can support the development of a culturally sensitive method for a Thai researcher to develop horizontal ways of knowing in order to balance dominant knowledge in the Thai health care system. Narrative outcomes from this approach give participants' voices greater opportunities to be heard and may be used as a basis for the development of appropriate and acceptable health care services for people who live with VHD.

CHAPTER 4

RESEARCH METHODS

...And yet, there must be freedom- if we are to speak. And yes, there must be power- if we are to be heard. And when we have both (freedom and power) let us not be misunderstood. (Anasuya Sengupta, Lady Shri Ram College, New Delhi, cited in Taylor, Gilligan & Sullivan, 1995, p. xi)

Introduction

This research contributes to knowledge about the health care experiences of rural people with VHD in Thailand. The importance of a narrative inquiry approach was established in the previous chapter with the discussion about the selection of an appropriate research methodology and method that would answer the research questions and provide an optimal process and tools for the collection and analysis of data. Guba and Lincoln (2005) writing about qualitative approaches in the postmodern paradigm state that “inquiry methodology can no longer be treated as a set of universally applicable rules or abstractions” (p.191) and the core of postmodernism is the ideology of doubt. As Richardson and St. Pierre (2005) state:

The core of postmodernism is the doubt that any method or theory, any discourse or genre, or any tradition or novelty has a universal and general claim as the “right” or privileged form of authoritative knowledge. (P. 961)

This study is concerned with using appropriate tools to ensure that the participants’ health care experience stories are heard as a fundamental of narrative approach. This concern requires the researcher to carefully frame questions for exploration, listening intently to others, and be thoughtful in the analysis of the texts as the task of the narrative researcher is to develop “probing questions about what it is we are doing- questions about standpoint, about role of the researcher, about how we know about another person and what it may mean” (Josselson, Lieblich & McAdams, 2003, p. 5). As there is no straightforward approach and method for narrative study, the researcher must imagine and think inductively during the research process, so it is necessary to note and reflect on what the researcher has learned, encountered, understood and dealt with in the challenges of conducting narrative research (Josselson, Lieblich &

McAdams, 2003). Richardson and St. Pierre (2005) argue that writing is a method of qualitative inquiry in learning about the research process and therefore the research process and approaches of this study have been written up relating how it was conducted in Thai context and based on Thai values and norms regarding narrative notions that are also deeply grounded in everyday life of Thai people. This concurs with Richardson and St. Pierre (2005) who write about postmodernism writing that “poststructuralism, then, permits- even invites or incites- us to reflect on our method and to explore new ways of knowing” (p. 962).

This chapter addresses the important issues relating to the research methodology and methods such as participants, ethical concerns, methods for collecting and analysing data, and validity of the study. The chapter starts with participants’ details and the inclusion criteria, participant recruitment method, and the participants’ characteristics. Ethical issues related to narrative study are provided. การคุยแบบเปิดอก-Karn-Keoy-Bab-Pead-Ok (open and honest conversation) as the key to eliciting participants’ life-stories which provide the essential data of the study is discussed. The criteria of research validity is used to evaluate the quality of the study are described. Finally, the analysis and interpretation process of the life-stories of participants is provided.

The research started after the procedures for conducting the research were approved by Massey University Human Ethics Committee (see Appendix A) and the research ethics committee of Mahasarakham Hospital in Thailand which provided formal access to the hospital (see Appendix B). I met with health professionals at the hospital clinics to describe the nature and the aim of this research project and left information sheets at the clinics. Local health professionals contacted people diagnosed with VHD and informed the potential respondents of my personal details and the nature and aim of the research and also provided the information sheet. I approached all prospective participants, who were interested to participate in this study, in person. After that, I provided each individual with detailed information regarding this study, informed them of their right to refuse to participate and withdraw from the study at anytime without penalty and discussed any concerns of prospective participants. Those willing to participate were asked to provide their names, addresses, and contact details. The respondents decided

the time and place for conducting the data collection. Informed consent was obtained upon meeting and before the interviews proceeded.

Participants

Twenty women and ten men aged 31- 80 who were diagnosed with VHD were willing to participate in this study. Details of participants' general demographic profile clinical characteristics and their experience with health care are in Appendix I. In an interpretive study like this, an intense focus that allows in-depth data collection from individuals experiencing the phenomena under study is more important than large numbers of participants (Morse, 1989; Munhall & Oliver, 1986). Purposive sampling was the method for recruiting participants and criterion sampling is a method of purposive sampling (Patton, 1990; 2002). In this study the criteria for recruiting participants were: a diagnosis of VHD, attendance at an inpatient or outpatient department at a secondary hospital, over 15 years of age, ability to speak and understand the Thai language, and at least one attendance at a health facility.

Demographic data is essential in narrative research as this data increases the possibility of a contextualized analysis of participants' life-stories. As demographic data provides personal identities that represent the human character of a narrative, demographic data provides possibilities for gaining better understanding of the participants as individuals, (for example their socioeconomic status) while analysing the participants' life-stories as the researcher is aware of participants' lives in a general social context. The participants' social contexts gives depth to the meaning of their life-stories as Stevens (1992) states that demographic data is helpful the interpretation of interview data and in the comparison of findings to other studies.

Ethical Issues

Ethical research practice is important to be addressed to ensure the conducting narrative approaches without any potential harm of the participants (Rosenwald, 1996). Josselson and Lieblich (2001) assert that researching life stories closely involves the personal truths of the participants, therefore, the researcher "must be grounded in deeply humanistic ethics" (p. 286). Reasons or justifications for conducting research are based on humanistic ethics and as Josselson (1996) says "we work with core aspects of

people” (p. xiv), and those personal life-stories are taken to larger audiences (Atkinson, 2002). Therefore, procedures for informed consent, privacy, confidentiality and consideration of risk are vital for research on human beings (Bryman, 2008; Mishler, 1995). All research procedures in this study were approved by the Massey University Human Ethics Committee (see Appendix A).

Consent and privacy

Mishler (1995) suggests that informed consent procedures minimise negative social and personal consequences and support the participants to assess the risk of participating in a study. This study used standard ethical guidelines for the study of human subjects. These guidelines included the consent to participate, information for the participants about the nature and purpose of the study and their right to participate or decline without penalty. The consent process consisted of local health professionals giving a written information sheet (see Appendix C and D) to prospective participants. The prospective participants could discuss any concerns about the study and their participation with the study prior to my contact. After the participants decided to participate in the study, I also provided verbal information about participation in the interview indicating consent. Each participant was also told that he/she could decline to answer any question or choose not to continue participating at any time.

Participants were provided with additional time to consider and discuss the research project with their families and health care personnel at the provincial hospital. I arranged a follow-up appointment with potential participants to ascertain their decision and to talk about the nature of the study and participation in the study. The process of informed consent was completed with those potential participants who were willing to participate in this study signing their name on the informed consent form (see Appendix E and F). However, the participants were informed that they could decline from participating in the study at any time even if they signed their names on the consent form without penalty.

Potential harm

Harm to participants could be physical harm, loss of self-esteem, stress, and psychological distress (Bryman, 2008). This study was likely to cause no discomfort to the participants, however, in naturalistic research it is important to protect the

participants proactively (Erlandson, Harris, Skipper & Allen, 1993). Therefore, in this study, I prepared by ensuring the support for the participants because if the participants become distressed, I as the primary researcher would be the first person to support the participants and would refer them for appropriate help and support. However, all of the participants appeared to enjoy telling their stories. I observed that the participants appreciated the opportunities to address their concerns on health care and some participants said that they were happy and keen to tell the stories because these stories may be used to help others informing the development of health care provision for people with VHD. None of the participants reported any discomfort and distress during the conversation, after the end of conversation and until the end of the data collection period. My contact details including phone number and address were provided in the information sheet. Therefore, the participants could ask for help and support at any time if they became distressed during the data collection period between November, 2006 and April, 2007.

The identification of persons and places has been kept confidential through the use of pseudonyms. Anonymity is a fundamental guiding ethical principle (Holloway & Jefferson, 2000). Confidentiality is very important in ethical practice. Bryman (2008) suggests that maintaining the confidentiality of records can prevent harm to the participants. Data analysis and reports have been treated confidentially as a critical component for reducing potential harm. Each participant was identified with a number instead of their name to ensure anonymity and these were known only to me. Pseudonyms were used when reporting the results, and the list of pseudonyms can be seen in Appendix L. The audiotape records, transcripts, and personal data and illness history of the participants have been stored separately from their consent sheets and their codes in a locked file cabinet at the Faculty of Nursing, Maharakham University and will be kept for a period of ten years. Only I have access to participants' information which can identify identity of the participants, and other people have not able to identify health care experiences of each participant. I have taken responsibility for shredding paper data and deleting electronic data.

Talking about personal health care experiences in terms of viewing, thoughts about what health care services are look like and feelings about care and treatment and its

outcomes and needs and expectations about health care provision with someone they just met may lead the participants to experience difficulties. To avoid this possibility, the interviews began with collecting demographic data. A structured demographic record sheet was used to guide this data collection (see Appendix G and H). The participants were encouraged to give as little or as much information as they liked in answer to these questions. In general, the demographic discussion was of a more quantitative nature such as age, sex, marital status, education level, occupation, income, and economic resources. The demographic information is very helpful in the interpretation of interview data by identifying the difference between demographic characteristics as well as allowing the comparison with findings from other studies. The demographic discussion eased us into the interview, as knowing about the respondent's life-world before talking about personal matters can overcome interview constraints and anxiety (Schwartz & Jacobs, 1979; Stevens, 1992). Demographic discussion in this study let me know about the participants' lives before moving to conversations about health care experience. After the demographic collection, participants were encouraged to discuss their illness duration, current symptoms, treatments, the level of symptom distress and the effects of illness on their lives. After that participants were engaged in การคุยแบบเปิดออก (open and honest conversation) about their health care experiences which invited the participants to tell as their stories as they wanted.

Getting Data: Engaging in การคุยแบบเปิดออก (Open and Honest Conversation)

In this study the empirical data was derived from the narratives of people with VHD. Their stories described and explained the experience of living with VHD and focus on access and satisfaction and dissatisfaction with health care services. To explore the perspectives on health care of individuals living with VHD, this study depended on interviewing strategies. Interviewing was the primary vehicle for data collection in narrative research (Duffy, 2007). Narrative interviewing provides narratives which are an ideal medium for researching and understanding individuals' lives in social context (Elliot, 2005). The goal of interviewing which is named การคุยแบบเปิดออก (Open and Honest Conversation) in this study was to elicit narratives about health care experiences. Individual interviews were completed with 30 participants during 2006 and 2007.

Two basic notions of interviewing include interviewer as a miner or as a traveller. The miner stands for modern social science notions that knowledge is given and the traveller refers to a post-modern constructive understanding which values a conversational approach allowing reconstructed stories to be told.

The potentialities of meanings in the original stories are differentiated and unfolded through the traveller's interpretation; the tales are remolded into new narratives, which are convincing in their aesthetic form and are validated through their impact upon the listeners. (Kvale, 1996, p. 4)

In this study, I was a traveller and conversation was the focus during interviews in accordance with the constructivist nature of this study. Conversation with participants is a key method to access participants' narratives. Kvale (1996) argues that conversation is necessary for sharing personal knowledge of people in society and can bring interview research closer to the domain of humanities because participants formulate answers in "their own conceptions of their lived world" (p.11). Weiss (1994) states that qualitative interviewing is a basic method for understanding participant experiences through learning of other lives within their social contexts.

A conversation is a process of two people understanding each other. Thus it is characteristic of every true conversation that each opens himself to the other person, truly accepts his point of view as worthy of consideration and gets inside the other to such an extent that he understands not a particular individual, but what he says. The thing that has to be grasped is the objective rightness or otherwise of his opinion, so that they can agree with each other on the subject. (Gadamer, 1975, p.347)

Mutual relationship is demanded for encouraging people to tell personal life-stories because relationship between teller and listener correlate to how much the life-story is told (Linde, 1993). A trusting relationship is necessary as it is a supporting factor to foster Thai people to be openness during conversation, especially about personal stories. Openness conversation which is named เปิดอกคุยกัน-Pead-Ok-Keoy-Kun (prepared to tell all) is facilitated by trust between narrator and listener. Thai people have specific

thoughts about how far to voice their thoughts during any conversation which is related to how much they trust the listeners. Thai proverbs relate to the level of disclosed information and include *สาวไส้ให้กากิน-Soa-Sai-Hai-Ka-Kin* (tell a secret to an enemy) - at this level all the information is withheld from listeners who are considered as people from the opposite side or as an enemy. The narrators consider that they are not to be trusted. However with *เปิดอกคุยกัน-Pead-Ok-Keoy-Kun* (prepared to tell all), almost all details and depth of information are disclosed because the narrators fully trust the listeners. The narrators also believe that the listeners are sincere and empathetic toward them. As trust is important for openness during conversation among Thai people, in this study, repeated interviews are considered as I observed that during the first conversation, the participants appeared to distance themselves from points of view about health care.

I was aware of the importance of trust which impacts on the level of openness of conversation. Building trust is the key to encourage the participants to disclose their health care experiences. *เปิดอกคุยกัน-Pead-Ok-Keoy-Kun* (prepared to tell all) was the level of conversation that facilitated participants to tell the full story about their experiences. As I was seen by the participants as a health care professional, this could make them cautious when narrating their health care experience stories. I noticed this caution at the first round of meetings when the participants mostly provided general and neutral opinions and referred to other people to reference their own stories. They used phrases such as *เท่าที่ได้ฟังมา* (someone else's opinion, not mine), *หมู่เพื่อนว่าให้ฟัง* (other people say this, not my idea), *กะลือนำบ้านนำเมืองเพื่อนว่า* (my opinion is similar to everyone else), *อันนี้กะสู้ตอบว่าจั่งได้ได้ยินแต่เพื่อนว่ามันเป็นจั่งซั้น* (I have no answer but other people would answer you this way). Deep, complex and sensitive opinions from their own perspectives were usually provided at the second round of meeting. Repeated interviews is a practical method for narrative research (Atkinson, 2002) which focus on personal life-story because this repeated interview demonstrates that the researchers are interested in hearing about their experience enabling the building of a trusting relationship (Holloway & Jefferson, 2000).

Thai cultural stance is integrated as the significant part of conversation with participants to encourage and empower them to tell stories about their own health care experiences.

The Thai cultural features facilitate the participants to be more comfortable during the conversations. The supporting factors for การคุยแบบเปิดอก-Karn-Keoy-Bab-Pead-Ok (open and honest conversation) include ความเป็นกันเอง-Kam-Pen-Kun-Eang (treating people with respect), เอาใจใส่-Ooa-Jai-Sai (attentiveness), ความไว้เนื้อเชื่อใจ-Kam-Wai-Neou-Cheiu-Jai (trust that what they say is valid and that they will not be named) and กาลเทศะ- Ka-La-Te-Sa (time and place).

ความเป็นกันเอง-Kam-Pen-Kun-Eang (treating people with respect) is an important factor to encourage Thai people to be comfortable with the conversation. I was aware of this importance and I also understand the ways of life of people in rural areas as I was brought up in this area. I built ความเป็นกันเอง (treating people with respect) by behaving in acceptable and respectful ways, the same as the rural people, which will be discussed in the next sections and using the Issan language during conversation.

ใครมาถึงเรือนชานต้องต้อนรับ (a welcome where the visitor does not take anything on the initial visit and accepts all treats such as drinking water from the resident) is a way of showing that guests are welcome. In the same vein, accepting this welcome also can form ความเป็นกันเอง (treating people with respect). This greeting is also a strategy to reduce tension which leads to การคุยแบบเปิดอก (open and honest conversation). As all of conversations were at the participants' homes, I observed that I was welcomed by the participants. This was because when I arrived and exchanged greetings, all participants invited me to rest in the place that was prepared for conversation, such as on the mat under the tree, on the bench in front of participants' homes, or on the mat inside their homes. Their family members also ให้การต้อนรับ (made me welcome as a guest), exchanged greetings and some joined in conversation. The participants also provided some beverage for me. This is a part of การต้อนรับ (welcome as a guest). I accepted all of these greetings with the full respect which is necessary for Thai people to start การคุยแบบเปิดอก (open and honest conversation).

เอาใจใส่-Ooa-Jai-Sai (Attentiveness) is an important factor to initiate and maintain the trust relationship between participants and the researcher (Elliot, 2005). In Thailand,

attentiveness is necessary for open and honest conversation and this was aware throughout this research process. For example, I went to meet with one participant and heard from the participant that another participant was not well and had been hospitalised and had just been discharged. I went to visit the participant and on that day, because I felt that I became a friend of the participant. In Thai culture, friends usually visit their friends when they are unwell which mean that they เอาใจใส่-Ooa-Jai-Sai (Attentiveness) toward others.

ไว้เนื้อเชื่อใจ-Kam-Wai-Neou-Cheiu-Jai (Mutual relationship of trust and respect). The relationship between the researchers and the participants is one of the important factors in the flow of information (Atkinson, 1998). I was aware of the need to establish a ความไว้เนื้อเชื่อใจ (mutual relationship of trust and respect) relationship that could help the participants express their opinions through การคุยแบบเปิดอก (open and honest conversation). Trust and respect were the key to encouraging participants and I observed in this study that the participants realised I was willing to listen to their stories. I noticed this by the responses of the participants when I brought back their transcriptions for them to be edited. Some said that they were surprised that I noted everything, whatever was said. They appeared delighted about this and, in the second round of conversation, their narratives flowed more freely than during the first round of conversation.

กาละ เทศะ-Ka-La-Te-Sa (Time and place) is essential for the conversation.การพูดคุยต้องมีกาละเทศะ โดยเฉพาะการแสดงความคิดเห็นส่วนตัวต้องมีความเหมาะสมกับเวลาและสถานที่ (a personal conversation needs consideration of the appropriateness of time and place). Generally, time and place of an interview are important aspects that can affect the quality of the interview (Elliot, 2005; Gorden, 1975). In Thai culture สถานที่ (place) is considered the factor which can foster or inhibit the flow of conversation. Revealing personal opinions in a public space is not a norm of Thai people in rural areas, as the proverb suggests ความในไม่ให้ออกความนอกไม่ให้เข้า (don't talk about private life in public and don't talk about other people in the house). Thai people are cautious when giving their personal opinions in public. In particular, talking about personal issues of others is similar to betraying them and the teller should not be trusted. Conversation about other people's business is considered as a waste of time and only people who have no

important things to do have these conversations. As the aim of the study is to explore personal clients' points of view, conversations should be held at their homes which can support Thai people to be more comfortable because they will discuss personal stories in the private areas. I was also viewed by the clients as a person who was to be respected in Thai culture and could be told confidential personal stories. In addition, possibilities for talking in public are rare in Thailand. As can be observed in this study, all of the participants chose to have the conversation at their homes instead of at the hospitals. They said that they preferred to talk about their experience at home. This helped to maximise the flow of information and protect the privacy of the participants.

เวลา (time) is important for การคุยแบบเปิดออก (open and honest conversation), therefore, การคุยแบบเปิดออก (open and honest conversation) needed to take place at a convenient time for the participants. Participants said that they did not want further conversation at the hospital as time was limited because of the activities of health care services. Time also at the hospital was decreased because of the need to travel to hospital and back home. Therefore, it was not convenient to hold a conversation at hospital on the follow-up days. The participants also viewed that การคุยแบบเปิดออก (open and honest conversation) needed plenty of time and they considered that, at their homes, they had more control over their time than at hospitals. Some also said that the time at the hospital was only for the follow-up activities. It should be concluded from the participants' points of view that time at the hospital was more limited than at their homes. The perception of unlimited time at home encourages การคุยแบบเปิดออก (open and honest conversation) which fosters full narratives of the participants' health care experiences. The conversations lasted on average about one and half hours each. No participant refused to complete the interviews. All of the participants were also invited to participate in follow-up interviews. Follow-up interviews were conducted with all the participants.

Symmetry in conversation that focuses on ways to encourage participants to คุยแบบเปิดออก (open and honest conversation) can foster a balance of control in conversation between participant and researcher. The participants have more control over conversation where the participants are the focus. As well as focusing on participant-centred conversation, I also used implicit responses such as remaining silent, through body language, and facial expression, instead of acknowledging, commenting, or proceeding to the next question.

This usually encouraged the participants to continue with additional content. Non-verbal communication enables respondents to continue with story-telling and tends to be more effective than verbal communication (Kvale, 1996; Gorden, 1975). These techniques also provide the participants with more control and power during the interviewing process. Mishler (1986a) asserts asymmetry in power is caused by the dominance of the interviewer and argues that this imbalance during interviewing suppresses participants' stories and states that

... absence of narrative in reports of interview studies is an artefact of standard procedures for conducting, describing, and analysing interviews: Interviewers interrupt respondents' answers and thereby suppress expression of their stories; when they appear, stories go unrecorded because they are viewed as irrelevant to the specific aims of specific questions; and stories that make it through these barriers are discarded at stages of coding and analysis. (p. 106)

Mishler (1995) proposes an alternate role for interviewers and interviewees to reduce the asymmetry of power in interview. The alternative roles include giving the right to control the flow and content of the interview to participants, accepting the informants as collaborators, and using findings to advocate in participants' interests instead of to serve dominant interests. I was aware of the need to balance power in the process of interviewing because this encourages the participants to tell their stories. Telling life-stories can raise the awareness of the participants through an understanding of themselves and their world; it can also help the researcher and other people to understand the lives of the participants by listening to and interpreting the narratives. Chase (1995) argues that by shifting the control of interviewing to the participants, researchers can gain a better understanding of the perspective and life world of participants. Hearing the voices of people living with VHD provides the opportunity for a positive change in health care for those living with this disease.

A flexible interview guide (see Appendix J and K) was used as a guide to การคุยแบบเปิดอก (open and honest) conversation because participants are likely to spontaneously provide narratives in the context of interviews about their experience (Elliot, 2005; Mishler, 1986a) and most people like telling stories (Elliot, 2005). Structured interviews are not

appropriate to support a conversation about participant experience. Mishler (1986a) argues that a structured interview is inappropriate and inadequate for conducting research focusing on participant points of view where the aim is to give meaning and understanding of their experiences. At the beginning of this study, I had used a structured interview guide to gain specific stories about health care experiences, but I found that a short form of information such as yes or no to the questions was told instead of stories and the conversation paused as the participants tried to answer my inquiry. They also asked for clarification of the questions and said that they worried that they would not give the correct answers. They also worried that if they gave the wrong answer, this would waste my time. Some said that they felt a lack of confidence with their knowledge, therefore they said it was hard for them to give appropriate answers to the questions because they have limited education and knowledge about health care and some also said they had nothing to tell. This situation may have been influenced by the nature of provider-centred conversation in Thai health care services that the participants deal with and also by the position of knowledge as was discussed in a previous chapter. Elliot (2005) states that structured interview suppress the flow of stories, and the structured interview guide invites people to report rather than tell stories (Chase, 1995). In addition, people prefer to tell personal life-stories in their own ways (Atkinson, 2002), therefore, in this study a flexible list of topics was considered as an appropriate guide for the conversations.

Participants rarely have conversations which are focused mainly on their own concerns with health professionals, they are likely to only provide information to meet the expectation of the inquirer, Kvale (1996) writes “in professional interviews there is usually an asymmetry of power: The professional is in charge of the questioning of a more or less voluntary and naïve subject” (p. 20). Therefore, I considered a rigid interview schedule was not suitable to encourage participants to tell their health care experiences because this rigid schedule was similar to the dominance of health professionals in conversations in the health care context. A flexible interview technique was used as the guideline for conversation can help both to maintain the conversation and elicit data for qualitative analysis, especially in narrative research. A conversation which focuses on participants’ stories needs to encourage the participants to take control on the conversation. As Chase (1995, p.3) says:

If we want to hear stories rather than reports then our task as interviewers is to invite others to tell their stories, to encourage them to take responsibility for the meaning of their talk. A successful interviewer manages to shift the weight of responsibility to the other in such a way he or she willingly embraces it.

I introduced broad topics using reflexive, open-ended questions. A broad question covering the topics of the study is one way to allow the respondents to choose the start of any narrative. Weiss (1994) states that “any question is a good question if it directs the respondents to material needed by the study in a way that makes it easy for the respondents to provide the material” (p. 73). This start to interviewing also builds rapport (Gorden, 1975; Weiss, 1994). Open-ended interviews can lead to a more free association of ideas and deeper responses (Atkinson, 1998) and Kvale (1996) states that active listening is more important than questioning techniques. I used non-specific language and open-ended questions when introducing questions about research topic such as “tell me about your health care experience”, “do you remember an occasion when you go to hospital?”, and “can you tell me about your feelings when interacting with health care providers?”. I used follow-up questions to encourage participants’ conversations by framing subsequent questions using language that reflected the respondent’s language (for example, “what does *ຍາຟອນ*-Ya-Phon mean?) and the questions also developed after listening to the audio-tapes and reading the verbatim transcripts which was used during repeated interviews. May (1989) suggests that the researcher develops interview questions by techniques which encourage the use of appropriate language in the interview. Chase (1995) asserts that “questions should be phrased in everyday rather than sociological language” (p. 3) within the orientation of participants. Chase (1995) reported a experience of interviewing where academic language in interview questions encouraged participants to report rather than tell stories and distracted participants from their experiences. I used several techniques such as probing questions, both verbal and non-verbal, during the interview depending on the situation to encourage the respondents to continue speaking, and non-verbal noises and gestures such as “hmmm”, a nod of the head, and expectant facial expression. I requested an elaboration of the story with probes such as “can you give a more detailed description of what happened?”, “do you have further examples of this”, “tell me more about that”, “how did you feel about that?”, “move on” or “let’s go back to the point where you

underwent the operation”. When the participants had a problem getting started, I used probe questions such as “can you tell more about that?” and “what was the experience like for you?”

Maintaining Rigour

Validity in qualitative research demonstrates to the qualitative research reader that the study approach is acceptable and study results are valid (Speziale, 2003). Narrative inquiry is interdisciplinary and a wide range of approaches are used in narrative studies, consequently, scholars of narrative research have proposed various quality criteria. Hatch and Wisniewski (1995) review and summarise qualitative research which discusses the criteria for the quality of the narrative. They introduce a list of the criteria which includes adequacy, aesthetic finality, accessibility, authenticity, believability, credibility, compellingness, explanatory power, fidelity, moral persuasiveness, persuasiveness, plausibility, resonance, sense of conviction, trustworthiness and verisimilitude (Hatch & Wisniewski, 1995, p.129). Trustworthiness and authenticity are usually used as criteria for evaluating the quality of narrative inquiry (Holloway & Freshwater, 2007) as the inquiry sits in the constructivist paradigm (Guba & Lincoln, 2005) and have been used to evaluate the quality of this study.

Trustworthiness as proposed by Lincoln and Guba (1985) include credibility, dependability, confirmability, and transferability. Credibility refers to the internal validity in the empirical research conveying into insiders’ experiences. Strategies to enhance credibility include prolonging engagement, using member checks, triangulation, persistent observation, having enough materials to provide the context of the study, and peer debriefing (Lincoln & Guba, 1985; Erlandson, Harris, Skipper & Allen, 1993). Prolonging engagement, persistent observation, and peer debriefing are the methods used to support the credibility of this study. As I have conducted research involving people with chronic illness in Thailand for seven years, and also have been practiced in health care for seventeen years I am not a stranger to the health care issues and can understand the context of information about health care and illness. Data display was used to identify the relationship between the themes and concepts and to make conclusions. Data display is persistent observations that provides “depth” (Lincoln & Guba, 1985, p. 304) of interpretation. The findings of this study were presented to the meeting of doctorate students, and staff which was held by School of

Health Sciences and Social Services, Massey University for sharing research experiences. The feedback helped the interpretive process because professionals outside the research context clarified and reviewed perception, insights, and analysis (Erlandson, Harris, Skipper & Allen, 1993).

Dependability refers to reliability by providing documents for an external check of empirical studies (Erlandson, Harris, Skipper & Allen, 1993). Dependability is the clarity and reproducibility or conformity of methodological and analytic decisions and interpretation of data (Sandelowski, 1986). A dependability audit is used to ensure the consistency of the study. In this study, an audit trail was developed between the researcher and the supervisors. The interpretation process has been conducted by the researcher under supervision of the supervisors to assure the consistency of the interpretation process. The process of conducting the research has been described in detail. Extracts of narratives are provided to support interpretation claims.

Confirmability is based on the quality of data which is objective information from the participants rather than from the researchers (Morse & Field, 1996). Confirmability is the degree to which the research findings are the products of the inquiry and not the biases of the researchers (Lincoln & Guba, 1985). Confirmability is indicated by a confirmability audit providing adequate data for external reviewers. The sufficiency of data helps to determine that the conclusions, interpretations, and recommendations are based on the empirical data (Erlandson, Harris, Skipper & Allen, 1993). In this study, the findings are inductively derived from the participants' narratives and the narrative inquiry guides data collection and analysis. Moreover, the researcher consulted with supervisors in order to reconfirm the analysis of data. The data and findings can be used by readers to assess confirmability of the study. I also provide narrative extracts and categories which can help the reader to determine the confirmability of the study.

Transferability means that the findings have possible meaning to others in a similar situation (Speziale, 2003). Potential users are the people who determine the wider application of the findings to other respondents and other contexts. An inquiry is judged in terms of the extent to which its findings can be applied to other contexts or with other respondents (Lincoln & Guba, 1985). Strategies to facilitate transferability include thick description and purposive sampling. Thick description means that the study provides

sufficiently detailed description of data in context and with sufficient detail and precision to allow the readers to understand the context. Purposive sampling enables the development of rich detail for adequate description by maximising the range of specific information (Erlandson, Harris, Skipper & Allen, 1993). In this study, both thick description and purposive sampling support transferability of the study findings. Excerpts from the accounts of individuals living with VHD and social and health care contexts are provided in this thesis for the readers to justify the transferability. Elliot (2005) suggests that the generalisability of individuals' narratives is informed by the cultural framework providing understanding of the meanings shared by the whole of a community.

Authenticity is essential to validate the quality of a qualitative study within a constructivist paradigm to ensure that constructivist research outcomes are sufficiently "trustworthy, related to the way others construct their social world (Guba & Lincoln, 2005, p. 205) and the criteria include fairness, ontological authenticity, educative authenticity, catalytic authenticity, and tactical authenticity (Guba & Lincoln, 2005). Fairness is an authenticity criterion and is necessary for ensuring that the research is faithful enough to use as a guideline for social action. Fairness is also a criterion for authenticity in constructivist inquiry which can be confirmed by preventing the marginalisation of participants, respecting inclusion ensuring that all voices have a chance to be represented and stories are "treated fairly and with balance" (Guba & Lincoln, 2005, p. 207). Fairness is considered necessary for validity of narrative inquiry (Riessman, 2008) and

...the truths of personal narratives are neither open to proof nor self-evident. We come to understand them only through interpretation, paying careful attention to the contexts that shape their creation and to the world views that inform them. (Personal Narrative Group, 1989, p. 261)

Blumenfeld-Jones (1995) uses the name 'fidelity' to refer to what it means to the teller of the story (subjective interpretation) as a validity criterion, "an obligation towards preserving the bounds between the teller and receiver by honouring the self-report of the teller and the obligation of the original teller to be as honest as possible in the telling" (Blumenfeld-Jones, 1995, p. 28). Therefore, fairness is an authenticity criterion in this

study which participant stories and narrative interpretation were provided through out the result chapters which can ensure that both participants and my voice were represented in this study.

Data Analysis

Conversations were recorded for the collection of participants' narratives. In narrative analysis, taping and transcribing are necessary (Kvale, 1996; Riesmann, 1993). Tape recording allowed me to concentrate on the interviews without distracting the respondent by hand-writing notes of the data. However, Schwartz and Jacobs (1979) mention that both the respondents and the interviewer may be frightened by the tape recorder. I was aware of this problem and I asked about the respondent's feelings and observed my own feelings. I and all of the participants felt comfortable with the presence of the tape recorder and did not notice the presentation of the recorded device during the conversations. The tapes were transcribed verbatim by the primary researcher.

Miles and Huberman (1994) suggest that the process of preparing data for analysis includes organising the transcripts by correcting, editing, and typing. All individual interviews were audio-taped. I personally transcribed the interviews from the audiotapes. The process of transcription forced me, as the researcher, to listen closely and attend to every word. I repeated this process to ensure the accuracy of the transcript for valid analysis and interpretation of interview data. Mishler (1986a) suggests that a carefully prepared transcript is one of the key points for a successful study. I had the benefit of having been present and involved in the creation of the spoken data and its transformation into the written data which was a time consuming and exacting task. It took about nine to ten hours to fully transcribe one hour of tape. The process involved writing down a first hearing on paper and then typing this into a word processing program on a personal computer. Then I checked a draft printout against the tape, and made corrections. The resulting verbatim transcripts produced written text in Thai alphabet which were translated into English by me as follows:

*[ตอนเป็นเด็ก] ไปเรียนหนังสือกะ เรียน [ไม่ต่อเนื่อง] บางทีก็กะเรียนที่บ้านหมู่กะ เกิดเป็นไข้ได้ไปนอน [โรงพยาบาล]
บางทีก็ขาด [เรียน]เดือนหนึ่ง เดือนหนึ่งไปสองเที้อสามเที้อ โคนจมนันสิกำริบขึ้น
มันสิปวดคนำข้อกะได้ไปนอนโรงพยาบาลเป็นเดือนสองเดือน มันกะมากะเรียนที่บ้านเขา (วันชัย)*

[When I was a child] I could not go to school regularly because I got fever and was admitted at hospital. Sometimes, I could not catch up at school. Some times, I had to go to hospital 2-3 times a month or was admitted for one month because the disease was exacerbated. I had a pain in my joints and was admitted for about 1-2 months. Therefore, I could not catch up with study to the same level of my friends (Wanchai).

These written texts of participants' narratives both in Thai and English provided the data base from which the final analysis was accomplished. These transcripts were read and reread countless times in the course of the analysis.

Thematic narrative analysis is the method of analysis in this study. Riessman (2008) claims that the content of narratives is the core concern of all narrative studies. Riessman (2008) insists that thematic analysis is the most straightforward and appealing method of analysis in applied settings. Reissman also points out that use of this analysis method is growing among nursing and other health professionals to examine participants' experiences of illness.

Miles and Huberman (1994) describe the components of data analysis as "data reduction, data display, and conclusion drawing/verification" (p. 10). Data reduction is the part of analysis in which data is selected, focused, simplified, abstracted, and transformed. Condensing data includes selection, summarising or paraphrasing, which is "being subsumed in a larger pattern" (Miles & Huberman, 1994, p.11). Data reduction was the first part of data analysis of this study. Riessman (2002) points out that the strategies for data reduction and interpretation consist of reducing the narrative to the core narrative and the analysis of its structures. The core narrative provides a skeleton plot which can be used to compare the plots of individuals who share a common life event. In the process of analysis, I asked the question: what is this story about? It is important to determine the point of a story. I read through the data many times and then I began the narrative analysis. Each story was reduced to an adequate paraphrase, which is a technique adapted from the one described by Polanyi (1985). The paraphrases are based on the main plot and context of actions. The paraphrases portray the involvement of the narrators and reveal the participants' evaluation. The paraphrases

may provide the answer to the point of the stories (Mishler, 1986b). These transcripts and their corresponding adequate paraphrase were used to do a narrative analysis.

Table 4.1 An Example of Data Reduction

เรื่องเล่า / Story	Summary of Story	Paraphrase
<p>ที่แรกพอหมอบอกว่าเป็นโรคหัวใจรั่ว ะตกใจ ฉันไม่เคยได้ยินจักเพื่อเหาะ กะเลยถามหมอมว่ามีโอกาสหายบ่หมอ หมอหั่งบ่ตอบแกลงหัวชื้อๆ กะไปหาหมอตามหมอนัดตลอด ไปเฝ้ายามกักรักษาเจ้าของ หมอเพื่อนกะถามว่าสิผ่าบ ฉันกะหย่านเหาะหย่านบ่พื้นหลังผ่า กะไดอินหมู่เพื่อนเวาให้ฟังว่าผู้ลางคนกะบ่พื้นหลังผ่าตัด กะเลยบอกลูกศ้วว่ากะสิกินยารักษาไปจั่งชี้หละ กัันฮอดยามตายกะจบท่อนั้นแล้ว</p> <p>I was frightened when I know that I had Hua-Jai- Rhieu, I never heard about this before. I asked the doctor if I had a chance to be cured. He moved his head around without answering. I have gone to see doctor regularly and I have taken drugs for care and treatment. Doctor asked me if I would like to undergo an operation or not. I am fearful about not recovering after the operation because I heard that some patients never gain conscious after operation. I told my husband and my son that I would like to take drugs. If it is the time to die, it is just the end.</p>	<ol style="list-style-type: none"> 1. Information about valvular regurgitation and care for this disease is not available. 2. The participant perceives that this disease and care for the disease is life threatening 3. The participant could not find information from health care provider. 4. Rumour about health care from lay person has informed the narrator about illness management. 	<p>Health care information is necessary for people with VHD but it is not freely available for them to manage this illness because of the perception that this disease and treatment is life threatening.</p>

The second part of data analysis is the data display. The display can be matrices, graphs, charts, and networks which improve the clarification of the qualitative data (Miles & Huberman, 1994) (Figure 4.1). The concept connections between the participants' health care narratives were analysed. This process of analysis was completed after constructing and reconstructing life stories material. This method was accomplished by the construction of visual and written synopses of each narrative in order to compare and contrast the stories and to distinguish the differences. The stories of individuals

with VHD were re-examined to find narrative extracts with the best fit with the analytical findings.

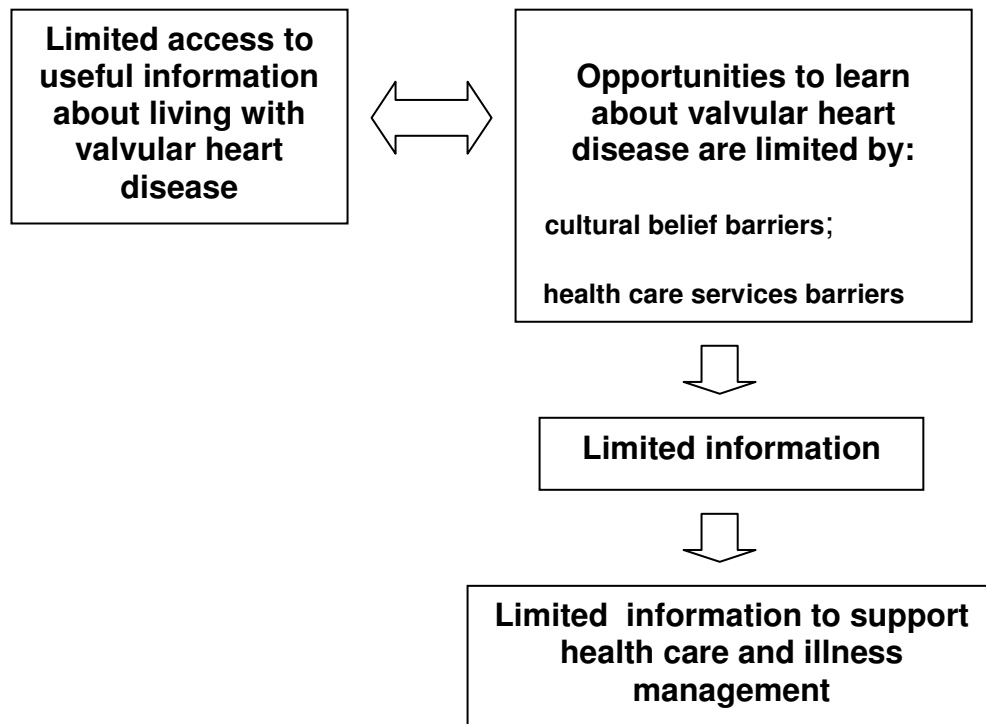


Figure 4.1 An Example of Data Display

The third activity is drawing conclusions and verifying the findings. At this stage, the researcher decides the final conclusion of the meaning of the data and develops an “intersubjective consensus” (Miles & Huberman, 1994, p.11) which represents the relationship of each participants’ experience and wider contexts to support the validity of the study. Denzin (2002) states that this step of interpretation “brings the phenomenon alive in the worlds of interacting individuals”(p. 359). This technique can highlight the interpretations of individual narratives compared and contrasted with other narratives and wider social contexts.

Participants’ life stories revealed three significant health care narratives including autonomy of life with VHD, the maximisation of resources for management of life with VHD, and the effort of learning for life with VHD. The details of narratives will be provided in the results chapters. I also identify the relationship between the concepts and conclude that these three concepts are influenced by disease-oriented health care

provision which lead the participants to face the challenges of managing life with VHD. I also identified related factors of these challenges which include partnership between clients and health professionals in health care, available of health care information, and health care resource distribution which will be further discussed and provided in Chapter Eight.

Conclusion

This research utilises a narrative interpretative design to understand the experiences of persons with VHD. Life stories of individuals living with VHD were collected using ethical processes which were approved by the ethics committee of Massey University to prevent potential harm to the participants. In the process of data collection, informed oral or paper consent was obtained from each participant. Confidentiality and rights of all participants were highly regarded and protected. Trustworthiness and authenticity are the quality criteria of this research. The data collection, analysis, and the findings reports are concerned with credibility, dependability, confirmability, transferability, and fairness which support the validity of the study. The purposive sampling of thirty adults with VHD allows for thick description of the data. The participants were encouraged to talk about their health care experiences by my use of symmetry control in the interviewing process. Life stories were audio-taped and transcribed into written data. The participants' narratives were analysed with three steps which include data reduction, data display, and conclusion drawing. The findings from this study will be described in the following results chapters.

THE FINDINGS

I know that when I move deeply into my writing, both my compassion for others and my actions on their behalf increase. My writing moves me into an independent space where I see more clearly the interrelationships between and among peoples worldwide. Perhaps other writers have similar experiences. Perhaps thinking deeply and writing about one's own life has led, or will lead, them to actions that decrease the inequities between and among people and peoples and that decrease the violence. (Richardson & St. Pierre, 2005, p. 967)

CHAPTER 5

AUTONOMY AND LIFE WITH VHD

Introduction

Participants' stories revealed that when living with chronic illness, VHD in rural Thailand, having self control was necessary. According to participants' stories, assertiveness was necessary for making decisions about their condition and seeking help. Participant's stories revealed their assertiveness about their decision-making. Rural people also faced a range of difficulties in order to access health care services. However, the participants managed to overcome obstacles due to the perception that health care services were necessary to support life with chronic illness. Participants were committed to ensuring that they could access the most suitable and appropriate health care for illness management to achieve well-being.

Decision-making Assertiveness

Participants relied on their own decisions which were informed by their points of view about disease and health care. Their life-stories revealed that the participants integrated information from health professionals with their own views to evaluate and justify their conditions and choose suitable and appropriate ways of illness management which can ensure achievement.

Basing decisions on own expectations

Generally needs and expectations about health care were important factors influencing individuals to decide to seek health care and choose health care options. Participants had their own needs, goals, and expectations about living with chronic VHD. Rural Thai people viewed illness as causing physical impacts such as symptom distress which was significant reason underlying their decision making about seeking health care. One participant decided to refuse an operation because she asserted that the illness did not have negative physical impacts.

I refused the operation because I was normal. I did not have severe symptoms and did not have pain and tight chest. It was not enough reasons for undergoing the operation. I will take drugs like this. (Jintana, interview 1)

On the other hand, when the illness impacted significantly on their life, participants made the decision to choose a medical treatment such as heart surgery. Bhunchorn's story revealed that the decision to undergo an operation was influenced by impacts of illness on daily activities. He stated:

I was severely tired. The symptoms happened just when I had a bath. I had to stop washing myself for some time. After bathing, I had to sit for some time before I could dry myself. One time I went to catch fish with a net in a shallow pond around 50 centimeters deep. I could not finish the job. I had to wait until my wife found me. [She went to look for him because she was worried that bad things might have occurred.] So I thought that I could not bear any more. I decided to undergo an operation. (Bhunchorn, interview 2)

The impact of treatment on their health was an important influence of participant decision making and they decided about using health care services in relation to their physical distress. They based the decision to seek help on the outcome such as reducing symptom distress.

I sought help at the district hospital for tiredness and a cough. A physical exam and x-rays were done and heart disease was diagnosed. I did not believe that I had heart disease. I told a doctor that I did not have heart disease. I thought I had asthma because the heart beat was normal. The doctor said "listen to me, you have got heart disease." Half a small tablet was prescribed. I did not have confidence with its potential because it was too small an amount to be a drug. I took the drug for one year. One day I had a severe pain in my leg. It was very painful. I could not move the leg. My cousin took me to the emergency room at the district hospital. I was referred to the provincial hospital for proper care and treatment. After being admitted for one week the symptoms disappeared and I was discharged. After that I went to follow-up appointments at the provincial hospital for care and treatment. (Chaichana, interview 1)

Participants viewed the outcomes of health care in a holistic manner such as the impact on the level of social functioning such as resuming a working role. Participants

preferred taking medication to undergoing an operation and indicated that medication is useful to help them to live with VHD.

After taking medication, I felt a lot better and I could work. I could walk without being severely tired. Before taking medication, I was severely tired every single time, even turning on my side on the bed made me have difficulty breathing. I got a lot of improvement, more than 50%. I thought that I choose to take medication and not undergoing the operation. (Nuchchanad, interview 2)

They perceived that medications were the treatment of choice for the disease and felt that taking medication enables them to have a normal life which was the essential goal for them. One participant said:

I had a lot of improvement after I was treated with the drugs. Before taking the drugs, I was thin. At first I did not have a significant change but after 4-5 months, I gradually improved. I put on weight and felt good. Other people also told me that I look like I do not have heart disease because of my healthy general appearance. (Chaichana, interview 1)

Participants perceived that medical advice which was that an operation is necessary did not fit with their well-being goal. The following examples indicate this preference:

*I asked *ນາຍ*–Moh (doctor) if I have to take drugs after the operation or not. The doctor insisted that the drugs are indispensable after the operation the same as before the operation. I said that I would not undergo the operation. I wanted to take drugs, which would be better. The doctor asked about improvement. I told him that I felt a lot better and I could work. (Nuchchanad, interview 2)*

The life-stories clearly showed that the participants had the assertiveness to make decisions about illness management.

*An operation was advised in the initial phase when I was treated at the hospital. *ນາຍ*–Moh (doctor) asked me whether I wanted to undergo the operation. At that*

time, I decided to refuse and wanted to be treated with the drugs because I thought that the drugs can cure this disease. (Ardoong, interview 1)

If care and treatment could cure disease, it would be good...However, if I had to take drugs after the operation, I would not want to undergo the operation. Taking drugs causes lower risk than the operation. I also was worried that I may not recover after the operation. Therefore, I prefer to take medication rather than undergo an operation. (Sadudee, interview 1)

Holistic well-being is more important than renewing the deformities of the heart valves. This view influenced by lay points of view about health differs from the biomedical point of view. Participants felt that taking medication could ‘cure’ VHD. This perception was supported both by the positive effects of taking medication and lay information. However, taking medication cannot renew the deformities of the heart valve (valves). This treatment option was used when an operation was not available and for reducing the signs and symptoms of VHD complications such as heart failure, and medications were prescribed to reduce the work-load of the heart. In fact, taking medication is not effective treatment for VHD as it only reduces the signs and symptoms. It appears that the participants may not have knowledge about effective ways of managing VHD and only observed a reduction of their suffering.

Decision making based on life circumstances

Decision making about illness management by rural people in Thailand was strongly influenced by their social and cultural context. The reasons underpinning their decision were strongly informed by the circumstances of their life rather than clinical reasons. Participants based their decision about health care options with consideration of its impacts on the physiological, psychological, socio-economical, and spiritual dimension of their lives.

I am old I do not want to get unbearable suffering from the operation wound. I think that taking drugs is enough. The drugs helped me to have less severe symptoms. If I took the drugs, I would be normal. (Phisud, interview 1)

An operation was advised because, after taking the drugs, I did not get cured and did not have a significant improvement. The symptoms only were relieved. I could not undergo an operation at a tertiary hospital in Bangkok because I wanted to go back to live in my home town At that time my father passed away. I asked for a referral and I was referred to a provincial hospital. I got services from that hospital 1-2 times. I was referred to a tertiary hospital, which is in another province for nearly one year. The operation was advised again. I refused because at that time there were many problems in my family. My husband was neglected and there was nobody to look after my children. I worried that after the operation I would have hardship because no one would cook for me. I may not be in good health. I may have to stop working. Moreover, I have to take the drugs after the operation. I asked for a referral to get the drugs from a provincial hospital which is not far from my village. (Nuchcanad, interview 1)

Family well-being was considered as an important part of individual health of people in rural areas. Maintenance of family well-being is an important reason in convincing rural people to make a decision about illness management. Some decided to undergo the operation due to the family conditions. Bhunchorn said:

The heart operation was advised but I refused and took medication for one year. I changed my mind because my wife was pregnant with our second child. A doctor asked about the operation again, this time I accepted and I accepted even though I might die by the operation. (Bhunchorn, interview 1)

However, a number of participants refused undergoing surgery as they considered this could impact on family members and this is contributed to by not having access to health care. One participant said:

Undergoing an operation may cause hardship for my children... I refused [the heart] operation. (Reingjai, interview 2)

Cultural belief is a key reason used by rural people to justify their illness management. A number of beliefs about dying and the relation of operation to dying was an

underlying reason which influenced the decisions of rural Thai people about their illness management. Dying is considered as a normal event that no one can avoid as one participant said:

Dying can happen at anytime and I would accept if it happened. (Jintana, interview 1)

Participants viewed that undergoing an operation could not change this event.

I fear dying, however, I refused the heart operation. I think that I will die either undergoing the operation or not. The operation cannot change this. (Thongphakay, interview 1)

Operations are widely perceived as a significant cause of dying and the heart operation is particularly significant. Some participants refused the operation based on this perception.

I may die during the heart operation and I also wanted to die without blood spread out of my body...I will have wound when I die. I want to die without wound. (Reingjai, interview 2)

Life after death is a general belief of Thai people. Some participants refused the operation as they valued the importance of life after death.

I wanted to have perfect body after dying. I did not want the operation scar which would be last on my body and would be existing in my soul world. I will not undergoing the heart operation. (Aphichad, interview 1)

An intervention, such as surgery, is considered as the effective treatment for VHD where deformity of the valve is corrected alleviating stenosis and regurgitation. However, perception of holistic health is widely accepted in Thai culture rather than having a perfect body which is an important concern of disease orientation approaches informed by the biomedical model. The life-stories of the participants revealed that the participants preferred to achieve holistic well-being which was the important

fundamental basic of decision making about health care options. They did not view the heart operation, which can revise the heart valve deformities, as fostering better living. The meaning of good health for rural Thai people focused on both their own self and their families.

Overcoming a fear of dying

A fear of dying from operations is common belief of rural Thai people and participants' stories revealed the assertive decision-making of people with VHD in rural area, as there was unclear information to reassure them about the safety of the heart operation and they considered that a heart operation could put their lives at risk. Participants had to overcome this fear when they decided to undergo a heart operation.

At first I was afraid to undergo an operation. I had heard that people who underwent the operation, all of them died, no-one survived. My father said that "you have to accept this. Everyone will die eventually, no-one can avoid this. When we are born we die. It is your hardship and you have to bear it by yourself." At that time, I had severe illness. I could not eat and had shortness of breath....I decided to risk the operation. (Laddawan, interview 1)

Athipod and Ardoong said that even though the operation was not fully accepted, they had to undergo it because the distress was unbearable.

I did not want to have an operation at first because I was afraid I might not recover. I thought that I would only take drugs. Taking the drugs was only for relieving symptoms and I got more severe illness. I had more and more severe symptoms and felt as though I had nearly died. Therefore I decided to undergo an operation. (Athipod, interview 1)

I decided to undergo the operation because of having syncope six times when I was riding a bicycle uphill. This mostly happened when I was alone. If no one found me and helped me in time, I did not know what would happen. I completely accepted what will happen. I think that "Die means die, survive is to survive." I went to hospital with my children to seek help for the operation. (Ardoong, interview 1)

Participants' accounts appeared as if participants made decisions to undergo an operation when they were faced with undue suffering for a long time because of the delay accessing a heart operation. This situation meant they could have missed the opportunity to maximise well-being by undergoing the operation at the appropriate time. The participants faced distress caused directly by both the symptoms of VHD and limited health care options, as well as indirectly due to the lack of useful information to support the participants' understanding and decision-making about care and treatment.

Determination to Access Health Care

Access to health care is necessary for people living with chronic illness to gain a maximum level of well-being. Participants in this study were aware of the importance of support from health care services and they had a strong determination to access health care. One participant said:

I was satisfied and wanted to go to hospital for the follow-ups because this made me feel that หมอ-Moh (health professionals) were being close. If something wrong happened, I would always get help. (Wason, interview 1)

Support from health professionals was viewed as importance for living with illness. The participants said that meeting with health professionals helped them to know about their conditions and the means to manage their illness.

I got advantages from the follow-ups because I had a chance of knowing about my condition and knowing means for illness management...I went to every follow-up appointment. (Nuchchanad, interview 1)

Visiting หมอ-Moh (doctor) helped me to know about the disease. If I did not go to see the doctor, I would not know what was going on...if I missed the follow-ups, I would not know how to care myself. So, I went to the follow-ups regularly. (Reingjai, interview 1)

The assertiveness and determination to manage difficulties of access to health care services of rural people with chronic illness can be seen through their life-stories where they managed to overcome difficulties and accepted the costs created by the treatments.

Overcoming traveling difficulties

The participants lived in rural areas in Thailand where public transport is not always convenient, for example, in some villages there is only one round trip to town each day. Participants lived between 10-100 kilometers from town and some dealt with this distance by hiring private cars which cost around 400-500 bahts (around 16-20 NZ\$) a round trip. Participants and their family were strongly determined to access health care services. Many participants experienced traveling difficulties when they lived in remote areas as children. At that time there was a lack of public transport which was a significant obstacle to easy access to health care services needed on time to prevent VHD.

I got a fever and joint pain when I was 8-9 years old. I could not turn over by myself. My parents helped me to turn over. My parents thought that it was only a general fever. They bought ยานแก้ไข้ -Ya-Kae-kai (anti-pyrogen drug) to treat me. They observed the symptoms for 3-4 days and I was getting worse. They hired a private car to take me to a clinic in P district. At that time, there was no public transport in my village. The doctor said that “It is too late. Your son has got heart disease. However, I will try to treat him.” I was treated at the clinic for two days. After that, I was admitted at district hospital for one month. (Wanchai, interview 1)

Participants bore the distress of traveling difficulties by ทำใจ -Thum-Jai (make mind to accept) due to the attempt to access health care services. Participants said that traveling to health care services gave them more distress, they said that they were ทั้อทั้ -Tho-Thae (feeling powerless), tired, exhausted and often got car sick. Participants talked about how ทำใจ -Thum-Jai (make mind to accept) was used to cope with the constraint of travel.

I went to Bangkok very often for follow ups. This made me เบื่้อ -Bhieu (feeling bored), ทั้อทั้, and ทั้คร้าน -Khi-Kharn (not having motivation to do). Sometimes just

looking at the bus, I felt tired. Sometimes I wanted to stop going to get care and treatment. It was harder to travel after I got อัมพาต -Aum-Ma-Bhat (paralysis). Because I was not healthy, I usually got car sick and felt very uncomfortable. (Wanchai, interview 1)

Because of the lack of a vehicle and no young people living with me, it is hard to get to the hospital. If I was going to a follow-up at a nearby hospital, it would be more convenient. The district hospital is near my village but the road is not good. The provincial hospital is far from my home but the road is good. Now I have gone for the follow-up at a provincial hospital. At the end of the day of the follow-up, I was exhausted and got car sick. I had to rest and could not do anything. I only cooked rice that evening. (Sunisa, interview 1)

ตั้งใจ -Thum-Jai (make mind) to accept the hardship of traveling to the hospital. It is impossible for it to be more convenient because I do not have a car. Sometimes I had to walk for three kilometres in hot sunny weather. The last bus to my village is at 12 o'clock. If I missed the bus, I would take other buses which drop me on the main highway. After that I have to walk three kilometres to my home. (Chidchanok, interview 1)

Some chose to go to primary health care settings in communities for access to more convenient health care.

I was tired before the appointment day. I went to a nearby hospital or private clinic. I could not go to provincial hospital because it was too far. (Somsongsang, interview 1)

Participants' family also supported access to health care services by a range of ways such as trying to earn more income and borrowing money from others.

I could not go to a hospital by public transport because I got อัมพาต-Am-Ma-Bhat (paralysis). It was hard to get on and off buses. My children went to work in

Bangkok and sent money to me. I used it to hire a car for going to hospital for follow-ups. (Phloydang, interview 1)

After the operation, initially, I was very sick and could not travel to the hospital by bus. I hired a car for travelling which cost 1,200 bahts [48 NZ\$] per round trip, my husband borrowed this money paying for the travel cost... Those expenses caused debt and my husband said that if you were not sick, we would not have the debt. (Thongsay, interview 1)

Living at a distance from health care settings created difficulties of access to health care and participants needed to be determined to overcome barriers to seek help from health professionals. Providing necessary health care options in rural areas is needed to improve accessibility to health care for people who live in rural and remote areas.

Overcoming health care services challenges

Participants managed to access health care services, even if they faced inconvenience created by the services. Participants' stories revealed difficulties caused by misdiagnosis that led to more distress such as for example, difficulties in being referred to other health care settings. One participant said:

I was severely tired and went to a private clinic. VHD was diagnosed. Drugs were prescribed and I took the drugs for one month. I would like to get proper care and treatment. Therefore, I went to the district hospital. X-rays were done. The doctor said that "you have got tuberculosis." TB drugs were prescribed. I went to ask the doctor at a private clinic. หมอ–Moh (doctor) insisted that I have valvular stenosis. After this I took drugs from the hospital for 5 days, but the illness got worse. Therefore I stopped taking TB drugs. เจ้าหน้าที่–Jao-Nha-Thee (government health care worker) visited me at home because of my absence. เจ้าหน้าที่–Jao-Nha-Thee (government health care worker) told me to go back to the hospital. I went to the hospital, TB drugs were prescribed again. I wanted to find out more about my illness. So, I went to the private clinic where the doctor also worked in the hospital. หมอ–Moh (doctor) did a physical exam and heart disease was diagnosed. He sent me back to the district hospital. I was referred to a

provincial hospital. I was admitted for seven days. After that I was referred to the tertiary hospital. (Bhunchorn, interview 1)

Another participant stated that going to hospital was inconvenient, however, she managed to go to the hospitals for the follow-ups regularly.

I go to the hospital for follow-ups every one to three months. It was not convenient. I left home and reached the hospitals before sunrise because, if I went [to the hospitals] late, I would get back home late... However, I have to go for the follow-up because my life depends on doctors. (Chidchanok, interview, 1)

Because specific investigation was not available at primary health care settings, some participants experienced paying for extra expenses in order to access health care services. The participants tried to manage this limitation by going to private clinics or other health care settings.

There were no special examinations at the provincial hospital. EKG and chest x-rays were done. Special techniques for heart investigations were not done. So I did not know what was going on inside the heart. I was very tired and was willing to know about the heart problem. I went to find out about this and had to pay for this. I paid 2,000 bahts [80 NZ\$] for a special investigation and 940 bahts [37.6 NZ\$] for the cost of drugs. The next appointment will be in the next 14 days. (Usawadee, interview 2)

The national health care insurance scheme requires people to register with a specific health care setting to access health care services. People must be registered and attend a registered hospital to get free health care. To access free health care services that are not available at a registered hospital, the patient needs a referral from a registered hospital. If the referral is not processed, people have to pay health care costs themselves. This situation caused difficulties for participants. The referral note provided the participants with access to free secondary and tertiary health care services. Therefore the participants had to go to both registered and provincial hospitals to access one health care service for VHD. Participants said that the referral note was necessary to get

coverage from the national health care insurance under สามสิบบาทรักษาทุกโรค – Sam-Sib-Baht-Rak-Sa-Took-Rok (30 bahts for all disease) scheme’s worth of coverage.

I went to get the referral note from the district hospital before I went to the follow-up for heart disease at a provincial hospital. This note covers three months. Once the doctor at the district hospital forgot to make the appointment to get the referral note, I went to the provincial hospital without the note. หมอ-Moh (doctor) at provincial hospital said that “if you do not have a referral note, drugs are not available.” (Soybhet, interview 2)

I went to the district hospital to get a referral note before going to the provincial hospital. The referral note may cover two or three months, the doctors order this. I took it to get photocopies. I handed them to เจ้าหน้าที่-Jao-Nha-Thee (government health worker) in order to get drugs. At the end of the covering period, I went to the district hospital to ask for a new one. หมอ-Moh (health professionals) said that “if you do not have this note, you have to pay for the cost of the drugs.” (Chaichana, interview 2)

Participants determined to access health care service sought support from their family going to get a referral note for the participants.

My niece [she is a health care provider who works at a primary health care unit] went to get a referral note for me...If I did not have this note I would have to pay 2,000 bahts [80NZ\$] per follow-up. (Phloydang, interview 2)

My daughter went to the district hospital to get a referral note before I went to the provincial hospital. Sometimes she went by bus or motorcycle. Normally this note covers two months...Once the doctor provided a referral note that covered only one month. I did not read the note before going to the provincial hospital. So I had to pay for the cost of the drugs. (Reingjai, interview 2)

Participants also sought support to ensure regular access to health care. One participant said:

I dared not to go to a hospital alone. I live far from the hospital and take a long time for traveling to the hospital by public transport. I worried that I would have abnormal symptoms such as dizziness. Therefore, my sister usually goes [to the hospital] with me. (Laddawan, interview 2)

Participants managed and adjusted their life in order to access health care services. For example, as they lived far from health care settings, they moved to live closer to the hospitals.

After the heart operation, I moved to live at my birth village because the follow-up appointments during the first month [after the operation] were every week. (Bhunchorn, Interview 2)

Access to health care services required the participants to have a strong determination to manage difficulties caused by health care services. People with chronic illness prepared themselves to be ready for the help from health professionals as their aim was to achieve better health by using the necessary support.

Access difficulties

A number of difficulties were experienced by people with VHD in relation to access to health, Isari said that there were extra expenses for the travelling costs for her son to accompany her when going to a distant health care setting.

I went to the follow-up at the heart centre hospital after having valvular replacement six months earlier. It was hard for me to travel alone. My son had to go with me. I spent a lot of money at each follow up. (Isari, interview 1)

Participants' stories indicated that getting health care led to difficulty in balancing the family budget. Participants who had to spend more money than the family income to access health care had to borrow money from other people.

Sometimes, I borrowed money from a neighbor or my cousins around 100-200 bahts [4-8 NZ\$] for the cost of travelling to the follow-up...I tried to go to the hospital every appointment. (Nuchchanad, interview 1)

Participants experienced difficulties caused by travelling to health care settings. They had difficulties according to the travel cost.

I went to the follow-up at the tertiary hospital for one year after my operation. At first the appointment was every month and then it changed to every three months for a blood test. The doctor asked if “it is easy or not for you to get care and treatment at this hospital.” My husband told him that it is not easy because we have limited money but have to spend a lot of money. The expense was more than one thousand bahts [40NZ\$] per follow-up. (Thongsay, interview 1)

The cause of travelling costs related to a lack of regular public transport in rural areas. One said:

The lack of public transport makes me angry. It is a problem going for follow-ups. This creates a greater burden for me. I have to pay more to hire a car. The cost of hiring a car is high. (Chomphunuch, interview 1)

The cost of travelling led to difficulties of budget management. Some managed this problem by borrowing money to overcome the money problem in order to access health care services.

Sometimes I have to borrow about 100-200 bahts [4-8 NZ\$] from a neighbor or from my cousins for travelling to follow-up for care and treatment. Sometimes I feel embarrassed, sometimes I feel nothing. I tried to get to the hospital for every appointment but sometimes I did not have money on the day of appointment. Therefore I could not go to the hospital. However I tried to go the following week and never left it longer than one month because I know that a regular follow up is important to prolong life. I will survive and live longer with my children. (Nuchchanad, interview 1)

Participants experienced constraints when interacting with health care services. This difficulty was revealed in the participants' life-stories. The participants' life-stories

reflected that some had experienced difficulties when they interacted with health professionals, for example, being hurried, feeling distressed and uncomfortable.

My life depends on the hospital. Half of my life is spent in the hospital. I was annoyed and did not want to go to the hospital. I was tired and had dizziness from travelling by public transport. Sometimes I got services from health care providers who made me more annoyed because they used bad words to talk to me. (Pitsuda, interview 2)

I hurried all the time when I was at the out-patient department in the hospital. I hurried to get through the steps of the health care service. I had to measure my blood pressure and, at the same time, blood was taken for a blood test. [These services are at different counters and clients have to wait in queue until their name is called.] This made me frustrated. If the blood was not taken on time to send to the laboratory there would be a delay in getting care and treatment. It takes time to get results for the doctor. The doctor uses the results for investigation. I felt that I had to hurry all the time when I went to follow up. (Somsongsang, interview 2)

It took a very long time to get a blood test, this caused too long a delay for care and treatment. I left home at 7 o'clock and the follow up processes finished at noon or 1 o'clock in the afternoon. These made me tired. It would be better to reduce the time for the blood test. It was only 10 minutes at the hospital in Bangkok but at the provincial hospital, the test took one hour. (Wanchai, interview 1)

However, participants were determined to get regular health care services.

*I relaxed after I went to hospital for the follow-up because I got drugs and completed the appointment. I always worry that I might forget the day of the follow-up. I worried about being *ต่อว่า* -Tho-Wa (criticized) by health care providers for missing the follow-up. It felt good that I did not have to worry any more about what day it is because of the follow up. (Thumphitak, interview 2)*

Participants prepared and managed themselves to comply with the flow of health care services. On the follow-up day, one participant said she adjusted daily activities.

On the appointment day, I always get up in early and prepare food before going to the hospital...After blood is taken [for the test], I have breakfast. I do not have breakfast before the blood taking. (Sunisa, interview 1)

Another participant said the need to access the services, sometimes meant meals were missed.

[On some follow-up days] I was hungry and thirsty because I dared not to go out of the waiting area. I worried I would miss if เจ้าน้ำที่ -Jao-Nha-Tee (Government health care worker) called me to get the services. (Thumphitak, interview 2)

Participants' stories revealed inconvenient health care services led them to feeling uncomfortable. For example:

It was not convenient and it was not easy going when I went to the hospital. I felt irritation and crabby. (Chidchanok, interview 2)

One participant said spending a long time waiting for health care services led her to have more distress.

During the follow-ups, I felt tired from a long time of waiting and because my health was not good, I felt more tired and irritated. (Neunchawee, interview 2)

Some participants coped with difficulties caused by health care services by trying to accept and deal with any inconvenience caused by health care provision. The excerpts revealed that the participants accepted entirely any inconvenience caused by health care services. Some participants also tried to give reasons for the inconvenience and tried to be docile with health care services, for example being ทำใจ- Thum-Jai (make mind to accept because it is impossible to avoid).

It was not convenient and it was not easy going when I went to the hospital. I felt irritation and was crabby because there were a lot of clients. I had to realize that I could not set the time when I could go back home. I could not plan to get drugs at 11am and go home after that. It was never as I planned. So I felt irritated. I have always gone to the follow-up because I care about my health. (Chidchanok, interview 2)

I had to be patient when I went for the follow-up appointments at an out-patient department. There were a lot of people at the department. Sometimes I went back home at nearly 2 o'clock in the afternoon. I accepted that it is normal because clients came from every part of the province, the services are not arranged for me only. (Ardoong, interview 1)

On the appointment day I woke up in the early morning and packed food before going to hospital. Blood was taken and I had breakfast after that [around 8.00-9.00am]. I waited for the results of the blood test. After I got the results [around 10.30-11.00 am], I went to the doctor's room. After that I got drugs [around 11.30-12.00 am] and went back home. I reached home around 2-3 o'clock in the afternoon. That was a long time waiting for services. I had to realize- Thum-Jai (make mind to accept) to accept because there are a lot of clients. I did not have a hard time only sat and waited. (Sunisa, interview 1)

There were a high number of challenges caused by inconvenient access to health care services and participants tried to manage to reduce and overcome the obstacles. This effort indicates that participants had a high control of their self-management of illness due to their strong determination and acceptance that health care is a key of managing life with chronic conditions.

Accepting life with loss

Loss as a result of access to health care services was experienced by rural people with chronic illness. Participants said that accessing health care led them to face several losses and talked about the loss of property and productivity.

At that time I had been going for follow-ups at the tertiary hospital for more than a year. I had to travel a long way to a distant hospital. The cost of traveling was high and I had to pay for meals outside the home. I had to sell the rice farm, it was 4-5 rais. (Bhunchorn, interview 1)

He went on:

I spent around 10,000 bahts [400 NZ\$] by selling 4 cows when I underwent the heart operation. (Bhunchorn, interview 1)

The cost of drugs was high which has caused me to be poor. The cost of going to the tertiary hospital was more than 1,000 bahts [40NZ\$] per trip. I had to borrow money to travel to the hospital. This made me poorer and poorer. (Chomphunuch, interview 1)

Some participants told stories of productivity loss due to not being able to work.

The operation had to be postponed after I got อัมพาต -Am-Ma-Bhat (paralysis). I had waited for nearly two years for that balloon valve dilatation to be done. I had some improvement but because of left side weakness, I still had fewer activities....I could not work for wages. I only helped my parents on their farm. (Wanchai, interview 1)

I thought that I had some improvement because I was not fatigued and did not have syncope. The heart beat is normal without a heavy heart beat. The heart has got better but I have got numbness of hands and feet and dizziness in the afternoon. In general I think that my health has not had significant improvement. I can ride a bicycle but I dare not to go too far from my home. I am always reminded of the syncope in the past. So I try to avoid that. The doctor ordered a lot of rest. I don't go to work on the farm any more. I just stay at home. I only eat and lie down like this every day. (Ardoong, interview 1)

Participants prepared to accept the loss due to their determination to access health care services. Some participants said that they faced limitations to working as they wanted. These participants could not manage their lives with VHD in productive ways, for example, they had to accept low paid work to comply with health care and illness management.

I cannot go to work in Bangkok because the follow-up appointments are every 1-2 months. The cost of travelling back from Bangkok to see the doctor at the provincial hospital is high. I cannot work in Bangkok any longer. Nowadays I am working in my village. My income has decreased from 5,000-10,000 bahts [200-400 NZ\$] per month to 2,000-3,000 bahts [80-120 NZ\$] per month. This is below the family budget. Family expenses have increased. My children are studying at a higher level which leads to higher family costs. (Bhunchorn, interview 1)

Illness management was viewed as the contributing factor that deterred some participants from seeking a normal working life. At one stage, because of the high need for intensive illness management, one participant said he had to move to be closer to a health care setting and had to quit work.

After the operation I moved to my birth village in A province because the appointment was weekly in the first month. After that I moved back to my home village. One year later I went to the same hospital every month for the follow-up. For nearly two years after the operation I did not work because I had to go for the follow-up very often. Therefore, I could not work. I was also worried that the operation scar may separate because the scar was very big. It covered nearly my entire chest area from top to bottom. [It left a lot of scar tissue.] Other people also did not want me to work with them. They were worried that I could not work. They may have thought that I would have health problems while I was working with them. I also wanted to keep myself from harm. Two years after the operation I started working again. (Bhunchorn, interview 1)

Udomluk's story also illustrated how illness management caused restrictions to her job.

I have had regular follow-ups every month to check the anti-coagulant level and get drugs. If my health status improved, I could go to Bangkok and work selling fresh sugar cane juice. I could ask the doctor to extend the appointment interval from every month to every 2-3 months. If this was impossible, I would go back to follow-up every month even though it is a long way to travel from Bangkok to the hospital. The follow-up is important for good care and treatment for heart disease. (Udomluk, interview 2)

Some lost businesses to access health care services.

The cost of an operation at a private hospital was 300,000 bahts [12,000 NZ\$]. My family members agreed to pay for this. We sold two farms because of this expense. I did not want to sell. I wanted to keep the farms for my children. I thought that I would not be cured because at that time I had severe symptoms. I thought that I would live only a short time after the operation. My mother and my husband wanted me to undergo the operation. Therefore they sold the farms to get money for the operation. (Somsongsang, interview 1)

Participant life stories revealed that rural people who live a distance from health care services put a lot of effort into ensuring access to health care services. It can be concluded that in rural Thailand, health care provision for people with chronic illness is not well established. This conclusion is based on the participant stories which showed the need for strong autonomy to manage access to the help and support required to live a normal life and have well-being with chronic illness.

Conclusion

Autonomy and assertiveness are necessary for living with chronic illness in rural areas as a number of challenges can influence decision making about health management. The challenge of access to health care means people with chronic illness need to be assertive to access suitable and health care services. Participant stories revealed rural Thai people have a choice of health care and decision making about health is influenced by social and cultural values and beliefs. The stories showed how they overcome difficulties to balance and manage life with chronic illness, integrating VHD with their lives with family in rural and remote areas.

CHAPTER 6

THE EFFORT OF LEARNING FOR LIFE WITH VHD

Introduction

Participants put a lot of effort of seeking significant information about disease and illness management as their awareness was challenged by having a disease of the heart that they perceived as the most important organ. Participants used a range of strategies to gain enough information to ensure management of life with VHD. They knew that health professionals could provide appropriate and reliable information for understanding about their conditions and ways of illness management. Unfortunately, communication challenges with health professionals led the participants to try to clarify and understand information in their own way rather than challenging health professionals to provide clear and understandable information. Their hesitation to raise concerns was influenced by wanting to be thoughtful and to avoid annoying other clients and care providers as a usual part of Thai culture. Participants also considered lay persons as optional sources to learn about life with chronic illness, they valued others direct experiences and the tales that shared by lay persons as a alternative source of useful and reliable health care information.

Knowledge Seeking

Understanding of health conditions and knowing suitable and appropriate ways to manage illness is necessary for life with chronic illness. Therefore, seeking information is a key activity for living with long-term illness. Participants in this study were aware of the importance of reliable health care information as can be seen through their life-stories. Learning about disease was a significant aspect of life with VHD.

The heart and survival

The participants suggested that the heart is vital for surviving and that learning opportunities were important to live with the disease. Participants' stories revealed their awareness of the importance of gaining information for understanding about their condition and making decisions about illness management.

I went to many clinics and hospitals to confirm the diagnosis. I wanted to make sure [that I have heart disease]...It was also ensured better opportunity to get information which can be used to support the decision for choosing care and treatment. (Bhenpapa, interview 2)

Participants' stories revealed awareness that the heart is the most important organ which was a driver for knowing about the disease. For example Bhenpapha (interview 1) said that:

The heart is the most important organ. I wanted to know about the disease clearly.

Chidchanok (interview 1) reflected on the importance of the heart as it is central to the life.

The heart is important. If I have heart disease, I would have no long life and would die soon. If the heart stops working, I will die.

Because the heart is important for surviving, some participants said that it was necessary to clearly understand about the disease. Therefore, opportunities to learn about VHD are essential for living with the disease. Bhenpapa (interview 2) asserted that it was important to learn about the disease.

Sometimes, I was not clear and had doubt about the illness... It is important to know about the illness. I wanted to know exactly about this.... I asked หมอ –Moh (doctor) to describe it until I understand about it.

Participants were conscious of the importance of learning opportunities and they realised that meeting with health professionals could increase learning possibilities. Bhenpapa said that meeting with a specific care provider increased the opportunity for learning and was viewed as necessary in order to access useful information.

I wanted to get care from the same doctor at every appointment because หมอ – Moh (doctor) is familiar with my illness. หมอ knew the whole of my illness and had mutual understanding. They would provide prompt and continuous treatment. The different doctors had to take time to review the illness history before they could deliver care and treatment. I wanted to meet with a specific หมอ but I did not meet with the same doctor.... At one appointment, my illness was worse and I asked a nurse to meet with หมอ P. I met with หมอ P who I have met and known. However, I did not have the chance to express all of my concerns because he hurried....The doctors have to hurry to be on timeI do not have confidence about my illness....I save money to go to a private clinic where I can talk about all of my concernsThis is a reason for going to a private clinic. The doctors at the clinic provided enough time because they earned income from this. I am willing to pay because I have a chance to say what I want.... [At hospital] I have to stop talking without finishing what I want to speak about the symptoms. I do not talk about all of those concerns. (Bhenpapha, interview 2)

However, not all participants wanted to know about their condition, despite its importance, it is difficult to accept heart problems. As Chidchanok (interview 1) said:

I had a tired and an abnormal heart beat after working around 5-6 months. I did not want to know that I have got heart disease. I was afraid that หมอ –Moh (doctor) will tell that I have got heart disease.

Being diagnosed as having heart disease provided an incentive for people to put an effort into learning about their conditions. Participants were prepared to learn and value knowledge about their condition and about illness management. The information was significant to justify and evaluate about care and treatment choices.

Health professionals as a reliable resource of information

Health professionals were perceived as resources of understanding about health and disease. Participants' accounts also revealed that the participants viewed health professionals as information resources. Consequently, meeting with health professionals

was identified as essential to learn about suitable and reliable health and disease information. The participants' life-stories revealed that access to information was mainly through meeting health professionals. Athiphod's life-story reflected that meeting with health care professionals provided learning opportunities about the disease.

At the period when I had a severe cough, I thought that I may have heart disease ... So, I went to a private clinic to ask about this. ໗໓໐-Moh (doctor) at the clinic that provided that heart disease treatment for my mother. (Athiphod, interview 1)

Bhunchorn said that health professionals know the most about health. He always followed what the health professionals said even if he did not have clear understanding about the reasons for the treatment because information from different health professionals was often contradictory. He accepted all the treatments that were provided.

I took drugs for treating tuberculosis with doubt about the diagnosis because I did not have knowledge [about the disease]. ໗໓໐ –Moh (doctor) at a private clinic told me that I had got heart disease, but at a district hospital ໗໓໐ said that I had got tuberculosis. I believe ໗໓໐ at the hospital, there were many health care providers who did investigations. ໗໓໐ at the hospital also learned and had knowledge [about health]. I had to believe what they said because I did not have knowledge about this [the disease]. (Bhunchorn, interview 2)

Ardoong, another participant commented that because the information was provided by health professionals it was perceived as the most reliable information about illness management. He totally trusted and believed the information about his illness conditions. This information led him to face deterioration of disease because of delaying access to treatment.

I was taken to a private clinic because I was unconscious and perspiring. ໗໓໐ – Moh (doctor) said that I got mild symptom of heart disease. I didn't go to the clinic again for the follow-ups for one year again because I thought that it was a curable disease. After I had syncope six times, I sought help again. If I had

known the disease has to be treated, I would follow up regularly but หมอ did not tell me anything [about regular treatment]. (Ardoong, interview 1)

Health professionals are an importance resource of information about health, disease, and illness management. Clients who can access health professionals are likely to have better learning opportunities for managing life with chronic illness. However, people who have less opportunity to access health professionals, for example, living a great distance from health care settings such as in rural and remote areas, have limited learning opportunities. In this study, limited leaning opportunities from health professionals was evident, some participants did not have a clear understanding about their conditions which led them to experience difficulties in decision making about the illness management.

Lay person as an information resource

Participants tried to maximise opportunities of learning to live with VHD by valuing information from lay people and seeking information from them.

I was in fear of dying from the operation during the period of waiting before the operation. หมอ-Moh (nurse) who knew this fear, asked me to go to see post operation patients. My fear disappeared because I asked about what they felt after the operation. They said that they felt a lot better. (Witchaya, interview 1)

Direct experience is important and can help people to have less fear about their conditions. One participant said:

I had palpitations and sought health care at the hospital. X-rays were done and หัวใจโต-Hua-Jai-To (Cardiomegaly) was diagnosed. I was frightened because I never heard about this. I was in fear that it was an incurable disease similar to ตับโต-Tub-To (Enlarged liver). Another patient sat near me and heard about my fear as I was talking with my daughter, he said “do not worry, หัวใจโต does not a cause dying the same as ตับโต. I also have หัวใจโต. Nowadays, I have a good health by taking medication. (Jintana, interview 1)

Information from people who were close to participants was powerful and impacted on the participants' perception about care and treatment.

My friends told me that the heart operation can lead me to die soon...this caused me have more fear of the heart operation. (Soybhet, interview 1)

Direct experience was valued as a significant source of information. Listening to people telling their own experiences about access to health care convinced participants to make decisions about illness management such as that the heart operation can endanger life.

While I was waiting to meet the doctor at the heart clinic, I talked with other patients. Many of them who underwent the heart operation said "it is equal to dying when undergoing the operation." I had less confidence and was not sure about the deciding to undergo operation. (Thumphitak, interview 1)

Listening to positive experiences about taking medication convinced some participants to refuse the heart operation. One said:

I had a chance to talk with people who get care and treatment at provincial hospitals. One of them said that she was advised to undergo the heart operation but she refused because she was old. She chooses to take medication and it was 8 years already. She had a normal life without health problems. Another patient said that he took medication for 9 years and still be survives. Therefore, I refused the operation and choose to take medication. (Chaichana, interview 1)

The risk of dying caused by heart operation was confirmed by the experience of other clients and was important information effecting perception and also decision making about the treatment outcomes.

One of my neighbors who underwent the operation for valve replacement passed away just two months after the operation. This [event] led me to have more fear of the operation. (Soybhet, interview 1)

I knew many people with โรคลิ้นหัวใจ-Rok-Lin-Hua-Jai (VHD). One was my wife's cousins. She was young, aged around 30 years old and had undergone the heart operation for valve replacement. After the operation, she was healthy, however, six months after the operation she passed away while she was sleeping. Another man was also healthy and again, he passed away six months after the operation. I do not want to undergo the operation. I ปล่อย-Pong (let it go), everything depends on บุญกรรม-Boon-Krum (Karma). (Chaichana, interview 1)

One participant said the experience of her friend changed her decision.

At first, I decided to undergo the heart operation. The death of my friend from the operation changed my mind. (Pitsuda, interview 1)

Tales of life with VHD was a significance source of information and stories were shared with the aim of better understanding about life with chronic illness and ways to manage life with chronic conditions. Participants' stories revealed the tales which were shared as information resources.

Participants learned from the tales of the risk of heart operation.

I heard [the stories about] that some patients never gained consciousness again after the heart operation. (Chidchanok, interview 1)

Participants relied on the tales of heart operations and used it to support their decision about the choice of treatment.

My neighbor told [a story about] how they heard that some people [who underwent the operation] had to have the operation again to renew the valve after the first operation. I don't want to have pain from the operation and I would take only medication. (Chidchanok, interview 1)

My cousin told (a story) that of ten people who underwent the heart operation, none of them survived. Moreover, my neighbor told a similar story that of the

three to four people who underwent the operation, nobody survived. I was afraid (to die from the operation like them). I would not undergo the heart operation.

(Ardoong, interview 1)

Stories about disease and illness were a significant resource for people with chronic condition living in rural Thailand. Participants' stories revealed sharing stories was wide spread among participants. The stories were powerful and influenced participants to make important decisions about their conditions and illness management. Through the participants' life-stories, it appears that lay information is considered as reliable information resource for rural Thai people to use for supporting the decision about illness management.

Learning Opportunities

Communication is a means to share information and increase learning opportunities. Mutual communication requires people to focus on the needs of both the teller and listener which means that careful listening is an important skill to develop. In order to achieve the aim of communication to meet the concerns of clients, it is important for health professionals that during communication there is opportunity for clients to raise their concerns, enough time and communication using understandable language is available. Participant' stories revealed experiences of communication challenges which can decrease peoples with VHD learning opportunities.

Challenges in raising personal concerns

Although the participants were aware that learning opportunities were increased by meeting with health care professionals, these meetings did not always increase learning opportunities because the participants still did not have the assertiveness required to discuss their needs. Participants saw care providers as in 'higher' positions and as having 'higher' knowledge than themselves. This is a widely accepted view among Thai people. In Thai culture, people with the privilege of raising questions are the persons of higher status, for example, in a family, parents can question their children. If people of lower status question, this would lead to relationship problems. Phloydang said that

Sometimes, I had questions but I dared not to ask หมอ –Moh (health professionals). I just listened what หมอ said. I kept listening although I could not understand. I was shy and worried about annoying them. They may wonder why I ask. I was fearful that if they asked back, I would not have [proper] answers. I always keep my doubts to myself and never ask หมอ. I just ask other clients about the doubt ...I do not ask หมอ because they are far from me. I am just an ordinary person. If I ask, it is similar to be คือกักคือแน่นแท้ - Keou-Kuk-Keou-Nhae-Thae (behaving on the ways that so assertive as people who have expertise, privilege, or high status). (Phloydang, interview 2)

Sadudee's story reflected the feeling of being inferior when she interacted with health professionals. This feeling led her to be passive in communication. It was rare for the participants to raise their concerns.

I was อึดอัดใจ -Uod-Ud-Jai (feeling uneasy going) when I was meeting with หมอ – Moh (doctor). I was fearful what they may ask me. I did not have knowledge to answer the questions. I was ลำบากใจ -Lum-Bak-Jai (feeling frustrated and stressful) during talking with หมอ. I was อึดอัด -Uod-Ud (feeling under pressure) when they asked me. I did not ask หมอ because I am poor. I do not have money. Care and treatment depend on what they would like to give to me. (Sadudee, interview 2)

In Thai culture, people usually think and are concerned about others first, this is widely accepted as it can ensure that they are sympathetic toward others which is important for Thai social living. The participants' stories also revealed that the nature of Thai people who usually เห็นใจ - Hen-Jai (sympathetic) towards each other was a contributing factor in reducing possibilities to raise their concerns. Phrom said he had sympathy toward other clients which made him hesitate to raise any concerns.

Sometimes, I had questions to ask but I sympathised with other clients who had to wait for care and treatment. Almost all clients complain about a long time to wait. So, I let it go. (Phrom, interview 2)

เกรงใจ - Keing-Jai (behaving way that avoids annoying others) is another concern of some participants that deterred them from asking for information.

During follow up at each appointment, I did not have a chance to ask the doctors. There were a lot of clients at the out-patient department. I thought that I would ask about how to do daily living. I dared not ask because I was worried that this may make other clients wait longerThere are 4-5 clients in the doctor's room. If I take too long to ask questions, other clients may feel annoyed. I have to เกรงใจ. (Sunisa, interview 2)

เกรงใจ is a norm in Thai culture. A lack of this manner is unacceptable and also leads others to have negative feelings such as หงุดหงิด - Ngud-Ngid (feeling irritated and annoyed) to people who are considered lacking in ความเกรงใจ – Kuam-Keing-Jai (being thoughtful).

Sometimes, I did not ask the doctor about my doubts because there were a lot of clients waiting for follow up ...There are 4-5 clients in the same room while one client gets service from the doctor. There is no privacy. It is not like the time I went to the tertiary hospital. I went into doctor's room one by one. If I have a question, I ask. At a provincial hospital, I worried that if I ask, other clients may feel หงุดหงิด. So I did not ask. (Athiphod, interview 2)

Not only other clients were put first, some participants also เกรงใจ to health professionals and put their needs for information to the side during meetings at each follow up.

At hospital I dared not to ask หมอ –Moh (doctor) anything because there are a lot of clients ...เพื่อน –Pein (pronoun for people with higher status than the speakers) looks busy. I worried that หมอ –Moh (doctor) may have to hurry to get on with his/her duties. (Somsongsang, interview 2)

At each follow- up, I did not have a chance to ask the doctor about my concerns. หมอ –Moh (doctor) looked in a hurry, I noticed by the high speed talking. I think

it may be caused by a lot of clients waiting for check upsThere were many clients in the investigation room. Four clients sit together in a check up room. The patients go to get service from the doctor one by one. I never asked any questions during the follow- up with the doctor. (Usawadee, interview 2)

Cultural barriers including hesitating to raise concerns by being thoughtful reduced learning opportunities to gain a clear understanding about their conditions and resulted in inadequate information to use for health management. These are the important barriers of people with this disease to the access of suitable and appropriate information from health professionals who are the reliable source of health information.

Challenges to learning created by health care delivery

Ways of health care delivery relate with participants' learning opportunities, however, because of high workloads, there was limited time for participants to learn from health professionals. Participants perceived that the limited time during visits to the doctor was an obstacle to communication and asking for clear information. The participants concluded the cause of the time limitation was the high number of clients being treated.

Sometimes I did not have a chance to ask anything because the doctors did not have time for me... เฒ่า –Pein (pronoun for people with higher status than the speakers) was rushing the patients through.... Sometimes, เฒ่า gave a prescription document to me and waved his hand toward to door.... I think, this means เฒ่า was asking me to go out of the doctor's room. It is right. What do you think? Please tell me. เฒ่า pushed the record file toward me and pointed his hand. It means that เฒ่า was asking me to go out of the doctor's room. (Bhenpapha, interview 2)

As time is the key to increase communication possibilities, some participants choose to gain more control over the time by selecting private health care options where enough time for communication was provided. They perceived this as the best opportunity to gain an understanding about their health and illness.

I went to a private clinic at first when I got the illness.... I had plenty of time to ask a doctor at the clinic, I asked until I got clear information. (Somsongsang, interview 2)

I had a cough and went to the district hospital, where anti-cough medicine was prescribed for one month. I had no improvement. I went to a private clinic where I knew the doctor. This doctor treated my mother. My mother also got heart disease. At the clinic, EKG and x-rays were done and หัวใจโต -Hua-Jai-To (cardiomegaly) was diagnosed. หมอ -Moh (doctor) at the clinic had time to tell me about the diagnosis. (Athiphod, interview1)

I saved money to go to a private clinic. I wanted to have enough time to ask หมอ -Moh (doctor) questions until I got clear information which enables me to have better understanding about my disease. (Bhenpapha, interview 2)

These quotations illustrate the difficulty associated with accessing information and how time was important to learn information about health and disease. Participants realised the importance of learning from health care providers and they also knew that they could not ‘control’ the free services which are provided by government hospitals. Thereby it was necessary to seek out other options which helped them to have enough time to communicate with care providers.

Participants’ life-stories revealed that meeting with different doctors at each follow-up also led to limited opportunities for learning about living with VHD. The opportunity for participants to gain more information was limited due to being hesitant to start conversations when meeting with different care providers and increased the difficulty of asking for information. Aphichad said that meeting with different medical providers at each appointment decreased the opportunity to get information about health care.

I think that going to see a specific doctor at each appointment is good because it would be much easier to have a conversation. Nowadays, I do not know who I will meet at each appointment. Therefore I do not know how to have a conversation with the doctors. (Aphichad, interview 2)

Chidchanok talked how meeting with a specific medical provider when going to the hospitals for the follow-ups was not always available.

I never met the same doctor twice at each appointment at the hospital. This meeting depended on the arrangement of เจ้าหน้าที่ -Jao-Nha-Thee (government health care worker). It was not similar to going to a private clinic. I met with the same doctor every time. (Chidchanok, interview 2)

Because of the limitation of health care resources and the high number of clients, health care services are insufficient to meet the level of demand. The participants are placed in a queue to meet with available health care providers instead of a specific one. The participants experienced a limited chance to meet with a specific doctor in the hospitals.

At the hospital, I have no chance to meet with the same doctor. It is impossible because there are a lot of doctors, a lot of examination rooms, and a lot of clients. I have to go to any room that is set for me. (Chidchanok, interview, 2)

The participants' life-stories reflected that meeting with different health care providers decreased learning opportunities. At each appointment, the time was used by health professionals to learn about the participants' illness stories all over again.

I went to my follow-ups and met with different doctors at each appointment. This was like going back to the beginning point every time. I had to talk about the illness story each time to let each doctor to know about my illness. (Phrom, interview 2)

I have met with several doctors and never met with the same doctor twice at each appointment. I had to tell my illness history again and again to each doctor. I spent most of the time answering the same questions which were asked by different doctors. (Ardoong, interview 2)

The participants reflected that opportunities to gain better understanding about their conditions and about living with the disease was limited by the time which was used by health professionals, for example physicians, to learn about the participants' illness stories. At each appointment, participants met with different physicians who had limited knowledge about the participants' illness history. The learning opportunities were lost in the depersonalized health care services. The participants also insisted that meeting with a specific health professional, such as meeting with a specific physician, should increase the possibility of understanding about the disease.

The same doctor would not inquire again about my illness history because หมอ – Moh (doctor) had this information already. หมอ would look at other parts of the illness ...หมอ would know overall about my illness. It would not just only be going on and on telling the same story of my illness. I have no chance to tell other things, I only tell about the same thing. หมอ –Moh (doctor) would have time to tell me about my illness. (Phrom, interview 2)

Meeting with the same doctors would be better than meeting with different doctors. หมอ –Moh (doctor) may remember about the illness history. They will have time to do more physical exams. They also will provide more health and illness information. (Reingjai, interview 2)

Athiphod and Phoydang had experiences of both individualised and deindividualised care. They suggested that meeting with specific medical providers provided better opportunities to learn about living with the disease.

Nowadays, I have met with different doctors at each follow- up. I wanted to meet with the same doctor because หมอ –Moh (doctor) knew about my illness already. The different doctors only asked about symptoms. This was different from when I went to my follow up at the tertiary hospital after the early period of the operation when I met with the same doctor. He gave me information and more details about my illness. He told me when the new valve would be replaced. Meeting with different doctors at each appointment is like just going to the

hospital to get drugs without a chance to gain more knowledge about my illness.
(Athiphod, interview 2)

I met with different doctors when I had follow-ups at a provincial hospital but I met with the same doctor at a tertiary hospital. I wanted to meet with a specific doctor because หมอ –Moh (doctor) knew about my illness. The different doctors did not know and had to ask me again. The same doctor did not ask because he knew already. A specific doctor remembered about the progress of my illness. I thought the doctor will also tell me about the progress of my illness. Therefore, I will have more information about the illness. (Phloydang, interview 2)

Health care provision with a focus on individualised concerns such as a demand for privacy was limited. The need for privacy was much more important for some participants who wanted to raise concerns about sensitive issues. Limited opportunities to communicate confidentially with care providers led to limited opportunities to access useful information. The participants' narratives revealed that the health care settings did not provide enough private space for each individual. Because of limited privacy, they just kept quiet about their sensitive concerns such as the impact of sexual activity. The participants said that some topics were very personal and they needed privacy if they were to get information, for example:

I am not a perfect wife. I cannot do all of what people who are married do. I cannot work to earn income. I leave my husband to earn income alone. I have got this diseaseI have a problem when I sleep with my husbandI worry that I may die by this activity. I am fearful of dying. I have to talk about this with him. He has understood about this. (Pitsuda, interview1)

Pitsuda went on:

I had shortness of breath during sexual activity. I thought that I will tell the problem to the doctor. I wanted to get advice about this. I did not ask the doctor about this. I did not have this activity very often. It is a long time since I have

one. I knew my limitation. I was too shy to talk about this. I dare not ask.
(Pitsuda, interview 2)

Although I had questions about sexual relationships, I never asked the doctor. At each follow up, I just told about the symptoms or other abnormal things. The doctor ordered the drugs and made the next appointment. I did not have the chance to ask about this. (Bhenpapha, interview 2)

Crowding of clients at health care settings means health professionals face a high workload and limited time for communication with their clients. The time is likely to be used to support key services with the orientation on disease such as illness investigation and treatment prescription. The time is not sufficient to communicate in depth about client' needs such as ways to manage to live with the illness which fit with their social circumstances and can support people with chronic illness to live a normal life.

Challenges of communication with health professionals

The training of Thai health care providers is based on the western medical model. Medical terms are commonly used among care providers. Communication with each other is in this specific language and almost all medical terms are English. In Thailand, English is not an everyday language and Thai people do not communicate in English. However, during the interaction with health care personnel who are familiar with medical terminology, care providers may forget to make the words understandable for the clients. This medical language functions as a 'gate keeper' to health care information because it is unfamiliar to the participants. The language of medical practice is a barrier to participants asking questions about the illness. The following narratives reveal that the participants experienced ongoing difficulty and have expressed that medical language limits opportunities to learn about health and illness. The participants told stories reflecting their perspective and the effects of their response to unfamiliar words.

หมอ –Moh (nurse) provided a chance to ask a question. I did not know how to raise a question. They used ภาษาหมอ- Pha-Sa-Moh (medical language). I did not

understand and did not know what they said. I did not know what to ask. (Phrom, interview 2)

I could not understand what หมอ-Moh (doctor) was talking about in the examination. หมอ used medical language for communication...I did not know the meaning of it. (Wason, interview 1)

Participants indicated that they could not have a clear understanding about their conditions because health professionals were using medical language which was not understandable for them. One said:

Last year an echocardiogram was done to check my heart disease. This special examination is delivered once a year at the provincial hospital by staff from the tertiary hospital. During the examination, I could not understand what they were talking about, they used medical language in communication. I could remember only “forty by sixty” and did not know the meaning of it. The doctor who did the examination asked me “would you like to undergo an operation or not?” I did not want to undergo surgery because I thought that I was normal. I could work as usual. หมอ –Moh (doctor) said that if you would like to, go to see them at anytime. (Wason, interview 1)

Participants perceived that a lack of clear understanding about illness management led to a lack of access to continuing health care services.

I knew that I got heart disease when I was pregnant. I sought help for prenatal care at a private clinic. หมอ –Moh (doctor) did a physical exam and found an abnormal heart beat. I was referred to the hospital. Many urgent investigations were done. The doctor said that “this is a life-threatening disease and you have severe symptoms”. I did not know what was going on because I could not understand what they were talking about. They were talking in English. I knew only that this was a threat ... the disease was dangerous to my life. The doctor said “You have to undergo valve dilatation urgently.” I was sent to undergo ถ่างลิ้นหัวใจ –Thang-Lin-Hua-Jai (valvular dilatation). I did not know about this

process clearly. After that I did not take any drugs. I did not get any advice about how to manage to live with the disease. After I gave birth, I never followed up to get care for the disease. Several years later, I got ฝឹ້อຍ –Mhiey (weary). I went to a hospital very often to find out about the illness. This is like going back to the starting point again. (Udomlak, interview 1)

The participants in this study reported that they perceived their voices were not heard during interaction with care providers. They indicated that they were not communicating during encounters with people in the health care services and when they tried to communicate the care providers did not allow mutual communication to develop.

I went to work in a chemical factory at R province after I finished junior high school. I did not take drugs for five months and I got a fever. I went to a private clinic in C province. I thought that it is important to let ໗໓໐ –Moh (doctor) to know that I had heart disease. I told ໗໓໐ that I had heart disease. ໗໓໐ did not listen and injected the drug to treat fever. After the injection, I got heavy a heart beat and a tight chest. I was referred for admission to the hospital. (Wanchai, interview 1)

I had abdominal discomfort and could not sleep. I went to a private clinic in the district. Gastritis was diagnosed and ໗໓໐ –Moh (doctor) said that an injection would be applied via the muscle. I told that I had heart disease and that with an anti-clotting drug, intramuscular injection is prohibited. ໗໓໐ said “I am a doctor, I learned about this. I have knowledge. Go to bed, I will inject the drug.” I had to accept that. After the injection I had a large ຈຳເລີ້ອດ –Jum-Leaud (ecchymosis) that caused leg pain. I could not walk and three hours later, I was admitted to a private hospital. During the two days of the admission, the intramuscular injection was applied again in other leg. I wonder if it may be because the health care providers did not know about this. Both legs turned purple and I did not have enough blood supply to my heart. I was getting worse. Two units of blood were transfused. (Somsongsang, interview 1)

Mutual and symmetrical communication between people with chronic illness and care providers is a means to gain knowledge about disease and illness management. Communication with balanced power can increase the possibility of learning possibilities for both clients and care providers. Sharing knowledge in a symmetrical way helps clients to gain more understanding which fosters positive health care outcomes. At the same time, care providers also have opportunities to gain a better understanding of illness responses of clients who have expertise from their direct illness experiences. This can help care providers to be sensitive to individual concerns and provide specific care and treatment which fits in with the needs and expectations of each individual. Participants had limited learning opportunities as they faced the challenge of communication with health professionals in order to gain better knowledge about their condition and illness management. They indicated that they were not communicating during encounters with health professionals. When they did try to communicate, the care providers did not allow mutual communication to develop. The challenges were likely to be caused by the gate keeper language, flow of health care service, provider-centred communication, and Thai cultural awareness. This can lead rural people with chronic illness in rural areas to have limited information to manage life with VHD.

Conclusion

Participants were aware that the heart is a vital organ, therefore they tried to seek information to gain understanding about their condition and appropriate ways of illness management. Participants were aware that health professionals are a reliable source of health, disease, and illness management knowledge however, cultural barriers to raising concerns and the flow of health care services reduced learning opportunities. Participants also valued lay information and the tales relate to health care as significant information which they used to support and help them to make decisions about their health care choices. It can be concluded by these life-stories that rural people did try and were prepared to learn about the management of their illness. They were ready to carefully listen to available health care resources to gain a better understanding about their conditions as their willingness of living with a good quality of life with chronic illness.

CHAPTER 7

THE MAXIMISATION OF RESOURCES FOR THE MANAGEMENT OF LIFE WITH VHD

Introduction

Living with long-term illness demands continuing support for managing life during disease exacerbation and remission. Hospital-based care in Thailand is appropriate and adequate to support people who can access health care settings. Participants' stories revealed access to health care settings help them to gain a better health status for a better quality of life. However, providing hospital care without expanding networks of care in the community can lead to limited effective long-term illness management especially in rural people who live some distance from hospitals. As the need of access to continuing support, people with chronic illness who live in rural areas in this study were using all health care resources including health professionals and local healers. The participants also tried to develop self-management skills based on available information in order to manage to live with chronic illness. Participants' life-stories revealed that they using information without clear understanding to make decisions about care and treatment and the management of their daily living.

Health Professional Support

The support of health professionals is necessary for the management of life with chronic illness. The support is significant particularly at the time of exacerbation of the illness. Current Thai health care is well established to provide appropriate and suitable support when people with long-term illness are hospitalised.

Hospital care

Participants thought that support from health professionals in hospital helped them to manage life with a chronic condition. The following stories represent the participants' positive feelings and attitudes toward health care workers.

I got good care from หมอ-Moh (health care worker) when I underwent the heart operation. พยาบาล-Bha-Ya-Ban (nurse) provided good care...They did similar as

they are my ลูกหลาน-Look-Lan (being children or grandchildren). (Witchaya, interview 2)

I was satisfied when I got health care services. พยาบาล –Bha-Ya-Ban (nurse) advised about the ways to look after myself such as avoiding stress. They called me in the sense of respect. It was also warm welcome [while the admission]. (Isari, interview 1)

Health care services helped to relieve participants' distress caused by disease symptoms.

After the heart operation, I had good health. In the past, I felt เหนื่อย –Nhieoy (shortness of breath) while I did daily activities such as having a shower or walking. Nowadays, I can walk and work as a builder with out เหนื่อย –Nhieoy (shortness of breath). (Bhunchorn, interview 1)

I got the improvement after the operation, I can work. I can walk without being tired. Before the operation I had to stop during walking to the rice field. The operation gave a new life for me. (Athipod, interview 1)

Access to health care services can improve the quality of life for people with chronic illness, VHD reducing the distress caused by VHD symptoms. As long as they have access to hospital care as observed through the participants' accounts, it appeared that current health care services provided a range of support for illness management in order to gain a better quality of life.

Hospital follow-up

Participants told stories of having continuing care though access to regular follow-up. Participants said they a number of benefits from meeting with health professionals such as regular monitoring of their condition and illness management adjustment.

After heart disease was diagnosed, I have got care and treatment from the hospital. The follow-ups are every 1-2 months. Blood taking, getting blood results and getting drugs are the regular services. (Sadudee, interview 1)

Participants observed that the treatment was adjusted related to their conditions. One said:

*At each follow-up, the blood test is done. If the blood result was not good, អ្នកវេជ្ជ-
Moh (doctor) would change the drug dose. (Nuchanad, interview 1)*

Meeting health professionals helped the participants to know about the illness conditions. Participants said that information about their conditions gave them confidence about living with chronic conditions.

I got benefits of knowing about the disease progress from អ្នកវេជ្ជ-Moh (doctor) at the check-up appointment. I was ស្រួលចិត្ត-Sa-Bay-Jai (mellow mind) to know what was going on about my condition. (Nuchchanad, interview 1)

Visiting អ្នកវេជ្ជ-Moh (doctor) helped me to know about the stage of disease. If I did not go to see អ្នកវេជ្ជ, I would live without knowing about my condition. (Reingjai, interview 1)

Some said health professionals made them feel confident that the services were always available.

I was satisfied and wanted to go to the hospital for the follow-ups. Going to the hospital made me feel that health professionals were close to me. If I had abnormal symptoms, I would have help at any time. (Wason, interview 1)

Participants' stories revealed that health professionals provided information which helped them managing life with chronic conditions.

Meeting with អ្នកវេជ្ជ-Moh (health worker) was good. If I had abnormal conditions, អ្នកវេជ្ជ would advise means to manage the problems. If I missed the follow-ups, I would not know how to look after myself. (Reingjai, interview 1)

At each follow-up appointment I was advised about life with VHD such as the restriction of drinking water and avoiding too big a meal. I felt good because I knew the ways to care for myself. (ReingJai, interview 2)

Participants' stories revealed that the health care services while they were at hospital were a significant support to manage distress from symptoms. They were also satisfied with current health care services as they got a number of benefits as long as they could access the hospital. However, the health care services were not always enough to help people with chronic illness who live distant from health care settings as can be observed through participants' accounts which are introduced in following concepts.

Integration of Indigenous Practice in Care

Hemolytic streptococcus group A infection is a leading cause of sore throat and some people with this infection are prone to the development of rheumatic fever which can lead to VHD when appropriate treatment to antibiotics is not accessed. Therefore, people who live distant from health care services are prone to VHD more than people who have more opportunity of access to medical care. Participants said that they integrated indigenous practice into their care when they got a sore throat.

Management of colds and sore throats

Living in rural areas distant from health care settings led some rural people to seek help from local healers to help manage their health problem. The limited specific health care services to prevent VHD led some participants to seek help from nearby traditional healers in communities. Herbs were used to treat a sore throat and a fever.

Sometimes I had a cold and sore throat when I was young. I went to see หมอยา – Moh-Ya (indigenous healer who use herb as a treatment) and herbs were used to treat a cold. It was called ยาฟัน -Ya-Phon (herbs which are crushed and diluted in water and used as drugs). I did not get other treatments. At that time only one อาน้ำย -Aa-Nha-Mai (primary health care unit) was in town. The health care setting was far from my village. It was not convenient to go. (Bhenpapha, interview 3)

When I was young, aged around 17-18 years, I had a fever, a sore throat, a cough, and pain throughout the body. At that time, the doctors were only in town and we did not have อานามัย -Aa-Nha-Mai (primary health care units) near my village. My father was a หมอยา–Moh-Ya (indigenous healer who use herb as the main form of treatment), he treated me with herbs. He used the root of the herb, ฟน-Phon (crushing thing with stone), diluted in water. I drank it. The symptoms were relieved. (Sunisa, interview 3)

I had a fever and a sore throat when I was a child. At that time we did not have อานามัย -Aa-Nha-Mai (primary health care unit) or a hospital near my home. They were only in the provinces. So I went to seek help from หมอพื้นบ้าน -Moh- Bheun-Bhan (indigenous healer) to get ยาฟน -Ya-Phon (a herb is crushed by stone and the resulting powder diluted in water by Moh-Ya) and took it for 2-3 days. The symptoms disappeared. (Thumphitak, interview 2)

Colds and sore throats are viewed as common diseases without severe consequences, this perception may also led some people with this illness seeking help or using their own management for only reducing the disease symptoms instead of accessing appropriate health care such as taking an antibiotic for preventing the consequence effects of streptococcus group A infection that can lead to valve (valves) deformities. The participants' accounts also revealed that because of difficulties of access to health professionals, they sought help from indigenous healers for the management of a cold and sore throat. Valvular heart disease is preventable by access to effective preventive management including a throat swab and an antibiotic such as penicillin (Naiggolan, 2006). Therefore, some rural people who could not access health care as a result of isolation got VHD at a later time in their life.

Management of VHD complications

Indigenous healers are a significant local health care resource for people living in rural Thailand. Rural people seek help from this alternative health care resource as well as from health professionals. Participants in this study integrated indigenous health

practices in their management of life with VHD. One participant said that she sought support from several indigenous healers.

I was tired and had palpitations. I could not eat and was vomiting. I sought help from หมอเสี้ยน -Moh-Sen (indigenous healer who uses massage as the treatment). หมอเสี้ยน told me that I had heart disease. I went to the district hospital and the doctor told me that I have got heart disease. My mother went to see หมอดู -Moh-Doo (fortune teller). หมอดู told her that my illness was caused by a ghost on the farm. My mother asked for หมอลำผีฟ้า -Moh-Lum-Phee-Pha (indigenous healer who performs a ritual dance for spiritual healing) to heal my illness. (Laddawan, interview 1)

Participants' stories revealed that the needs and expectation about care and treatment were not met.

I got medications for the heart disease. I wanted to get care and treatment for my weakness. Nowadays, I could not get this care [from the hospital]. I still walk and drag my right foot along the floor. I could not lift it off the floor. I could not put the shoe on because it made me fall. I had to walk with bare feet on the hot ground. I also could not speak clearly. (Soybhet, interview 1)

I wanted to get care and treatment for weakness. I was advised about physical therapy while I was admitted for the heart surgery, ten years ago. I did not gain new means to manage the weakness. (Wanchai, interview 2)

Participants sought help from indigenous healers as they wanted to get care and treatment to meet their need and expectation level of maximum well-being. One said:

I got advice about how to do physical rehabilitation since the initial period of weakness [8 years ago]. Nowadays there is no care or treatment for this. หมอ -Moh (doctor) never touched it. I would like to be cured from weakness by health care and treatment services and get a strong arm and leg again. I went to seek help from หมอพื้นบ้าน -Moh-Bheun-Bhan (indigenous healers). I went and got

treated by black magic power for healing but it did not work. I also took herbs and had no significant improvement. Now I have done physical exercises myself. Sometimes I could not exercise, I would love to get this care from health care providers. (Phloydang, interview 2)

Participants said that the treatment for the complications were not enough and motivated them to seek alternative health care services. They perceived that the indigenous practice helped them to gain better health. Integrating indigenous practice into the management of chronic illness can increase physiological and psychological well-being. Participants' life-stories revealed the positive impacts of access indigenous healers.

I was admitted one week because of left hemi-paralysis. Three para [paracetamol] were prescribed for care and treatment. This was all the care and treatment for the weakness. During the recovery period at home a neighbor said that หมอพระ -Moh-Pra (monk who acts as indigenous healer) in C province can treat the weakness. I went to get care and treatment which included เป่า -Pao (blowing wind from mouth), นวด -Nheud (massage), อบสมุนไพร -Oph-Sa-Moon-Phai (boiling herb and get its streaming applying to the body), ยาต้ม -Ya-Thom (boiling herb). I drank ยาต้ม -Ya-Thom (boiled herb) for one week. อบสมุนไพร -Oph-Sa-Moon-Phai (boiling herb and get its streaming applying to the body) for my arm and leg. My daughter did นวด -Nheud (massage) for me at my weak arm and leg. I was treated with these for one month. Then I could walk again. I also took drugs for heart disease from the hospital. I wanted to be cured, that is why I sought help from หมอพระ. (Thongphakay, interview 1)

I got numbness and I sought help from หมอยา -Moh-Ya (indigenous healer who uses herbs as the main form of treatment). The herbs were used for massage, and adding to drinking water. The herb roots were crushed by stone and its dust mixed into water. I drink this solution instead of water. The numbness is decreasing after taking these drugs. (Ardoong, interview 2)

Participants said that support from indigenous healers had a positive effect on their emotional well-being.

Nowadays I seek help for weakness from หมอพื้นบ้าน - Moh-Bheun-Ban (local healer). I heard that this หมอ -Moh (doctor) is good. I wanted to try because I wanted to have improvement. I wanted to be cured and walk as normal. I สบายใจขึ้น -Sa-Bay-Jai- Kheun (gain better stage of mind) after I got help. (Thongsay, interview 2)

Willingness to achieve well-being enabled some participants to seek help from alternative health care to manage life with chronic illness. One said:

I sought help for weakness from หมอพื้นบ้าน-Moh-Bheun-Ban (local healer). I heard that this หมอพื้นบ้าน was good. I wanted to try because this help me to be improved. I wanted to be cured and could walk as normal. I สบายใจขึ้น-Sa-Buy-Jai-kheun (mellow mind) when I got help. (Thongsay, interview 2)

Some participants coped with the limited health care services from health professionals nearby their homes by seeking help from alternative health care options such as private clinics, primary health care settings or indigenous healers in communities.

I had dizziness but I did not go to a provincial hospital because it was not the appointment day. I went to a private clinic near my home, medicine was injected and the symptoms relieved. I will go to the hospital only on appointment day. If I do not go on the appointment day, I may not see the same doctor. (Phloydang interview 2)

I got numbness in my leg and I told a doctor about this. A drug for numbness was prescribed and I took the drug for one month. At the next follow-up I met with a pharmacist. The pharmacist ordered me to stop that drug because this drug has an interaction with ยาละลายลิ่มเลือด -Ya-Lha-Lhay-Lhim-Lheud (anti-clotting drugs). I stopped taking it and did not know how to cope with the

numbness because I did not have a chance to meet the doctor who prescribed that drug. So I went to seek help from a private clinic and หมอยา -Moh-Ya (indigenous healer who uses herb as the main form of treatment) in the village. (Ardoong, interview 2)

Seeking spiritual care can support people with chronic illness to maintain social integrity and peace of mind. Participants' stories revealed the effected of this kind of care on the maintenance of social networks and spiritual healing.

I went to the temple regularly because I missed my friend who also goes to the temple. During religious practices, my mind is calm. Sometimes I felt as if I was free from illness and I was healthy like normal people. I had a cheerful mind and did not feel tired and fatigued. If I stay at home I think too much without direction. I have a calm mind when I go to the temple. (Phloydang, interview 1)

I go to จ้าศีล -Jum-Sil (staying in the temples and practicing religious rituals) at the temple in the village. This helps me to have a comfortable mind. I do meditation which helps to distract me from thinking only about illness. I do religious practices that lead to relaxation. During this occasion, I could accept my illness. I do not have a lot of thinking and the symptoms were relieved. Taking drugs is only for relieving symptoms but it is not for cure. (Bhenpapha, interview 1)

These accounts of integrating indigenous health practices for managing illness indicates that rural people sought a variety of ways to maintain a normal life when living with chronic conditions in rural areas. These accounts also illustrate determination of rural people to manage and maintain continuing health care services by using all available resources in the community. It can be concluded that current health care provision needs to address and expand health care services to provide continuing care that meets the needs and expectations of people in rural areas. When living distant from health care services, rural people increased health care resources by valuing and using local alternative healers to achieve better access to continuing care in order to manage to live with long-term illness.

The Puzzle of Managing Life with VHD

Understanding of disease and suitable and appropriate illness management is necessary to live with chronic illness. However, it appeared that participants had limited understanding about their conditions and illness management.

Illness, care, treatment, and management puzzles

The participants said they did not have a clear understanding of the disease as illustrated by participants who said:

The junior doctors did not tell me about my illness progress. They only prescribed drugs and arranged the next appointment. I wanted to meet with the senior doctors to get careful care and treatment and they may tell me about the disease.... I would know about progress of the disease. (Chaichana, interview 2)

I wanted to know what is going on about my illness that it is either better or worse when I go for a follow-up. I do not know about this. Every follow-up, I get medication and go home. (Thumphitak, interview 2)

Participants reported that they had limited information about their disease. They indicated that they did not know about the diagnosis, the meaning of heart disease, the progress of the illness and the prognosis. The participants said:

I do not understand about my illness, why at first the diagnosis was โรคลิ้นหัวใจ – Rok-Lin-Hua-Jai- (valvular heart disease) and at a later date the diagnosis was ลิ้นหัวใจรั่ว- Lin-Hua-Jai-Rhieu (valvular regurgitation). (Reingjai, interview 2)

I met with many doctors for care and treatment. There was different information from each of them. Some doctors told me that I could not undergo an operation. Someone told me that I have to undergo an operation. Someone said that my heart was normal. This led me to question why the information about the illness was very different. Therefore, I ignored it and I went on with my life. If I got difficulty breathing while I am working, I would ask my friends about

management of the symptoms. They also experienced tiredness when they did hard work. (Thumphitak, interview 1)

Adhering to appropriate treatment is necessary when living with chronic illness which is enabled by understanding about care and treatment. Participants' stories revealed that participants had a lack of understanding of the importance of having continuous care and treatment.

I sought help from a provincial hospital when I got ill for five years. I did not know that I got heart disease. Therefore, I stopped going to the hospital because I was still tired. I thought that the care and treatment were not appropriate. My cousin told me about the clinic which was at another province. I went to the clinic, the doctor said that I got หัวใจอ่อน-Hua-Jai-Oon (weak heart) and four medications were prescribed. I took these medications for three years until I got อัมพาต-Am-Ma-Bhat (paralysis). After that, I went back to provincial hospital, and หัวใจรั่ว-Hua-Jai-Rhieu (valvular regurgitation) was diagnosed. (Neunchawee, interview 1)

Another participant did not access health care services as a result of an unclear understanding about her conditions.

I knew that I got หัวใจโต-Hua-Jai-To (cardiomegaly) by the examination of mobile x-rays. The film showed that I had mild หัวใจโต and a doctor said that this could be an initial phase of the หัวใจโต. I did not seek help for ten years because I thought that it was normal and at that time, I could work. My health gradually got worse and I was tired. I sought help from various health care settings and finally, หัวใจตีบ-Hua-Jai-Teeb (valvular stenosis) was diagnosed. After that I did regular follow-ups. (Nuchchanad, interview 1)

Clearly understanding about the disease, care, treatment and management is necessary for supporting people with chronic conditions to manage their life with the illness. Participants' accounts showed that rural people have unclear understanding about their

conditions including disease diagnosis and illness management, however, used available information and knowledge to manage their life with chronic conditions as can be seen by the following concepts.

Lay and personal decisions about illness management

Clear understanding of the illness condition was required by people with VHD to make the decisions about care and treatment choices. Participants' stories appeared that because of unclear information provided by the health professionals led to them making decisions about illness management by their own understandings about illness management.

I feared dying, I refused to undergo an operation. I would die just the same, the operation can not change this. The doctor said that "The heart beat is normal just only has mild rapid beats but you will not be cured after the operation." I told ^{ນັ້ນ}–Moh (doctor) that I will not undergo surgery. (Thongphakay, interview 1)

Participants tried to gain more understanding by making an effort to gain understanding and supporting their illness management by seeking information from lay persons such as families and friends. Some participants based the decision about illness management which was informed by lay information.

I refused an operation at first because I worried about dying. My cousins told me that of ten people who underwent operations, nobody survived. Moreover, my neighbor told a similar story that of three to four people who underwent an operation, nobody survived. I was fearful and did not undergo an operation in the first years of treatment for heart disease. (Ardoong, interview 1)

Some participants said that they preferred to have a normal life. They asserted that they wanted to keep their social functions instead of risking loss of their role as a complication of surgery.

More than 10 years ago, valve replacement was advised. I worried that I may have more severe illness and may die. I discussed this with my mother-in-law, she said “why will you undergo an operation? You can work and can go out.” (Witchaya, interview 1)

I thought that I would undergo the operation. I went back home to consult with my siblings. They said that “after the operation, you will not have any one to help you to do housework.” My children are too young and my husband neglected me when I got heart disease [I do not have others to look after me after the operation]. This is similar to living alone. My siblings live in other villages which are far from my home. I may have a long life without an operation. I can help myself in daily living. If I had an operation wound, I would find ลำบาก -Lum-Bak (hardship). Therefore, I did not undergo the operation. I went to the follow-up and the doctor encouraged me to undergo the operation again. หมอ -Moh (doctor) said that “You will be free from being tired and will not have shortness of breath.” I consulted my cousins again and they did not agree and told me that “It will be better to die without a wound.” At that time, I had a severe illness that made them think that I will die. (Nuchchanad, interview 2)

Because of an unclear understanding about care, treatment and management of illness, even though participants were informed that the heart surgery was an effective treatment, some participants still did not access surgery and believed that undergoing the operation would be a risk to their lives. The perception about the risk of the operation was based on discussion with friends and family and influenced important decisions about VHD management. Participants identified that taking medication was much safer than undergoing an operation. This perception was driven by lay persons' information and their direct experience:

The doctor told me that the operation is for curing โรคลิ้นหัวใจ -Rok-Lin-Hua-Jai (VHD) and, if I did not operate, I would have to take drugs all of my life. I did not undergo the operation because I was worried that I may not recover after the operation. I was not sure whether I will survive or die. As I knew, someone

who underwent a uterus operation passed away. This led me to think that the heart operation causes a high risk which can lead me to face dying when compared with uterus operation which has a low risk of dying. (Phloydang, interview 1)

I asked the doctor about the risk of an operation. หมอ –Moh (doctor) told me about the death rate from the operation was ten out of one hundred. I thought what I will do if I was the one of ten. I had two minds whether I will undergo operation or not. (Thumphitak, interview 1)

Sometimes participants made a decision based on their life circumstance, for example:

I am old I do not want to get unbearable suffering from the operation wound. I think that taking drugs is enough. The drugs help me to have less severe symptoms. If I took the drugs, I would be normal. (Phisud, interview 1)

A number of participants felt undergoing surgery also increased the burden for family members and made a decision to choose treatment options that was appropriate for their circumstance.

Undergoing an operation may cause hardship for my children. If I die, I want to die without blood spread all over my body. The doctor said that taking the drugs all my life will be necessary after the operation. I asked about the prognosis, หมอ –Moh (doctor) told me this will be fifty/fifty. So, I am afraid that I may not recover and will also have a wound. If I die, I would like to die without a wound. (Reingjai, interview 2)

หมอ –Moh (doctor) advised me to undergo an operation. I was worried that I may not recover after the operation and may die. I did not undergo the operation now. At that time I took the drugs and adjusted to live with the least symptoms. Now I can work and have a rest when tiredness occurs, for example, I stopped on the way when I was walking to the farm, which is far from home around one kilometer. If I am severely tired, I will ask my niece riding a motorcycle to take

me to the farm, or have a rest at home. If I feel I had severe illness and could not tolerate it, I would undergo the operation. (Sunisa, interview 1)

An intervention, such as surgery, is considered as the effective treatment for VHD where deformity of the valve is corrected alleviating stenosis and regurgitation. The life-stories of the participants revealed that while the participants preferred to be healthy they did not view the heart operation as fostering better living.

Participants preferred taking medication to undergoing an operation and indicated that medication is useful to help them to live with VHD. They perceived that medications were the treatment of choice for the disease and felt that taking medication enabled them to have a normal life which was the essential goal for them.

I had a lot of improvement after I was treated with the drugs. Before taking the drugs, I was thin. At first I did not have a significant change but after 4-5 months, I gradually improved. I put on weight and felt good. Other people also told me that I look like I do not have heart disease because of the healthy general appearance. (Chaichana, interview1)

Participants in this study felt that taking medication could ‘cure’ VHD. This perception was supported both by the positive effects of taking medication and lay information. When an operation was not available and the signs and symptoms of VHD complications such as heart failure occurred, medications were prescribed to reduce the work-load of the heart. In fact, taking medication is not effective treatment for VHD as it only reduces the signs and symptoms. Participants did not realise this and only observed a reduction of their suffering. The life-stories clearly showed that the participants have limited information about living with VHD and also want to avoid the risk to life from the heart operation, for example:

An operation was advised in the initial phase when I was treated at the hospital. ^{ນາໂສ}–Moh (doctor) asked me whether I wanted to undergo the operation. At that time, I decided to refuse and wanted to be treated with the drugs because I thought that drugs can cure this disease. (Ardoong, interview 1)

Not undergoing surgery within an appropriate time contributes to the development of VHD complications such as heart failure and cerebral embolism. Abnormalities of the valve (valves) lead to turbulence of blood flow which creates blood clots or emboli which can cause cerebral occlusion. A long period of waiting to revise valve deformities can lead to a high risk of complications. Therefore, the heart surgery needs to be undertaken in a timely manner to prevent these complications. Participants appeared prone to risk of complications because they had an unclear understanding about their condition which effected decisions about choosing care and treatment.

Lay and own direct illness management

Participants talked about how they could not comply with advice from care providers because the information did not fit in with their living conditions. These living conditions included health status, eating habits and socioeconomic conditions.

Participants could not comply with food management as instructed because the advice was in contrast to their habits and they were constrained by lack of money. Because of the illness some participants could not work, consequently, they did not have enough money to buy food as advised by care providers. However, some participants tried to comply with the advice along with lay and personal beliefs about illness management that fitted within their life context and met their needs.

The prohibition of salt and ผงชูรส -Phong-Choo-Rod (monosodium glutamate) was advised. I tried to avoid salty food but I am used to a salty diet. Therefore sometimes I can not tolerate it. I take a salty diet every 2-3 days. I take salty diet for one meal on that day. (Thongsay, interview 1)

I was advised to stop eating pork and ผักชี -Phuk-Chee (dill). Sometimes, I took these. I tried to decrease the salty diet but if it was too plain, I could not eat. So, I increased some more [salty food] to get more flavour. This helps me to have a better appetite. (Usawadee, interview 1)

I was advised by หมอ –Moh (doctor) to take the same kind of food everyday because some kinds of food have a negative interaction with ยาละลายลิ่มเลือด-Ya-Lha-Lhay-Lhim-Lheud (anti-clotting drugs). หมอ said that it will lead to the problem of adjustment to the drug. In real life, it is hard to follow this advice because I am poor. I eat what I have. I cannot take regular kinds of food. I try to eat more protein. I know that eating is important for care and treatment of heart disease. (Wason, interview 1)

Witchaya said that practical advice about performing activities was not provided. She did what she considered to be appropriate without clear information to support her actions.

I was advised about working. หมอ –Moh (doctor) told me that “I do not want you to do hard work”. I could not stop working because I am used to work. I have to continue working. I do as I can and do not work over my limits. During working, I have a chance to exercise at the same time. I cannot just live without work as advised by care providers even though I know it is good advice. (Witchaya, interview 2)

Bhenpapha said that she was discouraged by health professional to seek information to develop self-management skills. She had to handle the problems by herself.

Sometimes I had to go to the hospital before my appointment because I had to work. Working caused a shortness of breath. หมอ –Moh (doctor) did not understand and said “why do you work? You know that you cannot.” I wanted to tell him that I care for and love myself but I have to do this because there is no one else to do the jobs. In the past, I forced myself to work while I had shortness of breath. At a later time, I asked my husband to help with housework. (Bhenpapha, interview 1)

Sharing knowledge was evident as part of the effort to seek knowledge to manage their daily activities. Participants used their own selves and others experiences to support

them to develop self-management knowledge, several participants indicated that their direct experiences were used as part of learning about health management.

I never consulted หมอ –Moh (doctor) about how to do activities and working. I tried to do the activities. If I was tired, I would have a rest. I keep working when it does not cause tiredness. I still drive a รถเตี้ยเตี้ย – Rod-Tak-Tak (modified two wheeled tractors similar to a truck used by the farmer), work in the farm such as ดำนา -Dam-Na (growing rice in a mud farm) and เก็บข้าว –Kiew-Khao (harvesting rice by hand using a curved knife) and work as a builder. I am working without rushing and I am not tired. หมอ only told me not to do hard work. (Chaichana, interview 2)

หมอ –Moh (doctor) provided advice and I did not ask. หมอ told me “do not do hard work.” I did not know about the level of hard work and what would be the appropriate point to stop. I tried to do activities such as I trying to carry wood and stop when I had a shortness of breath, take a deep breath and not do that activity again. (Reingjai, interview 2)

Living with chronic illness demands clear and practical understanding that fits with individual circumstances to manage daily activities. In this study health professionals provided information aimed at supporting people to develop appropriate self-management skills. Unfortunately, when the information was not clear enough, participants could not use it. However, participants tried to develop their understanding and apply the information to support the management of their chronic condition in order to have a normal life. They integrated and considered a variety of sources of information from their own understandings through direct experiences and that of lay persons to support their management to achieve maximum level of well-being.

Conclusion

Existing Thai health care is effective to support people to achieve appropriate and suitable when they have access to health care services at health care settings. However, services in communities, especially in rural areas are still under developed as demonstrated through the participants' life stories of their effort to seek help from local

healers, family, and people in community. Participants in this study valued a variety of practices including local indigenous practice and respected the direct experience of others as they integrated the practices informed by indigenous and lay people in their management of life with chronic illness in rural Thailand.

CHAPTER 8

DISCUSSION

Introduction

People living with VHD experience a high level of distress caused by the disease symptoms such as dyspnea on exertion, palpitations, a limited appetite, insomnia, or irritation, which can prevent people with VHD from performing daily activities and fulfilling family and social roles. When they seek help from health care services, they can also experience a number of challenges, in particular people who live at a distance from health care settings such as in rural and remote areas, have difficulties accessing health care. The findings of this study revealed that rural Thai people with VHD experienced difficulties managing life with VHD and are affected by health care resource distribution, limited partnership opportunities with health professionals, and the availability of health care information. Consequently, living with VHD in rural areas requires people to be very determined to overcome health care access difficulties. The participants in this study sought health information from a variety of sources due to needing the knowledge and skills to live with VHD. Participants used a variety of health care resources including health professionals, indigenous health practices, lay people and their own direct experiences, to manage the challenges of living with VHD in rural areas distant from health care settings (summarized in Figure 8.1). In this discussion, health professionals refer to nurses, doctors, and other health workers. Health professional groups are identified by the specific name such as nurses or doctors. Care providers refer to health professionals and indigenous health practitioners.

Communication and Managing Life with VHD

Participants in this study said that they required knowledge to develop self-management of VHD. According to Cudney, Sullivan, Winters, Paul and Oriet (2005) difficulties accessing health care information meant clients faced a variety of challenges related to self-management. Many studies exploring clients' illness management found that clients had inadequate knowledge and a lack of understanding about their disease (Aǵard, Hermerén & Herlitz, 2004; Horowitz, Rein & Leventhal, 2004; Rodriguez, Appelt, Switzer, Sonel & Arnold, 2008) and this limitation negatively affects illness management of people with chronic disease (Aǵard, Hermerén & Herlitz, 2004).

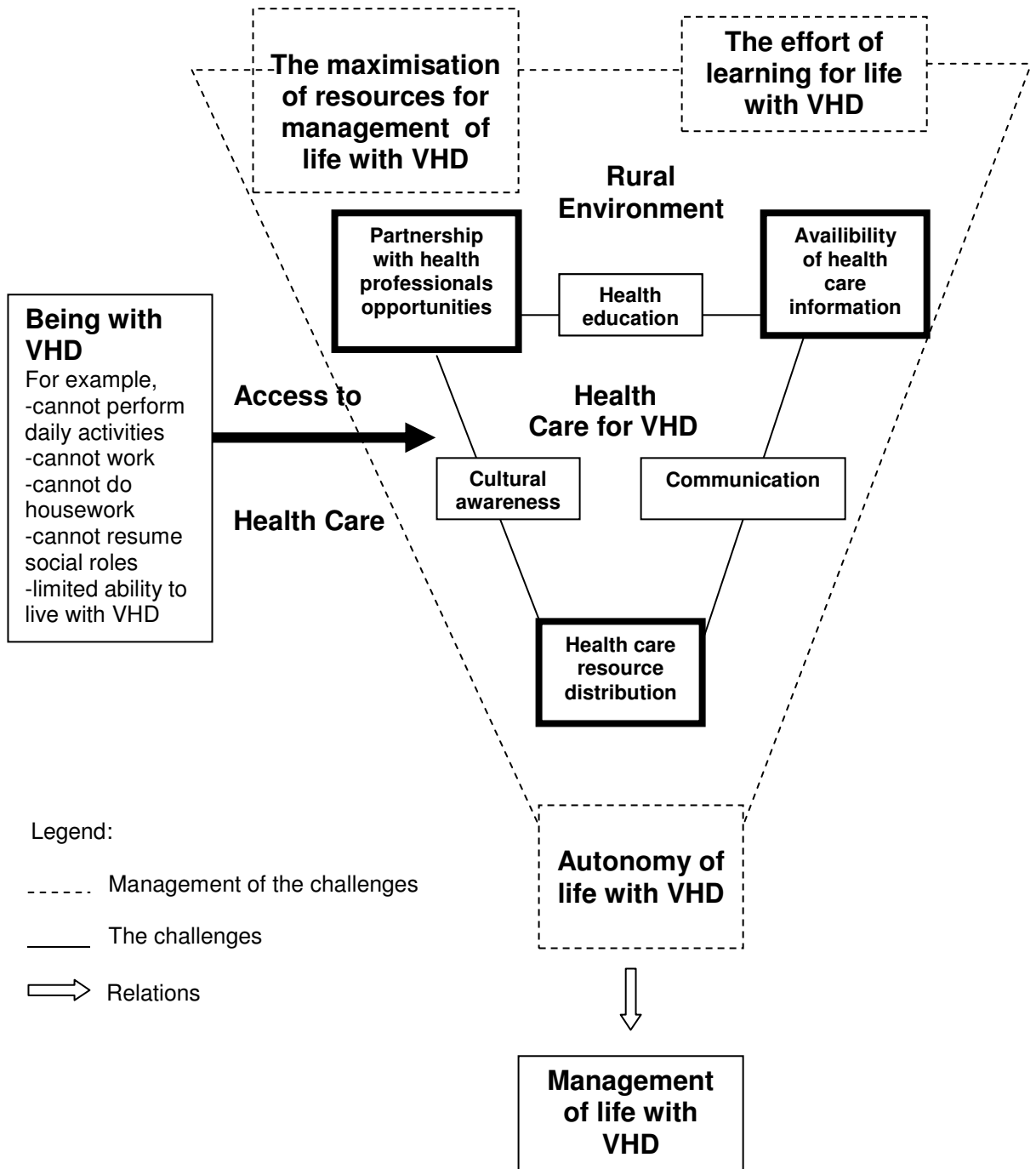


Figure 8-1 The Challenges of Management of Life with VHD in Rural Thailand

Communication is a key to the learning process particularly for gaining knowledge to support actions which need decision-making and problem-solving skills. Living with chronic conditions requires people to have a clear understanding of the condition in order to apply knowledge to live with their diseases. Communication with health professionals is, therefore, fundamental for clients to gain understanding about disease and illness management. In this study, participants experienced limited learning

possibilities due to professional gate keeper language, cultural differences between health professionals and clients, and provider-centred communication.

Interaction without using understandable language is a barrier to accessing health care information even when the opportunity to meet with health professional arises. In this study, clients and health care providers appeared to use different levels of language, both written and oral, which contributed to difficulties in learning about the health conditions and ways of illness management. Some participants pointed out that they did not understand what health care providers said because the health professionals used ภาษาหมอ-Pha-Sha-Moh (medical language) which was perceived as 'gate keeper language' by clients. Clients heard what care providers said but did not necessarily have a clear understanding of what was meant. Using different levels of language during communication led to misunderstanding about health information (Sparks & Nussbaum, 2008). Therefore, clients cannot use the information to support decision making about their condition, for example not understanding level of severity can lead to a delay in seeking appropriate health care services. Also, in this study some participants refused a heart operation based on an unclear understanding about the result of an echocardiogram. Limited information about advantages of the heart operation when a deformed valve is renewed and the heart gains normal function, was provided with ensuing issues of limited understanding about the suitable treatment for VHD. Health professionals could not convince participants to accept the heart surgery which is the effective for treating the deformed valve. Health professionals used medical terms without confirming the understanding of the participants. Communication without confirming clients' understanding can reduce access to health care and lead to clients' dissatisfaction with health care services.

The current Thai health care system is based on western biomedical models and western medical knowledge (Bureau of Policy and Strategy, 2005). Health care texts are usually translations of English medical books, and English medical terms are still commonly used for communicating in the health care environment. Thai and English are very different and some medical terms are not able to be translated into Thai, therefore, some terms are English words written in the Thai alphabet. Even if some medical terms are translated into Thai, there are still differences in the cultural meaning. Using a different

language for communication is a barrier to accessing health care services and creates unsatisfied clients frustrated by health professionals' language (Tod, Lacey & McNeill, 2002). The participants' narratives revealed that health care services often did not meet their needs and expectations as Tod, et al. (2002) also report, misunderstandings about treatment meant patients' expectations were not met and this could lead to a loss of confidence in, and also reluctance to use the services. Using understandable language to communicate with clients is essential to help clients manage to live a normal life with chronic illness.

Provider-centered communication contributes to limited learning opportunities of clients. Participants' narratives illustrate the asymmetry of the communication between the participants and health care providers which led to a lack of useful health care information. Participants said that during health care encounters the time was used to answer providers' questions and there was rarely time to raise their concerns. Provider-centred communication is a barrier for clients accessing health care information (Fisher, 1984; Gwyn & Elwyn, 1999; Kim, Odallo, Thuo & Kols, 1999; Rhodes, et al., 2004). If communication focuses mainly on the concerns of health care providers, this communication leads to limited opportunities for clients to learn to manage to live a normal life because they may know only about disease, the main concern of disease-orientated health care provision. Knowledge about disease was not enough information for participants to deal with other concerns. Focusing only on disease may also lead to dependency on health professionals for illness management. For example, people with VHD learn through communication with care providers that they have valve deformities that need medication. Therefore, the participants said that their lives relied on medication and some said that they did not know of other ways to manage living with VHD.

Communication focusing on client concerns is essential for clients' achieving illness management. Living with long-term illness demands management that is appropriate for each individual which can be ensured by careful listening to identify the needs and expectations of clients. If health professionals were aware of, and concerned about providing and supporting clients to develop self-management knowledge and skills to fit each person social context, then maximum well-being could be achieved by client centred communication. Client-centred communication contributes to the quality of

life of individuals diagnosed with chronic diseases by encouraging clients to raise their concerns and allow them to speak more comfortably (Carroll, et al., 2007). Good communication with health care providers encourages clients to manage their fear, to take responsibility for illness management, and live with disease in positive ways (Hickey, 2004; Kralik, Brown & Koch, 2001).

Encouraging clients to be assertive and active during communication is needed so health professionals can ensure clients' health care information needs are met. Providing an opportunity for clients to raise their own concerns can also shift communication to be more client-centred. Doctors fail to respond to a request for comprehensive information about heart disease such as its diagnosis, signs and symptoms is one of the causes of limiting understanding about the heart failure condition (Ågård, Hermerén & Herlitz, 2004). In the study by Ågård, et al. (2004), the participants were rarely able to ask questions to gain more health care information from the physicians. Rhodes, et al. (2004) also report that clients are rarely able to ask questions during communication with medical providers and care providers did not confirm client's understanding of information. Understandable health care information is necessary for clients to develop health care and illness management skills but this can be difficult because health care information is not freely available and care providers have limited opportunities to share the information. This limitation can be caused by providing care according to standard guidelines for VHD management such as medication prescription and collecting blood specimen to monitor anti-coagulant level in order to prevent adverse effects of using anti-clotting drugs. Therefore, it is necessary for the clients to ask questions during communication with health care professionals, this can encourage health professionals to be more aware of clients' needs and expectations. Beisecker (1990) reports that clients' questions encourage better understanding of treatment and treatment outcomes. Lack of assertiveness is clearly an obstacle to gaining information needed for effective managing life with chronic diseases.

Cultural awareness

Communication in a culturally sensitive manner is required in order to ensure clients' understanding about disease conditions, care and treatment. In this study, people with VHD in rural areas in Thailand have different perspectives on health, disease, and treatment from those of health professionals as can be seen through participants'

narratives focusing on holistic well-being which differed from the disease orientation focus on treating valve deformities. For example, some participants considered taking medication was appropriate and helped them achieve holistic well-being as reducing symptom distress through medication helped them carry out daily activities and social functions, rather than undergoing an operation to treat a heart valve. Although health professionals use the Thai language to communicate with clients, clients may not understand what they are saying because of cultural differences regarding the meaning of words. This difference can lead to clients refusing to use health care knowledge provided by health professionals, as Pattenden, Roberts and Lewin (2007) claim differences such as language and beliefs about illness and its treatment leads to difficulties for clients managing the disease.

Culture strongly influences the ways that people in each society give meaning to illness and illness management (Kleinman, 1988). Health care services which have little concern about cultural differences create significant barriers to health care services for managing life with long-term illness. Cultural meaning about the heart by lay people is different from health professional knowledge which leads people with VHD to interpret care and treatment for VHD differently from health professionals. Giving meaning to diseases provides a means of dealing with the diseases. This influences the decision to seek health care services (Tod, Lacey & McNeill, 2002). In Thailand, difference meaning of health and illness of lay Thai people and health professionals is exists. Lay Thai people focus on holistic health of the whole person rather than considering the defect of a specific organ such as the heart. For lay people, the aim of health management is mainly to achieve a level of functioning to meet requirements of daily living and social roles. This is different from Thai health professionals who focus on disease management and cure.

In medical terms heart disease refers to a heart defect which leads to an inadequate blood supply to the body. Therefore, the treatment for heart disease aims to increase the blood supply, for example, by providing medication to increase cardiac output. Valve (valves) deformity is the cause of VHD which leads to a low cardiac output. Therefore, correcting this deformity such as replacing the deformed valve with a prosthetic valve is the treatment for restoring normal function of the heart to generate as adequate cardiac output. However, Thai people have a different understanding which is rooted in the

cultural meaning of heart disease. Thai people believe that the heart is the most important organ. If the heart stops working it means life is over. The heart is seen as the entire means for living, not only for the physical function of pumping the blood to the whole of the body, but also as the soul, the mind, and thinking organ (Sindhu, 1992). The heart is the central point of an individual's entire life and is the symbol of well-being. Defects of the heart mean that life will never be perfect anymore. This is the reason why Thai people pay a lot of attention to the heart and feel desperate when they know or guess that they may have heart disease. Participants considered that a heart operation could put their lives at risk. Therefore, as the heart is the most important organ, numerous stories from lay persons about negative outcomes of heart surgery convinced some of the participants in this study to decide to refuse a heart operation.

Some rural people with VHD in this study were hesitant to undergo the heart valve replacement operation. Therefore, it is necessary that health professionals are aware of the influence of culture on how people with VHD make decisions about their illness management. Clear information concerning clients' cultures is needed to provide help for people with VHD to evaluate their conditions and choose the appropriate treatment. Communication focusing on clients' cultural meaning is a key to supporting people with this disease to develop appropriate illness management.

Participants' narratives revealed that เกรงใจ- Kreing-Jai (behaving in a way that avoids annoying other) is the Thai cultural stance appears to be a leading cause of limited clients' challenges and negotiation with health care system. Health professionals in particular nurses, need to advocate for and facilitate clients to voice their needs and expectations as this could provide direction for health care development. Participants in this study were not likely to challenge health professionals during encounters with them. The participants' narratives show that they tried to compromise with health care professionals, coping by making up their minds to accept everything by ignoring their negative feelings and trying to calm down (called ท้อใจ-Thum-Jai). Limited challenging of health professionals by clients may also contribute to the limited opportunities to develop better health care services for VHD management because of the absence of the voice of clients which is necessary to develop the best practice of health professionals. Therefore, encouraging clients to have space to voice their views needs to be addressed

to ensure better health care for rural Thai people. As the participants did not ask for information to clarify their condition, some still lived without fully understanding the illness and its care and treatment.

Nurses and health education

Nurses were invisible as providers of health care information. Participants in this study were less likely to identify nurses as the significant health professionals providing information. Nurses were perceived as a key professional when clients were hospitalised, the people who provided bed-side cares nursing and interventions which are focused on reducing disease symptoms such as medication administration and hygiene cares. Participant accounts revealed that nurses focus on providing care in the helping role, monitoring function, and administering and monitoring therapeutic interventions and regimens. It appeared that nursing had a limited focus on the teaching-coaching function. However, nurses are the significant health professionals that can provide health education to improve the quality of life of individuals with chronic illness (Kutzleb & Reiner, 2006). Benner (1984) suggests that teaching and coaching is an important nursing role to ensure and support clients to learn about ways of being and coping with an illness. In Thailand, not all rural primary health care units have registered nurses, even in health care settings where nurses are available, the opportunities for providing health education are limited. Boonthong (2000) found that nurses who worked in primary health care settings in Thailand take a health history, a health assessment, and diagnosis, provide primary treatment, and follow-up care. Information provision was not reported in this study.

Nursing care that focuses on providing health education requires improved listening skills which can improve access to health care for people with VHD. Being fearful to have an operation was a significant obstacle that prevented participants in this study from accessing effective treatment. It was evident that participants based their understanding and made decisions to refuse the heart operation on unclear information. Generally, nurses who have good listening skills are a key health professional to support clients to gain knowledge about disease, care and treatment. As the evidence in this study communication with Thai people in rural areas required cultural sensitivity from health professionals, development of cultural sensitivity requires open listening skills. Howorth and Dluhy (2001) report that effective interaction depended on hearing and

attending to the life world of clients. Therefore, it is important for nurses to focus on improving their listening to provide sufficient health education to meet clients' needs and expectations. In this study it was also found that participants were hesitating to raise their concerns during interaction with health professionals. In order to increase learning possibilities, nurses need to be more focused on encouraging clients to communicate and share their experiences, needs and expectations. Through communication focusing on clients' concerns nurses can gain a better understanding about their worlds by knowing the name of the disease and symptoms in the clients' language, which would improve communication between nurses and clients (Howorth & Dluhy, 2001).

Living Distance from Health Care Resources

People who live in rural areas are likely to have difficulties in accessing health care services. All participants in this study lived in rural areas with some participants living in remote areas. This creates difficulties in accessing advanced medical services. Participants said that they faced difficulties accessing specific investigation services, for example, some experienced difficulty in obtaining the definitive diagnosis necessary for disease management. Consequently, some participants were treated without a full investigation and this resulted in suffering from symptoms of VHD, the treatment and development of complications such as a hemi-paralysis. This evidence supports the finding that limited access to health care services in rural areas can lead to disease progression.

Inequity in health care resource distribution for heart disease exists globally. This inequity can be seen by the numbers of vulnerable people who have less access to health care services than privileged people. A number of studies indicate that people who are younger, men and those of high socioeconomic status access health care services more than women and individuals of low socioeconomic status (Keskimäki, Koskinen, Salinto & Aro, 1997; Melville, Packham, Brown, Weston & Gray, 1999). How far people live from the health care setting increases difficulties of access to health care services and the challenges of living in remote areas includes travel difficulties (Chan, Hart & Goodman, 2006; Probst, Laditka, Wang & Johnson, 2007) which limits access to services (Harris, Aboueissa & Hartley, 2008; Melville, Packham, Brown, Weston & Gray, 1999; Payne & Saul, 1997). Winters, Cudney, Sullivan and Thuesen (2006) report that people living in rural areas have fewer visits to care providers than in urban areas

and also experience higher financial burdens due to traveling costs, and physical burdens such as symptom exacerbation caused by the long time traveling in order to access health care.

Inequity of health care resources exists in Thailand as the distribution of health care resources is determined by the structure of the health care system and centralized health care is a feature of health care provision. Consequently, effective health care services for VHD such as surgery and advanced technology for disease investigation such as echocardiography, are available in tertiary hospitals and also in private hospitals located in urban areas. In order to access surgery at a tertiary hospital, people who live in rural areas and are registered at primary health care settings in communities are more likely to have difficulties than people registered with tertiary hospitals because of the need to be referred from primary to secondary and finally tertiary health care settings. After that process they are put on the waiting list at tertiary hospitals in the same way as people who registered at tertiary hospitals for the heart operation. Alternatively they may choose to pay more to access services in the private sector.

Lack of health care options is likely to be influenced by inequity of resource distribution both of health professionals and health care facilities. In Thailand, the policy of increasing the distribution of health providers to expand care services in communities is still under-developed (Centres for Disease Control and Prevention, 2000). Inequity of health care resource distribution in Thailand can be confirmed by the difference in incidence rates of people with VHD in rural areas compared to people living in urban areas. Even though preventable, there is a high incidence of VHD among people living in rural areas in Thailand (MoPH, 2007). This implies that health care options for preventing VHD development are limited in rural areas. Participants' narratives also confirm that limited health care services lead to under treatment and a failure to prevent VHD. Primary and secondary prevention which prevent people who have streptococcus group A infection from developing rheumatic fever is not provided.

Limited access to specific investigations for VHD may lead to increased vulnerability to life threatening complications. In this study, rural people experienced a number of VHD complications such as paralysis as a consequence of cerebral embolism. Schocken, et al. (2008) state that effective disease identification techniques are necessary to prevent

heart failure development in client groups with disease that leads to heart failure. For VHD, an echocardiogram provides important information to help the doctors to diagnose and evaluate the severity of the disease in order to make decisions about illness management (Kelly, 1999; Scott, 2001). Appropriate management to prevent heart failure which is caused by VHD complications needs a definite diagnosis. Appropriate treatment also prevents people with VHD from dying from such as embolism (Petty, et al., 2005). Limited access to advanced medical care is a significant cause of disease deterioration and risk of dying from complications. Improvement of health care provision ensuring continuing care such as home-based care and using nurses as care managers could improve care for rural people with long-term illness in Thailand.

Nurses and Health Care for People Living in Rural Areas

Focusing on preventive health care provision is required to increase accessibility for rural people in Thailand and this could increase numbers of health professionals such as nurses involved in providing care for those people. Currently, effective health care services for people with VHD are provided by cardiologists who work at secondary and tertiary hospitals but those advanced health care services are not readily available to people diagnosed with VHD in rural and remote areas as discussed above. A greater focus of health care provision on prevention and life-style management, through increased facilities and resources at primary health care level would support people with VHD in rural areas and also may lower the incidence of VHD in the future.

Currently, in Thailand, the focus of health care services for chronic illness management is on cure rather than prevention. This can be observed through government health care expenditure which is mainly focused on treatment rather than on prevention and health promotion. An example is in the health care scheme for HIV/AIDS, almost all the budget is for medication and medical care (National AIDS Committee, 1997). Similarly failure to develop appropriate services for the prevention of VHD can be demonstrated by the high incidence of VHD still existing in Thailand.

Primary prevention includes throat swabs and antibiotic prescriptions to prevent rheumatic fever (Naiggolan, 2006) and ongoing antibiotic treatment is required as a secondary prevention to prevent recurrent of rheumatic fever, is an important method to

prevent VHD (Nkomo, 2007). Penicillin, which is the drug of choice for both primary and secondary prevention has a high potency for preventing the consequence of hemolytic streptococcus group A infection (Manyemba & Mayosi, 2003; Roberston, Volmink & Mayosi, 2005). Therefore, access to primary health care services is essential to prevent the disease. A focus on cure may contribute to less awareness of health professionals of the need to provide effective treatment to prevent the disease. Because the focus of VHD management is not on prevention, health professionals in particular nurses who work at primary health care units may focus on screening to find new cases of people with VHD in order to refer clients to secondary and tertiary hospitals as discussed above. Participants' narratives confirmed this focus. Participants told stories about the concerns of health care professionals at primary health care settings to investigate for definite diagnosis of VHD which is necessary for referring clients to secondary and tertiary health care settings. It is also important to focus on protecting people in the community from the effects of hemolytic streptococcus group A infection, to prevent rheumatic fever, and its recurrence, this is part of primary health care provided by health professionals such as nurses. This approach should also increase the accessibility to health care for VHD for people who live in rural areas as health care resources would be available at nearby health care settings. This would decrease the health care burden as a lower numbers of people will develop VHD.

In addition, shifting to focusing on prevention could decrease the financial burden of Thai health care because from participant demographic data, the cost of care and treatments of VHD appeared to be supported mostly from Thai government sources. Nowadays, Thai health care has a high financial burden due to the effort of providing universal health care coverage to ensure equity of access to health care (NHSO, 2003). Almost all of health care funding under this scheme is funded by the Thai government. This means the funding is limited as the government funding is also needed to support other sections for development of Thai society such as education, infrastructure and social welfare. As health care provision relies on limited funding, it is necessary to set priorities for spending relative to health care. As a high number of people with chronic disease such as hypertension, diabetes mellitus and heart disease (MoPH, 2005; 2007) lead the Thai health authorities to spend more on disease treatment rather than on prevention and health promotion. In case of VHD, people with a lower income account for high VHD numbers which means they are likely to rely on government for accessing

health care services, in this study 27 people out of 30 used the universal health coverage system by using 30 baht card, free card, elderly care, and disability card to access the care for VHD. The high cost of treatment for VHD can lead to limited funding for VHD prevention as secondary prevention needs ongoing antibiotic treatment to prevent recurrence of rheumatic fever. Therefore health care focusing on VHD prevention can decrease health care costs in the future because reducing VHD incidence.

Participants' narratives revealed the fact that rural people could not get consistent care and treatment from health professionals. The stories of integrated indigenous health practices confirms the needs for continuing care for people with chronic illness in rural areas to support them to achieve well-being. Participants used their own experiences and lay information to manage their daily living. Limited access to continuing care causes a higher level of distress such as suffering from symptoms of the disease and its complications. In this study, participants experienced lifestyle constraints caused by VHD symptoms and its complications. Continuing care could be managed by specific health managers such as primary health care nurses, delivering consistent and individualised care. According to McGilton, et al. (2003) nurse-led clinics improve ongoing care for people with long-term illness by improving knowledge and skills of illness management through self-care (Shearer, Cisar & Greenberg, 2007). Pottle (2005) also found that nurse-led clinic increase access to health care, and health care provision using nurses as a managers to provide comprehensive health care services help clients to achieve a better well-being (Palmer, Appleton & Rodrigues, 2003), better clinical outcomes such as lower distress caused by disease symptom (Marek, Popejoy, Petroski & Rantz, 2006), and reducing health care cost by decreasing hospitalisation and increasing clients' working days (Hammer, 2001, Young, et al., 2003).

Presently nurses in rural areas have limited opportunities to offer health promotion and continuing care. Limited resources are available to support nurses to provide care, there are shortages of staff, limited case management networks, and a lack of role models such as advanced nurse practitioners are all barriers to providing advanced nursing care to ensure health promotion and consistent care for people living in rural and remote areas in Thailand. Nurses who work in rural areas face high workloads because the ratio of nurse to population is lower than in urban areas (MoPH, 2005). The shortage of

nurses in rural areas is higher than in urban areas. According to MoPH (2009) the number of nurses in rural areas is under the projected number.

As nurses who work in isolated locations also have limited networks, new approaches to client-centered and preventive health care provision would increase possibilities for nurses who work in these areas. Nurses could facilitate client's families and people in communities to become care networks and knowledge resources to expand health care possibilities. This could increase the number of practical health care options and reflect multiple points of view of people in communities. This type of health care may also be more accepted and encourage people to access services because this type of health care encourages partnership for illness management.

Working in Partnership

In rural areas of Thailand health care services for VHD are not enough to support people with VHD to achieve their maximum level of wellness. Therefore, rural people seek alternative health care to meet their needs for the continuing care necessary to live well with VHD. Participants talked about integration of indigenous health practices as a consequence when they got a cold or a sore throat. They also sought help from indigenous healers when they had VHD complications such as weakness. These evidents demonstrate the need to work in partnership as a fundamental for successful VHD management for people living in rural areas Thailand.

Limited development of infrastructure such as public transport in rural areas in Thailand creates difficulties of access to health care services. In order to increase access to health care, community-based health care provision seems fundamental for better accessibility. Integration of alternative health care such as indigenous practices could increase health care resources and also shift the focus of care onto community-based care. In this study, indigenous health practices were considered by participants as a reliable health care resource. This practice helped the participants to access support and ongoing care which helped them to meet their needs and expectations for holistic health care. Balanced relationships between health professionals and indigenous health care providers needs to be addressed to strengthen care for people with VHD in rural areas. Good relationships between care providers can expand the health care network and improve continuing care for people with chronic conditions. Integration of, and support for,

indigenous health practices is required to reform health care provision aimed at improving access to care for people with VHD in rural areas in Thailand. Integration of indigenous health practices help clients to gain a better health status and improved quality of life.

Rural Thai people focus on holistic health which leads them to seek alternative ways to manage life with chronic illness to ensure their needs and expectations about wellness are met. Narratives from participants about unmet needs and expectations, and limited choices for health care, highlight the way that current health care is disease orientated. Thai people prefer health care which is based on a long term relationship between clients and care providers. Productive relationships developed through mutual personal knowledge between clients and care providers are important and it also appears that clients, their families and others in community play a part in illness management. Holistic strategies are not common practice as current Thai health care is dominated by western biomedical models and care providers base their practice on this model. Prevention of VHD and associated life style improvement is not identified as equally important as cure. Health care services based on this model lead to the fragmentation of care for people with VHD, the concerns are to on eliminate of signs and symptoms of VHD. Fragmented care and treatment is an obstacle to optimal long-term cardiovascular care (Marshall, Walizer & Vernalis, 2004).

An holistic health care approach enables people living with heart failure to have a better quality of life through an improvement in symptoms, an increase in functional capacity, better disease understanding and are more involved and responsible for their wellness (Rhodes, 1998). In addition, the trajectory of cardiovascular disease includes both the acute and recovery phases (Van Horn, Fleury & Moor, 2002). Routine acute health care cannot support the chronically ill to achieve optimal well-being. A more holistic approach can help people with chronic conditions to manage to have a normal life at an appropriate level of well-being. These could be the participants' reasons for seeking help from complementary cultural indigenous healers to meet the holistic care needs. Integrating cultural indigenous practices could improve health care outcomes as clients' needs and expectations are met.

Participants' stories about the impact of complying with health care and illness management included the loss of control over daily living and working because of demands of the treatment regimens. Health care resources based on a central location can undermine independence and health professionals who are overworked due to high client numbers can only perform routine tasks, and have limited opportunities to develop better health services to foster a healthy society, which is their aim. Working in partnership between clients and care providers could improve care by reducing the health care provision workload and, therefore, health professionals may have greater opportunities to improve health care delivery.

Opportunities for clients and health care professionals to share responsibility for health care needs is necessary for living with chronic illness in rural areas. "Independence, self-responsibility, and self control" (Delmar, et al., 2006, p. 262) gives people with chronic illness the ability to achieve a meaningful life with chronic illness. A sense of control for clients is a key factor in encouraging effective health care and illness management. Cecil (1998) reports that less control by physicians leads to more compliance and improves clients' satisfaction with health care services. Limited control of illness management leads clients to have a sense of powerlessness and also contributes to a high burden on the health care system as higher number of clients to care for. Also, health professionals who face high workloads and handle more severe cases of VHD could be more at risk of too much stress from working and this could have a negative effect on care providers' life and the quality of care. Health professionals who do not have enough time to provide quality health care services to support clients to achieve maximum well-being, cannot help clients achieve their goal of being healthy. Sharing health care and illness management is necessary for individuals to live a normal life with VHD aiming for clients to have better control and have more balance in life with chronic disease.

Participants' stories revealed that their autonomy was an important aspect of life as they worked to manage and overcome challenges in living with chronic illness in rural areas. The level of control correlates to the level of independence, more independence means a higher sense of control. Independence is important for managing chronic illness (Miller & Iris, 2002). Glasgow, Davis, Funnell, and Beck (2003) suggest that self-management is the key to chronic illness management and improving the quality of life, while

dependence on care providers in illness management is a negative influence on quality of life (Grimes & Cole, 1996). The fear of losing autonomy, independence and being a burden on others are factors related to suicide thinking among terminal cancer patients (Filiberti, et al., 2001). So having control is necessary for people to manage life with chronic illness, promoting clients' autonomy is necessary to support them to manage difficulties of living with long-term illness where health care resources are limited. This has a positive impact on both their physiological and psychological well-being. Self-management helps people with chronic disease to cope and have fewer disease relapses (Kennedy, et al., 2003; Maltais, et al., 2008), thus reducing the utilization of health care services (Maltais, et al., 2008).

Living with chronic disease requires the support of family and community. Social support can help people to manage their illness better and improve their quality of life as the support fosters people with chronic illness to adhere to treatment regimens (Kynge & Rissanen, 2001). Limited support from family and community creates more difficulties for people with VHD such as when a family member does not have a clear understanding about the functional capacity of the clients whereas they could support the person by helping them to maintain activities that are appropriate with their functional heart ability.

Participants' narratives illustrate how people with VHD can be isolated from this support. Families and the community have limited opportunities to support clients to manage VHD as the current Thai health care for VHD focuses mainly on a cure. Cudney, Sullivan, Winters, Paul and Oriet (2005) report that people with chronic illness described feelings of isolation and fear of rejection from their families and communities. As deformities of valve are not visible in contrast to people who for example lose a limb, and it was hard to tell others about illness caused by VHD. One participant in this study said other people in the community may think that people with VHD pretend to be ill, therefore, sympathy and support from people would not be forthcoming. In order to encourage families and community to involve in health care for people with VHD, needs and expectations of people with VHD, families and communities are to be addressed. Because these points of view are important to develop appropriate health care support those with VHD to live and fit their life within their social context.

Health care providers in Thailand generally ‘work for’ people focusing on providing care to meet gold standard and care guidelines based on medical concerns rather than ‘work with’ clients as the partner of care team and concerned with providing care to meet clients needs and expectations. Participants in this study indicated that health care is handled entirely by health professionals and the health care system had limited interest in integrating support from the family and community into the care for individuals with chronic illness. The ‘work for’ concept leads health care professionals to have more control and power than the client, family, and community. Consequently, there is a wide gap in health care knowledge and skills between client and care providers. As a result clients are further isolated from the health care system, and their families and communities also depend on health professionals for health care.

In addition, in Thai culture, health professionals have higher status and this is widely accepted by people in Thai society. Health professionals are seen as mercy workers and Thai people usually respect and trust health professionals and always look to them as the best people to know about health and disease. Thai people usually give all the credit for health care and illness management to health professionals. They feel relieved, peaceful, and confident that health professionals can help and manage every facet of health and illness management. Some participants said that their existence was up to health professionals. However, health care provision could focus on ways to improve life-style management and encourage clients and family participation and cooperation, in a client-centred manner. It is believed that the delivery of health care to support the ‘work with’ manner influenced by the notion of client-centred care could increase health care resources as better cooperation and participation in the care for people with VHD would result.

Conclusion

The participants in this study diagnosed with VHD, experienced many challenges living with the disease before, during, and after interacting with health care services. These challenges reveal the effort people living with chronic illness have to put into overcoming a number of challenges to seek help and support with the aim of gaining maximum well-being. This confirms that disease-oriented health care is a leading impediment to managing life with long-term illness. The barriers to health care services and to achieving quality of life for those living with VHD are increased by cultural

factors and health care structures. These barriers create difficulties of access to necessary information leading to limited understanding about illness and illness management. Unclear understanding about care and treatment effects participants' decisions on treatment reducing the possibility of gaining maximum levels of well-being. Health care resources in rural areas in Thailand appeared to be inadequate to support continuing care for people with VHD to maintain their illness management. This insufficiency is caused by inequity of health care resource distribution and by not encouraging families and community to participate and cooperate in care for people with VHD. Nursing practices are well established in hospitals but need to expand and develop interventions to ensure they are client-centred, continuing and working in partnership care is provided which is appropriate to support people with VHD to manage their illness with quality of life.

CHAPTER 9

CONCLUSION

Introduction

This chapter focuses on the implications arising from the participants' data and the discussion and recommendations are provided. The narratives of individuals with VHD revealed the challenges they faced as they manage life with VHD. Challenges related to the availability of health care resources, the availability of health care information, and opportunities for participation and cooperation. The conditions contributing to these challenging factors included a centralised health care structure, an inequity of distribution of health care resources, and inequality of power between care providers and clients; these have been discussed in previous chapters. Acceptable health care services for people with VHD should be developed to support community-based care and client-centred health care provision to foster equity of health care resources, and to enable equality of power between care providers and clients during health care interactions. This form of health care provision will support people with VHD to gain better access to health care and achieve optimum well-being.

Recommendations for Health Care

The development of suitable and appropriate health care to support people in rural areas requires health care practices and education which facilitates a preventive health care focus, clear understandable communication, encouragement of self-management, development of support networks in rural areas, and valuing the importance of mutual listening.

Moving to preventive health care

A health care system which solely focuses on curing disease causes difficulties for people living with VHD, particularly those who live in rural and remote areas. When the health system is focused on curing, health care resources are provided to relieve signs and symptoms and eliminate the disease.

Developing preventive health care services is an appropriate and cost effective approach to health care management for people with VHD. Strategies for prevention of VHD are

based on the control of respiratory infection which can be handled by health care providers at primary, secondary, and tertiary health care settings. It is important to encourage health professionals who work in primary health care settings to focus more actively on prevention of VHD. This may reduce the number of individuals with VHD in the long term. As WHO (1992) reports, in those countries where health care provision focuses on preventing the recurrence of rheumatic fever, VHD is not a major health problem. Nowadays, in Thailand, a number of primary health care units are available situated close to individuals with VHD. If the focus of health care provision for VHD shifted to prevention, it would foreshadow an increase in health care options for people VHD in rural areas. It is also expected that the number of people with VHD in Thailand would reduce.

However, the important challenges of preventing people from development of VHD is how health professionals can manage to support people adherence to continuing and long-time antibiotic prophylaxis which is a requirement to prevent recurrence of rheumatic fever. In order to foster the adherence of clients, Harrington, Thomas, Currie and Bulkanhawuy (2006) recommend that identifying influencing factors for treatment adherence by listening to clients' opinions about rheumatic fever prophylaxis, is important to promote clients' adherence to secondary prophylaxis. Support networks are also recommended, as Kyngäs and Rissanen (2001) suggest that social support is a predictor of good compliance of people with a chronic disease.

Rural support network development

Limited health care options for people with VHD led by disease-oriented health care provision which prevents the development of other health care resources such as preventive VHD management, information to manage everyday life with VHD and support networks for people with this disease in rural areas in Thailand. A social network is necessary for people with chronic disease to deal with health problems, for example, if family members know that valvular replacement is necessary, they may encourage and support clients to accept the surgery. Developing support networks in communities may increase accessibility to health care for people with VHD as a consequence of the variety of health care resources available in each community. These networks may also support people with VHD to have a normal life with others because of the understanding about VHD and knowledge of how to support people with VHD to

manage life with illness management within their social roles. Arther, Wright and Smith (2001) suggest that support groups create caring environment which helped people with heart disease to express their feelings, relieve anxiety and surface their suppressed emotions.

Health care provision aiming to provide continuing care needs to support nurses to take care coordinators roles. Coordinated health care provision increases the support networks for people with chronic illness in communities so a wider range of people get involved with illness management through greater cooperation of health professionals, family and community. Living with a chronic condition such as VHD needs support from health professionals who function as coordinators of care (Van Achterberg, Stevens, Crebolder, de Witte & Philipsen, 1996). Pugh, et al. (1999) suggest that the use of nurse case management in collaborative health care partnerships may be an effective way to manage chronic disease in the community. Van Achterberg, Stevens, Crebolder, de Witte and Philipsen (1996) also report that clients whose complete health care is coordinated by the nurses perceive that they have more network member support. In addition, when care is coordinated by nurses as case managers for people with chronic conditions, these people have a significant improvement in their quality of life (Battersby & the SA Healthplus Team, 2005). In Thailand, nurses account for the highest proportion of health professionals and they work at every level of health care provision. Therefore, preparing nurses to be coordinators of health care would increase the care support network for people with VHD in rural areas, and support them to achieve the maximum level of well-being. Rural nurses are likely to be isolated from peer support networks, it is important to develop supporting resources such as mentoring and professional development for those who work in remote areas.

Community-based health care provision is another health care model which increases the support network. Missik (2001) suggests health care services which encourage people to perceive that the services can be accessed easily, promote and encourage people to use health services. This kind of health care provision increases the possibility that clients can access a variety of health care services in the community because other people and local healers will participate as well in illness management. Home-based care in which nurses deliver home visits also encourages clients to perceive that they have support after discharge from hospitals (Hermiz, Comino, Marks, Daffurn, Wilson

& Harris, 2002). Using home-based or community-based care improves the clients' quality of life (Hammer, 2001; Marek, Popejoy, Petroski & Rantz, 2006; Palmer, Appleton & Rodrigues, 2003) and reduces health care cost (Stewart, Marley & Horowitz, 1999).

Indigenous health care is still widely practice in rural Thailand. Valuing indigenous practices as health care resource can increase rural health care networks. In this study, indigenous health practices were significant health care resources for Thai people in rural areas. Encouraging health professionals to work with, and support, indigenous healers by integrating current medical skills such as identifying and referring people at risk of acute rheumatic fever to access antibiotic treatment, would support preventative health care. Indigenous healers also provide alternative health care which can support people with VHD complications by increasing their well-being.

Recommendations for Nursing

The knowledge gained from rural people with VHD who shared their valuable health care stories, showed that, nurses must understand the everyday challenges that clients face and based their practices on knowledge about health and health care in clients' points of view. The inclusion of knowledge about health care informed from clients understanding and actions, supports the understanding of nursing knowledge as a dynamic process that addresses the real problems of health care access and interaction, rather than presuming ideal conditions for clients.

The results of this study also demonstrate the significance of autonomy for rural people with chronic illness as they overcome the challenges of living at a distance from health care resources. As shown, autonomy is a important quality when living with chronic conditions, therefore, nursing interventions should support and value autonomy as part of client-centred care as a core of nursing practice. The participants' accounts revealed that disease-orientated health care provision contributes to the challenges of managing their lives, expanding nursing practice to become more client-centred can help develop health care that is more accessible, acceptable and more suitable in the context of client's lives. Examples of practice that can shift nursing care to ensure the client is at the centre of nursing interventions include focusing on self-management development, encouraging mutual communication, and improving listening skills.

The encouragement of self-management

Individuals living with VHD experience limitations to life as described in previous chapters. Based on narratives of the participants, their experiences of health care were influenced by the disease-oriented care, the distribution of health care resources, and the inequity of power between care providers and clients. These factors influence the participants' experiences of living with limited independence.

The ability to have a normal life is perceived by individuals with VHD in this study to be as important as being cured. Delivering health care focusing on clients' needs and expectations and inviting people to cooperate in its care, treatment and management, gives people with VHD more opportunities to develop self-management knowledge and skills. Encouraging self-management, for example, by having nurse-led health clinics which focus on supporting people with chronic illness to develop self-management skills decreases emergency department visits and hospitalisations (Coultais, Frederick, Barnett, Singh & Wludyka, 2005).

In Thailand, advanced nursing care such as using nurses as care managers is usually practicing in secondary and tertiary hospitals. This practice can support the development of clients' self-management knowledge and skills. However, it is not often that this type of advanced nurse-led clinic is provided at community hospitals and primary health care units. Building peer networks between advanced nurse practitioners and nurses who practice at a distance from health care settings to focus on developing clients' self-management skills is cost effective.

Community nursing curriculum should also include educational programmes to support the development of advanced nursing knowledge and skills to provide care for people with chronic disease. Rural nurses in Thailand are likely to provide health care outside their scope of practice in an effort to provide care including diagnosis, treatment of illness, prescribing medication (Boontong, 2000). This can increase the nurse's legal risk. It is important to prepare nurse practitioners who work in rural areas in Thailand and increase the opportunity for them to be eligible for more ongoing training is an important factor to support nurses in these areas. It is a priority of nursing education institutions to support ongoing education for rural nurses.

Support mutual communication

Participants' narratives also showed that the knowledge to manage life with chronic illness was mainly limited by a lack of useful information about living with VHD. When health care information is withheld the participants had limited control and were dependent on health professionals to manage life with VHD. Obstacles to accessing information which are revealed in this study include cultural differences between clients and health professionals, and in particular, language level differences.

Communication using understandable language is necessary to encourage people to access health care information. Communication with medical terms is likely to create difficulties for clients' to learn about illness and its management (Rogers, Wallace & Weiss, 2006). Focusing on translating health language for clients' use may make health information more accessible. Preparing health information which is useable by those who live with VHD is recommended to reduce the impact of gate keeper language. It is recommended that health professionals who work in Northeastern region, Thailand develop an information handbook based on cultural meanings about health and illness, using the language of people who live in these areas. The provision of this handbook and encouraging other health professionals to use the handbook for providing health education, may facilitate access to information about life with VHD. As Little, et al. (2004) suggest that it is important to use understandable information in a handbook to increase learning opportunities and encourage clients to raise concerns and discuss their health care and illness during meetings with health professionals. Participants in this study use ภาษาอีสาน- Pha-Sa-Ei-San (Issan language) which differs from the Thai official language and health language, so preparing information about how to live with VHD in ภาษาอีสาน- Pha-Sa-Ei-San (Issan language) is recommended. Preparing information about VHD also needs to be co-written with Thai people who live in the Issan culture. Health knowledge which should be developed carefully with useable language for lay persons may reduce the gap in power and knowledge between clients and professionals. It is believed that a handbook on VHD which uses understandable words and pictures instead of medical terms and complicated descriptions would help people to learn more about their disease and how to manage life with VHD and support control and independence.

Cultural difference as an obstacle to accessing health care information also needs to be addressed. Alerting health professionals to the impact of cultural differences when communicating with clients may encourage them to clarify the meaning of information and establish that clients are gaining a clear understanding about topics during communication. For example, it is important to provide time for clients to discuss VHD based on their points of view and also establish their needs and expectations about care and treatment. These methods can reveal the perception of clients about life with VHD and increase access to information. Access to health care information may increase if cultural sensitivity is demonstrated during health care interactions. Training courses for health professionals needs to include knowledge about health language understanding of lay persons in each community and health students need to learn what it means to live with disease from the client's point of view. This knowledge may help students to have more cultural sensitivity in clinical practice which is necessary if they are to support and encourage clients to learn to live with a chronic condition.

Listening skills

Open listening is likely to be missing from health care practice because of the focus on disease-oriented health care provision which leads to the focus of communication, being providers' concerns rather than clients concerns. Open listening is essential for good communication and for delivering client-centred care. Appropriate communication helps clients to manage fear, encourages them to take part in illness management, and to live a normal life with their disease (Thorne, et al., 2004). Less open listening by health professionals makes it difficult for clients to raise their concerns about health care and illness management. It was rare for participants in this study to ask any questions during interactions with health professionals. Encouraging clients to ask questions during health care encounters is one method to encourage active communication. Harrington, Noble and Newman (2004) report that interventions aim to coach clients in question-asking techniques encourage better participation by clients in consultations with doctors.

Preparing health professionals such as nurses to be open listeners and to actively involve clients in communication should be encouraged in clinical practice and also be included in health care education. Encouraging nurses to provide time for listening is crucial to encourage clients to be more assertive when raising their concerns. Listening may also facilitate cooperation, a mutual relationship and equality between care

providers and clients. The health curriculum should stress how open listening is important for developing providing care based on an empathetic relationship with those who are cared for. This education may encourage nursing students to be sensitive listeners when they are working in health care settings. Consequently, individuals living with VHD would have more opportunities to share their stories and may receive better individualised health care to meet their needs. Nurses may also have more opportunities to develop healthcare services because clients' needs and expectations are more likely to be explored and used to guide more acceptable and accessible health care services. Open listening and active communication should support satisfaction with the health care encounter for both clients and nurses. In addition, having a chance to share with, and be listened to, by nurses can empower clients. Nurses also gain benefits when providing this type of care, according to Brown, McWilliam and Ward-Griffin (2006) client-centred nursing practice supports the development of professional autonomy which is needed to work in dynamic health care contexts.

Recommendations for Conducting Narrative Research in the Thai Context

Narrative research was used in this thesis to explore health care experiences through the life-stories of people with VHD who live in rural areas. It is evident that the open sharing of stories during the research journey is guided by trust both by the researcher and participants. Encouraging participants to trust in what they say and integrating the Thai cultural stance during conversation is necessary for encouraging open and honest conversation.

Trusting in the value of life-stories

Participants' life-stories are needed to support better understanding about health care provision. To understand about health care it is important to value life-stories of those who live with chronic conditions. This means it is essential for clients' voices to be listened to by health professionals and other people in society, as Davies (2003) suggests, public involvement in health care services is required for healthy development of a health care system. Research into the narratives of individuals living with illness may help health care professionals to focus on delivering health care services which will better meet the needs of clients. Narrative research into the experiences of people with VHD may guide practice for the prevention of VHD and may also encourage better

decision-making about health care delivery because policy and health care provision would be informed by the voices of people who know best about their situation.

Encouraging people to trust in their knowledge

It is also important to ensure that participants' stories are considered relevant ways of knowing. Thai participants perceive themselves as the objects of study rather than experts who can share knowledge. This perception of lack of equality prevents participants from fully participating in the research journey; for example participants try to find the correct answer instead of discussing what they know about life events. Focusing on empowerment of the participant is highly recommended for research undertaken in the Thai context. Allowing participants to take control while conducting research means using a flexible rather than structured interview guideline to support participants to talk about what they know rather try to give correct answers for structured questions. Returning transcripts to the participants for clarification and editing by the participants and working with the participants to analyse and interpret their life-stories are also methods to empower participants to view themselves as relevant sources of knowledge.

Taking a Thai cultural stance on the narrative approach

Storytelling is commonly used by Thai people which provides the possibility of developing a culturally aware research methodology. Full stories are the core of narrative studies and Thai people tell this kind of story during การคุยแบบเปิดอก-Karn-Kioy-Bab-Peid-Ook (open and honest conversation) to others who are trusted by the storytellers. Therefore, during conversation, trust needs to be developed. In order to build trust during research in the Thai context, a specific Thai cultural stance is needed such as the researcher being aware of the importance of attentiveness which is necessary for open and honest conversation which fosters full storytelling. Therefore, when conducting this research, I accepted the participants' greeting with full respect because I was aware that this respectful stance is an important starting point of trust building in Thai culture. It is contended that a culturally aware methodology is an appropriate method to develop inductive knowledge to provide ways of knowing and means to deal with issue of concerns.

Possibilities for Future Research

Participants' narrative revealed the absence of nurses from their health care experiences. It is a priority to explore nursing care for people with chronic diseases in rural areas Thailand. Examples of research projects are exploring rural nursing practice, evaluating of health care curriculum on nursing care focusing on rural health, exploring health policy relative to rural health practice, evaluating the model of rural health practice, and implementing a developed model of advanced rural nursing practice. These research projects would increase information for understanding rural health care and help nurses to gain more understanding, and they may use this information to improve care delivery which ensures accessibility for rural people.

Conducting research aimed at the development and implementation of health care models for people who have high risk of VHD development with focus on prevention would be useful. Research projects with a preventive focus may foster the possibility of reducing the incidence of VHD because this disease is preventable. In addition, access to health care services is necessary for preventing VHD complications.

Research projects to explore health care and illness meanings are needed in order to gain information which is the foundation for the development of client-centred health care provision. Expanding ways of understanding about illness and health care would focus more on the concerns of clients. Health care provision may also be more appropriate and acceptable for those who live with the illness. Consequently, clients are likely to achieve maximum level of well-being with support from health care services.

Based on participants' narratives, financial constraints frequently attributed to challenges of life with VHD. Analysis of the financial impact on people with VHD, their family, the health care system, and other social sectors should be the most important future research project. Research projects focus on health economics may raise awareness and encourage more concern to develop appropriate health care services for people with VHD.

Research for evaluating the impacts of health care policies on people who are not eligible to get benefits should be considered to balance the research that follow-ups the outcomes of the policies. Conducting research with people who cannot access the

benefits from the policies may provide different points of view as a basis for health professionals or policy makers to develop equitable health care schemes.

On Reflection

Participants' stories revealed a range of challenges related to health care provision in rural areas in Thailand. Living with VHD at a distance from health care resources created a number of difficulties for people living with the disease. To overcome the difficulties, autonomy of people with VHD was needed, this autonomy is required and contributed to how they make decisions about seeking health support and how they manage challenges created by the limited health care. It was evident that their families and people in the community provided a variety of support such as knowledge derived from direct experiences, and they used information from both lay persons and health professionals for the development of self-management knowledge and skills. People with VHD had limited learning opportunities when interacting with health professionals due to cultural differences and ways of health delivery barriers such as high workload leading to limited time for providing comprehensive care. The cultural barriers include health professionals using different levels of language from rural people with VHD and the hesitancy of clients to raise their own concerns. Dealing with providing care for a high numbers of clients created by disease-oriented health care delivery attributed to the difficulties of learning possibilities such as limited time, limited privacy and meeting with different health professionals. Due to the limitations of health care resources, people with VHD maximise available and accessible health care resources to manage life with VHD in rural areas. Families, people in the community and indigenous practices appeared as being reliable resources to support the needs of preventive, continuous and holistic care.

Overall, participants' stories reflect how people with VHD experienced distress which could be avoided by shifting the focus of health care provision to individualised illness management rather than the current disease-orientated health care delivery. Disease-orientated health care which is informed by the dominant knowledge of health professionals needs to be balanced by multiple voices of people with direct experience of chronic conditions. It is implied that health care provision that relies on a hierarchical way of knowing leads to limited appropriate health care for people with chronic illness to support them to achieve a maximum level of well-being. Narrative as a means to

surface events related to health care provision difficulties through multiple points of view, is recommended as a method for research and a basic foundation to inform practical knowledge and to develop acceptable and accessible health care provision for people with chronic illness.

From participants' points of view, community-based and client-centred care is required to support rural people with VHD in order to manage their life with long-term illness. If health care provision is based on a foundation of community-based philosophy, this type of care can provide greater continuity of care due to an increasing health care network in the community.

Open listening when health professionals communicate with clients is a successful key for the improvement of both community-based and client-centred care. Listening to clients' stories is recommended to support a basic foundation of community-based and client-centred care. It is believed that using narrative approach in nursing research can encourage nurses to be better listeners.

In my experience, open listening to participants' stories helped me gain a deeper understanding about health care practices. This understanding supported me to believe in my own abilities and this belief facilitated a willingness to develop appropriate nursing care informed by participants' voices. Nurses with open listening skills can support the development of health care for people living with long-term illness as they are likely to have greater understanding of the people who they care for. In addition, careful listening is a key to understanding, which is fundamental of caring as Mayeroff (1971, p. 19) says and cited by Corbin (2008) that:

We sometimes speak as if caring did not require knowledge, as if caring for someone, for example, were simply a matter of good intentions or warm regard. But in order to care I must understand the other's needs and I must be able to respond properly to them, and clearly good intentions do not guarantee this.

However, due to the requirements of high workloads, listening is likely to be missing from nursing practice as Davies (1990) reflects in the stories "What Ruby Really wanted" as Davies focused on providing physical care but "I'd almost forgotten to give

her [Ruby] what she wanted most- someone to listen [to]" (p. 97) and concluded having no one to listen to is an important cause of suffering. I would contend that by using narrative approach, clients' voices are more likely to be heard.

Narrative research provides a range of understandings and ways to deal with problems in clinical practice to help nurses design and implement new care initiatives. Medical and clinical knowledge is insufficient to support nurses to deliver care for people with a chronic illness. Narrative research which values a variety of ways of understanding about health care problems and provides ways to use and develop comprehensive knowledge for understanding the dynamic of clients' social context informed by clients' voices, should increase the possibility of empathetic nursing care. Based on knowing from multiple points of view, nursing care provision for people with chronic illness would move to focus on more individualised care. Open listening encourages both an understanding of the other persons and also one's self which is an important component of believing in the competency of clients and in one's own competency. Believing and valuing a variety ways of understanding about nursing care provision and ways to manage health problems would support innovation in nursing care. Nursing care that is based on a range of knowledge will increase the possibility of providing appropriate services to support people with chronic conditions to live a normal life and achieve a maximum level of well-being.



Massey University

8 November 2006

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Dear Supatra

Re: HEC: Southern A Application – 06/58
Exploring the health care experiences of individuals living with acquired valvular heart disease

Thank you for your letter dated 2 November 2006.

On behalf of the Massey University Human Ethics Committee: Southern A, I am pleased to advise you that the ethics of your application are now approved. Approval is for three years. If this project has not been completed within three years from the date of this letter, reapproval must be requested.

If the nature, content, location, procedures or personnel of your approved application change, please advise the Secretary of the Committee.

Yours sincerely

Professor John O'Neill, Chair
Massey University Human Ethics Committee: Southern A

cc Prof Carol McVeigh
School of Health Sciences
WELLINGTON

Appendix B: Approval letter from Mahasarakham Hospital



MK

Supatra Buatee

Ph.D. candidate, School of Health Sciences

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September, 2006

Dear Ms. Supatra,

According to your research proposal and letter of September 13, 2006. We have no problem and welcome your study to Mahasarakham Hospital. We looking forward to receiving you in our outpatient and inpatients department within the hospital.

Yours sincerely,

A handwritten signature in black ink, appearing to be 'Sakchai Tonmat'.

(Mr. Sakchai Tonmat)

Chairman of The Research Committee,
Mahasarakham Hospital.

Appendix C: Information Sheet

Exploring the Health Care Experiences of Individuals living with Acquired Valvular Heart Disease

Information Sheet

Research introduction:

My name is Supatra Buatee, doctoral candidate at the School of Health Sciences, Massey University, I am carrying out a research project to describe the illness experiences of individuals with acquired valvular heart disease under the supervision of Professor Carol McVeigh.

Invitation to participate in research:

About 30 adults diagnosed with acquired valvular heart disease and admitted to either outpatient or inpatients within Maharakham Hospital are invited to participate in this study. It is expected that 30 participants will be sufficient to support the aims of this study. You will receive the information sheet about this study and my address from the clinic. You will have time to decide and consult your family members about participation in this study. At the first contact, full details about the project will be provided and all questions will be answered. An appointment will be arranged depending on your preference to follow up your decision regarding participation. I will respect your decision. Refusal to participate in the study will not affect your care and treatment at the clinic. If you agree to take part, I will go through the information sheet with you and arrange for you to sign the consent form.

Participant involvement:

You will be asked to complete a personal information form which consists of age marital status, education, occupation and so forth. You will be asked to participate in an interview that will be last form 30 minutes to 1 and a half hours and the interview will be audiotape recorded. Notes will be taken regarding for important issues. **The interviews will take place in hospital or your home at a time that is convenient to**

you. During the interview section, I will ask you about your experiences with valvular heart disease, experiences in health care, your needs and expectations of health care. Follow-up interviews may be required **if the information you provide needs clarification. I will also seek your permission to review your health care records.** The information from your health records **that I would like your permission to collect includes: treatments and functional heart class.** Any information obtained in connection with this study that can identify you will remain confidential. I will take responsibility for keeping the research information in a locked filing cabinet at the Faculty of Nursing, Mahasarakham University, Mahasarakham Province, Thailand for ten years. All research information will be erased following that period of time.

Participant rights:

Participation in this study is voluntary. You have the rights to ask any questions about the study and ask for the audio tape to be turned off at any time during the interviews. You are under no obligation to accept this invitation. You have the right to decline to answer any particular questions and withdraw from the study at any time. Anonymity and confidentiality will be maintained at all times.

Once the research project is complete:

A summary of the research findings will be sent to you and made available on the notice board at Mahasarakham Hospital. Article will also be submitted to professional journal for publication.

If you require further information about this research please contact:

Supatra Buatee, Faculty of Nursing, Mahasarakham University, Mahasarakham, 44150, Thailand. Telephone number 043-754357 ext 2343;

email: supatra.b@msu.ac.th

Head Nurse of inpatient or outpatient clinic, Mahasarakham Hospital, Mahasarakham Province, 44000, Thailand. Telephone number 043-740993 - 6

Professor Carol McVeigh, School of Health Sciences, Massey University, New Zealand. Telephone number 64 4 801 2794 ext 6942;

email: C.McVeigh@massey.ac.nz

Ethics approval

This project has been reviewed and approved by the Massey University Human Ethics Committee: Southern A, Application 06/58 and permission letter from the Director of Hospital, Mahasarakham Hospital, Mahasarakham province, Thailand. If you have any concerns about the ethics of this research, please contact Professor John O'Neill, chair, Massey University Campus Human Ethics Committee: Southern A, Telephone 64 6 350 5799 ext 8635, email: humanethicssoutha@massey.ac.nz

Appendix D: คำชี้แจงเพื่ออธิบายสำหรับผู้เข้าร่วมโครงการ

การศึกษาประสบการณ์เกี่ยวกับการใช้บริการสุขภาพในผู้ป่วยโรคลิ้นหัวใจพิการ

คำชี้แจงเพื่ออธิบายสำหรับผู้เข้าร่วมโครงการ

คำนำ

ดิฉันชื่อ นางสาวสุพัตรา บัวทิ นักศึกษาปริญญาเอกทางการพยาบาล มหาวิทยาลัยเมสซีกำลังศึกษาวิจัยเกี่ยวกับแนวทางการพัฒนาบริการสุขภาพเชิงป้องกันสำหรับผู้ป่วยโรคลิ้นหัวใจพิการจากประสบการณ์ของผู้ป่วยโรคลิ้นหัวใจพิการ ภายใต้การดูแลของศาสตราจารย์แคโรล แมกเว

การเข้าร่วมโครงการวิจัย

ผู้ใหญ่ที่ได้รับการวินิจฉัยว่าเป็นโรคลิ้นหัวใจพิการจำนวนประมาณ ๓๐ คนที่เข้ารับการรักษาที่แผนกผู้ป่วยนอกหรือแผนกผู้ป่วยใน โรงพยาบาลมหาสารคาม ซึ่งเป็นจำนวนที่คาดว่าเพียงพอสำหรับการศึกษานี้ ดิฉันได้จัดเตรียมเอกสารคำชี้แจงเกี่ยวกับการศึกษาครั้งนี้ ท่านสามารถติดต่อรับเอกสารได้ที่พยาบาลประจำคลินิก หากดิฉันมีโอกาสดำเนินการชี้แจงเกี่ยวกับการศึกษานี้ด้วยตนเอง ดิฉันยินดีตอบข้อซักถามของท่าน เพื่อให้ท่านเข้าใจดียิ่งขึ้นและดิฉันขอมอบเอกสารคำชี้แจงฉบับนี้ให้ท่านเพื่อทำความเข้าใจและปรึกษากับสมาชิกในครอบครัวของท่านก่อนตัดสินใจให้คำตอบในการศึกษาครั้งนี้ ดิฉันยอมรับผลในการตัดสินใจของท่านไม่ว่ากรณีใดๆ ถ้าหากท่านไม่ยินดีเข้าร่วมในการศึกษานี้จะไม่มีผลกระทบต่อการรักษาของท่านที่โรงพยาบาลมหาสารคามแต่อย่างใด หากท่านยินดีเข้าร่วมการศึกษานี้ ดิฉันยินดีที่จะอธิบายคำชี้แจงรายละเอียดในการเข้าร่วมศึกษาเพื่อให้ท่านเข้าใจมากยิ่งขึ้น หากท่านมีความเข้าใจดีแล้ว ดิฉันได้จัดเตรียมเอกสารเพื่อให้ท่านลงนามไว้เป็นหลักฐานว่าท่านยินดีเข้าร่วมในการศึกษานี้

วิธีการวิจัย

หากท่านยินดีเข้าร่วมโครงการนี้ ดิฉันขออนุญาตสัมภาษณ์และบันทึกเสียงครั้งละ ๓๐ นาที ถึง ๑ ชั่วโมง ๓๐ นาที และอาจจะสัมภาษณ์เพิ่มเติมอีก ๑ ถึง ๒ ครั้ง ส่วนเวลาและสถานที่ในการสัมภาษณ์ขึ้นอยู่กับความสะดวกของท่าน ในขณะที่ทำการสัมภาษณ์ ดิฉันขออนุญาตบันทึกเทปการสนทนา และท่านสามารถขอหยุดการบันทึกเทปได้ตลอดเวลา ในการสัมภาษณ์ดิฉันจะถามคำถามส่วนบุคคลและคำถามเกี่ยวกับประสบการณ์การเจ็บป่วย ประสบการณ์เกี่ยวกับการดูแลรักษา ตลอดจนความต้องการและความคาดหวังในการรักษาพยาบาล นอกจากนี้ในระหว่างการสนทนาดิฉันขออนุญาตบันทึกข้อความสำคัญในระหว่างการสนทนา และข้อมูลจากบันทึกสุขภาพของท่าน

เกี่ยวกับการรักษา และความรุนแรงของโรค หลังจากนั้นดิฉันจะนำรายละเอียดของข้อมูลที่รวบรวมได้ทั้งหมดจากผู้เข้าร่วมการศึกษานี้ไปวิเคราะห์รายละเอียดของเนื้อหาต่อไป ภายหลังการวิเคราะห์ข้อมูลดิฉันจะนำผลสรุปที่ได้จากการศึกษาส่งให้ท่าน ข้อมูลทั้งหมดจะถูกเก็บไว้อย่างปลอดภัยที่คณะพยาบาลศาสตร์ มหาวิทยาลัยมหาสารคาม

สิทธิของผู้เข้าร่วมโครงการวิจัย

การเข้าร่วมการศึกษาคั้งนี้เป็นไปด้วยความสมัครใจของท่าน ไม่ว่าท่านจะเข้าร่วมในการศึกษานี้หรือไม่ก็ตาม ท่านยังคงได้รับการรักษาพยาบาลจากเจ้าหน้าที่โรงพยาบาลตามปกติ ท่านมีสิทธิที่จะยกเลิกการเข้าร่วมการศึกษา หรือยุติการให้สัมภาษณ์ได้ตลอดเวลาตามที่ท่านต้องการ โดยไม่มีผลกระทบใด ท่านสามารถสอบถามข้อสงสัยต่างๆเกี่ยวกับการศึกษาวิจัยคั้งนี้ได้ตลอดเวลา ข้อมูลที่ได้จากการสัมภาษณ์ทั้งหมดจะได้รับการรักษาเป็นความลับไม่มีการเปิดเผยชื่อ จริง การนำเสนอข้อมูลเป็นไปในภาพรวม

ติดต่อสอบถาม

หากท่านมีข้อสงสัย หรือคำถามที่เกี่ยวข้งกับการวิจัยคั้งนี้ สามารถติดต่อสอบถามได้ที่ นางสาวสุพัตรา บัวที คณะพยาบาลศาสตร์ มหาวิทยาลัยมหาสารคาม หมายเลขโทรศัพท์ ๐๔๓-๗๕๔๓๕๗ ต่อ ๒๓๔๓ หรือ อีเมล supatra.b@msu.ac.th

หัวหน้าหอผู้ป่วยนอก หรือ หอผู้ป่วยใน โรงพยาบาลมหาสารคาม จังหวัดมหาสารคาม

ประเทศไทย ๔๔๐๐๐ หรือทางหมายเลขโทรศัพท์ ๐๔๓ - ๗๕๐๕๕๓ - ๖

Professor Carol McVeigh, School of Health Sciences, Massey University หมายเลขโทรศัพท์ ๖๔ ๔ ๘๐๑ ๒๗๕๔ ต่อ ๖๕๔๒ หรือ อีเมล C.McVeigh@massey.ac.nz

จริยธรรมการวิจัยในมนุษย์

โครงร่างการวิจัยนี้ได้ผ่านการพิจารณาจากคณะกรรมการจริยธรรมการวิจัยในมนุษย์ มหาวิทยาลัยแมสซี ประเทศนิวซีแลนด์ (The Massey University Human Ethics Committee) หมายเลข ๐๖/๕๘ และได้รับอนุญาตให้เก็บข้อมูลจากผู้อำนวยความสะดวก โรงพยาบาลมหาสารคาม หากท่านมีข้อคำถามเกี่ยวกับจริยธรรมในการวิจัยคั้งนี้สามารถติดต่อสอบถามได้ที่ประธานคณะกรรมการจริยธรรมการวิจัยในมนุษย์ มหาวิทยาลัยแมสซี Professor John O'Neil, Massey University Campus Human Ethics Committee: southern A หมายเลขโทรศัพท์ ๖๔ ๖ ๓๕๐ ๕๗๕๕ ต่อ ๘๖๓๕ หรือ อีเมล humanethicssoutha@massey.ac.nz

Appendix E: Consent Form

**Exploring the Health Care Experiences of individuals living with
Acquired Valvular Heart Disease**

Participant Consent Form

This consent form will be held for ten years from completion of study in a locked filed cabinet at Faculty of Nursing, Mahasarakham University, Mahasarakham Province, Thailand.

I have read the Information Sheet and have had the details of the study explained to me. My questions have been answered to my satisfaction, and I understand that I may ask further questions at any time.

I agree/ do not agree to the interview being audiotape recorded.

I wish/ do not wish to have my audiotape recorded returned to me.

I agree/ do not agree to have my health record released for this study.

I agree to participate in this study under the conditions setout in the Information Sheet.

Signature: Date:

Full Name – Printed

Appendix F: แบบฟอร์มสมัครเข้าร่วมโครงการวิจัย

การศึกษาประสบการณ์เกี่ยวกับการใช้บริการสุขภาพในผู้ป่วยโรคลิ้นหัวใจพิการ

แบบฟอร์มสมัครเข้าร่วมโครงการวิจัย

แบบฟอร์มนี้จัดเก็บไว้ที่ตู้เก็บเอกสาร ณ คณะพยาบาลศาสตร์ มหาวิทยาลัยมหาสารคาม
จังหวัดมหาสารคาม ประเทศไทย เป็นเวลา ๑๐ ปี หลังจากการศึกษานี้เสร็จสมบูรณ์

ข้าพเจ้าได้อ่านและ/หรือได้รับการอธิบายเกี่ยวกับโครงการวิจัยนี้
ข้าพเจ้ารับทราบและเข้าใจวัตถุประสงค์การวิจัยและรายละเอียดของการศึกษานี้
ตลอดจนได้ซักถามและได้รับคำตอบจนเป็นที่พอใจ
ข้าพเจ้าทราบว่าหากมีข้อสงสัยสามารถซักถามได้ตลอดเวลา

ข้าพเจ้ายินดี/ ไม่ยินดีให้ทำการบันทึกเทปในขณะที่สัมภาษณ์

ข้าพเจ้าต้องการ/ ไม่ต้องการเทปบันทึกการสัมภาษณ์ของข้าพเจ้าคืน

ข้าพเจ้ายินดีเข้าร่วมโครงการวิจัยครั้งนี้ตามเงื่อนไขรายละเอียดการเข้าร่วมโครงการวิจัย

ลายมือชื่อ วันที่

ชื่อ-นามสกุล

ที่อยู่

.....

Appendix G: Demographic Information

**Exploring the Health Experiences of individuals living with
Acquired Valvular Heart Disease**

Demographic and Personal Health Information

ID #

Address

Age Sex Marital status

Education level Occupation

Income Economic resources

Number of family member who live in your home

Length of time to travel from your home to hospital

Medical expense

Length of time that you have been diagnosed with valvular heart disease

The number of admission in hospital in last year

Current symptoms

Treatments

Functional Heart Class

Weight Height BMI

How much have symptoms distressed or bothered you during the past 7 days including today: one means the least and ten means the highest

1.....2.....3.....4.....5.....6.....7.....8.....9.....10

The least symptoms	The highest symptoms
distressed/ bothered	distressed/ bothered

Appendix H: ข้อมูลทั่วไป

การศึกษาประสบการณ์เกี่ยวกับการใช้บริการสุขภาพในผู้ป่วยโรคลิ้นหัวใจพิการ

ข้อมูลทั่วไป

เลขที่

ที่อยู่

อายุ เพศ สถานภาพสมรส

ระดับการศึกษา อาชีพ

รายได้ ความเพียงพอของรายได้

จำนวนสมาชิกในครัวเรือนที่อาศัยอยู่ด้วยกัน

ระยะเวลาที่ใช้เดินทางจากบ้านมาโรงพยาบาล

สวัสดิการการรักษาพยาบาล

ระยะเวลาที่เจ็บป่วยด้วยโรคลิ้นหัวใจพิการ

จำนวนครั้งที่เข้ารับการรักษาในโรงพยาบาลในรอบปีที่ผ่านมา

อาการที่เกิดขึ้นในช่วง ๗ วันที่ผ่านมา

.....

.....

การรักษา

.....

.....

ระดับสมรรถภาพของหัวใจ

ระดับการรบกวนชีวิต ในรอบ ๗ วันที่ผ่านมา โดย ๑ หมายถึง รบกวนน้อยที่สุด ๑๐ หมายถึง รบกวนมากที่สุด

๑.....๒.....๓.....๔.....๕.....๖.....๗.....๘.....๙.....๑๐

รบกวนน้อยที่สุด

รบกวนมากที่สุด

Appendix I: Participant Characteristics

Thirty individual interviews were conducted with 20 women and 10 men. A general demographic profile for the entire sample of 30 informants is provided in Table 1. More than half of the participants were between 30-59 years old. The education level of the majority of the participant was primary level (27 people) and twenty two participants were married.

Table 1 Demographic characteristics of participants

Characteristics	Frequency
Gender	
Female	20
Male	10
Age (years)	
30-39	7
40-49	8
50-59	7
≥ 60	8
Marital Status	
Single	3
Married	22
Widowed / Divorced / Separated	5
Education	
Primary level	27
Secondary level	3

Table 2 Most of the participants were farmers (20 people). Only four participants had an adequate income.

Table 2 Economic status of participants

Characteristics	Frequency
Occupation*	
Farmer	20
Laborer	3
Weaving	1
Merchant	1
Unemployed	9
Average patients' family income (baht/year)	
500-3,000	5
3,001-6,000	4
6,001-10,000	5
> 10,000	12
Uncertain income	4
Adequacy of income	
Adequate	4
Adequate with debt	4
Inadequate	1
Inadequate with debt	21
Source of funding	
30 baht card	7
Free card	13
Elderly card	4
Disability card	3
Government card	3

* Some respondents were working at more than one job

Table 3 shows that the majority of the participants had a New York Functional Heart Class II (24 people). Most of the participants had been ill for more than five years (23 people). The majority of the participants had dyspnea on exertion (20 people) and

shortness of breath (15 people) (Table 4). Most of the participants had moderate level of distress (13 people) and severe level of distress (10 people).

Table 3 Clinical Characteristics of participants

Characteristics	Frequency
Functional class	
Class I	4
Class II	24
Class III	2
Duration of illness (year)	
1-5	7
>5-10	19
> 10-15	3
> 15	1

Table 4 Symptoms and distress experiences of participants

Characteristics	Frequency
Symptoms*	
Dyspnea on exertion	20
Shortness of breath	15
Palpitation	9
Chest pain	8
Insomnia	5
Dizziness	4
Cough at night	2
Nocturnal diuretic	2
Paroxysmal Nocturnal Dyspnea	1
Level of distress	
Mild (at level of 1-3)	7
Moderate (at level of 4-6)	13
Severe (at level of 7-10)	10

* One person has more than one symptom

Table 5 Health care experiences of participants

Characteristics	Frequency
The cost of traveling to hospital (Bath)	
≤ 100	13
101-200	12
More than 200	4
The traveling time (Minute)	
30	8
31-60	9
61-120	10
More than 120	3
The treatment	
Operation	
No operation	19
Valve replacement	9
Balloon valve dilatation	2
Drugs	
Warfarin	28
Digoxin	24
Diuretics	20
Propanolal	7
Peniciline	6
Enalapril	4

Table 5 shows that 16 participants spent more than 100 bahts on traveling to hospital. The majority of the participants (22 people) took more than 30 minutes to travel to hospital. Most of the participants did not undergo an operation (19 people). The majority of participants were prescribed warfarin (28 people), digoxin (24 people) and diuretics (20 people).

Appendix J: The Interview Guide

The Interview Guide

Interviews will be conducted with initial questions and used as the guideline for interviews. The researcher will use the interview guideline flexibly when interviewing each participant. The interview questions may include:

1. illness experiences
2. experiences in health care
3. need and expectation of care and treatment
4. quality and quantity of health care provisions and outcome of care and treatment

Interview guideline:

1. How would you describe about your illness?
2. What is your view about care and treatment?
3. Could you describe the most important care and treatment for your illness?
4. Tell me about thoughts and feeling about care and treatment of your illness?
5. How would you describe the outcome of care and treatment?
6. What do you think are the most important ways to care and treatment valvular heart disease?
7. What helps you to manage your life after you have got valvular heart disease?
8. What has been the most helpful to you during illness? How this been helpful?

Appendix K: แนวการสัมภาษณ์

แนวการสัมภาษณ์

ข้อคำถามที่ใช้เป็นแนวทางในการสัมภาษณ์ประกอบด้วย

๑. ประสบการณ์การเจ็บป่วย
๒. ประสบการณ์เกี่ยวกับการดูแลรักษา
๓. ผลการดูแลรักษา
๔. ความต้องการและความคาดหวังเกี่ยวกับการดูแลรักษา

แนวคำถาม

๑. เมื่อท่านทราบว่า เป็นโรคลิ้นหัวใจพิการ มีอะไรเปลี่ยนแปลงและเกิดขึ้นกับตัวท่านบ้าง
๒. ท่านให้ความหมาย อธิบายการเจ็บป่วยด้วยโรคลิ้นหัวใจพิการอย่างไร
๓. ขอให้ท่านบอกและอธิบายการดูแลรักษาที่ท่านคิดว่าสำคัญที่สุดในการดูแลความเจ็บป่วยของท่าน
๔. ช่วยบอกและอธิบายความคิดตลอดจนความรู้สึกของท่านเกี่ยวกับการดูแลรักษา
๕. ช่วยอธิบายผลของการดูแลรักษา
๖. สิ่งใดที่ท่านคิดว่าสำคัญในการดูแลรักษาโรคลิ้นหัวใจพิการ
๗. อะไรที่ทำให้ท่านสามารถดำเนินชีวิตได้ตามปกติหลังจากเป็นโรคลิ้นหัวใจพิการ
๘. สิ่งใดที่มีประโยชน์ต่อท่านมากที่สุดระหว่าง การเจ็บป่วย และมีประโยชน์ต่อท่านอย่างไร

Appendix L: Pseudonym List

Aphichard	Ardoong	Athipod
Bhenpapha	Bhunchorn	Chaichana
Chidchanok	Chomphunuch	Isari
Jintana	Luddawan	Neunchawee
Nuchchanad	Phisud	Phrom
Phloydang	Pitsuda	Reingjai
Sadudee	Somsongsang	Soybhet
Sunisa	Thongphakay	Thongsay
Thumphitak	Udomluk	Usawadee
Wanchai	Wason	Witchaya

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