

Understanding Taiwanese Family Adaptation to Chronic Heart Failure

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## Dedication

This dissertation is dedicated to my father, Chin-Hsien Peng and my brother, Szu-Chai Peng, who though are not able to witness me getting a Ph.D., are with me in spirit.

## Abstract

This hermeneutic phenomenological study explored the lived experiences of individuals and families adapting to living with chronic heart failure, using the Family Adjustment and Adaptation Response Model as the guiding theoretical framework. The report was based on the analyses of 17 interviews with either individuals or families from a medical center in a metropolitan city in Taiwan. The findings showed that chronic heart failure struck the family with ripple effects to multiple areas of family life—the well-being of individual family members, family functioning and interactions, and the relationships between the family and its social networks and community. The processes of adaptation involved families' efforts to reduce or manage demands by utilizing their existing capabilities, to strengthen and expand resources (including improving family functioning patterns), and to change meanings that shaped how they responded to their situations. Many aspects of the experiences reported by these families in Taiwan were similar to what has been described in previous studies of family experiencing chronic heart failure in other countries. Nevertheless, the findings demonstrated that the influences of cultural or religious beliefs in family meanings played an important role in the process of family juggling the pile-up of demands with their capabilities. Implications for health care providers and future research are offered.

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## **Introduction**

There has been a body of literature accumulating regarding the impact of illness on various family members, as well as the impact of family on individual family members' physical health, and the role of family in all aspects of health care (Campbell, 1986; Campbell & Patterson, 1995; Turk & Kerns, 1985). Chronic heart failure (CHF) is one of the health conditions investigated extensively in western countries due to its increasing prevalence, mortality, and medical cost. In the United States alone, an estimated 5.1 million adults age 20 and older have CHF, and the incidence increases with age. CHF was a primary cause of nearly 56,410 deaths and a contributing cause of 274,601 deaths in 2009 (American Heart Association, 2013). It is the number one cause of hospitalizations for Americans age 65 years and older (Rich, 1997); and the estimated total direct and indirect cost for the diagnosis and treatment of CHF in 2013 is \$32 billion (American Heart Association). These numbers are expected to rise steadily in the near future with the aging population in developed countries and the increasing numbers of people surviving from cardiac event(s) or other types of precipitating conditions earlier in life (Cowie, Mosterdft, Wood, Deckers, Poole-Wilson, & Sutton et al., 1997; McMurray & Stewart, 2000).

In order to be better prepared for serving this increasing population, scholars and clinical practitioners in the health field have paid major attention to investigating the well-being and quality of life for individuals and caregivers who live with CHF (e.g., Bosworth, Steinhauser, Orr, Lindquist, Grambow, & Oddone, 2004; Brännstöröm, Ekman, Boman, & Standberg, 2007). Research shows that both parties are deeply impacted by

this illness, suggesting that the experience of adapting to living with CHF is indeed a family affair (Callahan, 2003; Hilscher, Bartley, & Zarski, 2005). However, a review of the related literature shows that empirical research on the family unit remains in its infancy despite the overall increased clinical interests in family-centered care. Most studies in this body of literature investigate persons' experiences of adapting to living with CHF at individual level constructs (e.g., self-efficacy, psychological distress, etc.). In addition, most studies have been deficit-oriented, in that individual or family stresses are the focus of the research questions or interpretations rather than family strengths and resiliencies.

A similar trend of issues regarding the CHF literature can be found in Taiwan. Only a few empirical studies that investigate persons' experience with CHF can be identified. Research interests of those studies concentrate on depression, knowledge of the illness, and self-care behaviors of the persons with CHF. The experiences of families adapting to living with CHF have not been addressed adequately in Taiwan. Family members have not been the focus of inquiry nor have they been involved in any part of the research process. Familial level of adaptation, to my knowledge, has not been examined. This is not surprising given that the family field has not been officially established in Taiwan until recent years. The available studies have been conducted by health professionals whose medical training is mainly individually-focused. Heart diseases have been the second leading cause of death in Taiwan for many years, for instance, causing 11.1 percent of total deaths in 2012 (Ministry of Health and Welfare, 2013). As suggested by Cowie and his colleagues (1997), Taiwan is likely to have

increasing numbers of people diagnosed with CHF along with the advances in treatments of heart diseases and ageing of the population. Since living with chronic illness is a contextual experience, it is important for health professionals in Taiwan to begin to understand family experience of adapting to living with CHF through empirical research.

### **Purpose of Research**

The purpose of the current study is to identify key components of family strength and family resiliency in the process of adapting to living with chronic heart failure (CHF) while we try to understand challenges facing the families in the context of Taiwan. In other words, the current study aims to answer the question: What challenges and protective processes are present in the process of adapting to CHF for families in Taiwan?

### **Contributions of This Study**

The findings of this study will enhance our understandings of challenges as well as protective family processes involved in the adaptation process to living with chronic heart failure (CHF) in Taiwan. This new knowledge will be useful for health professionals to help families to identify and enact their protective processes as soon as the families face the challenges of CHF. The new knowledge will also help the general public in Taiwan to accept and support families who go through this adaptation process. Furthermore, the findings of this study will have implications for the appropriateness of applying the Family Adjustment and Adaptation Response (FAAR) model to a Taiwanese sample and for potential modifications needed for future development of applications of the theory.

## **Review of Related Literature**

Chronic heart failure (CHF) is a syndrome that develops slowly as a consequence of damage caused by any structural or functional cardiac disorder, such as coronary artery disease, chronic hypertension, cardiomyopathy, valve dysfunction, alcohol misuse or viral infection. It is often not recognized until a more advanced stage with a group of clinical symptoms and signs secondary to circulatory and neurohormonal responses to abnormal left ventricular function. Common symptoms of CHF may include dyspnea, fatigue, limited physical activity tolerance, pulmonary congestion, and peripheral edema. These symptoms may result in frequent office visits and hospital readmissions (Hunt, Abraham, Chin, Feldman, Francis, Ganiats et al., 2005).

Treatment of CHF usually starts with lifestyle regimens, such as dietary sodium and fluid restriction, exercise training, limitation of overly strenuous physical activity, weight monitoring, and smoking cessation. Pharmacological therapy is also added in the treatment plans, including but not limited to, diuretics,  $\beta$ -blockers, Angiotensin Converting Enzyme (ACE) inhibitors, Angiotensin receptor blockers, and Adosterone blockers (Doba, Tomiyama, & Nakayama, 1999; Hunt et al., 2005). Mechanical assist devices and surgical strategies may be utilized with more advanced CHF patients. When CHF is no longer treatable medically, heart transplantation or other types of heart replacement therapies may be considered as viable treatment options for persons with end-stage CHF (Swedberg, 2005).

Since the trajectory of CHF is often characterized by disabling, progressive, and irreversible functional decline with uncertain prognosis that demands daily management

as well as invasive and/or intensive medical care at times, healthcare professionals have been concerned about the well-being and quality of life for families living with this illness. A general conclusion across previous studies is that, in addition to the physical symptoms, CHF impacts on multiple dimensions of daily life that requires constant efforts of the family to cope and to adapt. Although research suggests that the response of individuals and families to CHF varies, I will, in the following section, describe the main findings of previous studies regarding stresses facing families who live with this illness, and coping strategies used by this population.

### **Stresses.**

*Role limitations of the persons with CHF.* Loss of functional ability and its psychological effects are major sources of dissatisfaction in day to day living among persons with CHF (Grady, Jalowiec, White-Williams, Pifarre, Kirklin, & Bourge et al., 1995). These people often have symptoms that are debilitating, which limit them from engaging in activities they used to do or want to do, such as working, family responsibilities, and social activities with family and friends. Use of diuretics, a common form of medication therapy for CHF, also significantly affects the ability of persons with CHF to participate in social activities. As a result, they often report feeling imprisoned by their failing bodies and hindered from being themselves (Ekman, Ehnfors, & Norberg, 2000; Nordgren, Asp, & Fagerberg, 2007). Grief and loss are common emotional responses to their loss of social roles associated with daily activities (Zambroski, 2003). For instance, some persons with CHF are frustrated that they are unable to work, which causes financial strain. Plus, failure to accomplish personal and professional goals leads

to a sense of personal failure and meaninglessness in life (Nordgren et al.). Being unable to meet family roles and maintain social roles within their social circles or their profession also evokes a sense of uselessness, guilt, and isolation in persons with the illness (Evangelista, Kagawa-Singer, & Dracup, 2001; Nordgren et al.).

Being physically limited also means that persons with CHF have to depend on others in performing daily functioning. In fact, not only do persons with CHF struggle with the loss of independence (Evangelista, et al., 2001; Nordgren et al., 2007), but caregivers are also stressed by added-on responsibilities. Brännstöröm, Ekman, Boman, and Standberg (2007) revealed that some caregivers in their study experienced physical burden and sleep disturbances because of assisting the persons with CHF (e.g., dressing, cooking, cleaning, and shopping) and worries regarding the conditions of their loved ones. Some caregivers were so worried that they were unwilling to leave their loved ones home; as a result, they had problems keeping up their own interests and became socially isolated as well.

***Emotional and psychological distress.*** Both persons with CHF and their caregivers have been documented as experiencing moderate to high level of psychological distress, with the patients being more distressed than the caregivers (Evangelista, Dracup, Doering, Westlake, Fonarow, & Hamilton, 2002; Mårtensson, Dracup, Canary, & Fridlund, 2003; Rohrbaugh, Cranford, Shoham, Nicklas, Sonnega, & Coyne, 2002). For the persons with CHF, feelings of frustration and depression arise as a result of facing challenges associated with limited physical ability and loss of social roles (Bosworth et al., 2004; Zambroski, 2003). For the caregivers, depression comes from chronic stress associated

with bearing the responsibility of looking out for their loved ones and providing care on a regular basis (Brännstöröm et al., 2007).

The unpredictability and uncertainty of CHF process also lead to a great deal of anxiety and fear among persons with CHF and their caregivers (MacMahon & Lip, 2002). They fear a sudden worsening in the patients' conditions and worry that they do not have enough information and knowledge to recognize the symptoms and to decide on treatment options and systems of care, which might result in death of the patient (Brännstöröm et al., 2007; Ekman et al., 2000; Evangelista et al., 2001; Mahoney, 2001; Winters, 1999). Persons with CHF also fear losing control over their physical ability, the possibility of inability to be productive or return to work, and being a burden to their family and friends (Bosworth et al., 2004; Evangelista et al., 2001).

***Loss of sexual intimacy and other relational issues in the couple/family.*** Loss of sexual intimacy was commonly experienced among couples living with CHF. In a sample of 62 persons with a New York Heart Association (NYHA) classification III or IV heart failure, approximately three quarters of them reported a marked decrease in sexual interest and in the frequency of sexual relations since illness, a quarter had ceased all sexual activity, and a half experienced a marked reduction in sexual satisfaction (Jaarsma, Dracup, Walden, & Stevenson, 1996). Westlake and colleagues (Westlake, Dracup, Walden, & Fonarow, 1999) conducted a study examining sexual relationship issues among 63 couples living with CHF and found that both the persons with CHF and their partners were troubled by decreased frequency in sexual activities. However, both studies

indicated that changes in sexual relationship did not affect the marital relationship negatively.

Another relational issue in the literature is that of protective behaviors—hiding worries and troubled thoughts and feelings from each other—among family members as they strive to cope with CHF. For example, persons with CHF hide their physical discomfort and delay going to the doctor or being hospitalized until absolutely necessary partially because they want to retain their independence and do not want to be a burden to their family members (Zambroski, 2003). On the other hand, caregivers experience being constantly worried and alert to be ready to step in and to rescue, but they tend to avoid talking about death with the person with CHF (Brännstöröm et al., 2007). This form of relational coping strategy was seen as not helpful but as creating increased psychological distress in individual partners as well as problems in the couple relationships for male post-myocardial infarction patients and their wives (Suls, Green, Rose, Lounsbury, & Gordon, 1997). Although there is limited understanding of couple relationship and family dynamics in response to CHF, a similar pattern of results from this population can be anticipated.

***Lack of knowledge and information about CHF.*** Stull and his colleagues (Stull, Starling, Hass, & Young, 1999) suggested that information and knowledge about CHF are central to the adaptation process for persons with the illness. However, previous studies showed that approximately 40% of persons with CHF lacked understanding of this illness, including the nature and seriousness of their own condition (Buetow & Coster, 2001; 林敏玲、邱艷芬，2001). This lack of understanding among persons with CHF

might have reinforced a belief that nothing could be done about their symptoms (Rogers, Addington-Hall, Abery, McCoy, Bulpitt, & Coats et al., 2000) and was correlated with poor self-care behaviors (林敏玲、邱艷芬). Lack of open communication between the persons with CHF and their doctors was also commonly identified in these studies. While some persons with CHF viewed this as problematic (Rogers et al., 2000), others indicated that they did not want to know about their conditions or additional information on this illness (Buetow & Coster, 2001). Nevertheless, two studies (Bosworth et al., 2004; Nordgren et al., 2007) revealed that family and friends had difficulty understanding the full range of disease problems or the severity of patients' conditions, which at times resulted in hard feelings in the persons with the illness and interfered with their abilities to cope with CHF.

**Coping strategies.** Coping strategies are often seen as mediating factors between the stresses and the adaptation outcomes (MacMahon & Lip, 2002). Here I summarize three major coping strategies widely documented in the related literature.

***Making accommodations.*** After understanding the nature of CHF, both persons with the illness and their caregivers tried to learn how to live within the changed and limited life situation. They changed lifestyles, and adjusted daily life activities and routines according to the patients' physical abilities and needs (Brännstöröm et al., 2007; Nordgren et al., 2007; Stull et al., 1999). In some cases, they replaced previously enjoyed activities with new ones that better matched with the current condition of the patient to make life more pleasurable and joyful in the midst of living with CHF (Bosworth et al., 2004).

***Enacting resources.*** Families utilized a variety of resources to deal with challenges brought about by CHF. For instance, the persons with CHF used their sense of joy and humor to ease their discomfort (Ekman et al., 2000); they sought information about the illness and relied on their own past experience to determine the severity of their conditions and to take corresponding actions (Ekman et al.; Zambroski, 2003). Inputs from social support networks, health professionals, and/or families who had similar experiences were noted as valuable resources. A trusting relationship among family members and between the family and health professionals was also crucial for the families, especially when the persons with CHF were in such a severe condition that they could not make decisions for themselves (Brännstörms et al., 2007; Ekman et al.).

***Finding meaning/spirituality.*** Previous studies suggest that adapting to living with CHF involves a process of family members finding and establishing meaning in their illness experience (Mahoney, 2001; Stull et al., 1999). As suggested by Mahoney, the normal course of family life is disrupted in the initial phase of their experience of CHF followed by incoherent and incongruent understanding of the illness. Some acknowledge regrets regarding past lifestyles that resulted in the disease process (Westlake & Dracup, 2001), but others question and resent why they had to go through this experience (Evangelista et al., 2001). Family members then strive to make sense of and find purpose in their current experience, which is reported to be an important mechanism in the adaptation process (Bosworth et al., 2004). In previous studies, metaphors that family members had used to describe their experience included: a challenge to overcome, a value to make them strong, a weakness or an enemy to fight, a

gift from God, or a roller coaster to ride (Bosworth et al.; Brännstörms et al., 2007; Evangelista et al., 2001; Mahoney). Individual, familial, and social values, spiritual or religious beliefs, and life philosophy are often involved in this meaning-making process (Callaban, 2003; Stull et al.; Westlake & Dracup). The meanings that individual family members derive from the illness experience influence how they perceive the illness and their responses (emotions and actions) regarding day to day living, decisions of care, and the future (Evangelista et al., 2001). For example, some persons with CHF, elders particularly, come to accept their conditions as a part of natural life and embrace the life they had left with their families (Ekman et al., 2000; Evangelista et al., 2001).

In summary, the available research concerning family members' experiences of adapting to living with CHF has revealed that persons with the illness and their caregivers, mainly marital partners, are all impacted by the illness. Stress arises as a result of changes across physical, psychological, emotional, relational and social aspects of daily life. These changes and challenges necessitate family members to make adjustments in their daily life activities. The experience of adapting to living with CHF involves use of individual, familial, and social level of resources; and most importantly, a meaning-making process.

### **Critique of the Heart Failure Literature**

Despite the contributions that previous studies have made to date, there are questions not yet fully answered in this body of literature. First, most studies reviewed in this chapter have focused on individual family members' experiences of CHF. Only four studies (Evangelista et al., 2002; Mahoney, 2001; Mårtensson et al., 2003; Rohrbaugh et

al., 2002) collected information from both the persons with CHF and their caregivers. It is apparent that CHF does not only impact daily functioning and the emotional state of the persons with CHF and their caregivers, but also has direct consequences for the family unit, such as family roles, family routines, family communication and interaction, or family functioning. Since much of the care and out-of-hospital management of CHF occurs in the family setting (Young, 1991), it is important for family scholars and health professionals to understand changes and challenges that accompany CHF at the family level as well as family efforts to adapt to living with this illness (Hilscher et al., 2005).

Second, studies that involve or focus on caregivers' experiences of adapting to living with CHF have primarily been limited to spousal partners. By emphasizing the spousal partners they leave out other family members who may well be impacted by CHF. In addition, some families may not be organized around a marital unit when it comes to dealing with challenges associated with CHF. Since the incidence of CHF increases with age and reaches approximately 10 per 1000 population after age 65 (American Heart Association, 2010), it is possible that adult children are impacted and/or involved in the care of persons with CHF, depending on the age of the children and/or other factors (e.g., geographical distance, emotional proximity, commitment to care, or demands from other dimensions of their lives) (Callahan, 2003). Thus, it is important to include family members beyond the spouse in future research.

Third, although some studies identified coping strategies utilized by families, most of the available studies concerning individual and/or family adaptation to living with CHF have been deficit-oriented. They focused on individual or family problem areas

such as functional impairment, psychosocial distress, deteriorated quality of life, poor self-care behaviors, inadequate knowledge of the illness and treatment, or maladaptive coping styles (e.g., Bennett, Cordes, Westmoreland, Castro, & Donnelly, 2000; Klein, Turvey, & Pies, 2007; Mårtensson et al., 2003; Rogers et al., 2000). Nevertheless, the results of Rohrbaugh et al. (2002) showed that marital partners perceived a high level of marital quality in spite of feeling psychologically distressed individually. Participants in the study of Jaarsma et al. (1996) reported satisfactory marital relationship even if they experienced loss of sexual intimacy. These results not only suggest the value of exploring family level of adaptation, but also indicate the importance of investigating the protective processes that facilitate couples and families successfully dealing with challenges related to CHF.

Fourth, the current understandings of individual and family adaptation to living with CHF are mainly based on research conducted with samples of male Caucasian patients and/or their caregivers in western countries (e.g., the United States and Sweden). Little is known about the illness experience of other ethnic groups in these countries or people in other parts of the world. Kleinman (1988) suggested that the illness experience of individuals and families (including how they define, perceive, and treat the illness) is influenced by the society and culture in which they are embedded. For instance, traditional Chinese philosophy of Confucianism emphasizes the centrality of the family when managing life problems. As a consequence, persons with CHF may seem to be passive in the management of their illness; instead, they may turn over to their families all the decisions of care (Kleinman; Taylor-Piliae & Molassiotis, 2001). Therefore, it is

important to investigate family experience of adapting to living with CHF with diverse groups, so that health professionals can have a better chance of providing culturally appropriate care.

Of course, there is still a long way for family scholars and health professionals to go to fully understand the complexity of family adaptation to living with CHF. The current study explores lived family experiences in a group of families who live with CHF in Taiwan, using the Family Adjustment and Adaptation Response (FAAR) Model as the guiding theoretical framework.

## **Methods**

The current study attempted to identify key components of family experiences in the process of adapting to living with chronic heart failure (CHF) in the Taiwan context. A qualitative research design was chosen in the study because qualitative inquiry is helpful to “uncover and understand what lies behind any phenomenon about which little is yet known” (Strauss & Corbin, 1990, p.19). In addition, qualitative inquiry closely captures the complexity of a phenomenon (i.e., a meaning, a process, or an experience) from informants’ perspectives and contexts (Bogdan & Biklen, 1998; Denzin & Lincoln, 2000), which fits the goal of this study.

The study was particularly informed by hermeneutic or Heideggerian phenomenology, which aims at gaining a deeper understanding of meanings embedded in everyday aspects of human experience as it is lived (Van Manen, 1990). Hermeneutic phenomenology was a suitable methodology for this study because it is used to discover what a particular phenomenon is and what is not, and because it allows for the illumination of meaning attributions in context (Wilding & Whiteford, 2005). While the data generated from this phenomenological perspective documents the subjective meanings that adapting to living with CHF has for participants and their family, the text allows me to develop knowledge that is respectful of the social realities of those living within this situation. [A more thorough description of hermeneutic phenomenology can be found in Appendix A.]

## **Theoretical Framework**

In order to answer the research question, the Family Adjustment and Adaptation

Response (FAAR) Model (Patterson, 1988) was adopted as the guiding theoretical framework in the current study. The FAAR model suggests that families attempt to maintain or arrive balanced functioning (*family adjustment* or *family adaptation*) by using *family capabilities* (resources and coping behaviors) to manage *family demands* (stressors or strains) through their interactions with *family meanings* (Patterson, 1988, 2002a). In this model, family demands include normative and nonnormative stressors (discrete event of change), ongoing family strains, and daily hassles. Family capabilities include tangible and psychosocial resources that families have, and active coping behaviors that families do. Both family demands and capabilities can emerge from individual family members, the family unit, or from various community contexts (Patterson, 2002b). Regarding family meanings, Patterson and Garwick (1994) postulate that when confronted with adversities families implicitly construct meanings about the specific stressful situations (family demands and capacities), their identity as a family, and their view of the world. This process helps families to comprehend their experience and to decide the appropriate responses (emotions and actions) to the adversities.

While the FAAR Model provides a family strength-based lens to this study, little is known about the appropriateness of applying this model directly to understand families in Taiwan. However, it serves as a starting point for me to organize and interpret the findings. Nevertheless, ecological and cultural contexts will be taken into consideration when identifying key components of adaptation processes for families who live with chronic heart failure in Taiwan.

### **Sampling Procedures**

**Sample recruitment.** Participants of the current study were recruited from a Heart Failure Center at one of the top medical centers located in a metropolitan city in Taiwan. Persons with cardiovascular disease are automatically enrolled in the Heart Failure Center on the basis of having a left ventricular ejection fraction (LVEF) of less than 40% documented by echocardiography or ventriculography, regardless of the original reasons they come to this medical center. Appropriate institutional review board approval for this study was received from the University of Minnesota before any contact was made with participants. The sample recruitment procedures involved three steps. First, a cardiologist at the center reviewed his caseload and identified adult patients ( $\geq 18$  years of age) with a history and a diagnosis of chronic heart failure (CHF) as potential participants. Second, the cardiologist and an affiliated nurse specialist informed those identified patients and their caregivers (family members or friends) about the existence of this research during the patients' regular follow-up appointments. I was then introduced to the patients and/or families in person during their doctor visits. Third, I briefly described this study and asked for permission to contact those who orally expressed interest in participating in this research for further details.

In order to avoid the situation where patients and their families felt that they were being forced to participate in this research because of worries about changes in patient-doctor relationship, the cardiologist and the nurse specialist only informed families about this research project and were not directly involved in any other parts of this study. Further contacts were made by me, who was not known by those families on any earlier

occasion. This arrangement allowed potential participants to have free choice of deciding whether or not they wanted to be a part of this research.

**Sample description.** A total of 21 patients, 14 family members, and one friend were approached. Seventeen patients and 12 family members agreed to participate in this study. Those who chose not to participate said that they did not want to participate because of limitations in patients' physical abilities and lack of time. The average age of the patients at the time of interview was 59.7 years (SD 16.3 years, range 21 to 82 years). Fourteen of the patients were male and three were female. Twelve patients were married, one was divorced, three were widowed, and one was never married. Eleven of the patients were diagnosed as having some forms of coronary artery disease in their medical history; one was diagnosed with cardiomyopathy; one was diagnosed with myocarditis; one was diagnosed with aneurysm; and three were on the heart transplant list at the time of their interview. One patient who was in recovery from heart transplantation was not able to participate in the interview due to weakness, but his wife and stepson participated. The demographic information shown above did not include this patient's profile. For the rest of the cases, eight patients were interviewed individually, and nine were accompanied by a spouse (four cases) or other relative(s) (two daughters, one son, one mother, one daughter-in-law, and one brother-in-law) during the interview. Four of the family members who were interviewed were male and eight were female. [See Appendix B for detailed descriptions of family characteristics.]

### **Data Collection Procedures**

I contacted individuals and families who orally expressed interest in participating

in this research either in person or via telephone, and explained the research purposes and procedures. Individuals and families were encouraged to ask questions and to raise their concerns. Face-to-face in-depth interviews were scheduled with those who orally agreed to participate in this study. Informed written consent was obtained from all participants prior to their participation in the interview. A total of 18 interviews were conducted during July-August, 2004. Eight of the interviews were with individual patients; eight were dyads with patients and one other family member; one was a triad with the patient and two family members; and one was a dyad with family members only.

The interviews were conducted at locations based on the participants' convenience and comfort. Eight interviews took place in a research office; three were conducted in a room for individual psychoeducation at the hospital; three were conducted while the patients were hospitalized for examinations that prepared them for heart transplantation; one was conducted while the patient came to the hospital for regular out-patient hemodialysis; and three were conducted at the participants' homes. All interviews were conducted in settings that ensured the participants' privacy, including the ones at their homes. Upon completion of the interview, participants received a gift (with value of \$7-10 USD) for participating in the study.

Each interview lasted from 1 to 2 hours, which included (a) a brief introduction about the researcher and about the research, (b) assurance of informed consent, and assessment of participant's comprehension, and (c) the actual interview. The official written consent document was given out and discussed in the beginning of the interview. A signature on the written consent was required before the interviews proceeded. A semi-

structured, in-depth face-to-face interview method was utilized in the study. Semi-structured interviews allow the researcher(s) to pursue areas of particular interest while maintaining considerable flexibility in digressing and probing as novel categories emerge (Berg, 2007; May, 1991).

An interview schedule was used to help guide the course of the interview. English translation of examples of questions asked in Mandarin included: “What would you say if you were to tell a story about what life has been for your family since the diagnosis of heart failure in one of your family members?” “In your experience of dealing with health issues (heart failure), who are usually involved and who are not? Why?” “How do you feel about heart failure, and its impact on you and your family?” “What kind of strategies and/or resources has your family been using to cope with this situation?” “Overall, what are the key elements that make your family life easier (or more difficult) in the situation of dealing with heart failure?” (See Appendix C for the complete English translation of the interview schedule). These questions were asked to participants not necessarily in the order they were presented in the appendix. Participants were encouraged to talk about anything related to their perceptions and experience of what and how their family adapted to living with chronic heart failure, and not to feel limited to the questions they were asked. Thus, not every question in the appendix was asked in every interview, depending on the appropriateness of the particular questions to participants’ conditions or to their prior responses to the general questions. Rather, the interviewer(s) used probes such as further questioning and/or reflecting back information the participants had shared as a

way to draw out more complete stories from participants and to clarify and stay close to their lived experiences.

All interviews were audiotaped and transcribed verbatim in Mandarin by trained research team members including myself. Linguistic details and nuances such as laughter, crying, silences, emphasis etc. were also marked for further analyses. I double checked all transcripts to ensure the reliability of the transcription. All research staff members were required to sign a non-disclosure agreement before they were involved in this project. Unfortunately, one interview tape malfunctioned, and therefore this interview was not transcribed and has been excluded from the analysis. But my memory of that interview helped to inform the data analysis.

### **Data Analysis Procedures**

There is no rigid set of rules to structure the research process in hermeneutic phenomenology. What it requires is to use good judgment and principles that are responsive to the particular questions and subject matter (Polkinghorne, 1983; Madison, 1988). Most important is to make the researcher's preconceptions explicit and to explain how they are used in the interpretation of the data and in generating findings (Lavery, 2003; Lopez & Willis, 2004). These preconceptions, or horizon of understanding, may include but not be limited to biases, assumptions, personal experience and knowledge, and theoretical and philosophical influences.

A template approach, as outlined by Crabtree and Miller (1999), was used to analyze the transcripts (in Mandarin) in this study. First, a preliminary coding template was developed based on key concepts in the Family Adjustment and Adaptation

Response Model (FAAR) plus previous research findings. Three broad code categories representing key components that shaped the family process and outcomes during the process of adjustment and adaptation formed the preliminary coding template: pile-up of family demands, family capabilities, and family meanings. Second, I listened to all the interview tapes and read through all the transcripts a number of times to be familiar with the text and to see if the coding template was appropriate to capture participants' narratives. Third, the template was used to conduct initial coding of text, in that I matched the codes with segments of the transcripts selected as representative of the code. The segments of similar or related text were then sorted, clustered, and reorganized. In this process, some initial codes were further refined, modified, or spliced together. It should be noted here that individuals' statements on their families were coded as family level of characteristics while I understood that those were individual perceptions or evaluations of their family. Fourth, I identified themes, or patterns, within each category by examining and connecting chunks of similarly coded texts, and compared those themes with the ones suggested by the coding template. Further modifications of the coding were made so that the themes could fit the data better. During the process of data analysis, I moved from the chunks or pieces to the whole of the words or stories of the participants back and forth several times, and compared one participant's stories with other participants' stories over and over again until a stable set of explanations/comprehensions for the researcher could be mapped. Although presented as a linear, step-by-step procedure here, the data analysis process was rather cyclical, or iterative and reflexive.

## **Trustworthiness**

I adopted several approaches to contribute to the trustworthiness of the research process. In the data collection phase, I and another scholar with experience in qualitative methods and in working with families conducted two interviews together (one dyad and one individual). We shared thoughts and emotional reactions with each other right after these interviews. We also discussed whether or not there was a need to adjust the interview schedule or interview skills so that rich stories of the participants' experiences could be obtained. I audiotaped my impression of the individuals or families and of their experiences right after each of the other interviews. Transcripts of these tapes served as references for interviews that followed and for data analysis.

I kept a reflective journal throughout the whole research process. I documented notes from the literature review, suggestions from my dissertation committee members, dilemmas in the coding process, preliminary interpretations of the interview data, outlines for report writing, as well as my thoughts, reflections, and speculations along each phase of the research process. I used this journal to examine my assumptions and biases, and to question how my interpretations came about (Hertz, 1997). For example, I wrote down my thoughts after I read my first draft of the report: "It is hard not to look at the problem areas of these families since I, as a health professional (nurse and family therapist), am trained to help families to solve their problems." I challenged myself for being deficit-oriented and redirected to giving family strengths more weight in my writing. In addition, I consulted with my advisor via emailing back and forth to examine whether or not the findings, interpretations, and conclusions were supported by the data (Creswell, 1998).

## **Findings**

This report is based on the analyses of 17 interviews. Findings of the qualitative analyses are organized and presented for each of the following domains corresponding to the FAAR model: pile-up of family demands and family capabilities. The domain of family capabilities includes two sub-domains: resources and coping strategies. Findings regarding family meanings are incorporated into the descriptions of family demands and family capabilities in order to show the interactions among these three components. Each domain includes several themes. Descriptions of each theme are supported by use of the English translation of direct participants' quotes in Mandarin. I choose quotes that are more colorful and easier to understand. Some quotes might seem to fit into more than one theme. I use my best judgment about where to put them. In front of each quote I list the identifying number for the patient's family and the role of the interviewee in that family. Pseudonyms are utilized in the quotes in order to protect participants' anonymity.

### **Pile-Up of Family Demands**

When asked the impacts of CHF on the family, four themes coded as demands emerged: (a) initial stressors related to CHF, (b) hardships developed overtime as direct results of CHF, (c) inconveniences and conflicts regarding daily management of CHF, and (d) difficulties of balancing multiple family needs. [See Appendix D for the entire list of coding in the domain of family demands.]

#### ***Initial stressors related to CHF.***

*Signs of CHF and family responses.* Sixty percent of the participating ill family members found out that they were in a CHF state through an unexpected cardiac event,

while the remaining 40 percent of them progressed from various cardiovascular disorders. Reported signs of CHF included: shortness of breath, edema, cough, chest pain, physical weakness, dizzy, weak muscle power, and liver or kidney failure. All of the participating family members with CHF had experiences of being in a critical medical condition and of multiple hospitalizations.

In seven interviews, participants shared that symptoms came very fast during the acute phase. Persons with CHF disclosed that they passed out and did not have memories of what happened. Family members, on the other hand, experienced a great deal of fear because they witnessed the ill family member struggling and falling unconscious without knowing what was going on.

Person with CHF (3): They (family members) cried while they were telling me what happened to me at the emergency room. I lay on the bed. I knew nothing. They were much more in pain than I was. I felt sorry for putting them through this experience.

Wife (5): My feeling during that time? Fear! My fear came from not knowing. I didn't know the severity of his condition. I never thought that he would need to go through heart transplantation. I didn't know about the consequences of this surgery. I never got in touch with this area of information, so I was very fearful.

*Physical limitations of persons with CHF.* For nine participating ill family members, the first change in their life after being diagnosed of CHF was that they reduced or were told to limit their activities because of weak physical abilities. Most of them were no longer able to engage in outdoor activities that they used to enjoy,

including taking a walk, playing sports, hiking, and traveling. Some of them stopped keeping up with their old hobbies, such as painting, writing, or shopping.

Person with CHF (4): What has changed since having this disorder is that my physical abilities are going down, and I can't move around a lot like before.

Daughter (4): That's right. She can't move too much. She used to visit my aunt in China once in a while, but now she needs to get permission from her doctor before we make any travel plan... Walking from her bedroom to the office next door then the way back is the only exercise she can take. She can't tolerate too much... She used to do painting at times, but even that is difficult for her now.

One couple revealed that the frequency and satisfaction of their sexual intimacy was compromised due to impaired cardiovascular functioning and side effects of CHF medication.

*Health care system strains.* In the beginning of facing CHF, families expected to receive help from health professionals. However, six families complained about strains from health care systems, such as delays on diagnosis, tests, and referrals, lack of skills or competence, limitations on current knowledge of disease, health resource discrepancy between rural and metro area, and lack of emotional support.

Person with CHF (2): I was almost killed by a physician during my hospitalization one time. It happened the day I was transferred from the ICU to a regular ward. A physician came and examined my condition. He told me that I was severely dehydrated, and that I needed to drink as much liquid as possible; otherwise, my condition would not get any better. When I was in the ICU, you

know, the nurses only applied a moistened cotton swab on my lips occasionally. That's all I got. When I knew that I was allowed to "drink" water, I was so happy. I drank a big bottle of water right away. But after a couple of hours, I felt that my head was about to blow up suddenly, very, very painful. They sent me back to the ICU and handled the situation. After I got better, that physician came to my bed and knelt on the ground crying for mercy. He said that he was inexperienced and asked for my forgiveness. You see, what patients can do if they are treated by an inexperienced doctor? I was lucky to be saved in the ICU; otherwise, I would be dead by now.

***Hardships developed over time as direct results of CHF.***

*Family caregiving demands.* Both the persons with CHF and their family members revealed that everybody's life was interrupted when having a sick person in the family. They experienced that the persons with CHF needed the most care during the hospitalization period and the duration right after discharge from the hospital. Family members had to be on call all the time and be ready to take unpaid family leave anytime as needed. Some persons with CHF were able to recover and regain independency afterwards while others lost some daily functioning and demanded long-term assistance at home. The caregiving demands were burdensome for some families, particularly for those who lacked resources to meet the demands.

Wife (15): When his condition is okay, life is pretty simple; we go to work, come home, and then go to bed. But when he is sick, oh, all family members would be running around without a break. Last time he was admitted to the hospital, the

older kids and I took turns taking care of him. We went back and forth between home, work, and hospital. Everyone had only two to three hours of sleep a day during that time. We were all exhausted. I wanted to take a rest so bad, I even wished to be hospitalized so that I could sleep for days. Just give me two days; that would be good enough.

Person with CHF (9): I feel that this chronic illness is too big of a burden on a family. Many family members and relatives are impacted. You see, if the family wants to take good care of the patient, someone has to give up his/her job.

Otherwise, the family needs to, has to, spend a lot of money hiring a long-term maid who can look after the sick, like what we have done. But if the family's finances don't allow this kind of expense, family members' choices are limited.

*Changes in family roles and responsibilities.* It was reported in seven interviews that persons with CHF had problems with meeting family roles. Particularly, female participating ill members talked about difficulties in performing domestic family responsibilities, and male participating ill members talked about frustrations of not being able to continue their work and/ or to find a new job that fit their medical conditions.

Person with CHF (13): I was able to keep up with those tasks (cooking meals for the family and babysitting grandchildren) in the beginning. Now I can't; my hands feel tight. Eating with hands is difficult for me, not to mention doing family chores.

Person with the illness (15): It's been two years that I don't go out and work. I am afraid of anything that may harm my heart. I can't lift a bag of concrete powder.

My work requires me to squat down a lot, which is not a comfortable position to me. I have to quit. The family needs money, this disorder really does a lot of damage to my life.

As a result, other family members needed to take on more responsibilities in order to maintain adequate family functioning. Sometimes role reallocation created stress on the member(s) who took on new responsibilities.

Wife (5): My husband used to be a banker, so it was always him who handled the family finances including our foreign assets. After he was admitted to the intensive care unit, he couldn't speak at all, nor could he sign papers or whatsoever. I became very anxious because I didn't know whom to ask when there was a problem, like filing a property tax refund, or anything that needed to be taken care of. I couldn't ask him, I couldn't ask the kids because they knew less than I did. What should I do? I didn't know! I had to figure things out by myself.

*Stress of care-giving and care-receiving.* In six interviews, the participants revealed that giving and receiving care were not easy at times. Some family members who were designated as the primary caregiver felt stressed out when there was no other member available to share the caregiving responsibilities.

Daughter (13): It seems that I am now all responsible for taking care of my mother. She is used to my care so she doesn't want anybody else to do the job. She complains about my siblings. But I have aneurysms too! I have my own family to take care of! I am very tired. I don't know how long I'll be able to

continue this way of life. My sister-in-law is a stay-home mother as well, but she's never stood up and said she'd like to help, never! It's so unfair!

Receiving help from family members or relatives, on the other hand, was distressing for some persons with CHF. They would rather be on their own than bother others because they were afraid to become a burden to their family.

Person with CHF (6): Originally my sister and brother invited me to live with either one of them so that my travel time to the hospital could be much shorter. But I think that they have their own families. Having me would inevitably create inconvenience for them. Of course they didn't think so, but I just felt that way. I have to adjust and face the fact myself anyway. Instead of bringing the pain of this illness to my family, I try to remain as independent as possible.

Wife (6): His siblings are very kind to us. They help us a lot. But that makes me feel stressed. We've owed them too much!

*Constant worries about the patient's condition.* In eight interviews, participants perceived CHF as an unexpected and unpredictable disorder. Symptoms could come fast and severe sometimes. Four persons with CHF articulated that they were often consciously worried about their medical conditions. Facing the threat of death all the time made them feel depressed, fidgety, and sometimes short-tempered.

Person with CHF (6): I feel like facing the threat of death all the time, this is difficult...Ok, I tell myself to let it go, but my family or relatives are always worried about me and ask me "how are things going? Is there anything wrong again?" It's really hard not to ruminate about my medical conditions.

Seven family members also expressed their worries. They feared that the patients' health might go down at any time since CHF was such an unpredictable disorder.

Stepson (5): I used to turn off my cell phone when I went to bed because I didn't like to be disturbed. But I have kept my cell on all the time since my stepfather was hospitalized. My mood has been ups and downs. For instance, I feel frightened every time I get a phone call after eleven P.M. Sometimes I feel I hear the phone ringing when I take a shower.

Mother (9): Being a parent, I watch my daughter suffering. I feel extremely sad everyday. I keep thinking, sigh, what can we do to treat this disorder? When is she able to regain her health? These thoughts are in my head everyday. I am very sad. I am very worried about her condition.

*Reduced social lives.* Five of the participating ill family members revealed that their family and social activities were affected after they had CHF, mostly due to physical limitations and/or fear of the uncertainty of the person's medical condition.

Person with CHF (12): We (friends) used to gather at the tennis club. But after I stopped playing tennis, we seldom contact each other.

Person with CHF (10): I am ill so I can't go out with them (other family members). Sometimes they go visit my in-laws; they don't even ask me if I would like to go with them or not. They think that I am ill; they are afraid that if anything happens to me on the road, they don't know what to do... Now, when I go out, I always carry medicine with me, especially Digitalis. But I haven't traveled with them (family members) for a couple of years.

Family members also mentioned that their social lives were reduced. Major reasons included caregiving demands and fear of the uncertainty of the person's medical condition.

Wife (15): This disease does affect our family life. Sometimes he asks the kids to do him a favor while they are in the middle of doing their homework or something, they have to stop and help him. Because he needs a lot of assistance and I have work to do. They can't go out as freely as they used to.

Stepson (5): I feel that every family member's social life is reduced after he is hospitalized. Like myself, I don't have time to hang out with friends. I think my mood is not good for chatting anyway.

*Financial strains.* In eight interviews, the participants acknowledged that they experienced financial strains. These strains were related to loss of income due to being out of a job, high medical costs (e.g., hospitalization, surgery, medication, or high frequency of doctor visits), payment to outside caretaker(s), ongoing family expenses (e.g., house payment, or raising children), and prior financial difficulties.

Person with CHF (8): I have been out of job for thirteen to fourteen months. The financial difficulty is enormous. In the past, my half-year income was enough to pay my expenses for a year, even during economic downturn. Now I have four doctor's appointments per month. The medical costs are high. Plus, it's not easy to find a stable job, because no one wants to hire a worker who frequently takes days off for medical check up.

Person with CHF (15): My work requires me to squat down a lot, which is not a comfortable position to me. I have to quit. The family needs money, this disorder really does a lot of damage to my life.

Wife (15): Yes, this illness affects our family a lot. We have one less person to earn income and we have one more person spending. Recently I am worried about the family finance. I used the money that I saved for kids' tuition on his medical bill already. I had to ask my son to get a student loan. He is just a senior high school student.

Lack of instrumental support from the community made the families feel disappointed. Three persons with CHF complained that assistance from public funding or local welfare programs was limited. For instance, in the compulsory National Health Insurance (NHI) system in Taiwan, patients with catastrophic illness certification do not have to pay any out-of-pocket expenses, including outpatient or inpatient expenses, when they receive medical care for the illness or related conditions within the certificate's validity period. However, CHF was not qualified as a catastrophic illness in the NHI system.

Person with CHF (6): Of course I am not saying that all cardiovascular diseases should be listed as catastrophic illnesses, but when the heart is already at the failing stage, why cannot CHF be classified as a catastrophic illness? Why is a person with depression qualified for the catastrophic illness certificate?

Depression does not kill a person necessarily, and the government thinks that it is catastrophic. CHF is life threatening, but it is not catastrophic?! It is difficult to

apply for the disability card as well, very difficult. I don't really get any official help to pay medical expenses.

Person with CHF (8): I asked my doctor if I could apply for the catastrophic illness certificate; he said no, because a person with heart failure might get better anytime. But, this disease (CHF) demands frequent medical check up. When you add up the amount of copay, you'll find that the expenses are high. If that amount of money could be saved month after month, that money could be very useful for a person with financial difficulties, like me. Other official social welfare program workers are passive. I have to keep searching for resources myself.

One person with CHF disclosed that financial strains affected his relationships with friends and relatives greatly, which in turn reduced his resources from unofficial support systems.

Person with CHF (10): I lost all my friends and relatives after I got this disease. When people first knew that I was sick; they called or came to visit. Sometimes they brought fruits or red envelopes (a little bit of money). After they realized that this disease was chronic and cost a lot of money, they started to back off. They were much richer than me and had a good life. They were afraid that I would borrow money from them. So they stopped calling, no contact at all.

***Inconveniences and conflicts regarding daily management of CHF.*** Three persons with CHF disclosed that they assumed themselves to be cured and perfectly healthy after they recovered from their first onset. They believed that there was no need for medication and/or other types of treatment regimens until they experienced a second

severe cardiac event. They then, as other participants in the study, realized that living with CHF required a long-term management of the disease and full compliance with the treatment plans on a daily basis. Although most participants recognized that being in full compliance with the treatment plans was helpful to prevent frequent hospitalizations and was crucial for the patients' prognoses, the effort of trying to be compliant itself caused inconveniences and conflicts in some participating families. Dietary restriction and weight control, smoking cessation, medication adherence, and regular follow-up were the four major topics identified as troublesome issues in the interviews.

*Dietary restriction and weight control.* Most persons with CHF said that they did not like the taste of food with low sodium content. But if family members were available to help the patients prepare the meals, it was easier for them to control their diet. Patients who lived alone or whose family members were not available to prepare the meals for them had a harder time to control sodium, fat, and liquid intake from take out food.

Wife (6): When he comes home, I cook for him. But he lives by himself most of the time, he has to dine out or purchase take-out food. Those are usually greasy and salty.

Person with CHF (6): That's right. Take-out food is usually greasier and saltier than home-made food. I try to pick and choose what I can eat. But it's really hard to fully control sodium content and water intake. Mistakes happen easily, including the physicians sometimes. Last time I had one tooth taken out, a resident doctor thought that I couldn't chew very well so ordered several plates of rice porridge to me. After one or two days, I gained two to three pounds and

started feeling uncomfortable. It took us a while to figure out that it was the high sodium content and water in rice porridge that caused the problems, haha.

Person with CHF (13): My daughter-in-law cooks differently than I do. I try not to say anything; otherwise, my son would be upset.

Daughter (13): She (the person with CHF) likes to eat salty food but my sister-in-law cooks plain food. If she complains about it, my brother would be pissed off and says that she is picky. To be honest, salty food is not good for health. But she has been eating this way for decades. It's really difficult for her to change. So, there are quarrels in the house sometimes.

*Smoking cessation.* This issue was identified as problematic in three families.

Although more than three persons with CHF in this study had a smoking history before being diagnosed of CHF, most of them quit afterwards because of uncomfortable physical reactions to nicotine. These particular three persons with CHF disclosed that smoking had been part of their life for a long time, and that it was their way of relating to friends. They did not want to lose their joy of smoking, nor did they want to reject friends' invitation. However, family members were afraid that smoking would do harm to the patient's health. Therefore, quarrels between the patients and family members often occurred.

Wife (1): You are the only one who refuses to quit smoking in our circle of friends. Other people, when they feel a little bit uncomfortable, one hundred percent of their reactions is to quit, really! Like your friend, Chung-Ming, he takes long-term medication and visits his physician once a month, he's already

quit. Another friend, Chia-Hung, told you that his doctor asked him to quit smoking after he underwent a cardiac catheterization for the first time. He thought it was no big deal and continued to smoke, then what happened? He went back to the hospital three months later and needed open heart surgery. He told you his story, but you just didn't listen! I am worried that your condition will worsen, just like Chia-Hung, if you continue to smoke. Everybody who cares about you encourages you to quit, but you don't change a bit.

Person with CHF (1): It's really hard to change once you are used to it.

Wife (1): It's all your excuse. What you need is the determination to change.

Person with CHF (1): But I feel miserable if I don't get to smoke a cigarette.

Wife (1): See (talk to the researcher), sometimes I get frustrated and angry at his responses. I tell him that I won't help him or take care of him when he feels uncomfortable.

*Medication adherence.* Inconveniences and conflicts relating to medication adherence were mentioned in six interviews. Persons with CHF talked about difficulties of remembering when to take what medication. Some of them were concerned that taking medication for an extended period of time might do damage to their body, such as liver and kidneys. Therefore, skipping doses of cardiac drugs happened to a few patients. Family conflicts occurred when family members noticed the patients' skipping behaviors or when the patients were frequently hospitalized due to poor control of their medical conditions.

Brother-in-law (11): He goes out early everyday. He likes to wander around the streets and parks. I don't know where to find him. Every time I ask him if he's taken his medication, he always says "Yes." But I see his medication left on the table a couple of times. I know he must have been lying to me. What's the point of going to his regular follow-up appointment if he's not cooperative? It's totally a waste of my time to accompany him. I tell him that his health is none of my business anymore!

Person with CHF (11): I take medications as scheduled, three times a day. It's just that he's not around when I do it. If I don't take medications, why do I keep coming back for follow-up appointments?

In addition, three persons with CHF revealed that there were times when they had other disorders left untreated because physicians were cautious about potential drug interactions. They had to suffer the pain and discomfort.

Person with CHF (3): My cardiac functioning is going down so everything becomes complicated right now. I had experiences where I suffered from a cold, gout, or like low back pain, the doctors prescribed medication to me. I felt something wrong after I took the pills. I went back to my cardiac specialist and he told me that those drugs were too strong for my body to tolerate. It's difficult to find a drug that's effective and safe for my condition at the same time. I thought, okay, I could live with low back pain but I couldn't live without a heart. It's rough, you know. Sometimes I just have to face this kind of dilemma.

*Regular follow-up.* Five persons with CHF and their family members complained that monthly follow-up appointments were time consuming. Plus, the outpatient clinic was open during office hours only. Both the patients and their caregivers had to take at least one half day off from work, which in some cases created problems at work.

Person with CHF (14): Sometimes it is just annoying. If we want to stay healthy, we must follow the doctor's suggestions, doing this examination today, going through that examination tomorrow, then something else the day after, like blood test, ECG, ultrasound scan, so on and so forth. I have to go through all the tests every once in a while. I feel annoyed. But the fact is that I am the patient, I am ill, these tests are necessary. It's okay with me to spend the whole day in the hospital doing all of that by myself, but my children always accompany me because they are worried about my condition. They have to take one day off from work although their work is busy. It's really inconvenient.

Son (14): The most inconvenient part of it is the long waiting time. Not only do the examinations take time, waiting to be seen by the doctor also feels like taking forever. Three hours of waiting is common. This is really too long...

***Difficulties of balancing multiple family needs.*** Although CHF had placed significant demands on the family's life already, there were other sources of demands that required the family's attention.

*Other illnesses in the family.* Seven persons with CHF disclosed that they were also living with other types of chronic illnesses, including diabetes, kidney failure, stomach cancer, and residual impairment resulted from bone fracture. Sometimes these

illnesses had more physical and/or psychological impacts on their daily life than CHF did. For example, three persons with kidney failure complained that too much of their lives were wasted on dialysis. Their activity arrangements were strictly tied to dialysis schedules, which made them feel that their choices in life, for instance, job, were limited.

Person with CHF (16): Dialysis is terrible and inconvenient. I used to accomplish a lot of things within one day, but now I can't do anything except for lying on the bed during hemodialysis and then half of my day is gone! In addition, I have a small business in China, and I go there every two to three months. I have to find a place for dialysis wherever I go. The medical system in China is not as adequately equipped as it is in Taiwan, especially in rural areas, which is annoying for me. My secretary usually goes to the hospital with me in China, in case anything happens. Not being able to be fully on my own is very inconvenient.

Illnesses of other family members were mentioned in five interviews, such as stomach cancer, adhesion ileus, gallstones, cardiovascular disease, aneurysms, and disabilities caused by polio or meningitis. These illnesses added more strains on to the family, in that the family needed to deal with impacts of multiple illnesses. For the person with CHF, he/she was unable to provide care to the other ill family member, and he/she needed care or assistance from whoever was available to him/her. Similarly, the other ill family member was not only unable to provide care to the person with CHF, but he/she also consumed family resources that were already limited. Healthy family members were faced with high demands while being low in resources.

Person with CHF (10): My wife's legs are paralyzed due to polio. She took care of me in the first one or two years after I got sick. Then her health condition went down, and she was experiencing perimenopause. She and the kids are not able to take care of me, so I must be very careful myself.

*Other ongoing demands in daily life.* Four families reported that they often needed to stretch themselves across multiple tasks of daily living, which made them feel exhausted sometimes. In addition to taking care of the person with CHF, these family members' tasks included going to work, doing family chores, and meeting the needs of other family members (e.g., babysitting grandchildren, and driving kids to daycare, to school or to afterschool programs).

Mother (9): I am worried about my daughter's condition. I am very willing to take care of her, but I can't be here with her all the time. My son is married and has children. I have to go to his place and take care of my grandchildren as well. I go back and forth between the hospital and my son's place sometimes, but my son doesn't like that. It's a struggle.

Daughter (13): Taking care of my mother affects my own family life. I come home from my mother's place around 6 or 7 P.M. I am tired already. But I have to pick up things that I am not able to do during the day time, like cooking, doing the laundry, watching kids' homework, and etc. I don't have much time for rest. My night time sleep is not enough. My husband has long hours of work and he picks up my oldest daughter at the afterschool program before he comes home. They arrive home around 11 P.M. All of us are exhausted everyday.

*Prior ongoing family strains.* Three families revealed that there were some unresolved family issues that obstructed family members in facing the disease jointly. These issues included parent-child conflicts, relational problems with in-laws, and tragic events in the family.

Wife (1): My oldest daughter committed suicide when she was 36 years old. It happened in July. We had no idea why she chose to end her life. She was perfectly okay the day before. The police came and told us that her body was found in a river next morning (tearing). After two months, my husband got ill. They (two events) all happened at once.

Person with CHF (1): I was never sick before that. I was sent to the hospital and underwent cardiac surgery suddenly in September. Before my daughter was gone, I had never been ill.

Wife (1): This daughter cared for him the most. They were very close. If she were still alive, he would listen to her advice and be willing to quit smoking. But she is not...

### **Family Capabilities**

Despite the fact that the families faced the adversities brought by CHF, the participating families were able to identify the strength of their families, including resources available to them, and resources and coping behaviors they utilized or created to deal with strains associated with CHF experience. [See Appendix E for the entire list of coding in the domain of family capabilities.]

**Resources.** When asked what resources were available to the families or resources that they thought were helpful to them in the process of dealing with CHF, three domains of resources emerged: (a) resources of individual family members, (b) family functioning and interaction patterns, and (c) social support.

***Resources of individual family members.***

*Positive attitudes.* In seven families at least one person pointed out that positive attitudes helped them to adapt to living with CHF. For instance, one person with CHF and one family member mentioned that rehabilitation during the recovery phase was a long process. The persons with illness would not have succeeded if they and their family members were not patient with the challenges and frustrations along the way. Others said that being hardy and remaining optimistic helped them to go on with their lives. Sense of humor was helpful in relieving stresses and worries sometimes.

Person with CHF (2): Let me tell you how I stood up again. Patience! A lot of help from patience! After the surgery, I found that it was difficult to get up. I felt extremely dizzy every time I tried to sit up. I had to lie down for a while and then tried again. I also needed to strengthen my muscle power in the arms and legs. After a series of training, I finally felt okay, no dizziness at all, when I sat up straight. The next step was to stand up. Again, I felt dizzy and fell quickly the first time I tried to stand up. The doctor told me that the only way was to take it slowly. All right, I took it slowly. I stood up, but weakened just in one minute. After another series of training, I stood up successfully. Then, the next goal was to walk from my bed to the bathroom. I thought it would be easy, but, no! I took a step

and fell right away. Stood up, took a step, fell. Stood up, took a step, fell. The nurses were there helping me and encouraging me. The day I finally walked to the bathroom by myself, all other patients and their family members in the room clapped. To be honest, I wasn't feeling too good inside during that time. I felt like a baby who's learning how to walk for the very first time in his life. It took me another ten to twenty days to be able to walk out of my room. Then I began to practice climbing up the stairs. I've never thought that it would be so difficult to climb up the stairs, but indeed it was. It was exhausting! Every movement I took, my heart was pounding. I felt like my heart wasn't mine, totally out of my control. Then my doctor taught me abdominal breathing. It worked pretty well. Gradually I was able to climb up a little bit. The whole process took me a lot of effort, a lot of practice, and a lot of patience.

Person with CHF (14): You must feel happy wholeheartedly. It helps a lot to deal with your illness. You must not think "oh, I have this disorder, I am ill" everyday. It doesn't do any good. You must turn yourself around. You must be optimistic.

*Sense of coherence and mastery.* In six families, someone disclosed that being aware of the current condition of the persons with CHF and accepting the reality that their lives had been forever changed made them feel a sense of calmness. After they evaluated and understood their given conditions, a sense of control and a sense of hope emerged. They believed that with the great help of the health professionals and their support systems they were able to manage the disorder and overcome the challenges that came with it.

Person with CHF (10): I have been observing. I sense that the doctors here are very professional. I feel very safe here. They arranged thorough examinations throughout my body. They analyzed my circumstances very carefully. I think my illness is in their control. I have also been reading books and learning what I can do to make my situation better. Therefore, I am confident that my condition will be stable soon and improve within a year.

*Knowledge and past experience of managing the illness.* In five interviews, the persons with CHF or family members talked about how their knowledge of health enhancement and past experiences of dealing with illnesses in the family helped them to manage CHF. They learned that complying with the treatment plans, including diet, exercise, medication, and regular check up, was the only way to remain relatively healthy. They also learned to evaluate their own conditions and knew when to seek professional help.

Person with CHF (6): I am very aware of how I am doing. I draw from my multiple years of experiences with this disorder. Long illness makes the patient a good doctor, you know. I can tell from my symptoms when it is okay, when I need to make an appointment, when I need to go to the emergency room, or even when I need to pack for hospitalizations, haha. I am always well prepared before I go to the hospital.

*Spiritual beliefs.* At least *one* member in seven families mentioned that they relied on the emotional support of spiritual beliefs in the process of facing CHF. Through prayers and conversations with a higher power they gained a sense of internal peace that

helped them to accept the fate that was assigned to the ill family member, as well as a sense of internal strength that helped them to hold themselves together and remain hopeful at difficult times.

Stepson (5): Seeking spiritual support has been helpful to my family. We went to a temple and made some wishes. We became vegetarians. I think that spiritual beliefs help us walk through many difficulties. When we face challenges and frustrations that are out of our power to change, we are more likely to adjust and think that maybe the situation is the best arrangement.

Person with CHF (16): I have a family hall for worshipping Buddha. I spend a lot of time there. Sakyamuni Buddha and Avalokitesvara (Guanyin) are my best friends, my best teachers. I talk to them, and I pray. That creates huge power. Therefore, I am not afraid of death at all.

***Family functioning and interaction patterns.***

*Commitment to be involved in the care.* The importance of having family members to be involved in the care of persons with CHF was stressed in 11 interviews, although some participants in this study experienced strains related to care-giving and care-receiving. In these interviews, seven persons with CHF expressed their appreciation for their family members' daily assistance. They sensed that their families were dependable. Six family members saw being involved in the care as a part of their natural responsibility as a parent, a partner, a child, or an in-law. They believed that their involvement in the care was crucial for the persons with CHF to successfully manage the

disorder. Therefore, they were very willing to make efforts to meet the patients' needs, even though they had to sacrifice a great deal sometimes.

Person with CHF (17): I am pleased that my son, daughter, and daughter-in-law are very filial. My daughter-in-law calls me and asks me how I am doing everyday. She helps me to arrange follow-up appointments. Like today, I don't know when I am supposed to be here (hospital). She's the one who contacts the doctor and arranges everything. I don't know what medication I am taking either. She always helps me to organize my medicines. I only need to take them out from my pillbox. I don't need to worry.

Daughter-in-law (17): These tasks are within my ability range. I think good family interaction is very important. He adapts pretty well. All I can do is to help him as much as possible.

Daughter (4): Basically our five siblings take turns, coordinate with one another. My work is more flexible, so I am the primary caregiver most of the time. Others help on weekends or when I have needs to do other things or take days off... We (siblings) didn't go through a discussion process. We automatically thought that things should be done this way. She's our mother, not somebody else, right? This is natural to our family interaction.

In two other interviews, persons with CHF disclosed that their family members checked in with them occasionally but were not involved in the care. These patients were pretty much on their own. Their family members provided care only when they were hospitalized. They wished that their family members could have been more involved. In

one interview, the family member complained that he looked after his brother-in-law (person with CHF) a lot, including diet control, medication, and follow-up appointments, but his brother-in-law did not like him to be involved. He felt very frustrated. On the other hand, this person with CHF responded that he would rather ask for a neighbor's help than his brother-in-law's help (family member), because his brother-in-law nagged him all the time.

*Close and trusting relationships among family members.* In 10 interviews, participants revealed that they were grateful for the close and trusting relationships among their family members. Some family members were not available to provide care for persons with CHF on a daily basis, but they would call and show their care regularly. Persons with CHF felt loved and cared for by knowing that they were on their family members' mind often. Close relationships among family members also facilitated the process of family organizing and working together to manage CHF.

Wife (1): Our kids visit us often. If they are not able to come, they call and check in how we are doing. They ask about their father's condition or what we plan to do on weekends or holidays. Very sweet and comforting.

Husband (9): She asked me to bring plums and mangos from China. I knew fruits were not allowed to bring in Taiwan, so I tried very hard to hide them from customs officers. To be honest, how many fruits can she eat at one time? Not many. I know some of these fruits will go bad before she eats them, but I still bring them to her. Fruits are not the point. There are a lot of things that money

can't buy. This is one of the keys to communicate our love and maintain the closeness in our relationship.

Person with CHF (9): That's right. When I look at the fruits, I think about him. I feel content.

*Family time together and family routines.* Participants in nine interviews mentioned that their families maintained close relationships by having family gatherings regularly. They usually got together every weekend or every other weekend. They kept this pattern even after the persons with CHF were sick. It was important for them to maintain family routines, in which they sensed some degree of family closeness, continuity and stability.

Wife (5): Our children don't live very far from us. We have a dinner together every weekend and we routinely go on family tour during New Year holidays. We have a pretty good balance between closeness and distance. Our hearts are united but our daily lives are separate. I think that a close bonding among family members is very important.

Person with CHF (14): We go out or have a meal together every weekend. It was always like this, before and after I got sick. Seeing family members around, especially my two granddaughters, makes me happy. I feel I am halfway cured, hahaha.

*Comfortable problem-solving and communication style.* Open communication is frequently identified as a family resource in the literature. However, only three families

in this study recognized the benefit of utilizing open communication as a means to deal with demands associated with persons with CHF.

Daughter (4): We don't avoid the problems. We face them directly. We focus on the issues and discuss what needs to be done in order to solve the problems. We put our thoughts on the table but we also add some sense of humor, some funny jokes.

In three other interviews, participants acknowledged that their family members did not always communicate with one another openly, but they mutually respected each person's way of handling stress.

Persons with CHF (6): No, we don't really argue on things.

Wife (6): No, we don't.

Persons with CHF (6): We've never argued on things related to my illness. I think it's because of mutual trust and mutual understanding. I told her (wife) before that when I'm angry, leave me alone. I may murmur, or I may take a walk to calm myself down. I try not to keep the angry feeling inside. When she's angry at me, I let her nag. I think it's better for her to let things all out. This way of communicating has kept us from serious quarrels.

*Family flexibility.* In four interviews, participants identified family flexibility as a resource to their families in managing CHF. They disclosed that their families worked as a team. They did not assign certain responsibilities to a certain family member. Rather, whoever was available and capable of meeting the demands would step up and take on

the responsibility. The rest of the family members supported that person by taking care of other tasks in life.

Stepson (5): I am not a regular nine-to-fiver. I don't need to show up in my office everyday. I can work from home. My time is flexible so we have two family members available to be the caretaker. Other people, if they are normal nine-to-fivers, I don't think that they are able to take care of the patient everyday.

Therefore, our situation is special.

In fact, several participants in other interviews shared that their families did not follow the traditional Chinese culture of expecting son(s) and daughter(s)-in-law to be the designated solo caregiver(s). Instead, they left all options open and kept flexibility in role assignments.

Person with CHF (2): People are very busy in today's society. I must learn to take care of myself. It's not like in the old days when daughters-in-law are required to serve their father-in-law and mother-in-law. It doesn't work this way anymore. If your daughter-in-law is not willing to be the main caregiver, but you force her to, then she may not treat you well, and you get angry, she's not happy. She may hope that you die soon. To be honest, I didn't raise my daughters-in-law so I shouldn't expect them to take care of me. Thankfully, my sons and daughters-in-law treat me very well even if they are very busy.

*Financial stability.* Participants in nine interviews pointed out that having financial stability in the family was crucial in dealing with CHF. They acknowledged that treating CHF was very costly and that their families would not have been able to survive

the challenges of CHF without financial stability. They felt lucky that they had personal savings, retirement pensions, instrumental support from extended family members, or health insurance coverage enough to pay off the medical expenses.

Person with CHF (2): I paid over a million NT dollars (equivalent to 33,333 US dollars) when I was discharged from the hospital. The NHI covered another two million. If we didn't have the NHI in Taiwan, my medical bill would have been three million dollars. I had personal savings. My oldest son and daughter-in-law were college professors, and had pretty good income. My second son had a shop and earned pretty well. Money was not an issue for my family. Like I said earlier, if a family doesn't have financial stability, the person with CHF would not have had a chance to beat the disorder. Family members would have been worried about living expenses and where the money could come from. It's hard for the family to locate extra money for getting the person with CHF a good quality of medical treatment. Then, it would be very likely that the person with CHF failed the treatment. So, having financial stability in the family is a basic tool to face challenges of CHF.

***Social support.*** All participants in the study acknowledged and appreciated resources they had from outside of the family. Identified resources involved social support from distant relatives, friends, neighbors, employers, coworkers, religious affiliation groups, health professionals, support groups, and social service programs. Types of support that these families received were organized into three categories: instrumental support, informational support, and emotional support.

*Instrumental support.* In 12 interviews, participants mentioned receiving good quality of medical services as a tremendous support for them. They applauded the health professionals (e.g., doctors, nurses, nutritionists) for their good skills and warm attitudes (i.e., responsible, friendly, patient, and caring). They observed that their health providers examined the conditions of persons with CHF very carefully before coming up with any treatment plan. They also appreciated that the team spent a lot of time communicating with the family regarding the patient's condition, the treatment plan, and what to look for in home care. Moreover, they received regular phone calls from the medical team checking in how everything was doing and making sure that the persons with CHF were able to obtain continuous and adequate support and care within their own social support system. All of these elements made the families believe that things were under control and a better future could be expected.

Person with CHF (3): Dr. Lee is excellent! He adjusted my medication so that I only need to take pills one time a day. That's very convenient. He is very careful and very caring. He conducts all my exams himself. I can sense that he really cares about me. Sometimes I go to see other doctors for other medical issues. They don't always answer my questions even if I ask them many times. But Dr. Lee is different. He explains everything before I can think of any questions. If I don't fully understand what he says, I feel free to ask more questions and he always answers them. He is very friendly. Also, he and his team usually follow up on me by phone one week and one month after I get out of the hospital, like undergoing the cardiac catheterization. I am very thankful for their care.

In addition to good quality of medical services, participants received instrumental support from their informal social network. Financial support was mentioned in four interviews, two from distant relatives, one from friends, and the other one from a religious group (i.e., Tzu Chi Foundation) and the Red Cross Society. In-kind assistance was mentioned in four interviews. Relatives or friends provided the families with food and other assistance as needed, for instance, taking care of children or accompanying the persons with CHF to doctor's appointments. Two family members mentioned that their employers supported them by allowing them to take family medical leave or flexible work hours so that they could take care of their ill family members.

*Informational support.* In 12 interviews, participants acknowledged that friends, relatives, support groups, and health professionals had been helpful in providing information regarding what CHF was, where to find a good doctor, how to treat the disease, how to manage it on a daily basis, and where to look for available social resources.

Wife (6): The first time he got sick, we only knew that he had chest pain, without any idea that it was a sign of myocardial infarction. We went to a clinic but the doctor refused to take him in. He was then transferred to the ER at a metropolitan hospital. They told us that his situation was very severe and that he must find a hospital with a cardiac ICU. We went to a couple of hospitals that might have a cardiac ICU, but all of their units were fully occupied. Our relatives and friends made phone calls to all hospitals in the city, and finally got him a bed.

Person with CHF (14): One of my students went to China. He mailed me some materials on what a person with cardiovascular disease should pay attention to in daily life. There was a lot of detailed information. I was very pleased that someone like him cared about me that much.

Wife (5): The medical team introduced us to a gentleman who had heart transplantation, like my husband. He shared his experiences of going through the whole rehabilitation process with us. He told us how to maintain a healthy life and what a wonderful life he is enjoying right now. He invited us to join the heart transplant support group, and my son and I plan on going to their gathering next time. His story encouraged our family a lot.

Person with CHF (8): The doctor explained how the medication worked and its side effects, as well as things that I needed to pay attention to at home. The nutritionist taught me diet control, which helped me to maintain my health.

*Emotional support.* All participants in the study identified some form of emotional support they received from their social network as helpful. In 13 interviews, participants talked about their relatives, friends and neighbors visiting them, showing their empathy and concern through phone calls, or praying for the persons with CHF. Participants in 11 interviews acknowledged the helpfulness of a familiar and trusting relationship between the family and health professionals. They mentioned that the medical team, step by step, encouraged them through the rehabilitation process. Through their interactions and exchanges with the medical team they believed that the health

professionals knew the patient's condition well and took good care of the persons with CHF. This trusting relationship gave the family a sense of security, comfort, and hope.

Daughter (13): When our neighbors come by to see her, you can sense that she is delighted and excited.

Stepson (5): This medical team gives me a strong sense of trust. I feel that my stepfather is safe in their hands. He is under the best care. It's like they take some worries and pressures off my shoulders, so I can feel free to have my own life.

That is the most important emotional support and resource for the family.

**Coping strategies.** When asked what the family did to overcome the difficulties in the process of adapting to CHF, four domains of coping strategies were identified: (a) making accommodations, (b) using existing and acquiring additional resources, (c) changing family interaction patterns, and (d) shaping appraisals.

***Making accommodations.***

*Adhering to treatment regimens.* Working closely with health professionals was identified as a fundamental strategy for the families to cope with CHF. Thirteen persons with CHF in the study disclosed that they complied with the treatment plans fully, which included changing lifestyle habits, taking medication, and undergoing regular follow-up appointments and physical examinations. The other four persons with CHF in the study chose to take medication as instructed and undergo follow-up appointments and physical examinations as suggested, but decided to change only some of their lifestyle habits. Diet adjustment, weight control, exercise, smoking cessation, and restriction on fluid intake and alcohol consumption were commonly mentioned in the interviews. Among these

behavioral changes, diet adjustment was identified as a family matter in eight interviews whereas other lifestyle changes were identified as individual tasks.

Person with CHF (1): I have changed a lot! I do almost everything the doctor asks me to do. I take medication everyday. I go to the examinations and follow up appointments as suggested. I don't eat salty and oily food. But there is no way to ask me to quit smoking. I have changed to a brand that contains less nicotine. This is what I am willing to compromise at most.

Wife (15): We watch out for what he eats. We don't let him eat food that is salty, greasy, or too sweet. We change our diet as a family because we think that's healthier for all of us. I prepare steamed food, fish, lean meat, and vegetables for the family a lot more often. I buy him some nutritional supplements sometimes, but his doctor suggests that we eat natural food, unless under critical circumstances.

*Adjusting living arrangement.* Eleven persons with CHF adjusted their daily living patterns as a way to cope with this illness. They reduced overall physical activities to match their limited physical abilities. In seven interviews, persons with CHF and their family members believed that the disease was caused by having a busy and stressful work life in the past. Therefore, persons with CHF reduced workload or stopped working at all to prevent further damages to the body. Four persons with CHF chose to slow down their pace of life. They kept simple life routines and/or reduced social activities. Six persons with CHF developed new hobbies, such as painting, walking, hiking, making pottery, traveling, writing books, and volunteering at the hospital.

Son (14): He used to have his own career and his life was very busy. After he was diagnosed of CHF, I was worried that his heart could not tolerate his busy schedule. I asked him if he could stay at home as much as he could and keep an easy and simple life.

Person with CHF (14): I understand their (family members) concerns, so I only attend important social events now. I keep a simple and regular routine, like going to bed and getting up early, taking a walk after breakfast, pretty much everything is on schedule. I also try not to abuse my body. I don't lift heavy stuff. I walk slowly. Life is better when it simpler.

Family members in five interviews also disclosed that they adjusted their lives according to the patient's medical conditions and needs in general. For instance, two daughters decided to quit their jobs and be the primary caregiver of their ill mothers. Their siblings supported them by paying them "salaries" so that these two daughters needed not worry about their own living expenses. In a couple of families, one or two family members were designated to stay with the patient at the hospital and to provide care or assistance as needed. These members also played the informant role to keep other family members updated about the patient's condition. Three families changed the patient's living environment to make the patient's life easier: one family remodeled their house to be handicapped friendly; one family moved to a building with elevators, and one person with CHF rented a hotel room close to the hospital.

Person with CHF (6): There is no hospital qualified for treating CHF in my home town. So I rented a long-term hotel room that's close to the medical center that I

usually go to. The benefit of staying at the hotel is that there is always someone at the front desk. When I feel something wrong, I can easily find a person to call an ambulance for me.

***Using existing and acquiring additional resources.***

*God and people help those who help themselves.* In five interviews, participants pointed out that a successful adaptation to CHF required the combined efforts of oneself, social support systems, and a higher power. They perceived health professionals as helpful in treating the disease. They also acknowledged the helpfulness of support systems in providing all sorts of assistance. However, they believed that the power of the human being was ultimately limited, and that blessing of a higher power was absolutely necessary.

Wife (15): If there was 95 percent of risk to the cardiac surgery, it meant that we only had five percent of hope. All we needed was hope! We would do everything we could to hold on to that five percent of chance. Where did hope come from? I sought spiritual guidance from Mr. Ding (a fortune teller). He told me that Avalokitesvara (Guanyin) was willing to help my husband. I immediately went to a temple to pray for her blessing. I also asked for Mr. Lan's (a psychic) help. I prayed very hard wishing that he (person with CHF) could make it. When the doctor was helping him at the hospital, we must need additional help from a higher power to save his life, too. One could not succeed without another. Both forces counted.

Nevertheless, participants acknowledged that all help from support systems and a higher power would have been useless if persons with CHF themselves did not treat their health issues seriously. Five persons with CHF shared that they tried to remain as independent as possible in their daily life, including practicing good self-care behaviors, paying attention to their own health conditions, and cooperating with health professionals. Only two persons with CHF in this study were passive in the management of their illness. They turned all the duties and decisions of care over to their family members.

*Seeking social resources.* In addition to receiving support, participants actively sought for various resources to meet the challenges related to CHF. In terms of instrumental support, two families hired a 24-hour attendant to take care of the person with CHF during hospitalization, and five families hired a live-in foreign home careworker to manage caregiving demands. Three persons with CHF chose to announce their medical conditions to people in their informal social network and kept them updated. By so doing, people around them learnt to be alert to acute symptoms of CHF and to respond quickly, such as reaching Nitroglycerin and/or calling an ambulance. Two persons with CHF who did not have caregivers asked for relatives' help when being hospitalized. In terms of informational support, participants in nine interviews shared that they did not always ask the medical team about how to manage CHF because they knew that health professionals were very busy. Instead, they often searched for information regarding CHF and related health topics in media such as books, newspapers, magazines, television programs, or on the internet. They also liked to attend speeches held by

medical institutions. In four interviews, participants disclosed that they counted on their close friends, relatives, and spiritual beliefs for emotional support.

Wife (5): My husband is from Switzerland. He has a son and a lot of relatives and friends there. We also have friends in Canada and Philippines. I call them everyday, especially his son, letting them know about his current condition and asking them to leave some encouraging messages on the answering machine. I play these messages to him everyday to make him feel that he is not alone in the painful process. As for me, I don't want to bother others with my own sadness and depressed feelings. I think people have their own problems in life. My mother and mother-in-law have passed away. I have their pictures in the living room. I talk to them and pray for their blessings everyday. This is my way of relieving stress and negative emotions.

Stepson (5): When I see her stressed out and struggling with insomnia, I think that she should see a counselor. It is a very long process from surviving from the surgery and going through the rehabilitation program, to managing the disease on a daily basis. Family members must stay strong and healthy in order to face all the challenges with the patient. What I do is to compartmentalize my brain so that I can handle multiple demands. But if I am in my down time, I cry, I pray, or write journal entries to get my sadness off my chest.

### ***Changing family interaction patterns.***

*Gains and losses from the experiences of living with CHF.* When asked what has changed in life after having a family member diagnosed of CHF, most participants

responded that CHF and related challenges were the main focus of the family in the beginning but gradually became a normal part of the family life as time passed by and as they had greater experiences in dealing with the demands. Participants in 10 interviews disclosed that they did not sense any loss in the family or life in general. Things were back to normal once they got used to life with the presence of CHF. Instead, they perceived this experience as gains in their lives. They had a chance to revisit themselves as a person and their relationships with others.

Person with CHF (2): What I learn from the experience is that people will come and help us if we usually treat people nicely.

Person with CHF (7): I feel like, I died once, now I have a second chance, a fresh start to my life. I cherish what I have. I want to be a good person from now on.

Wife (5): I don't feel that we have lost anything. I feel that we have gained a lot, too much! We received a lot of help and support from the society. We want to pay people back. We want to pay forward.

*Improving family relations and interactions.* Participants in eight interviews revealed that their family relations and interaction patterns improved after they went through difficult time together. Persons with CHF shared that they appreciated what their family members did for them, thus they learned to be nice to family members in daily life and to control their temperament when they suffered discomfort. Both persons with CHF and family members noticed that their family became closer, in that family members cared about one another more, had less argument, and either continued their normal frequency of family gatherings or even increased the frequency.

Person with CHF (3): When there is tension among family members, I hold myself back. I try not to get angry because I feel that I owe them too much. I need to control my temper.

***Shaping appraisal.***

*Accepting the natural course of life.* Participants in 13 interviews (mostly persons with CHF) shared that acceptance was an important transition that facilitated the process of their adaptation to living with CHF. They accepted that life must come to an end someday. They accepted the fact that they had the disease and that they could not avoid death. Therefore, the best way to live their lives was to face the challenges, do whatever they could to maintain their health, and leave the rest to God or fate. However, they also acknowledged that having a good quality of life was more important than prolonging the length of life. They would rather have a short life than sacrifice their dignity or give up joy in life.

Person with CHF (3): I don't think about having CHF. I don't let myself be restrained by the disease. I still love to go to amusement parks, ride the Pirate Ship. Of course, my family wants me to live longer. But I have lived for almost 60 years. It's enough. When I am alive, I want to be happy. It would be meaningless to be alive but have poor health, poor quality of life. I tell my doctor, if my condition is not treatable anymore, please give up on me and use his skills and time on other patients.

Daughter (13): I think all of us are prepared, including herself (person with CHF). If her condition is still treatable, we hope that she gets well soon, but if not, we

hope that she doesn't need to suffer for a long time. It's painful to watch her suffering.

*Planning for the future.* With the thought of accepting the natural course of life, three persons with CHF and their family members chose to set some goals for the near future. They found that having a clear goal in life encouraged persons with CHF to overcome treatment discomforts, and made them feel that life is hopeful and meaningful.

Stepson (5): My sister-in-law just gave birth to their first child. We told my stepfather that it is a Chinese tradition to hold a celebration party when the baby is one-month old, and that we want him to be there. I think this good news cheered him up and gave him some hope. He has been much more motivated to engage in his rehabilitation trainings lately.

Person with CHF (14): Having a goal for myself is important. I am working on two books. I want to finish them before I die. This goal encourages me to keep on living.

Four persons with CHF and one family member revealed that they have initiated conversations about end-of-life issues in their family. Some family members joined the conversations thinking that they needed to be prepared for the worst scenario but others avoided the conversations thinking that it might bring bad luck to the patient.

Person with CHF (6): It is necessary to plan ahead because we don't know when the symptoms will come and take my life. Once I have a clear plan about how I want my funeral to be and how my wife and children will get the best care even without me, I start feeling grounded and being able to face this disease.

Person with CHF (3): I tell my wife and daughters that I wish to donate my organs and that I just want a simple funeral. They say I am insane. They don't want to talk about it. But I keep telling them anyway.

## Discussion

This study explored the lived experiences of individuals and families adapting to living with chronic heart failure (CHF) in the context of Taiwan, using the Family Adjustment and Adaptation Response (FAAR) Model as the guiding theoretical framework. The findings showed that the nonnormative stressor, CHF, struck the family with ripple effects to multiple areas of family life—the well-being of individual family members, family functioning and interactions, and the relationships between the family and its social networks and community. The processes of adaptation involved families' efforts to reduce or manage demands by utilizing their existing capabilities, to strengthen and expand resources (including improving family functioning patterns), and to change meanings that shaped how they responded to their situations. Key components in the process of family adaptation to living with CHF were categorized into three domains: pile-up of family demands, family capabilities (resources and coping strategies), and family meanings.

In the domain of pile-up of family demands, the findings showed that persons with CHF suffered from symptoms of the illness, and faced the challenges in relation to changed physical ability and subsequent role limitations, and in some cases, other ongoing illnesses. For family members, caregiving demands and prior or ongoing illness were two sources of strains. Both persons with CHF and their family members felt distressed in response to caregiving and care-receiving, and worries about the medical condition of the persons with CHF. Family level of demands included changes in family roles and responsibilities, financial strains, conflicts regarding CHF management, other

ongoing demands and daily hassles, and prior ongoing family strains. Loss of sexual intimacy was also identified in one couple interview. At the community level, families reported health care system strains, inconveniences regarding adherence to treatment regimens, changed relationships with extended family members and friends due to reduced social activities or financial difficulties, and lack of instrumental support from the community and/or from the government (i.e., National Health Insurance System, NHI).

Most of the CHF related strains and hardships reported by individuals and families in this study support and validate findings from previous studies, suggesting that the impact of CHF is more similar across the world rather than unique to each culture. The compulsory NHI system in Taiwan, however, is a specific contextual factor to this group of families. For example, two persons with CHF complained that regulations and restrictions of this system contributed to their financial strains while another person with CHF was thankful that the NHI covered two-thirds of his medical bill. In fact, a person with CHF would be granted a temporary catastrophic illness certificate if he/she is put on a mechanical ventilator during hospitalization or a permanent certificate if he/she receives a heart transplant (衛生福利部中央健康保險署, 2013). It means that a person with CHF would not be qualified for catastrophic illness certification unless he/she is under a critical or terminal circumstance. In other words, most persons with CHF are likely to face the issue of high medical cost. Therefore, it is a matter of whether the person with CHF and his/her family have or acquire enough financial resources to cover the expenses.

In the domain of family capabilities, identified individual level of resources included positive attitudes, sense of coherence and mastery, knowledge and past experience of managing illness, and spiritual beliefs. Family level of resources included family members' commitment to be involved in the care, close and trusting relationships among family members, family time together and family routines, comfortable problem-solving and communication style, family flexibility, and financial stability. Community level of resources included instrumental, informational, and emotional support. Specific coping strategies that families used included adhering to treatment regimens, adjusting living arrangement, seeking social support, improving family relations and interaction patterns, and shaping appraisals.

While the findings corroborate individual and community resources documented in the literature, family level of resources confirm the propositions and observations of family scholars on crucial attributes of family resilience, such as commitment, hardiness, cohesiveness, communication, flexibility/adaptability, and time together and routines (McCubbin, 1988; Olson & DeFrain, 1994; Patterson, 1988). Among these family resources, family commitment, hardiness, cohesiveness, and family time together and routines were mentioned in more than half of the interviews, indicating that the Confucian concepts of filial piety and familism operated in the majority of these families.

According to the first chapter of the Classic of Filial Piety (Xiao-Jing), filial piety is considered as the root of all virtues. "Of all the actions of man there are none greater than those of filial piety." This concept is constructed on the fact that each individual would not exist in the world if his/her parents did not exist (Ko, n.d.). Therefore, the

expectations of respect for and devotion to parents, loyalty to family, and taking care of the elders are emphasized in daily practice of family life and family education. Elders believe that being respected and taken care of by their adult children are essential to their happiness and health (Chen, 2001). The idea of filial piety extends to the concept of familism in Chinese culture, in that each person does not exist as an individual alone but a member of the family. Each member has his/her position in the family, with corresponding family and clan duties or responsibilities. “Each role in the family represents a distinct part of the human body, and together they constitute an inseparable entity” (Ko, n.d.). In this study, all of the adult children (including a daughter-in-law) expressed their strong sense of filial obligations. Seven persons with CHF took pride when talking about their children and/or daughters-in-law being filial to them. Other family members, such as a mother and several partners, viewed caregiving as natural acts showing what is called “a family”. As Tang, Li and Liao (2007) observed, these Taiwanese families saw caregiving as a natural extension of members’ commitment to the family, which provided them with inherent motivation to care for their ill family members.

While some families benefited from strong sense of family unity and family involvement in the care of persons with CHF, for instance, better management of the disease and/or closer family relationships, several others experienced strains as a result of practicing filial piety and familism ideology. For example, a brother-in-law in this study felt an obligation to help the person with CHF adhere to dietary restrictions and other treatment regimens. Monitoring the patient’s behavior and health did not only create

psychological stress in the caregiver, but using nagging as a gesture of caring and concern or as a way of managing distress and frustration also led to negative interactions between the two, especially when the person with CHF did not follow through treatment recommendations. Initially, this family attempted to manage CHF by having the brother-in-law look after the person with CHF, but the family's effort to cope became a source of family demands in the end. This example suggests that when caregiving is based on family obligations and social expectations rather than on reciprocal affective ties, caregiving may not help the family adapt to living with the illness but add more strains onto the family. It also suggests that the adaptation process is complex and dynamic. What is considered as a resource, or a protective process, at one point in time may function as a demand, or a risk process, at another time (Patterson, 1988; Rutter, 1989, as cited in Hawley, 2000).

Another issue related to the practice of filial piety and familism was raised in a mother-daughter interview. The daughter complained that one of her sisters-in-law had never volunteered to take care of her mother or shared any caregiving responsibility. This complaint may partially be in response to uneven distribution of caregiving duties in the family; it also reflects role ambiguity in the family who lives in an evolving society nowadays. Traditionally, Chinese families expect a son, usually the first born, to live with his parents and to provide care in their old age. The wife of the son, or of the first son, is expected to take care of her parents-in-law on daily life as well. When the parents-in-law are ill or lose their abilities to take care of themselves due to age, it is usually assumed to be the wife's obligation to do the caregiving. To the contrary, a daughter counts less or

even as worthless because she is seen as belonging to another family once she gets married (or will be married) (Ko, n.d.).

As Taiwan modernizes and industrializes, however, more and more women earn degrees and participate in the labor force. The daily practice of filial piety and familism starts to be modified in the changing process. The restricted role expectations for daughters versus daughters-in-law gradually loosen. Some families hold on to the traditional views, some become wide open to all possibilities, and the others fall somewhere in between on the continuum. In this family, the mother lived with her first son and his wife. The wife of the first son had a job so family members expected less out of her for caregiving responsibilities. A married daughter was called back to take care of the mother because she was out of job during that time. The wife of the second son, on the other hand, ignored the caregiving demands in this family and chose to help her parents run a small business occasionally. While the daughter's involvement in the care was a great asset to the family, tension emerged or increased among family members (or in-laws) due to their lack of consensus on family organization (i.e., role expectations and role assignments) and family identity in the midst of societal modification.

Speaking of societal modification, five out of the 17 families in this study hired a live-in foreign home careworker as a way to manage caregiving demands. With the increase of aging population and smaller family size in Taiwan, it has been more and more common for families who lack the pool of available caregivers to hire a foreign worker to live with them and to care for a disabled or ill family member. According to Taiwan Association of Family Caregivers, there are nearly 700,000 disabled people in

this country; 65 percent of whom are cared for by their families, 28 percent of whom are cared for by live-in foreign home careworkers, and the remaining seven percent of whom live in health care institutions or use in-home services (as cited in 邱彥瑜、李映昕、林玲瑩，2013). Hiring a foreign worker versus using other types of services is also often a result of economic decision making. The average monthly cost of hiring a live-in foreign home careworker is 19,000-22,000 NT dollars (equivalent to 630-730 US dollars), which is less than half of the cost for hiring a Taiwanese careworker or two-thirds of the cost for living in a nursing home or other types of long-term care facilities (曾妙慧、繆震宇，2013). As of the end of February in 2014, there were 208,538 foreigners hired as a home careworker in Taiwan, with a 1.95 percent increase from the same time a year before (Workforce Development Agency, R.O.C., 2014), suggesting that the need of families continues to rise and that migrant workers may become one of major providers in long-term care services in the future. This coping strategy illustrates families' ability to expand their resources, flexibility in role assignment, as well as adaptability to an altering environment.

In the domain of family meanings, the findings indicated that three levels of family meanings were all involved in the process of family juggling the pile-up of demands with their capabilities. For instances, at the level of situational meanings, families' attributions of the cause of CHF and their understandings of the severity of patients' conditions influenced their attitudes and decisions towards treatment adherence and adjustment of living arrangement. At the level of family identity, families who maintained family bonding through regular family gatherings shared a strong sense of

family commitment in the care of their ill family members. At the level of world view, the belief that “God and people help those who help themselves” motivated persons with CHF to collaborate with their family members and health professionals on rehabilitation programs. This belief also encouraged family members to reach out and to seek as many resources as they could possibly get for meeting their challenges.

Moreover, the findings revealed that family views on life-and-death issues played a big role in the adaptation process due to the fact that CHF was a life threatening disease. As with many people in Taiwan, families in this study were under the influence of Confucianism and/or Buddhism when it came to issues of life-and-death. For instance, only a small portion of the families have talked about end-of-life planning; the others preferred to avoid conversations about death and dying, especially for family members. Discussing with elders or frail individuals about death and dying has been a deep-rooted taboo in Chinese culture. One reason for this is that people believe that talking about death may bring bad luck to the targeted person as if death will happen once people name it. Another reason for this phenomenon comes from the mainstream understandings of Confucian’s sayings “While you are not able to serve men, how can you serve their spirits?” and “While you do not know about life, how can you know about death?” from the chapter of Jih-lu Asked about the Worship of the Celestial and Earthly Spirits in the Analects. It is widely believed that Confucius thought one should be pragmatic and present-oriented (life) rather than trying to comprehend something that one has little contact with (death). Therefore, people often quote the sayings as the authoritative and canonical ground for their evasive attitude toward death-and-dying issues. Even though

some scholars think that this may be a misinterpretation of the Analects, this version of interpretation still affects Chinese culture deeply (釋慧開，2003).

Despite its influence on open communication regarding death-and-dying issues, Confucianism did help families in this study to cope with their adversities in several ways. In Confucian terms, life-and-death is a natural phenomenon. The meaning of life for human beings is for one to develop one's innate moral potential to the fullest while fulfilling one's responsibility in realizing the ideal of harmonious society. Adversity or stressful events are regarded as chances for individuals to grow by developing good traits and abilities (景怀斌，2007). These perspectives provided these families with a platform to accept the natural course of the disease and of life as well as to face the challenges proactively. They engaged in activities that fitted their sense of purpose in life. For example, two persons with CHF were writing their life stories into books because they learned from Confucianism that leaving behind great writings was one of the ways that man could be immortal. This is congruent with previous observation that having a sense of purposefulness and hopefulness in hobbies and activities contributes to the resiliency of persons with coronary heart disease (Hilscher et al, 2005; Westlake & Dracup, 2001).

For families who believed in Buddhism, the belief in fate helped them to accept their circumstances as part of the adaptation process. In Buddhism, life is a continuous existence with endless cycles of birth and death. Fate does not mean destiny but a net that is made up of many interrelated threads. What happens at the present is the result of what happened in the past; what one thinks, feels, and acts at the present sooner or later will reap the effect in the future. That is to say, birth and death, health and illness, wealth and

poverty are not the predetermined fate of a living being but a “corollary of action (karma)” (Takakusu, 2002). Therefore, the present is what it matters the most. For several persons with CHF in this study, death was not something to fear. Instead, they spent their energy on how to best use their current life, in that to remain in good health was to be morally good and peaceful, with little or no negative feelings about life.

### **Clinical Implications**

Because little attention to date has been paid to specifically address CHF experience from a family perspective in clinical practice or research in Taiwan, this study aimed at enhancing our understandings of family adaptation process to living with CHF by including multiple family members into the inquiry. Clinical and research implications are presented based on the present study’s findings and related literature.

**A need for health care reform.** Adaptation to living with CHF requires a long-term relationship with the health care system from the beginning of the first cardiac event to the end of the life journey of persons with CHF. However, several health care system strains have been identified as initial stressors to the family as well as in their ongoing management of this disease. The issues of delays on diagnosis, tests, and referrals, lack of skills or competence, health resource discrepancy between rural and metro area, medication related issues, time consuming of regular doctor visits, and high medical costs reveal the current structure of health care system in Taiwan to be problematic.

The present health care system in Taiwan features specialty-based practices, a self-referral system, and disease-oriented treatment which results in a fragmentation and redundancy of health-care services (Lin, Chou, Liang, Peng, & Chen, 2010). According

to a survey conducted by the Taiwan Healthcare Reform Foundation in 2013, families encounter several difficulties when they accompany their elder family members to seek health care services. The top four difficulties include: duplication in prescriptions, time consuming in outpatient clinics, taking the wrong pills at wrong time, and multiple visits to a variety of types of clinicians (陳思佳, 2013). However, people with chronic illness, especially for elders, usually have multiple medical conditions that demand a holistic and integrated approach. Same demands apply to persons with CHF. Therefore, a reform on health care delivery is needed to make illness management effective, and to improve people's health and quality of life.

An example of a new health care service model is the integrated practice unit (IPU) proposed by Porter and Lee (2013). Instead of organizing services around a single medical condition, an IPU provides services to a group of individuals with similar needs, including the related conditions, complications, and circumstances that commonly occur along with the disease. An IPU usually features a "single point of access" where persons with needs call one central phone number and the rest of the administrative and scheduling issues will fall into place. It is made up of a dedicated, multidisciplinary team of clinical and nonclinical personnel that provides the full cycle of care (i.e., outpatient, inpatient, rehabilitative care, education, counseling, and other supporting services) for the patient's conditions and their families. The wanted treatment outcomes can be codefined by patients, providers, hospital administrators, and/or other stakeholders, for example, the National Health Insurance program. The team of providers meets and works together regularly to discuss patients, processes, and results. The information on outcome

measures is designed to be made available to patients and providers in a timely manner so that they are able to redefine the goals and adjust treatment plans accordingly. This model has been applied to a variety of settings working with different medical conditions, and the improvement on patient outcomes and medical costs has been promising (Porter & Lee).

In a case of chronic heart failure, an IPU can target conditions that share a common pathological process—atherosclerosis—such as coronary heart disease, stroke, hypertension, diabetes, chronic kidney disease, or peripheral arterial disease (Dunbar-Rees, Panch, & Dancy, in press). The health care team may include, but not be limited to, case managers, physicians, exercise physiologists, nurses, pharmacists, echocardiographers, nutritionists, mental health professionals, marriage and family therapists, educators, and social workers, depending on the needs of the families.

**Initial assessment and intervention.** When a family calls for help through a central phone line of the IPU, a case manager can quickly scan for presenting problems, identify personnel to be involved for initial assessment, and set up a meeting. For instance, a person with chest pain may be sent to see a team consisting of a case manager, cardiologist, nurse, and educator the same day he/she calls. The findings suggest that not knowing what is going on creates great fear and stress for families living with CHF. Therefore, after a thorough examination is taken place and the person's condition is recognized, the team members can help the person and his/her family by providing information about the medical condition—diagnosis, signs and symptoms, etiology, severity of the patient's condition, prognosis, treatment options, management issues, etc.

The team should be aware that families may not fully understand the explanations and medical recommendations at first because of unfamiliarity with the medical terminologies or because of anxiety (陳思佳, 2013). The team may hand out a brochure for families to keep and allow them time to digest the vast amount of information. The team may also use metaphors to help families understand the situation. For instance, one family in the study found it helpful when the physician used a metaphor of a house with broken doors and windows that could not bear rains and winds to describe the heart situation. It is important to evaluate how much information the families have received, what they believe about the circumstance they are facing, and what plans they have for the future (Walsh, 2006, chap. 9). The findings suggest that situational meanings, such as family attributions about the causes and consequences of illness, influence family responses over time. Thus, one way the team can facilitate better family adaptation to CHF is to organize a family meeting and initiate conversations that help family members develop shared situational meanings (Patterson & Garwick, 1994).

The initial assessment includes working with the families to identify the most distressing issues that require the immediate attention at a given time or circumstance, and to define the proper goals for intervention. The findings in the present study indicate that families who live with CHF experience physical, psychological, emotional, relational, and social turbulences. Therefore, the targeted issues and outcomes can range from biological change, behavioral change, relationship change within the family, to relationship change between the family and its community, or even change in appraisal process. The health care team can start out the assessment by specifying which level of

focus the intervention seeks to change, for whom the intervention is intended and in whom will change occur (Fisher, 2005). This procedure helps to clarify if the composition of the health care team needs to be modified and whether the intervention can be operationalized by working only with individual family members or it requires multiple family members' participation.

Assessing family capabilities and meanings that facilitate successful adaptation is as equally important as assessing family demands. The evaluation can be done through a clinical interview, questionnaires, or a genogram. The work of McGoldrick, Gerson and Shellenbergerr (1999) gives a clear guideline to conduct a genogram, in which information regarding individual family members (e.g., birthdates, gender, age, ethnicity), nodal events in the family, emotional connectedness among family members, intergenerational patterns of interactions, and other therapeutically relevant information is represented schematically. While the genogram has been a valuable tool for clinicians to identify problematic intergenerational patterns in the family, it has a great potential to be a useful tool to track positive influences across generations that have contributed to current successes in family functioning (Walsh, 2003). As the findings of this study shows, previous knowledge and experience of managing illness in the family serve as resources for families to deal with current challenges. Helping families to identify resources and coping behaviors relative to their demands will empower the family to make efforts to overcome challenges along the adaptation process.

**Examples of issues for treatment.** Self-care behaviors are often emphasized as keys to optimal outcomes in the care of persons with cardiovascular diseases. Such

behaviors include adherence to dietary restriction, weight control, smoking cessation, medication, and regular follow-up. A variety of clinical interventions have been proposed to improve the self-care behaviors of persons with CHF in the literature (mostly in the nursing literature). Educational programs have shown short-term or no effect on self-care behaviors or the health status of persons with CHF and their partners (e.g., Agren, Evangelista, Hjelm, & Strömberg, 2012).

Jaarsma and colleagues (Jaarsma, Abu-Saad, Dracup, & Halfens, 2000) found that lack of knowledge was one limitation for self-care behaviors. In the current study, lack of knowledge in dietary control caused frequent rehospitalization for one person with CHF. He disclosed that he was told to reduce sodium intake without knowing the relationship between sodium intake and water retention so he did not take the advice seriously. He was not educated until he suffered shortness of breath easily and had several rehospitalizations. He suggested to the health care team that it would be a better approach if the nurse or nutritionist educated persons with CHF and their families about how the body functioned (physiology) before educating them about dietary modifications. In addition, family approaches aimed at nutritional changes have been confirmed to be effective in reducing cardiovascular risk (Family Heart Study Group, 1994, as cited in Campbell & Patterson, 1995), suggesting that it is beneficial to routinely involve family members in dietary control programs. For families who hire a foreign careworker at home, it is recommended to include the worker in the program as well because it is very likely that the worker does most of the meal preparation.

Judgement and decision-making was identified as another major limitation to self-care behaviors in an inquiry conducted by Jaarsma et al. (2000). Most patients in that study reported that they knew how to behave for their health but they chose to behave differently. The findings in the present study indicated that adherence to treatment regimens required lifestyle changes, which were perceived as demands from the community. Instead of building guilt in persons with CHF and their family members or creating tension between the family and the health care team for nonadherent behaviors, health professionals need to approach the family from the perspectives of the family.

The findings of the current study indicate that meaning-making was one factor associated with lack of adherence. For example, three persons with CHF continued their smoking habit because that was their way of relating to friends and because they did not want to lose joy in life. These patients are usually labeled “noncompliant” or “resistant” in the eyes of health professionals. Despite how frustrated the health care team may feel, accepting and respecting patients’ personal choices are necessary sometimes. In this case, encouraging persons with CHF to switch to low-nicotine cigarettes can be a midway solution. Helping family members to understand and respect the world view of life-and-death for persons with CHF may help families to adapt better, in terms of having fewer conflicts regarding smoking issues. Some families expressed gratitude for the help of social support groups in the interviews. Therefore, social workers can help families to build connections with support groups, in which families often find their experiences normalized and validated. Interacting with other families who experience similar circumstances also facilitates a meaning-making process that may alter the patients’

world view—find positives in smoking cessation, learn different ways of relating to friends, and be motivated to try (Patterson & Garwick, 1994).

Medication adherence issue was another example of how meaning-making influenced self-care behaviors. Several persons with CHF and their family members raised their concerns about medication side effects and redundancy in prescriptions across different specialists. One person with CHF who was also diagnosed with kidney failure disclosed that he chose not to take western medication but Chinese herbal medicine as a result of his concerns. In an integrated practice unit (IPU), team members such as cardiologists, nephrologists, and pharmacists, can reduce such worries by meeting and going over the patient's medication collaboratively. The Geisinger Health Care System in Pennsylvania is a successful example of this approach. The inclusion of pharmacists on a team to follow and adjust medications for patients with diabetes and heart disease has resulted in fewer strokes, amputations, emergency department visits, hospitalizations, and in better performance on other outcomes that matter to patients (Porter & Lee, 2013). The IPU can also include doctors of oriental medicine in the system so that both Western and Eastern medicine can come together for the best interest of patients' well-being.

In addition to meaning-making, persons with CHF may not be able to adhere to treatment recommendations due to other competing demands in life. Families in this study experienced enormous amount of time wasted in the waiting room for follow-up appointments, physical examinations, getting prescriptions, and multiple visits to a variety of types of clinicians for other medical conditions. Other strains such as work

demands and financial strains made it difficult to get to hospital appointments at times. Health care professionals need to be sensitive to other competing demands of the families and to work with them to find solutions. For instance, in order to best use the families' time, the IPU should strive to arrange all the related medical procedures on the same hospital visit. For those who have difficulties with medical expenses or financial strains, social workers can assist the families to seek social resources, such as the National Health Insurance waiver for the insurance fee, local government subsidization of middle-low and low-income households, or financial support from public or private organizations.

The findings of this study indicated that nonadherent behaviors had negative impacts on family relations and interactions, and vice versa. Some evidence has shown the positive associations among self-care behaviors and family functioning, such as communication, adaptability, decision-making, and problem solving (Franks, Campbell, & Shields, 1992; Sebern & Riegel, 2009). Family intervention could improve family relations as a means to enhance treatment adherence and the well-being of all family members. Clark and Dunbar (2003) proposed a Family Partnership Intervention (FPI) for HF, in which families living with CHF were taught to use autonomy-supportive techniques to improve their communication and interactions. Their pilot study received positive feedback from families and showed that a supportive and encouraging atmosphere helped persons with CHF to make positive choices about their health behaviors. Therefore, the IPU team members, such as nurses, marriage and family therapists, social workers, or any other professional with systemic or relational oriented training, can initiate family meetings to facilitate communication patterns that will foster

emotional connection and sustain mutual support within family relationships while respecting the independence of persons with CHF in making choices for their health, and life.

It should be noted that there is considerable variation in the ways in which families are affected by CHF and how effective they are in utilizing their capabilities to deal with the demands of the disease over time. First, families faced different challenges and demands at different phases of the illness—the crisis, chronic, and terminal phases—each required different resources and strategies over time. Second, meanings that each family attributed to living with the disease differed, which resulted in variations in the adaptation process among families. Third, families' pile-up of demands and capabilities varied across stages of the family life cycle. For instance, families of middle-aged persons with CHF experienced more financial strains due to unemployment and child-rearing costs, whereas families of older persons with CHF had more financial resources from personal savings and financial contributions of adult children. Thus, health care professionals need to revisit family demands and capabilities regularly and specifically after any change in the patient's condition. Health care professionals need to be flexible in helping families to meet up-and-coming challenges over the uncertain course of CHF. Furthermore, the context in which the adaptation occurs for each family needs to be taken into account.

### **Limitations**

The findings of the current study must be considered in view of several limitations. First, our sample was limited to patients and family members from one

institution. Even though this medical center offers services to families with diverse background (e.g., age, gender, education, socioeconomic status, regions), we cannot assume that the experiences of our sample of families represent all families who have a member with CHF in Taiwan. Second, participants were recruited in a natural setting. Family members were invited to participate in this study while they accompanied the patients to a regular follow-up appointment, indicating that these family members may have been more committed to be involved in the care of persons with CHF than their counterparts. Therefore, family identity shared by these families may not represent family identity held by all families in Taiwan.

Third, the data was collected after the patient was diagnosed of CHF for a while in most of the cases. Time from the diagnosis and living with the disease may have affected what participants reported. When participants were thinking back on multiple crisis events as well as some adaptation processes along the journey, it was possible that how some of them viewed the experience during the interview might not have been how the experience was viewed in the moment it happened. Some may argue that the data did not represent what really happened in these families. However, the data represented a natural meaning making process that the participants came to during the interview with the researcher.

The fourth limitation of the study was that the data was collected partially from individual interviews and partially from conjoint interviews. Treating individual family members' report about their family as family level constructs in the data analysis had the risk of confusing family reality with "family myth"—what Wamboldt and Wolin (1989)

refer to as internalized perceptions or stories each member has about his/her family, not necessary shared experiences with other family members. However, I made a conscious decision to combine information provided by these two different types of interviews for the purpose of obtaining as many insights as possible from this exploratory study and of identifying potential areas for further investigations.

### **Conclusions and Future Research**

The present study makes several contributions to the literature despite the above limitations. First, the findings provide greater insight and detail about many of the strains families encounter when living with CHF as well as specific resources and coping strategies that families use to manage these strains. These findings should further inform health care professionals about some of the important or pressing issues facing families during this stressful period and many ways that families are able to effectively handle their challenges. Second, the findings of this study indicate that many aspects of the CHF experiences for families in Taiwan are similar to what has been described in previous studies of family experiencing CHF in other countries. Nevertheless, the findings demonstrate that the influences of cultural or religious beliefs in family meanings play an important role in the adaptation process. Third, this study adds to the literature by expanding understanding of the adaptation process from an individual level of phenomenon to a family level of phenomenon in the context of Taiwan. The information provided by families in this study could serve as a foundation to enhance family-centered care for families living with CHF.

Fourth, clinical implications grant the usefulness of the FAAR model as a framework to map out the complex nature of the adaptation process and to identify possible avenues of intervention. In particular, the emphasis of viewing the family as a system going through repeated cycles of adjustment-crisis-adaptation with ever-changing demands and capabilities over time could be a useful approach to understand the family experience of facing uncertain prognosis of CHF along with developmental changes of individual members and the family unit from time to time. The notion of considering multiple sources of demands and protective processes in the ecosystem, especially the roles of contextual factors, should increase the sensitivity of health professionals and researchers to the influences of the health policies and the shifts of societal or cultural norms and values on family experiences of adapting to living with CHF in Taiwan. The concepts of bridging physiological, psychological, and social domains could fit well with Chinese culture of viewing health as being in harmony within and between the body, nature, and its social environment. Using the language such as “attaining balance or harmony” could be a starting point for health professionals to motivate the individuals and families to utilize and strengthen their capabilities for meeting challenges along the adaptation processes.

Several areas are worthy of future research. The themes and properties of the key components identified in this qualitative study may be useful for future quantitative studies to use structured questionnaires to examine the relationships among the biological indicators or physical well-being of persons with CHF, disease/health management behaviors, the quality of life of family members, family impact and responses, and socio-

cultural factors. A case study approach will also be helpful for a further understanding of different pathways of adaptation. Future research with a longitudinal study design assessing families at the time of diagnosis and then repeatedly over time will have the advantages to identify landmarks, transitions, and changes in family functioning and relations over time. Future investigation of the impact of hiring a live-in foreign home careworker on the family system, such as family boundaries, roles, organizations, interactions and dynamics, and the quality of care for persons with CHF at home will be helpful for health professionals to enhance clinical practice with families utilizing this type of service. Further implementation and examination of an integrated practice unit approach for families with CHF as suggested in this dissertation will be enlightening.

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## Appendix A

### **Hermeneutic Phenomenology**

Hermeneutic phenomenology, developed by Martin Heidegger (1889-1976), is an expanded version of phenomenology that aims at gaining a deeper understanding of meanings embedded or hidden in everyday aspects of lived human experience (Van Manen, 1990). In Heidegger's point of view, these meanings may or may not come to individuals' consciousness but can be gleaned from the narratives produced by them (Lopez & Willis, 2004). In other words, a hermeneutic inquiry focuses on what individuals' narratives imply about what they experience a phenomenon every day rather than what they consciously know about that phenomenon (Solomon, 1987). Moreover, Heidegger's (1927/1962) idea of pre-understanding emphasizes that humans and the world they live in are indissolubly related to an extent that individuals' realities, or subjective experiences, are invariably influenced by their social, cultural, historical, and political contexts. Thus, hermeneutic phenomenology involves the interpretation of the narratives provided by participants in relation to various contexts that are crucial for shaping and organizing their experiences (Gadamer, 1960/1989; Lopez & Willis, 2004).

Gadamer (1960/1989) suggested that humans develop a deeper understanding of something through a hermeneutic circle, and he describes this activity as a universal and inescapable feature of human existence (Wilding & Whiteford, 2005). The hermeneutic circle refers to an interpretive process in which individuals move between parts of experience and the whole of experience and back and forth over and over again (Kincheloe & McLaren, 2003). Kvale (1996) viewed the end of this infinite process as

occurring in practice when one has reached a sensible meaning, a valid unitary meaning, free of inner contradictions, for the moment. When undertaking research in a hermeneutic phenomenological approach, a double hermeneutic is involved. The researcher engages in a hermeneutic circle of understanding as participants are trying to make sense of their world (Smith & Osborn, 2003).

Koch (1995) stated “Hermeneutics invites participants into an ongoing conversation, but does not provide a set methodology. Understanding occurs through a fusion of horizons, which is a dialectic between the preunderstandings of the research process, the interpretive framework and the sources of information” (p. 835, as cited in Lavery, 2003). The metaphor “fusion of horizons” originally came from Gadamer (1976), who suggested that each individual has backgrounds of various assumptions, ideas, meanings, and experiences in living (Lopez & Willis, 2004). These backgrounds are basically the sum total of all contextual influences that make individuals who they are, and serve as a horizon from which individuals view the world and undertake any interpretation (Wilding & Whiteford, 2005). This concept indicates that the final result of the interpretive process, indeed, arises through a fusion of the text and its context, as well, as the participants, the researcher, and their contexts (Lavery, 2003).

Moreover, Heidegger (1927/1962) stressed that the technique of bracketing, as described by descriptive phenomenologists, is impossible. The researcher’s horizon of understanding within the research focus, including biases, assumptions, personal experience and knowledge, theoretical and philosophical influences, is viewed as essential to interpretive process. Although there is no rigid set of rules to structure the

research process, the researcher is suggested to begin a process of self-reflection when a decision to engage in research from a hermeneutic phenomenological perspective is made (Laverty, 2003). The researcher is also called to make preconceptions explicit and to explain how they are used in the interpretation of the data and in generating findings (Laverty, 2003; Lopez & Willis, 2004). From this hermeneutic perspective, there could be more than one valid interpretation of the narratives, but the meanings that are stated in the research findings must be as reflexive and rigorous as possible and be logical and plausible within the study framework (Lopez & Willis, 2004). “There are specific criteria and processes to ensure the authenticity of qualitative research. However, the ultimate check is in the text itself. It is the text, or data, to which the researcher is always accountable” (Allen, 1995, as cited in Wilding & Whiteford, 2005, p.101).

## Appendix B

### Family Characteristics

No.	Person with CHF			Family member(s)	
	Age	Gender	Marital status	Interviewed	Role
1	60	M	Married	Yes	Wife
2	71	M	Widowed	No	
3	60	M	Married	No	
4	75	F	Married	Yes	Daughter
5	66	M	Married	Yes	Wife, stepson
6	47	M	Married	Yes	Wife
7	21	M	Single	No	
8	40	M	Married	No	
9	44	F	Married	Yes	Mother, husband
10	42	M	Married	No	
11	69	M	Married	Yes	Brother-in-law
12	67	M	Married	No	
13	71	F	Widowed	Yes	Daughter
14	82	M	Widowed	Yes	Son
15	48	M	Married	Yes	Wife
16	63	M	Divorced	No	
17	78	M	Married	Yes	Daughter-in-law
18	76	M	Married	No	

*Note.* Person with CHF (5) was not able to participate in the interview because he was still in recovery from heart transplantation. The interview tape of No. 18 malfunctioned and was excluded from the data analysis.

CHF = chronic heart failure.

## Appendix C

### **Interview Schedule (English translation)**

#### **Introduction**

Hi, my name is Szu-Yi Peng, a current doctoral student at the University of Minnesota in the United States. I am working with Dr. Lee and Dr. Hsiung for the research project of “Establishing Family-oriented Interventions for patients with heart failure” at the Heart Failure Center. Thank you for agreeing to participate in this important research. As you probably know, we are trying to understand what family experience is and how they adapt when they have a family member with chronic heart failure. We think that the best way to find out is to ask families who have experienced this situation. This interview is voluntary. There are no “right” or “wrong” answers to any of our questions; we just want to hear what life is like for you and your family. If you don’t feel comfortable answering a question, you don’t have to. You may stop the interview at any time without penalty. I will be taping this interview. Later on we will transcribe the tapes, and we will use fake names in those documents. All information you give us will be kept confidential. Your name will never be associated with this study. Please read this consent form carefully. If you agree to participate, please sign your name at the bottom of this form.

#### **Assessing Participants’ Comprehension**

Before we begin, are there any questions you would like to ask? (Give the participants a couple of minutes to think about it.)

Do you understand what I want to know about you and your family? Do you have any questions to ask me about the type of questions before we get started?

I want you to feel comfortable to tell me only what you want to tell me. Do you have questions about what's going to happen if you don't want to answer certain questions, or if you decide to withdraw from this research?

Do you have any questions about why we are tape recording the interview?

What you tell me will never be identified with your name. Do you have any questions about how we will keep and report the information we obtain from you?

### **Interview Questions**

(Do not proceed unless you, the interviewer, have a completed informed consent document.)

I am going to start the tape recorder now, is this okay?

Thank you for signing and returning the consent form.

- First of all, could you please tell me who are in your family?
- How would you describe your family's experience of dealing with heart failure? (To encourage the conversation, another way to ask this question could be: What would you say if you were to tell a story about what life has been for your family since the diagnosis of heart failure in one of your family members?)

- What has changed (and what has not changed), if any, in your family since the diagnosis? (Another way to ask this question could be: What and how has the illness impacted on you personally, on your family as a whole, and on the relationship between your family and other outside systems?) (Probe if appropriate: In what ways have pre-illness roles and responsibilities changed for each family member since the diagnosis? How does your family reorganize itself to deal with these changes? Is there anything better in your family life as a result of the heart failure, and if so, what is that? Is there anything worse or more difficult in your family life as a result of the heart failure, and if so, what is that?)
- How do you or your family member view the situation of having a family member with chronic heart failure? (note: assessing family beliefs about the illness, which include beliefs about the cause of the illness, about mastery or control of the illness, about the fit between the family and health professionals)
- How do you feel about heart failure, and its impact(s) on you and your family? How do your family members express and communicate those feelings? (Probe: Is there any rules around talking/discussing about the illness or expressing emotions? Whom do you usually turn to? How do you feel about the rules?)
- Overall, what are the key elements that make your family's life easier (or more difficult) in the situation of dealing with heart failure?
- What kind of strategies and/or resources has your family been using to cope with this situation? What do you think about them? (Probe: What are the things or help that you and your family would like to have?)

- In your experience of dealing with health issues (heart failure), who are usually involved and who are not? Why? (Probe if appropriate: Besides the ill member, who has primary caregiving responsibilities for managing the disorder? How did that get decided? How does everyone feel about this arrangement? Could other members share responsibilities to alleviate a disproportionate burden on the primary caregiver?)
- Besides the family, who have been the key players in your family's experiences of dealing with heart failure? (Probe: Who are they? Extended family? Friends? Health professionals? What's the relationship between the family and those people? What's their role playing into the situation that your family is facing? What do you think about them? How can they be more helpful?)
- We have covered a lot of dimensions of your experience in this interview. Before we end this interview, I am wondering, is there anything else that you think we should know about how your family is doing right now but we've missed? Is there anything very important about your experience and you would like to make sure that I know? (Probe if appropriate: Are there other illnesses or events happening for the patient and/or for other family members? How are they entangled in what is going on in the family?)

Thank you so much for sharing your family experience with me.

## Appendix D

### Pile-Up of Family Demands

Theme	Sources of strains by system level		
	Individual family members	Family unit	Community contexts
Initial stressors related to chronic heart failure (CHF)	<ul style="list-style-type: none"> <li>● Persons with CHF:               <ul style="list-style-type: none"> <li>(a) signs and symptoms of CHF</li> <li>(b) physical limitations</li> </ul> </li> <li>● Family members:               <ul style="list-style-type: none"> <li>(a) fear</li> <li>(b) caregiving demands</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>● Loss of sexual intimacy for couples</li> </ul>	<ul style="list-style-type: none"> <li>● Health care system strains</li> </ul>
Hardships developed over time as direct results of CHF	<ul style="list-style-type: none"> <li>● Persons with CHF:               <ul style="list-style-type: none"> <li>role limitations due to physical disabilities</li> </ul> </li> <li>● Family members:               <ul style="list-style-type: none"> <li>caregiving demands</li> </ul> </li> <li>● Psychological distress:               <ul style="list-style-type: none"> <li>(a) stress of care-giving and care-receiving</li> <li>(b) constant worries about the persons with CHF</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>● Changes in family roles and responsibilities</li> <li>● Financial strains</li> </ul>	<ul style="list-style-type: none"> <li>● Reduced social lives</li> <li>● Lack of instrumental support</li> </ul>
Inconveniences and conflicts regarding daily management of CHF	<ul style="list-style-type: none"> <li>● Persons with CHF:               <ul style="list-style-type: none"> <li>daily management of the illness</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>● Inconveniences &amp; conflicts regarding daily management (dietary &amp; weight control, smoking cessation, medication compliance, regular follow up appointments)</li> </ul>	<ul style="list-style-type: none"> <li>● Treatment regimens</li> </ul>
Difficulties of balancing multiple family needs	<ul style="list-style-type: none"> <li>● Other illnesses of the person with CHF</li> <li>● Prior and/or ongoing illness of other family members</li> </ul>	<ul style="list-style-type: none"> <li>● Other ongoing demands and daily hassles</li> <li>● Prior ongoing family strains</li> </ul>	

*Note.* CHF = chronic heart failure.

## Appendix E

### Family Capabilities

Sub-domain /Theme	Sources of capabilities by system level		
	Individual family members	Family unit	Community contexts
Resources	<ul style="list-style-type: none"> <li>● Positive attitudes</li> <li>● Sense of coherence and mastery</li> <li>● Knowledge and past experience of managing CHF</li> <li>● Spiritual beliefs</li> </ul>	<ul style="list-style-type: none"> <li>● Family hardiness: Commitment to be involved in the care</li> <li>● Family cohesiveness:               <ul style="list-style-type: none"> <li>(a) Close and trusting relationships among family members</li> <li>(b) Family time together and family routines</li> </ul> </li> <li>● Family functioning:               <ul style="list-style-type: none"> <li>(a) Comfortable problem-solving and communication style</li> <li>(b) Family flexibility</li> </ul> </li> <li>● Financial stability</li> </ul>	<ul style="list-style-type: none"> <li>● Instrumental support</li> <li>● Informational support</li> <li>● Emotional support</li> </ul>
Coping Behaviors			
Making accommodations	<ul style="list-style-type: none"> <li>● Persons with CHF: adhere to treatment regimens</li> </ul>	<ul style="list-style-type: none"> <li>● Adjust diet</li> <li>● Adjust living arrangement</li> </ul>	
Using existing and acquiring additional resources	<ul style="list-style-type: none"> <li>● Persons with CHF: retain independency</li> </ul>	<ul style="list-style-type: none"> <li>● Seek social resources and social support (instrumental, informational, emotional)</li> </ul>	
Changing family interaction patterns	<ul style="list-style-type: none"> <li>● Person with CHF: nice to family members and people</li> </ul>	<ul style="list-style-type: none"> <li>● Improving family relations and interactions:               <ul style="list-style-type: none"> <li>(a) less argument</li> <li>(b) remain or increase the frequency of family gathering</li> <li>(c) care each other more</li> </ul> </li> </ul>	
Shaping appraisals	<ul style="list-style-type: none"> <li>● Accept the natural course of the disease</li> <li>● Second chance of life</li> </ul>	<ul style="list-style-type: none"> <li>● Accept the natural course of the disease</li> <li>● Plan for the future, including death</li> </ul>	

*Note.* CHF = chronic heart failure.