living with chronic illness:
support for family members who live with heart failure

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EXECUTIVE SUMMARY

Introduction

This study explores the role that families play in the experience of living with heart failure, and the ways in which health-care providers can help families to improve and sustain constructive support systems. The contribution of families in supporting a family member living with a long-term condition merits exploration, but little research has been undertaken in this area. This study focused on heart failure as an example of a long-term condition that is progressive but for which morbidity is strongly influenced by the effectiveness of self-care strategies. The study explored perceptions of the role of the family from the perspective of the person living with heart failure, from family members and from health-care providers.

Methods

Twenty-four families took part in family group interviews, and one group interview was run with health-care providers. In total, 70 people took part in the study. The interviews were semi-structured and mainly conducted in people's homes. Purposive sampling ensured that some diversity was obtained in the age and ethnicity of those interviewed. Pseudonyms have been used throughout this report to protect the anonymity of families.

Research findings

The findings of this research indicate that the generation of a shared understanding of heart failure as a long-term condition and adaptation to it by the family unit is important. The provision of support that is flexible and can change over time to meet developing needs is vital. The availability of knowledgeable and accessible services – in particular, primary health-care and specialist cardiology services – was acknowledged as important. The involvement of family members in the health-care system provides reassurance, knowledge about the condition and management that in turn leads to a sense of confidence within the family about managing heart failure; particularly important is support for the development of self-care strategies for medication and diet.

Discussion and limitations

This study has shown that families play an important role in supporting a member living with heart failure and make a significant contribution to their wellbeing and health. Together, family members build a shared sense of self-efficacy that promotes positive engagement in managing a long-term condition. It is important that health-care interventions take a family-centred approach not only to involve those people who matter but also in order to harness and build on support and strengths already available. This study shows that it is possible to conduct group family interviews and obtain valuable descriptive data. Further study would provide more knowledge on the positive contributions that families make to the experience of those living with long-term conditions. The study of other long-term conditions would broaden understanding of the patterns and meanings behind relationships. Studying families from more diverse ethnic and cultural backgrounds would further extend the meaning of the findings in the contemporary New Zealand setting.

Conclusion

This study provides descriptive data from a selection of families using sound and potentially replicable methods of data collection. One of the major contributions of the study is further understanding of the development of self-efficacy at a family level, rather than at an individual level only. The study highlights the importance of collaborative relationships between families and health-care providers.

1. BACKGROUND

Supporting and strengthening families through life events such as chronic illness requires a multi-faceted approach. It requires health-care providers to not only care for the individual within the family group (family as context), but also to work with the family as the unit of care (family as client). Earlier work has tended to view family members as those who provide care to other family members, without establishing whether they act as or feel like partners in care (Ward-Griffin & McKeever, 2000). A plethora of research charts the negative impact of living with and/or supporting someone experiencing chronic illness and the burden of caregiving (examples include Faison, Faria, & Frank, 1999; Hwang et al, 2003; Slattum & Johnson, 2004). This work is important for developing an understanding of those who may be at risk of becoming overburdened; the work does little to promote the primacy of the 'patient' and family as experts in managing conditions. Many families will have developed empowering partnerships and drawn on other strengths in living with chronic illness. The literature and practice guidelines give little acknowledgement to the role families play in managing long-term conditions. Work that recognises and explores this further can help to promote genuine collaborative partnerships between individuals living with chronic illness, families, caregivers and health and social-care professionals with the aim of promoting the wellbeing of the family.

1.1 Literature review

All New Zealanders are affected by long-term conditions – managing their own long-term condition, caring for family and whānau, as health and social-care providers or as taxpayers. Long-term conditions are 'the health challenge of this century' (World Health Organisation, 2005). It has been estimated that, globally, 60 percent of all deaths are due to long-term conditions. Over the next 10 years the number of deaths attributable to long-term conditions is predicted to rise by 17 percent (World Health Organisation, 2005). In New Zealand, long-term conditions account for more than 80 percent of deaths and are the leading cause of preventable morbidity, mortality and unequal health outcomes (Ministry of Health, 1999). Long-term conditions account for a higher proportion of illness and deaths among Māori, people on low incomes and Pacific peoples than among the general population.

Older people comprise a significant proportion of people with chronic conditions. Between 2002 and 2021, the proportion of the New Zealand population aged 65 and over will increase from 11.9 percent to 17.6 percent (Ministry of Health, 2004).

Heart failure (HF) is the inability of the heart to keep up with the demands on it and, specifically, its failure to pump blood with normal efficiency. When this occurs, the heart cannot provide adequate blood-flow to other organs such as the brain, liver and kidneys. Heart failure may be due to failure of the right or left ventricle, or both. The signs and symptoms depend upon which side of the heart is failing. They can include shortness of breath (dyspnoea), swelling (oedema), blueness or duskiness (cyanosis) and enlargement (hypertrophy) of the heart. The aim of therapy is to improve the pumping function of the heart. Management includes salt restriction, diuretics (to excrete excess fluid) and medication (to maintain a strong, regular heartbeat).

Heart failure is the only major cardiovascular disease known to be increasing in prevalence (Mair, Crowley, & Bundred, 1997). Hospital admissions for heart failure in New Zealand increased by more than 50 percent between 1988 and 1997 (Doughty, Wright, Gamble, & Sharpe, 1999). In the US, admissions for heart failure almost tripled between 1979 and 2004 (Fang, Mansah, Croft, & Keenan, 2008). The symptoms of heart failure can profoundly affect quality of life (Riedinger & Singh, 2006). Heart failure is one of the few long-term conditions where there is good evidence for the effectiveness of treatment and clear evidence that early and consistent treatment prolongs life. It is important that people are diagnosed accurately and managed appropriately to improve quality of life and to prevent unnecessary hospital admission. Heart failure was chosen as the condition of focus for this study because it is a condition that can be managed solely at home through medication and lifestyle changes (Bennet et al, 1998), and it is clear that the individual and their family can play a significant role in managing heart failure. Yet we know little about the best ways of devising effective support strategies (Schulze & Rossler, 2005) that complement family strengths. Before effective intervention studies can be drawn up that genuinely acknowledge the positive skills and input that families can bring, an understanding of what individuals and families perceive as strengths and how they describe positive partnerships requires exploration (Szmukler, 1999).

1.1.1 Older adults and family

In this study a broad and inclusive definition of family was adopted to include not only family members living together or related by marriage, blood or adoption but also extended families, whānau or other culturally recognised groups and 'fictive kin' – those people who are seen as part of the family through a close association. Recognition was given to the fact that families of older adults do not often take the form of a nuclear family structure centred on adults and children sharing a household. Family members may be dispersed around the world and variable levels of contact maintained. Still, family relationships are often the most important relationships individuals hold. A New Zealand study noted that families remain the most important social connection for older adults (Stephens, 2006), and this was not always based on immediate support but on a sense of permanent 'blood' connection (Breheny & Stephens, 2007). Family members are cited as the most important links central to maintaining social ties by older adults with children and spouses (Phillipson, Bernard, Phillips, & Ogg, 2001).

1.1.2 Families and chronic illness

The availability of emotional support and direct care for people living with illness is related to family functioning (Mitrani et al, 2006). Family functioning is dynamic; it changes over time in response to new demands. In relation to long-term conditions, the literature highlights the progressive impact of illness over time on social, economic and interpersonal functioning (Highnet, McNair, Davenport, & Hickie, 2004). Many dimensions of family functioning have been studied, and evidence suggests that living with a family member with a chronic illness can have an impact on them, but the evidence also highlights that the impact can vary, depending on the family's reaction, resources (such as time and money) and ability to cope.

A two-way relationship has been observed between family functioning and stress. Family functioning is a key factor in mediating the objective burden of care (events, happenings and activities) and subjective burden (the distress associated with the objective burden of care). Family functioning relates directly to stress (Mitrani et al, 2006). More objective burden of care is associated with lower family functioning, which in turn is associated with more anxiety, depression and perception of poorer health.

A significant theme in the literature on response to change within communities, families and individuals is the concept of resilience. A growing body of work on resilience and response to illness is emerging. Family resilience has been defined as "the path a family follows as it adapts and prospers in the face of stress, both in the present and over time. Resilient families positively respond to these conditions in unique ways, depending on the context, developmental level, the interactive combination of risk and protective factors, and the family's shared outlook" (Hawley & De Haan, 1996, p. 293). Originally, resilience was thought of as a personality trait; but over the past decade it has been redefined as a process rather than a fixed trait, and therefore open to modification (Luthar, Cicchetti, & Becker, 2000). Work around protective factors, specific attributes or situations that are necessary for the process of resilience to occur (Dyer & McGuinness, 1996) has come in and out of favour. Contemporary work on resilience now refers to 'defining attributes', characteristics that appear repeatedly and consistently (Walker & Avant, 2005). The defining attributes of resilience are presented as 'rebounding' and 'reintegration', where an individual wants to return to a regular routine and is ready to assimilate change in a positive or improved way (Flach, 1997). Family resilience refers to a collective resilience rather than individual family members being resilient (Walsh, 2003).

Following a review of the literature on families, positive functioning, resilience and chronic illness, the following key processes are put forward as critical in determining family functioning. They fall into three categories: belief systems; organisational patterns; and communication and problem solving.

1.1.3 Belief systems

Family belief systems affect the perception of what constitutes a crisis and the options available to deal with it (Wright, Watson, & Bell, 1996). Resilience is fostered by shared facilitative beliefs that increase options for problem resolution, healing and growth. They help family members to make meaning of difficult situations, facilitate a positive outlook and visualise ways to move on (Walsh, 2003).

1.1.4 Making meaning of adversity

High-functioning families have been described as having strong connections, approaching adversity as a shared challenge and holding a relational view of

strength; in joining together individuals strengthen their ability to overcome adversity (Walsh, 2003).

Well-functioning families have been described as having a sense of family that continually changes and adapts over time. In this way disruptive events such as illness can be seen as milestones in a shared life passage. Putting distress caused by events such as illness into context helps to normalise the event and helps family members understand difficulties, reducing stress and anxiety (Walsh, 2003).

Families that function well gain a sense of coherence, the emotional bonding that exists between family members (a sense of 'togetherness' and interconnection). Cohesion has been linked to the provision of help and support within families (Olson & Tiesel, 1991).

Strong links have been found between holding a positive outlook and coping with stress, barriers and crises (Earvolino-Ramirez, 2007). Key attributes of a positive outlook are hope, a belief that a better future can be envisioned and optimism that difficult times can be handled and will be overcome (ibid); however, competence (the ability to perform a specific task, action or function) is not a sufficient prerequisite. If the individual underestimates their potential for action, no adaptive strategies will be developed, so perceived competence is vital. This has been labelled 'perceived self-efficacy' (Bandura, 1995) and relates to a person's confidence and sense of control. Self-efficacy affects how people feel, think and act. A low sense of self-efficacy is associated with depression, anxiety and helplessness, while a strong sense of competence facilitates cognitive processes; self-efficacy levels can enhance or impede the motivation to act. Individuals with high self-efficacy choose to perform more challenging tasks. They set themselves higher goals and stick to them (Locke & Latham, 1990). Once an action has been taken, a highly self-efficacious person will invest more effort and persist longer than those with low self-efficacy. In the face of setbacks, the former recover more quickly and maintain the commitment to their goals. Self-efficacy also allows people to select challenging settings, explore their environments or create new situations.

A sense of competence can be acquired by mastery experience, vicarious experience, verbal persuasion or physiological feedback (Bandura, 1992). Mastery experience refers to the individual achieving a goal,

and is the most important factor deciding a person's self-efficacy; success raises self-efficacy, failure lowers it. Vicarious experience is a process of comparison between a person and someone else. When people see someone succeeding at something, their self-efficacy will increase; and where they see people failing, their self-efficacy will decrease. This process is more effectual where the person sees themselves as similar to their model. Social persuasions relate to encouragements and discouragements, which can have a strong influence; most people remember times where something said to them significantly altered their confidence. While positive persuasions increase self-efficacy, negative persuasions decrease it. It is generally easier to decrease someone's self-efficacy than it is to increase it. Physiological factors relate to a person's interpretation of physical symptoms. In stressful situations, people commonly exhibit signs of distress: shakes, aches and pains, fatigue, fear, nausea. A person's perceptions of these responses can markedly alter their self-efficacy. If a person gets 'butterflies in the stomach' before public speaking, those with low self-efficacy may take this as a sign of their own inability, thus decreasing their efficacy further, while those with high self-efficacy are likely to interpret such physiological signs as normal and unrelated to their actual ability. Thus, it is the person's belief in the implications of their physiological response that alters their self-efficacy, rather than the sheer power of the response.

Self-efficacy, however, is not the same as positive illusions or unrealistic optimism, since it is based on experience and does not lead to unreasonable risk taking. Instead, it leads to behaviour, sometimes at the edge of one's boundaries, but within reach of one's capabilities.

Study of the relationship between self-efficacy and specific health outcomes, such as recovery from surgery or adaptation to chronic disease, has found that people with high-efficacy beliefs are better able to control pain than those with low self-efficacy (Altmaier, Russell, Kao, Lehmann, & Weinstein, 1993; Litt, 1988; Manning & Wright, 1983). Self-efficacy has been shown to affect blood pressure, heart rate and serum catecholamine levels in people coping with challenging or threatening situations (Bandura, Cioffi, Taylor, & Brouillard, 1988; Bandura, Reese, & Adams, 1982; Bandura, Taylor, Williams, Mefford, & Barchas, 1985). Recovery of cardiovascular function in postcoronary

patients is similarly enhanced by beliefs in their own physical and cardiac efficacy (Ewart, 1992; Taylor, Bandura, Ewart, Miller, & DeBusk, 1985). Perceived self-efficacy can predict the degree of therapeutic change in various settings (Bandura, 1992, 1995).

1.1.5 Family organisational patterns

Families organise in various ways to meet the challenges they face. Resilience is bolstered by flexible structure, maintenance of relationships and social and economic resources.

The concept of 'adaptability' is particularly relevant to understanding how a long-term condition affects families. Part of the stress of caring, even at a distance, is due to changes in roles, and the need to adapt to new roles. The ability to be flexible in roles and tasks is paramount. Poor family adaptability has been noted as the most powerful predictor of depression in carers (Deimling, Smerglia, & Schaefer, 2001).

The ability to manage sustained changes to the structure of relationships is crucial to family functioning. One change brought about by chronic illness is degree of closeness, which is in turn linked to marital relationship satisfaction (Higgins, Bailey, & Pearce, 2005). The role of partner can change to one involving high levels of caregiving. Looking after a parent with a chronic illness can affect the parent-child relationship with the 'parentification' of children (children assuming care responsibilities for parents). A study of women caring for an elderly parent found evidence of conflict and role confusion (Murphy, 2000). Caring for parents can also affect relationships between siblings. Conflict can arise when one child assumes more responsibilities than others (Britnall-Peterson, 2004). Disagreements can also occur when family members have differing ideas about the family role in supporting members during illness (ibid).

Social and economic resources play a significant role in living with chronic illness. Perceptions of support, social networks and financial security and resources will be reviewed.

1.1.5.1 Perceptions of support

Perception of social support, as opposed to actual social support, has been linked with mental health but not physical health (Magliano et al, 2006; Schofield et al, 1998). Carers who perceive more social support demonstrate lower levels of depression (Pinquart & Sorensen, 2007). Given that perception of available support has a positive impact on carers' wellbeing, it is important that carers are aware of the availability of services that can assist in the care of a family member, and know how to obtain them.

1.1.5.2 Social networks

Evidence suggests that carers' social lives are affected by caring for a member with a long-term condition (Ekwall, Hallberg, & Sivberg, 2005; Magliano et al, 2006). Losing touch with existing friends after starting caring is commonly cited (Australian Bureau of Statistics, 2004). The provision of direct help (such as personal care, visiting and housework) by network members has been associated with more life satisfaction and positive mood.

1.1.5.3 Economic resources

Living with a long-term condition can lead to reduced hours or loss of employment, which can affect quality of life. Supportive social and institutional policies and practices are necessary to support families, along with the ability to access them when necessary. Other supportive mechanisms include flexible working hours to accommodate treatment, symptom patterns and caring responsibilities (Zodgekar & Fursman, 2008).

1.1.6 Communication and problem solving

Open and clear communication between family members has been linked to positive family functioning. Verbal exchanges of information and the ability to speak and listen to each other are important (Olson, 1993). Poor family communication is associated with more distress in breast cancer patients (Hilton, 1994), and direct communication is associated with less anxiety in families of recently diagnosed cancer patients (Edwards & Clarke, 2004).

2. METHODS

2.1 Research aims

This research aims to understand the role that families play in the experience of living with heart failure, and to explore how health professionals can help families improve or sustain constructive support systems.

2.2 Research questions

1. What supportive mechanisms do families living with a member with heart failure provide?

2. What has affected the family members' ability to support a family member with heart failure?

3. What are the characteristics of a positive relationship between family members and others in terms of living with and supporting a family member with heart failure?

4. What perceptions do families hold of the role of health professionals in managing a family member with heart failure?

5. What are health professionals' perceptions of the role of the family in managing family members with heart failure?

2.3 Research design

A cross-sectional design was chosen, with a number of families each taking part in a single interview. In addition, an interview was held with staff from a cardio-respiratory clinic, including medical and nursing staff and a Māori health worker.

2.4 Sample and recruitment

Purposive sampling – a non-random approach used to select people on the basis of particular characteristics – was undertaken to ensure some diversity in ethnic origin, age and severity of illness.

Age was considered to be important, since family structure and working life is likely to differ for those under and over 65 years of age. Only one percent of people living with heart failure are under 65 years of age, and since the aim was to explore the impact of heart failure on those in employment and with younger families, the sample comprised proportionally more people under the age of 65 years.

The literature notes higher rates of hospitalisation for heart failure for Māori and Pacific peoples. Families from different cultural backgrounds were sought to allow exploration of the complexities that culture may bring to family contribution.

The stage of heart failure was included as family contribution is likely to reflect the severity of the symptoms experienced, and families will face different challenges accordingly. Stages II and III of the NYHA classification (mild and moderate) for heart failure were used as a guide in categorising participants. In Stages II and III the symptoms of heart failure affect normal daily activities, but the person is unlikely to be highly debilitated or hospitalised. Stages II and III represent the largest population of people living with heart failure. People living with heart failure classified as Stage I or Stage IV were excluded from the study. In the case of Stage I, symptoms experienced do not affect daily life, and people living with Stage IV heart failure are largely hospitalised because of low functional capacity; including them in the study would reduce the ability to capture the everyday strategies people use in the home and family setting.

Families were accessed through three health providers: a cardio-respiratory outreach clinic, a Pacific primary health organisation and a cardio-pulmonary district nursing team. Meetings were held with staff from the above groups to explain the study and seek their involvement in the recruitment of families. Packs containing information about the study were given to staff to be passed on to people with heart failure who met the criteria. Some additional information packs were posted out with appointment notices from the cardio-respiratory outreach clinic to a broader group of people with heart failure. Recipients expressed willingness for the researchers to contact them by returning a consent form provided with a reply-paid envelope in the information pack. At this stage there was no commitment to take part. Confidentiality was respected at all times, and no names were given directly by the health providers to the researchers.

The research assistant followed up the respondents by phone to discuss the study and answer any questions. Listening was important in building a rapport at this stage. For those who wished to proceed, the researcher drew up a family network map indicating family relationships and the frequency of contact between individuals and the family member who had heart failure. People were encouraged to invite any family members who were involved in supporting them to a family interview.

Overall, there were 30 respondents and 24 chose to participate in the study. Of the six who did not proceed, four did not meet the study criteria (two people did not have a diagnosis of heart failure, one person was asymptomatic and one person had no family involvement).

2.5 Families participating in the study

Six women and 18 men living with heart failure took part in the family group interviews. The higher number of men corresponds with the higher incidence of heart failure in men than women in the population. There was a heavy weighting towards older participants in the European and other category (Table 1), which can be considered representative of the population in general.

TABLE 1: Participants by age, severity of heart failure and ethnic origin

	Māori		Pacific		New Zealand/ European	
Years	**<65**	**>65**	**<65**	**>65**	**<65**	**>65**
Mild	0	1	0	0	1	3
Moderate	2	1	1	2	2	11

The majority of family group interviews were attended by two to four family members, including the member living with heart failure. Seven family members were present at one interview, and in two cases the family member living with heart failure was interviewed alone. This occurred where there were no relatives in Christchurch but the family involvement was considered to be of interest to the study. In all, 70 people took part in the interviews. One group interview with four health-care providers was undertaken, comprising medical and nursing staff and a Māori health worker (Appendix I).

In one interview a family member who lived outside Christchurch was included by teleconference. Spouses and adult children were the family members most often participating in interviews but siblings, relations by marriage and in one case teenage children, also took part.

2.6 The interviews

In all but one case, families chose to have the interview at their home. One took place at the researchers' work premises. Ethical approval to conduct the study was gained from a regional ethics committee.

Family research is traditionally based on questionnaires and interviews, and one family member usually answers questions on behalf of the whole family. The views of one family member do not necessarily represent those of the whole family (Uphold & Strickland, 1989).

Whilst some of the principles and understandings of focus group research are applicable to family interviews, the differences between a family and a group are notable – for example, focus group members may have common characteristics but typically do not know one another and are not related.

Key issues to consider include the definition of 'family', gaining access, creating the interview relationship and management of data. The key practical issues that were considered during the interview are set out in Appendix II and the interview schedule in Appendix III.

Despite the complexities of conducting family research, conceptual, methodological and analytic methods that capture family-level data are needed to develop greater understandings of family care (Eggenberger & Nelms, 2007). Family research completed with family interviews that focus on the family as a whole may assist in discovering the shared family experience and family meanings that emerge with an illness experience (Chesla, 1995; Hartrick & Lindsey, 1995). In addition, family interviews foster awareness of the multiple voices within families, which are both autonomous and related (Hartrick & Lindsey, 1995).

2.7 Data analysis

All interviews were recorded and transcribed for analysis. Thematic analysis was used to determine the major recurring themes in the interviews, employing Boyatzis's (1998) approach, where a theme is described as "a pattern found in the information that at a minimum describes and organises the possible observations and at maximum interprets the phenomenon" (p. 3). Analysis involved reducing the data to significant statements or quotes, and then identifying themes to draw together significant statements and coherent patterns. Analysis then moved on to compare themes across transcripts and find relationships. At all times the analysis was guided by three questions: How are these findings meaningful in investigating the family experience? Do the data represent family-level data? Do these data describe an individual perception of a family member that contributes to understanding the shared family experience?

3. RESULTS

3.1 Introduction

The data from people living with heart failure and family members are presented as family data, and the data generated from the health-care providers are presented as appropriate. The family member living with heart failure has been given a pseudonym and other family members are identified by their title (such as husband). No differences were noted in culture, severity of the condition or age.

Analysis of the data generated through discussion with family members highlighted the following themes: the construction of a shared understanding of heart failure requiring some knowledge and acceptance of the condition, and adaptation to life with a long-term condition, including the ability to support one another in a flexible way; perception of support and social networks; and engagement with various services, including health-care services.

3.2 Construction of a shared understanding of heart failure

A shared understanding of heart failure between family members was fundamental. This was generated through knowledge of heart failure and its impact, acceptance that heart failure was a long-term condition and adaptation to manage the physical and psychosocial consequences of a heart-failure diagnosis.

3.2.1 Acceptance

Acceptance of the diagnosis of heart failure and its long-term and progressive nature was described as important by all families and health-care providers:

> One of the key issues is around the patient coming to terms with their own heart failure and understanding how it affects them and their limitations and then the family themselves coming to terms with the patient. (Māori health worker)

> …the main issues are firstly coming to terms with the diagnosis. (Doctor)

> The acceptance of the condition … that it's ongoing and is not a short-term disease. (Nurse)

Families stressed that they had accepted the condition and concentrated on moving on:

> You learn to accept up to a point, the difficulty is not to give in to it too really, but at the same time you can't overstretch yourself because as soon as you do you get a sharp response which says 'Hey, wait a minute'. (Ernest, Family 6)

> …acceptance on everybody's part that this is the way it is, is really important. (Wife, Family 17)

Acceptance of the diagnosis and the condition did not imply giving up or giving in to illness, but a rational understanding of what could be achieved and what needed to be reviewed in order to manage symptoms and the condition as effectively as possible.

3.2.2 Adaptation

Many families described a flexible, positive approach that allowed them to cope with adversity and adapt to a different lifestyle:

> Even if anything goes a wee bit wrong or anything like that, well, why get up in arms over it. (Wife, Family 17)

> Well, you just work around what's happening. (Wife, Family 18)

The principal carers in eight of the families described finding a job that allowed them to be flexible in the hours that they worked, or employers who allowed them to leave work as necessary to support their family, such as when they had to attend appointments:

> I'm only working part-time but that can be very flexible. I'm around here quite a bit of the time. I do quite a bit from home. (Wife, Family 6)

> I mean, as long as I get it done by eight o'clock in the morning I can go anytime, and then the odd night if he's been ill and he's had to go to hospital I don't worry about it, I'll go settle him in and even if it's one or two o'clock in the morning I'll still go to work because I'm independent, do you know what I mean. It really suits how I'm working now. (Wife, Family 17)

Several other family members described flexibility in their existing workplaces and its value for helping them to support family members.

Adapting to life with someone with heart failure was considered important and was evidenced in a number of ways. Families discussed refocusing their attention on the individual with heart failure:

I think it's just, it's quite easy, you just move aside a few things because she's got to be more important than those, so I think you just move her up into the more important level than perhaps I've thought of before. (Husband, Family 16)

Many described balancing care with household tasks and the need to let some activities go. One wife described only completing as much as she could:

If I can't manage the lawns today I leave it for tomorrow, I don't panic over it. (Wife, Family 17)

Activities (such as cooking and gardening) could be shared between members so that the member with heart failure could still be involved, but opt in and out as necessary. One father and daughter shared a paper round:

The thing about the paper run especially with Dad's condition, there's no time limit to do it, you don't have to think, I've got to do this because I've got to clock out by this time, but you can just go for that casual walk, say hello to people you know and it's like you don't have to rush about it, just stroll around. (Daughter, Family 7)

The father valued the social contact this provided, and he could work at his own pace, knowing that his daughter could finish the round if he was unable to.

Interviewees described keeping active as important. For some families this meant maintaining previous activities, although possibly at a slower pace:

Wife: He cut the tree off.

Husband: It was a metre high, it was too high, that peach tree.

Wife: I was holding the ladder, he was cutting the tree.

Husband: Yes, it was sawing, and keep sawing and everything, that's normal.

Wife: He just had to sit down every five minutes or so. (Family 21)

Others described undertaking the same activities, but in a modified format to suit their state of health and physical limitations:

Mowing the lawns, I love it but I'm restricted, riding a ride-on's just like driving your car, it's no different, but it's the end achievement, what I've achieved. (Jack, Family 14)

I would sit down at times when I should be standing and things like that, I developed a, developed behaviours of sitting down and doing things rather than standing up and doing them and so on like that. (Harold, Family 10)

Others cut down on the number of activities they pursued:

Colin (husband): You can't do the things you want to do. I still go to the supermarket and pole round with a trolley and buy veges don't I?

Wife: Yes, it is your only outing really. (Family 2)

For others, maintaining an active life meant focusing on new activities that were more appropriate. One man, for example, before his coronary artery bypass graft operation, was unable to drive, and wanted to have the independence of being able to drive long-distance for holidays. As soon as he felt able after the operation he took driving lessons, and he can now drive and visit places he couldn't before. Another family created raised beds in the vegetable garden to enable their father to access them alongside from his mobility scooter. After developing mobility issues and breathlessness on exertion, one man developed an interest in parrots – caring for them, feeding them and teaching them to talk. Several families described discovering computers and the internet at a relatively late age as a way of keeping up-to-date with news and activities.

Everyone interviewed appeared to be actively involved in managing their health, describing engagement in opportunities to improve it. Most opportunities were presented rather than sought independently. However, a key feature was the ability to see the benefit of engaging with the opportunities presented for long-term health. People described increasing exercise – for example, joining an exercise group (Jack, Family 14) and signing up for aquajog and treadmill training (Colin, Family 2), with a view to "getting better health so that I can do more [travel]" (Elizabeth, Family 5).

Some described dieting to lose weight, but more discussed how they had developed an eating plan and now had a healthier diet:

I don't eat any butter on the bread, only a bit on toast and even cheese, no, don't have any cheese, not fat but a bit of meat and lots of veges, that's what I always like. (Kevin, Family 21)

Making dietary changes and increasing exercise indicate acceptance of the condition as a long-term condition. As one health-care provider indicated:

> There are a few patients who came to the clinic and they thought that what they had was a transient thing, like having pneumonia for instance, you take a course of antibiotics for a week or two and then you are fine, which is not the case for heart failure because you need to be on medications all the time or long term at least. Once people start realising this you can actually see that there is a change in their attitude, a change in the way they are dealing with different things, and sometimes it's a positive change and on other occasions it is not.

Everyone interviewed for this study demonstrated acceptance that heart failure was a long-term condition, and their decisions about lifestyle reflected this:

> I had to start looking to change things and find solutions that were long term, not something that is going to be a temporary thing. (Simon, Family 22)

> I moved here because it would make life easier and more practical for services. (Natalie, Family 23)

The family had an important role to play in lifestyle changes through support and advice.

3.3 Perception of support and social networks

Perception of support was high amongst the families interviewed. All but three people living with heart failure lived with a partner or other family member. The three people who lived alone lived in a supported living environment such as a retirement village.

Maintaining a balance between promoting autonomy and the provision of support was important to families; this observation was further supported by the health-care providers:

> Some [families] are taking very active roles in looking after the patient who suffers with heart failure. Starting with monitoring their weight and documenting this in a diary and making sure that they are taking their medications on time, making sure that they are getting enough fluid. On the other hand, some perhaps by giving the patient enough room to be as independent as they can, they are actually doing something positive.

Eleven families discussed being mindful of protecting the independence of the family member living with heart failure:

> …because I'm firm, the last thing I want to take away from my husband is that um, part where he makes decisions, you know, so those times I have to be quiet and just sit and think. (Wife, Family 14)

> I think we have to bear in mind what Ernest's wishes are first and foremost and what he feels is comfortable and what he feels is right in terms of nobody taking over. It's Ernest's life, it is Ernest's body, it's Ernest's attitude to life and it's Ernest that it is happening to. (Wife, Family 6)

The ability to manage sustained changes to the structure of relationships is a key to positive family functioning. Chronic illness can affect the closeness or the quality of relationships. The role of partner can change to one involving much caregiving, and looking after a parent with a chronic illness can lead to children assuming care responsibilities for them.

The families interviewed recognised changes in their relationships as a result of living with heart failure but did not describe the changes as having a negative impact:

> It's not a chore coming to see Mum. (Daughter, Family 5)

> …circumstances have knitted us closer together basically, and we work as a team now. (Wife, Family 7)

> …it hasn't been a negative, we've been able to turn it into a positive and it still hasn't divided us, which you would think something as chronic as this or as dramatic as this would do. (Daughter, Family 9)

All of those interviewed described being socially active with clubs and groups, friends and family. Everyone was still mobile and the majority could still drive, which some described as vital for remaining socially active:

> I can still drive and that's a blessing, means I can still go out and visit friends. (Simon, Family 22)

Two people described the importance of their mobility scooter for remaining socially active:

> Before I couldn't go anywhere on my own but since I got my scooter I've gone everywhere, it is marvellous. (Wife, Family 9)

The ability to socialise was seen as important in part because it gave family members "something to talk about" (Family 7) when they met up.

When family lived in other parts of New Zealand and across the world, contact was still maintained, mostly by telephone, with the use of telephone calls over the internet (such as Skype) mentioned by some. Perception of support was important in understanding people's links. Even when a child lived some distance away and worked full-time, one mother did not see her inability to contact her son by telephone as negative – she used email instead:

> …because he's online all the time and I'm online a lot of the time so I send him a letter and another one comes back while I'm still collecting the others, you know, that sort of thing, and so I send a short reply and he sends a short reply and around and round it goes and I thought, this is really worth doing because it's just like having him here. (Brenda, Family 11)

Others took pride in hearing about the achievements of their children and grandchildren around the world, even though they didn't see them regularly:

> …and my oldest son, he's got his own company now and the other one is making lots of money, can take the family on a cruise just like that… (Simon, Family 22)

The majority of family members described feeling supported by other family members, either through their proximity and involvement if necessary, or through the provision of emotional support if they did not live close by:

> My family is very 100 percent support, supporting me and my husband, supporting with Mum, especially for Mum. And that's all you need, is a good support isn't it, and it makes everything go smoothly. (Daughter, Family 5)

> Wife: I know that you're there and if I needed you or [name] to do anything, or any of the family then yes, I would call. (Family 6)

Over half of the families described perceiving the local community as supportive; this enhanced their feeling of support and perceptions of opportunities for social contact.

The majority of people living with heart failure interviewed for this study were retired, so few could describe the impact of heart failure on employment. Two families did discuss the impact that not being able to work had on their family finances and the resulting low income. One family found this difficult to deal with, while the other did not. Many family members were still working, and changes in employment – for instance, moving to a job closer to home, reducing hours and seeking employment with flexibility – have been discussed earlier. In some instances family members did help financially to ensure that their family had the necessities; however, contributions also included giving time and labour to make things happen:

> I sit down with my five brothers and go we have a problem, not I have a problem, we have a problem and we collectively need to put the resources be it financial, be it physical. (Son, Family 9)

This highlights the importance of open and clear communication between members and the ability to problem solve when necessary.

The literature suggests that carers' social lives are affected by caring for a member with a chronic illness. The carers and family members interviewed for this study did not describe a reduction in the size of their social networks, although some did describe changes in the make-up of their social networks when they had altered activities and therefore came into contact with a different group of people.

3.4 Engagement with health-care services

Key issues discussed were relationships with health-care providers, accessibility and involvement of the family in health-care services.

Everyone interviewed described feeling confident in the health professionals they came into contact with, whether specialists, GPs, nurses or support staff:

> They have worked hard to make sure that I have the right processes operating, the right medication and balancing it, and it's not an easy job balancing nine or 10 different medications, so they all do their job properly and I would have to say that all those people have kept me alive. (Ernest, Family 6)

Many families described feeling able to talk to nurses and doctors about their health and any concerns that they had:

> …and you tell them things that you wouldn't actually tell anybody else. (Husband, Family 24)

Accessibility of services greatly enhanced the families' perception of being supported:

> Yes, because a district nurse comes every week and the cardiology department, cardiology outpatients, I can ring this or the heart failure clinic, can ring them any time. (Husband, Family 16)

> One good thing I've found about that is they said if you want to ring them at any time you're worried, they will you know, answer your call and be as helpful as they can. (Wife, Family 19)

> …always at least one nurse in this area that you could contact if you need it. (Wife, Family 20)

> They told me don't hesitate to be in contact. (Wife, Family 6)

Regular contact was described, with clearly negotiated follow-up appointments arranged. Noone described feeling left to manage alone.

Continuity of care – seeing the same nurses and doctors for follow-up appointments – was described by five families as important. It gave them confidence in the care provided, and on a practical level meant that they didn't have to tell their medical history over again to another person.

Families felt that there was a good range of services available to them, from formal to informal. Exceptions to this were the relative lack of readily available advice on financial entitlements and services for younger people (under retirement age) with heart failure.

All families were asked to describe what they felt facilitated relationships and family functioning within the health-care system. The responses fell into three categories: giving information to ensure that everyone was on the same 'wavelength'; the importance of listening to the partner and family; and timely access to appropriate services.

The dissemination of consistent and appropriate information was held as important by people living with heart failure, family members and health-care providers alike:

> Communication is a very important factor and underestimated sometimes in how we communicate and whether the recipient understands what is being said. A few times I've come across patients who have been told a number of times what is wrong or what their condition is but still they do not fully comprehend it. (Māori health worker)

No family member felt that they had been ignored by health-care staff or deliberately kept out of discussions, but several did specifically underline the importance of being listened to:

> I think they [health professionals] need to listen to the partner if they've got someone there. I think there are patterns, you need to be prepared and if you're not good at remembering you probably ought to write a list. (Wife, Family 10)

The ability to access services quickly was described by five families as important in enhancing relationships; it was considered to reduce stress and uncertainty. Prompt access to support from staff who knew them and were specialists in their field was important.

Every person living with heart failure interviewed for this study, bar two people, had at least one family member actively involved in their health care, which usually translated to attendance at GP appointments or clinic appointments. The benefits of such involvement were twofold: both the people with heart failure and the family members described benefits for themselves from their involvement. A key feature of the descriptions by family members of involvement in the health care was the shared sense of responsibility for the wellbeing of the person with heart failure:

> He told us about it and told us in a way that was very thoughtful. He slowly told us the bits and pieces and he was good. (Wife, Family 1)

A key role that family members described was that of advocate in conveying information about symptoms and medication in order to effect access to services and changes in medication:

> Part of the secret to that is to be articulate enough to know what is going on and be able to tell them what is going on and then they can deal with the problems. You do notice a lot of the patients in the hospital are not lucky enough to have a good advocate on their behalf. If everybody had a good advocate it would be a lot easier for the professionals to be able to do their work. (Hemi, Family 1)

> The medical profession can only go on the information they have and what they can read in terms of the situation and so in more recent times now I go along to a lot of his, Dad's, appointments. (Daughter, Family 9)

Benefits for the family members of being involved included greater confidence in helping to manage the condition:

> It's about being able to get it first-hand, the situation, so that if I needed to act, when in a situation where Dad couldn't, I've kind of got the package… I really think that having family involved, and those meetings, you know, those appointments with the likes of the heart specialists and that, it's really good because you actually know what you're dealing with … it gives everyone confidence and gives you confidence. (Daughter, Family 9)

This ability and time to ask questions and receive answers pitched at an appropriate level was appreciated and described by many families:

> As talked about before with [Outreach Clinic], the role that they play is very important. And when we go, well, we talk to the doctors too and it is very open-house sort of thing and I think that is good. You can get just about any help you want. (Wife, Family 1)

> …but I was really pleased because we went to the doctor a few weeks ago and we were able to ask some very straight questions. (Husband, Family 15)

> Dr [name] is wonderful, gave us a long, long time and answered all our questions. (Wife, Family 10)

> But [nurse] and them are good because, I mean, if I've got any queries I've only got to ask them and they'll explain, they tell me what tablets because he doesn't hear half the time and because I do the tablets you see, so they explain to me what has to be done. (Wife, Family 21)

Equally, the accessibility of a health professional by telephone to offer support and advice was highly valued:

> I feel quite comforted in knowing that if, like, Hemi is not well, I can ring [name] and the clinic, and if she thinks she needs to she will just get in her car and come out, and that is available from 7am to 11pm which is a brilliant service. (Wife, Family 1)

> His GP is very happy for me to ring, you know, I think we have good support systems. (Wife, Family 6)

> It's that security again, I think that you know you can just pick the phone up and ring and there's somebody that knows more than you and can advise you on what direction to take, that's very important. (Wife, Family 12)

All family members felt that they had built a relationship with health-care providers:

> I have got to know Ernest's primary caregivers so I'd say that that's part of the support, is that I feel that I have a good rapport with his doctor and with Dr [name] at the hospital. (Wife, Family 6)

With confidence and information, family members described being able to support their family member in a number of ways. The key areas were knowing when to seek emergency help, support with medication and support in maintaining an appropriate diet.

Half of all family members interviewed described calling for an ambulance, and family members played a major role in helping to decide whether emergency care was appropriate or not – a decision not taken lightly. Through discussion with health professionals, family members knew what symptoms to look out for and felt reassured that calling for emergency care was appropriate. These two factors made a major contribution to the decision to seek help:

> There are times when Ernest's colour is a horrid yellowish grey colour, totally drained, and one night, was it last week, I had to call the ambulance, and I've talked to the GP about this and he said you know, you make the call, and he said I think I'd be calling the ambulance. (Wife, Family 6)

Family members described using the information gathered in a number of ways to support another family member, such as passing information on, explaining important issues, filling in the gaps and discussing options:

> I think it's just a really neat opportunity because ... you know what Mum hears and understands from Dr [name] or whoever she's visiting is often a little bit different to what somebody else is hearing and the way that they're hearing it ... and the way that you interpret things is often different for different people so it's really quite nice to be able to ask questions ... they always welcome questions which is good ... but yeah, it's really nice to be able to go along and hear what he's saying and when we come home we can discuss it later.

Mum will say something and I'll be saying yeah, well hang on, we're also talking about something else here as well, so it's quite nice and it sort of fills in a bigger picture often, which is really quite nice because often my thinking is often ... in a different direction, so ... that's quite neat to be able to go along and be involved. (Daughter, Family 11)

Sometimes Ernest forgets something that is said or I will talk about it afterwards and even now he will say I didn't hear him say that, so I go to be able to hear that and also I find that sometimes they ask me questions about what is happening.
(Wife, Family 6)

Husband: Yes, [wife] always goes along because I only take in the half of it, so, that's what she's…

Wife: Just to have another pair of ears. (Family 18)

The majority of family members interviewed discussed their role in supporting the family member with heart failure by helping to manage diet and medication. This took the form of encouragement and helping to ensure that dietary guidelines were followed (low salt, low fat), particularly when the partner without heart failure cooked the family meals.

Family members often played a role in managing medication, such as reminding when to take it and setting out the medication to be taken, and encouragement to keep taking medication.

Where diet and medication were important factors in managing heart failure, families played an important role in self-management.

4.   DISCUSSION

4.1 Introduction

This study sought to interview families in which one member was living with heart failure, and explore the role that families play in the experience of living with heart failure.

The interviews illustrated that families were fundamental in helping to shape the experience of living with a long-term condition. Whilst discussion about causal inferences is beyond the scope of this study, the data do allow for the interpretation of patterns.

Fundamental to living with heart failure from all perspectives (families and health professionals) was the generation of a shared understanding of heart failure involving acceptance of heart failure as a long-term condition and then adaptation, mentally as well as physically and socially, to this fact. Resilience was evident at a family level rather than the individual alone, and was evident through belief systems, family organisational patterns and in communication and problem-solving, particularly through engagement with the health-care system.

4.2 Construction of a shared understanding of heart failure

Living with a chronic illness was seen as a shared family challenge. Families described acceptance of the diagnosis of heart failure and the long-term implications of the condition. Adaptation had occurred to incorporate necessary changes, and families had returned to a regular routine assimilating change in a positive way reflecting the concept of rebounding and reintegration (Flach, 1997). Descriptions of adaptation included high levels of cohesion between family members and the normalisation and contextualisation of the diagnosis and impact of heart failure.

4.3 Family organisational patterns

Families organised themselves in various ways to meet the challenges they faced. There was evidence that resilience within the families interviewed was bolstered by flexibility, the maintenance of relationships and social and economic resources. Families demonstrated the ability to be flexible in their roles outside of the

family, primarily in combining work with supporting family. Families also showed flexibility in relationships and had adapted to changes in roles to accommodate the role of carer. The ability to manage sustained changes to the structure of relationships is a key to family functioning. The quality of the partner relationship, in turn linked to marital relationship satisfaction (Higgins et al, 2005), was noted to be strong and supportive. However, it should be noted that partners were not required to provide high levels of physical care. Likewise, children did not describe 'parentification' (children assuming care responsibilities for parents), again possibly because they were not required to undertake high levels of physical care. No conflict appeared to have arisen between siblings, even when one child had taken on a bigger caring role than the others. This mainly occurred when other siblings lived some distance away.

4.4 Perception of support and social networks

High levels of perceived social support, as opposed to actual social support, has been found to be strongly linked with mental health (Pinquart & Sorensen, 2007). Family members interviewed for this study appeared to be largely aware of available support mechanisms, and were linked with agencies that could provide health and social care in addition to the care provided by family members. By virtue of the recruitment strategy, everyone had access to and the support of specialist medical and nursing staff at the primary-secondary care interface, and many others had additional primary health-care nursing support and domestic support.

Family members did not describe their social networks as having been affected significantly. People living with heart failure were more likely to describe a change in their social network and a reduction in social contacts. However, noone described a high degree of social isolation, and many described changing their interests or joining new groups in order to encourage social contacts. Families in this study appeared to be proactive in addressing any social gaps.

4.5 Economic stability

The majority of people living with heart failure interviewed in this study were of retirement age, and this will account in part for the relative absence of

financial impact from the illness. Three people lived in supported accommodation, but were positive about their living arrangements in terms of space and location. Many partners still in employment described reducing hours and seeking jobs with flexibility; however, again, this did not appear to have caused financial hardship as they were in a position to pursue such employment.

4.6 Communication and problem solving

Open and clear communication between family members was noted, including engagement with technology in order to stay in contact with physically distant family. Families represented an important connection for all participants, and their value was not always based on the ability to provide immediate support, but rather on a sense of permanent connection with others. Contact with family members and close friends was important to many of the families, and was often maintained through travel and telecommunications. At the same time, those with heart failure also maintained a strong sense of themselves as independent people, and family members were acutely aware of the need to step back to promote and allow independence. Many family members undertook care willingly as an expression of connection with and affection towards their partner or parents. This is consistent with an earlier study (Breheny & Stephens, 2007), which suggested that those who experienced caregiving as an obligation did so in the context of difficult relationships. Such relationships were not noted in this study. Previous research has also found the majority of caregivers report that they willingly provided care to the elderly (Davey & Keeling, 2004), and that carers may benefit from their caregiving experiences (Greene & Cohen, 2005).

4.7 Recommendations for practice

The following recommendations for practice arise from the study findings:

1. Health-care providers have an important role to play in generating a shared understanding of heart failure by providing information about heart failure and the long-term implications of the diagnosis to family members. Health-care providers can also play a role in helping to negotiate the importance of accepting the diagnosis, the potential impact on lifestyle, adaptations in lifestyle (particularly diet) and the importance of providing flexible support.

2. All families need to have access to appropriate services to support the management of heart failure, in particular primary health-care and specialist cardiology services. The availability of specialist support by telephone or through a home visit is highly valued. Open communication with families about the condition and its management is important.

3. The involvement of family members in care is important in building knowledge about the condition and management strategies. Involvement can foster a sense of confidence and perceived ability to provide support. Ensuring that family members are aware they are welcome to attend appointments and that their presence can be beneficial for both the patient and the wider family should be conveyed. Daytime appointments, whilst not an issue for this largely older age group, may act as a barrier for others; where this is the case, greater flexibility in appointment times could promote wider attendance by family members.

4. Build on the strengths of clients and their families and foster partnership between them. Family involvement can facilitate discussion on how the family can provide support, particularly in building effective self-management strategies for diet and medication.

5. Recognise families as a key source of information about their relatives' and their own needs.

6. Develop an action plan with the family to deal with potential deteriorations in health, including discussion on signs and symptoms and the most appropriate course of action.

4.8 Limitations of this study

This study of 70 people representing 24 families and one group of health professionals can provide only descriptive outlines of contributing factors and differences that may exist across cultures, age and severity of illness. While these things present some apparent diversity (for example, in level of contact, nature of relationship and contact over distance), the opportunity for identifying patterns of association or

correlations with these data is extremely limited. Small sample sizes by age and ethnicity constrain the ability to generate key associations, and this furthers our interest in extending the scope of future research.

A further clear limitation of this study is its focus largely on New Zealand European families. Within the scope of the time and funding available, it would not have been possible to do justice to appropriate cultural consultation, advice and research engagement of partners.

Acknowledging limitations need not undermine the value of the study findings. While the number of families involved is small, strong patterns emerged from the data. While major generalisations beyond elderly New Zealand Europeans with mild to moderate symptoms related to chronic illness cannot be made, every attempt has been made to show that the key themes derived from the data resonated with all families irrespective of cultural background, age or severity of condition.

5. CONCLUSIONS

The findings of this research indicate that the generation of a shared understanding of heart failure as a long-term condition and adaptation by the family unit to it is important. The provision of support that is flexible and can change over time to meet developing needs was seen as vital. The availability of accessible and knowledgeable services and professionals – in particular, primary health-care and specialist cardiology services – was considered important. The involvement of family members in the health-care system provided reassurance, knowledge about the condition and management that in turn led to a sense of confidence within the family regarding managing heart failure, and in particular, support for the development of self-care strategies for medication and diet.

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APPENDIX I:

Background to families interviewed

Family	Person living with heart failure	Ethnicity	Severity of heart failure	Age	Other family members interviewed
1	Hemi	Māori	Moderate	71	Wife & daughter
2	Colin	NZ European	Moderate	83	Wife, son & daughter
3	Tangi	Pacific Islander	Moderate	79	Daughter
4	Donald	NZ European	Moderate	71	Wife & daughter
5	Elizabeth	Māori	Class 2 mild	77	Daughter
6	Ernest	NZ European	Class 2 mild	74	Wife & daughter
7	Fred	NZ European	Class 2 mild	60	Wife, son & daughter
8	Alesana	Pacific Islander	Moderate	66	Wife, 4 sons & daughter
9	Gareth	NZ European	Moderate	84	Son
10	Harold	NZ European	Moderate	70	Wife & son
11	Brenda	NZ European	Moderate	60	Husband & daughter
12	Epi	Pacific Islander	Moderate	50	Wife & sister-in-law
13	Piri	Māori	Moderate	49	Wife
14	Jack	NZ European	Moderate	66	Wife
15	Rose	NZ European	Class 2 mild	80	Sister
16	Keith	NZ European	Class 2 mild	72	Daughter
17	Martin	NZ European	Moderate	74	Wife
18	Neil	NZ European	Moderate	79	Wife & 2 daughters
19	Peter	NZ European	Moderate	84	(Alone)
20	Ron	NZ European	Class 2 mild	86	Wife
21	Kevin	Māori	Moderate	50	(Alone)
22	Simon	NZ European	Moderate	79	Wife & daughter
23	Natalie	NZ European	Moderate	40	Husband
24	Mary	NZ European	Moderate	69	Husband

APPENDIX II:

Key practical issues related to the family interviews

Preparation	Arrange and co-ordinate interview time with one family member emphasising desire for participation of all family members.
	Arrange to conduct the interview in a setting that feels comfortable and is accessible for family members.
	As far as possible, ensure that family members and the interviewer are relatively close to one another and can see each other face-to-face.
	Engage the family through greetings and introductions.
	Address all family members directly, including children.
	Share background to the study and the interviewer's professional background to help situate the interview and create trust.
	Review key ethical concepts with the family including the purpose, time, confidentiality and the right not to answer a question.
	Discuss the ground rules for the family interview such as maintaining respect for one another.
	Explore family members' relationships with one another.
The interviewer/ family interaction	Approach the interview as a dialogue rather than as a structured interview.
	Employ the arts of listening and authentic presence.
	Begin the dialogue with an open-ended question.
	Explore issues further by using probing questions such as:
	> Can you tell me more about that?
	> How is your family feeling about this issue?
	Remain focused on uncovering the family experience, emotion and beliefs.
	Try to elicit responses from all family members.
	Avoid creating alliances with one family member or subgroup.
	Suspend judgmental comments and do not move into a therapeutic relationship, including giving advice.
	If one family member is interrupted by another family member redirect the conversation back in an appropriate manner.
	Convey acceptance of expressions of emotion.
	Attend to both the whole family and individual members.
At the end of the interview	Continue dialogue until no new information emerges.
	Share follow-up contact information.
	Express appreciation for participation with individual family members.
	If appropriate, acknowledge a family strength.
	Thank the family for their participation as a family.

APPENDIX III:

Focus group schedule

Introductions

Ask everyone to introduce themselves by stating their name, relationship to the person with heart failure and the frequency and nature of contact they have.

Ground rules

> Speak one at a time.

> Be courteous to one another.

> Feel free to ask questions about the study and process.

> Would like everyone to participate.

Questions

> What do you identify as the key issues around living with heart failure/someone in the family with heart failure? (Explore over time, and symptom severity.)

> Who is involved in supporting you to manage heart failure? (To be explored from various perspectives.) Do family members engage with those people mentioned by the individual living with heart failure?

> What defines a positive relationship between family members and others in terms of living with and supporting a family member with heart failure?

> What roles/aspects of care/support do you see yourself and others playing? (Explore individuals' and groups' perceptions of their role in the above. Explore individuals' and groups' expectations of the input and role of others).

> How has the nature of your involvement/support changed across illness episodes? (History of relationship – how has your relationship been in the past? How does support change, (eg, course of the illness, relapses?)

> What has impacted on your ability to support a family member living with heart failure? What makes these dimensions of support possible? What works well?

> What role do you feel health professionals, family workers and others can or do play in working with you to support a family member with heart failure?

> Are there any ways in which health professionals, community workers and others engage with you more effectively to help support a family member with heart failure?

> What changes do you anticipate within the family and in relationship to managing heart failure?