

It's not just about heart failure – voices of older people in transition to dependence and death

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Abstract

This paper explores the experiences of older people living with heart failure and their transitions from independence to dependence and for some death. New Zealand's ageing population is predicted to increase from 12% in 2001 to 25% by the year 2051, similar to the worldwide trend of ageing. A high proportion of these people will have one or more chronic illnesses. Associated with the increase in survival is a growing body of research examining the needs of the older person with heart failure and finding particular problems with end of life care. Older people face many challenges in living with their heart failure, in particular the transition to dependence. To study the transition a longitudinal qualitative study using General Inductive approach was used. Participants were interviewed every 3 months for a 12-month period during 2006–2008. A total of 79 interviews with 25 people were completed. Our findings showed that transition was not a simple linear process with the older person moving from one phase to another; instead their experiences illustrated the complexity of transitions they faced and what helped them to manage these. The older people in this study illustrated the importance of trust in health professionals and believed they would receive good care. Their fears revealed concerns about being a burden as they deteriorate and becoming more dependent. Understanding the complex issues related to transition to dependence can provide health professionals with a framework for assessment and approaches to providing the support required.

Keywords: chronic illness, older people, palliative care, patient's perspectives, transition

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Bettie Davis said old age is no place for sissies. (participant aged 78)

Life expectancy of older people is increasing worldwide (World Health Organisation, 2004). In New Zealand the expected increase in the proportion of older people aged 65 years and over is predicted to increase from 12% in 2001 to 25% by 2051 (Ministry of Health, 2002). Of these people a high proportion will have some form of chronic illness and it is likely that they will have more than one condition (World Health Organisation 2004). Associated with increased life expectancy are questions about meeting the needs of older people with

heart failure and the associated challenges with end of life care.

The study reported in this paper explored the thoughts, feelings and concerns of older people with heart failure and their transition from independence, dependence and for some death.

In their classic study on trajectories of dying, Glaser & Strauss (1968) referred to entry–re-entry deaths, in which there was a pattern of deterioration, readmission to hospital, discharge and then readmission with the cycle continuing until death. In a more recent study Lunney *et al.* (2003) examined the functional decline at the

end of life and found differences among four types of illness trajectories; sudden death, cancer, organ failure and frailty. For the latter three there was a substantial decline in functional ability during the last 3 months of life, with the final month associated with more disability. This has been referred to as terminal decline or terminal drop (Palmore & Cleveland 1976), a time most likely to incur increased health-care costs (Lloyd 2004). However, a prospective study (Gott *et al.* 2007a) exploring dying trajectories of heart failure patients in the United Kingdom found no typical heart failure trajectory.

Much research and clinical work has been devoted to heart failure management to reduce admissions to hospital and support the person in self-management (Doughty *et al.* 2002, Stewart *et al.* 2002). These approaches are indicative of the trend to support self-management and positive ageing for people with chronic illnesses (Ministry of Health, 2002, National Health Committee, 2007). Communication between health professionals and patients has been identified as a major problem for this group of older people (Rogers *et al.* 2000, Barnes *et al.* 2006a), with an increased incidence of depression (Lane *et al.* 2005) also lessening the likelihood of raising concerns. A reduced quality of life in patients with severe heart failure (New York Heart Association class III) has been found in both physical and mental dimensions, for example reduced self-care and depression (Schellberg *et al.* 2002). Symptom prevalence, particularly breathlessness and fatigue, found to be high (Barnes *et al.* 2006b). In another study half of the patients with heart failure had unresolved physical problems 24–31% had unresolved social problems and 23–27% unresolved psychological problems (Anderson *et al.* 2001). Health professionals on the other hand may not document problems that they cannot solve, thus there may be a degree of under-reporting. A review of medical, nursing and medication records found in the later stages of heart failure patients experienced a wide range of symptom control problems, with 25% not receiving treatment for pain (Nordgren & Sorensen 2003).

Transition is a natural process associated with changes in our lives, such as ageing, changing relationships and particularly with changes in health status (Meleis *et al.* 2000). Transition has been suggested as a valuable framework for understanding the experiences of patients with heart failure (Davidson *et al.* 2007); however, there is a need for more research in this area. Transition, has been defined by Bridges (2004) as the psychological reorientation to change with three phases (i) endings which involves letting go and experiencing loss in some form, (ii) a neutral zone which is an in-between phase, usually associated with uncertainty and (iii) the new beginning which may involve a new focus or new identity.

Methodology

The aims of this study were to explore the experiences of older people with heart failure from independence, dependence and for some death. The design was a longitudinal qualitative study using a General Inductive approach that enabled the tracking and exploration of the changes occurring to the older person over time (Murray *et al.* 2002).

Recruitment

Older people ($n = 25$) with the New York Heart Classification Levels 11–IV (Table 1) were invited to participate. The initial classification was made by the health professional and then reviewed at each subsequent interview by the principal investigator. Participants were recruited from three General Practices, a Heart failure clinic and four medical wards. The recruitment sites were invited to participate in the study by letter and telephone contact. Within the General Practices either the doctor or nurse asked the patient if they would be involved in the study. The Heart failure nurse

Table 1 Participants

Gender	Age	NYHF	Number of interviews	Status on completion of study	Number of comorbidities
F	75	3	4	Completed	4
F	80	3	4	Completed	3
F	81	2	1	Withdrawn	3
F	85	2	4	Completed	4
M	82	3	4	Completed	3
M	80	4	1	Died	5
M	80	2	4	Completed	7
M	90	3	4	Completed	8
M	86	3	1	Withdrawn	6
F	80	4	2	Died	6
F	88	3	4	Completed	6
M	86	3	4	Completed	5
M	81	4	2	Died	5
F	86	2	4	Completed	3
M	74	3	4	Completed	3
M	70	2	4	Completed	2
M	72	2	1	Died	4
M	86	3	4	Completed	3
F	78	2	4	Completed	4
M	89	4	4	Completed	9
F	85	3	4	Completed	3
M	78	2	4	Completed	4
M	76	2	4	Completed	4
M	76	2	1	Died	2
F	82	3	1	Died	2

M, male; F, female; NYHF is the New York Heart Association functional classification system used as one assessment of the stage of heart failure. Class 1 is mild and class IV severe.

specialist provided a list of possible participants and the medical wards were visited on a weekly basis to locate participants. They were then visited on the wards by the principal investigator and written information provided about the study. Following discharge they were contacted by telephone to see if they still wanted to be involved in the study. For people at home, possible participants were contacted by telephone, the study was explained and study information posted. All participants signed a consent form. Prior to each subsequent interview, participants were telephoned to ask if they still wished to participate in the study and if they agreed a date and time for the next interview was arranged. The study had ethical approval by the New Zealand Northern Regional Ethical Committee number AKY/04/04/04/084.

Data collection

Data were collected between December 2006 and February 2008, with interviews at 3–4 monthly intervals. Interviews were all conducted in the participant's home or residential care. The median range of time was 55 minutes, the longest interview lasting 90 minutes and the shortest interview 35 minutes. Participants were screened for depression at the first interview and at each subsequent interview using the short form Geriatric Depression Scale (Yesavage *et al.* 1983). Participants were invited to have a support person present. Following transcription of each interview, key issues that needed to be followed up were identified and were then explored in subsequent interviews.

Data analysis

The semi-structured interviews were transcribed verbatim and entered into NVivo 8 (QRS International Pty Ltd; Doncaster, Victoria, Australia) for analysis. The data were analysed using a General Inductive approach described by Thomas (2006) to allow the reduction of the extensive raw data into a summary format in line with the research objectives. General Inductive approach is derived from Grounded Theory. The initial transcripts were read several times then coding line by line was used to identify the reoccurring themes. A major point of inductive theory is to avoid preconceptions for narrowing what is observed and theorised (Ezzy 2002). Peer review by research colleagues of a sample of 10 interviews enabled checking of codes, categories and themes, with subsequent minor modification following discussion and agreement on recoding (Patton 2002). Participants could view the transcripts to ensure their accuracy, but only two did so and only one, who was a retired school teacher corrected grammar!

Results

A total of 79 interviews were completed out of a possible 100. Table 1 shows the numbers of interviews conducted with each participant and illustrates how a number of participants were unable to complete the interviews. Two withdrew after the first interview, four died after the first interviews, two died after the second interviews, with seventeen completing all four interviews. The ages ranged from 70 to 90 with a mean age of 81 years. The themes which emerged reflected the participants' experiences, not only of living with a life-limiting condition, such as heart failure, but life in general as they got older. For the participants, transition was not a simple linear process moving from one phase to another. The participants' experiences illustrated the complexity of transition in their lives, their challenges managing these and what worked for them. Their fears revealed concerns about being a burden to partners, family and friends. They had expectations of the health professionals as their health declined, revealing the importance of trust and their belief that they would receive good care. The results will be described under the major themes of acknowledging endings and losses, managing uncertainty and good care at the end of life. The two major subthemes of hopes and fears were common throughout the major themes.

Acknowledging endings and losses

Living life for the older people in this study involved acknowledging endings and losses, how they thought about these and how they responded to these losses. In acknowledging dying, some associated this with their age and saw this as positive.

I am 75 and don't worry. You have three scores and ten and I have outdone mine. (F75)

Some participants had already lost their partners, while for others who had partners who were still alive, there was the recognition that their partner would also die at some stage and questions about who would go first.

My wife is not really well, not by a long shot, and I don't want to, well sometimes I wish she would go before me so she couldn't be lonely. But then I say that is wrong, I should go first. That worries me (sobbing). (M86)

There was a temporal element in their thinking as they looked back to the past and thought about the future. Looking back to the past involved discussing how their lives had been and what had been achieved. In thinking about the future, some had a sense of hopelessness about this with nothing to look forward to. It

was evident that at certain times some of the participants were depressed and this was reflected in a higher Geriatric Depression Score.

There is no future. That is gone. I had some good years, I struggled through war and everything, raised the family. That end, come on you can't run away the end is coming and it's coming very fast. (M81)

Readmission to hospital meant once again being confronted with the possibility of further decline and death. These feelings subsided once their acute symptoms were controlled, but it was evident that for some being discharged with problems was still apparent. Not all participants were aware of their prognosis, but some had been given this information.

Oh my heart's on the blink. It's a bit wonky. I mean it's a bit tired. They told me that's it. I could go any time, they told me that. (F85)

Losses could be multiple and ongoing, particularly in their relationships and social networks, with loss of friends, hobbies, and for some a move from their own home to residential accommodation. For some this was reflected in their readiness to die which exposed the multiple losses they had experienced and how important some of these had been to them in their lives.

I would just like my life to finish I'm ready to die. I've had a wonderful life but it's just a little too long really ... I've had enough of life. All my relatives have long gone ... I have no family at all and my friends in my generation have long gone too. (F88)

While some participants were ready to die, others acknowledged their lives would at some stage end but were not ready to die, because they still had things they wanted to do and achieve and still had support networks with family or friends and their community. They had responded to some of their losses by replacing activities they could no longer do by finding other interests.

I don't want to fold my tent up or anything like that; there is a lot to do, interesting things. (M72)

There was the recognition of future losses and endings, but having choices made a difference. The next participant illustrated how choice is central to moving from their home to residential care and how further loss was limited by keeping his relationship with friends. Decision-making ensured a sense of control and security and the person maintained a sense of competence as part of this process.

We always discuss these things and with our peers too. We are putting our names down and working towards keeping things as simple as possible at home ... here at ... for example is a good place and a place where some

of our friends would be. It's a local place with hospital services also. (M76)

Uncertainty

Uncertainty was a common experience for all participants and they had different ways of managing this. The uncertainty had temporal dimensions in being about how to manage in the present on a day to day basis, but also about how they would manage in the future.

Trying to find out more information was important to some participants in managing the uncertainty of the future. Others did not want any further information and some found their religious beliefs, church and community a great support. Some had still been searching for answers.

I did read a book relating to death and spirituality and that sort of thing, because about a year ago I thought well I'm just ready for the boiler room now and someone recommended this book. It's about spirits and one or two things so I thought I'd read that and it opened up quite a bit for me and I thought of well it's not so bad after all. It sort of opened up a bit because basically death is a blank area, an unknown area really and that's the scary part about it. If you know where you're going or you think you know where you're going then the journeys not so bad. (M72)

Participants were conscious of further deterioration in their condition; aware this could happen creating uncertainty. What helped was having structure and working on a daily basis to minimise deterioration and establish a sense of control.

I'm constantly aware of watching my diet of what goes in, I'm constantly aware of trying to avoid stress, I live within those things. I'm aware of them all the time. I think I've done everything by the book as far as being told what to do, the weight control, the diet. (F78)

Living their lives by making the most of each day and pacing themselves with activities and rest periods was a way of actively managing, for those who could still do this. Being able to recognise deterioration is something that is incorporated into heart failure management programmes. Despite this, recognising what might be a worsening of their condition had been a learning experience as the following participant recounts her experience of leaving things too late:

I don't know why I didn't act myself, but then you're not always able to. I know what to watch out for now, I learnt a huge amount which I had no idea if ones hands were blue or nose was blue that that was a significant thing. (F78).

In dealing with the uncertainty of when death would occur, some participants had made preparations and had discussions with their family.

We have talked to the family and written down our wishes regarding our health care, living arrangements, and having ashes scattered in a particular place. We talk openly with our daughter and son about death and dying and all the associated issues. (M76)

Other people had not quite got around to the actual practicalities of the organisation around their own death, such as sorting through belongings and dealing with financial matters.

Good care at the end of life

Participants in this study had expectations of receiving good care as their condition worsened, this was important to them in thinking about the end of their life. The expectations of good care involved trust, confidence and hope, which were based on their past and current experiences of health professionals and health system. The relationships that some participants had developed with health professionals over the years were particularly important to them. They had expectations of this continuing as their condition deteriorated.

I would go back to my family doctor and because I trust him and his daughter ... she is a doctor too at the same place ... and I would ask them what to do. They are good to me ... if I have any trouble they tell me what to do, like get the ambulance to get to the hospital or anything else. I talk to my doctor like he is my uncle and he talks to me like I am his nephew. He has all my records so they know all about me so he can give me good advice about what to do. (M74)

The spectre of dependency was a major concern for participants, becoming 'bedridden' and a burden. These were fears they spoke about in thinking about their condition progressing. They expressed feelings of hope that in the event of this arising they would not be neglected would still receive good care and not be viewed as a burden.

I would want them to treat me nicely ... Provide me with good nursing care, not neglect me. (F74)

The fears of some participants were expressed in not wanting to continue with their life. This also reflected the importance to them of maintaining a sense of control.

And if I was extremely bad I think I would arrange to have a good send off. I think I would croak it ... die ... before I was dependent on health professionals for every little thing. I mean I think I would will myself to die ... that is as long as I was capable of coherent thinking. (M72)

Despite having positive experiences of healthcare and health professionals it was evident that some had experiences that gave them concerns, especially as their dependence had increased and they had become more reliant

on other carers, particularly if this had meant a move to residential care. For instance, a participant who was now virtually confined to bed, more dependent on the carers, spoke about his increasing anxiety, especially about how he would be handled.

The staff at the rest home and the hospital is generally quite helpful and especially the professionals ... the trained ones ... but those who aren't trained or not properly trained – like a lot of the night staff at both the rest home and the hospital – are a bit rough. They sometimes dump me down heavily on the bed ... or they come in to the room with a cup of something just put it down without saying anything and leave ... sometimes they just stand at the door and look and don't say anything. So, sometimes you get frightened to say anything. I do have people I can talk to but sometimes it's not that clear how much to say ... in that sense it's more complicated than when you are living with your family. That's the only thing really about being dependent on some health people. And I'm virtually bedridden now and I'm going to get more dependent not less so yes, I am a bit anxious about that. (M89)

Symptom control was important and was about being made comfortable. The older person's concerns about symptoms, included breathlessness and having this controlled were paramount, swollen legs impacting on their mobility, and increasing tiredness. Some of the symptoms were not related to their heart failure but other conditions such as strokes and other problems such as pain control.

Discussion

The experiences of the older people in this study will be discussed by referring to Bridges phases of transition. Bridges (2004) states 'only when you get into people's shoes and feel what they are feeling can you help them to manage their transition' (p. 59). However, this study illustrates that transition is not a linear process, but complex cycles of transition that may be overlapping at any one time. As such it provides an opportunity to understand the experiences of older people in a different way and consider how transition, as overlapping cycles of transition, may be a useful one for patients, carers and health professionals.

Endings, the neutral zone and new beginnings

McNamara (2001) noted how older people preferred not to think about death and dying, but in this study older people did acknowledge that as they got older their life would at some stage end. Living with this understanding involved different approaches to coping, such as avoiding thinking too much about their situation. That older people rarely give a thought to dying is not always

a sign of denial. Buetow & Coster (2001) referred to avoidance and disavowal, with the latter being perceived as healthy denial and a process used by patients to reduce emotional strain and gain hope. They identified three coping strategies; avoidance, disavowal and acceptance. Contrary to this, participants in this study demonstrated that older people could be using each of these at the same time to cope with different transition experiences in their lives, not just living with heart failure. Endings for the participants were not only about their thoughts on dying, but also about the multiple losses in their lives which were occurring or had occurred at different periods for them, such as partners, friends, homes and hobbies.

Seymour *et al.* (2005) noted how the older person dealt with the uncertainty of whether or not they would cope with each new day. Living with uncertainty was not only associated with endings or losses, as in the neutral zone that Bridges (2004) refers to, but in thinking about new beginnings such as, moving to residential accommodation or feeling hopeful about whether they would receive good care as their dependency increased. Participants were active in trying to prevent further deterioration not only in their heart failure, but to manage their lives with other conditions, manage their medications and make adjustments to their routines. This was referred to by Willems *et al.* (2006), as 'patient work', tasks a person performs to continue living. Symptom control issues were of concern to the older people and the research (Barnes *et al.* 2006b) discussed earlier in this paper highlighted that this is still problematic. Uncertainty increases with inadequate symptom control, but also does not meet the expectations of the older people in this study about receiving good care from health professionals. How can we ensure that symptoms are controlled? That Palliative Care and improvements in end of life care should be incorporated in the management of heart failure is not a new idea and has been identified by a number of researchers (Anderson *et al.* 2001, Ward 2004, Horne & Payne 2004, Aldred *et al.* 2005, Gott *et al.* 2007a, Barnes *et al.* 2006a,b), in government policy (Ministry of Health 2001) and in heart failure guidelines (The Cardiac Society of Australia and New Zealand 2002). The older person often has complex needs, and as identified has already developed positive relationships with certain health professionals which we should work to maintain. This would acknowledge the strengths of the relationships they have, limit further losses and uncertainly and provide the continuity of care identified as important to them.

It is suggested that rather than thinking about new beginnings as a final phase of transition, it would be useful to think of this at the beginning and as a goal for health professionals in supporting and working with the

older person. The new beginning could be about working with transition as a framework that could be discussed with the older person at the beginning and as an approach to supporting them as they become more dependent and face end of life. If we consider that new beginnings can be about hope and minimising fears, then this shifts thinking. In acknowledging what transitions the person is experiencing; what are the losses, past, present and possibly in the future. Focusing on how the person is managing these may be a way of promoting self-esteem and self-worth. Identifying approaches for those who are not managing their transitions is about assessing and recognising these.

There is an association between death and ageing, but also the view that, 'old people know how to die' (Lloyd 2004, p. 237). While the participants in this study may have acknowledged that they would die at some stage, they were concerned about the process of dying and how that would be managed. But their concerns about dying were overshadowed by those of increasing dependence; 'dependency remains a greater spectre than death' (Charmaz 1991, p. 80). While dependency is a normal part of the human experience Lloyd (2004) argues it has been overshadowed by the concept of active ageing. This focus on independence and self-management can limit health professionals' abilities to support dependence. Lloyd (2004) questions how we can preserve older people's dignity, privacy and comfort at this stage. Within the present study the complexity of their transition experiences can be identified and approaches to supporting them in the management of these can provide some guidance alongside their expectations about receiving good care at the end of life. Being neglected, feeling a burden and inadequate symptom control were the major concerns of the older people. This was further compounded by their fear of becoming bedridden. The fears that the older person may have can be a sign of any phase of transition occurring. Fear of being neglected was a concern of participants in this study. Neglect can come in a variety of forms, physical, social, emotional and spiritual. Grant *et al.* (2004) found that while General Practitioners acknowledged the importance of spiritual issues, most did not feel they had the skills or time to respond to meet this need. Emotional neglect can arise by feeling abandoned by health-care professionals; especially by those they have developed relationships with over the years. Physical neglect can arise in numerous ways, by just being lifted and moved in an inappropriate way, as a number of participants in this study recounted illustrated this. Social neglect can arise when the social dimension is not part of the health professional's assessment. In their longitudinal study, Murray *et al.* (2007) found that the physical decline that occurs with advanced heart failure was linked with social and psy-

chological decline. Neglect may be about not even acknowledging the losses or minimising the losses the older person may be experiencing.

Self-perceived burden has been associated with a number of negative outcomes, such as loss of dignity, depression, will to live, and request for physician-assisted suicide (Chochinov *et al.* 2005). Feeling a burden has also been associated with not being able to accept dependency. Ganzini *et al.* (2003) found that patients who they viewed as independent or valuing independence dreaded the thought of becoming dependent. The notion of dependence not only about physical dependence, such as losing the ability to walk, but other factors, such as having to move to a nursing home. These patients were described as inflexible and determined to remain in control requesting physician-assisted suicide.

Fatigue and dyspnoea are two common symptoms in heart failure and either of these will result in increasing degrees of dependence, as the disease advances more time will be spent on bed rest.

Health professionals can support the patient as they become more dependent, yet still have a focus on independence. But this should not be at the expense of enabling the person to manage increasing functional decline, dependence and the feelings associated with this. Understanding that patients may have feelings of being a burden and how this may limit their requests and expectations of health-care professionals is paramount.

There are implications for health professionals when patients make requests to them to end their lives. Rather than ignoring these requests or minimising them we need to explore what is really underlying the request. The sense of being a burden can arise from how the older person sees himself or herself as having no more value and feelings, such as worthlessness associated with loss of status, respect and dignity.

This study and the growing body of research (Horne & Payne 2004, Barnes *et al.* 2006a,b, Murray *et al.* 2007, Selman *et al.* 2007) exploring the impact of heart disease on older people, illustrates that discussions can take place and that older people can express their fears and concerns and their needs can be explored. Guidelines such as the 'Clinical practice guidelines for communicating prognosis and end-of-life issues with adults in the advanced stages of a life-limiting illness, and their caregivers' (Clayton *et al.* 2007) have useful suggestions for types of questions. Based on the experiences of the interviews in this study, simple but critical questions that can be asked include, what is really important to you at the moment? What are your goals? What are your hopes and fears?

Some of the participants in this study had already had conversations about their condition deteriorating

and making decisions about their place of care. For these people, advanced care planning could be an approach to support their preferences, but would require further research and investment within primary care. Considering their needs and other research discussed, a one discipline lead approach is limiting, as there is a need for integrated approaches across primary and secondary care. If people prefer to remain at home as in ageing in place programmes (Ministry of Health 2002), the transition experiences of their partners and carer's, particularly as these people are more likely to be older themselves would need exploring.

This is a study undertaken in one large urban area of New Zealand and as such is limited by its absence of the voices and experiences of those people living in rural communities. Although the number of participants was 25, this decreased over the study and only 17 participants completed all interviews. Based upon other research (Gott *et al.* 2007b) it was expected that there would be some loss of participants. However, 79 interviews were conducted reaffirming the reliability and consistency of the themes. It is acknowledged that as an emerging framework, more research is required to determine the usefulness of the approach to transition discussed in this paper.

Conclusions

This study proposes that understanding transition not as a simple linear process, but as complex cycles that interweave and working with the person to manage this complexity could be a useful approach and go some way to meet the expectations that participants had of health professionals in providing good care.

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Statement of competing interests

None.

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