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'Living on the edge of a precipice': The psychosocial experience of
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home.

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‘Living on the edge of a precipice’: The psychosocial experience of end-stage heart failure patients and their family carer managing at home

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Executive Summary

The initial motivation for this study came from a discussion with a senior cardiologist at a tertiary hospital who described the ‘awful’ life of patients with advanced heart failure and living at home. While cardiac services carefully monitored the patient’s progress, adjusting treatment as necessary, the psychosocial turmoil experienced by patients and their carers received less attention and support. Furthermore, patients with advanced or end-stage heart failure in this study had minimal contact with palliative care services that could advise on or provide symptom management and supportive care of psychosocial and spiritual needs.

A qualitative approach was utilised to explore the everyday life of patients and their carers dealing with the complexities and uncertainties of living with advanced or end-stage heart failure at home. The study, conducted within the Metro North Health Service District of Queensland, involved fifteen participants including seven patients, five current carers and three widows.

The key finding of this study was that the burden of heart failure increased over time and intensified when other co-morbidities occurred. While patients demonstrated a general acceptance of their prognosis, as their condition weakened the demands on the carers escalated. The intensity of the carer’s role and twenty four hours, seven days a week demand on their time effectively meant putting their usual life ‘on hold’. The protracted trajectory of heart failure might extend over months and even years.

The strain of the carer’s role was exacerbated by uncoordinated and discordant communication between service providers. When the patient

required intervention for another co-morbidity, such as depression or cancer, they often received advice that conflicted with their heart failure treatment. Patients and carers faced the dilemmas of not knowing which advice to follow. The lack of timely discharge planning and transfer of information from hospital to the patient's General Practitioner (GP), was another source of stress for all concerned. The carers lamented the loss of usual relationship with their loved one that was compromised by the necessary task of the carer's role. The relationship was challenged when for example, carers were required to attend to intimate care such as toileting and bathing, as well as take on the responsibility of monitoring the patient's condition and administering medications.

The participants in this study accessed a range of community and nursing services as well as receiving support from hospital outreach cardiac care programs. However, attending to 24 hours 7-day-a-week needs of the patients, which increased in the end-stage, was the carer's role. The carers carried out their role at a time when they too were emotionally vulnerable and physically weary. A collaborative and coordinated approach to services and discharge planning would go some way to easing the carer's load and anxieties. Furthermore, patients and carers need timely access to palliative care and other supportive services that can advise on symptom management and attend to the psychosocial care needs of those concerned.

Abstract

Heart failure patients experience a greater burden of symptoms, co-morbidities and overall poor quality of life than do cancer patients. Unlike their counterparts in cancer care, patients with advanced heart failure face a precarious and turbulent trajectory marked by acute episodes of 'life threatening emergencies', and complex symptoms, interspersed with plateaus of relative stability. The psychosocial effect of the roller-coaster life of advanced or end-stage heart failure is a relatively under-researched phenomenon.

Aim

This study aimed to explore the experience of patients with advanced or end-stage heart failure living at home and the effect of the situation on their family carer.

Methods

This study applied a phenomenological approach and inductive analysis, which aimed to interpret the every-day or lived experience of participants. Data collection methods were semi-structured interviews, observation and field notes where interviewers recorded their observations and details of the context of participants' home life pertinent to the inquiry.

Participants were purposefully selected based on their prognosis of either Class III or Class IV heart failure according to the NYHA classification. The total number of participants in this study was 15, which included 4 male and 3 female patients, and 8 female primary carers, 3 of whom had already been widowed. The widows contributed rich data about the whole experience from diagnosis to death, and shared their reflections on the emotional roller coaster life of being the wife and primary carer at home.

Results

Four main themes emerged from the data:

1. The burden of heart failure
2. Psychosocial isolation
3. The carer's role
4. Inter-service discordance

The burden of living with heart failure is compounded by the protracted progress of the disease, causing a precarious state of vulnerability for patients and their carers. Not surprisingly, the carer's role was dynamic and increasingly complex as the patient lost stamina and motivation. All participants were fully cognisant of their poor prognosis and disappointed that conversations about palliative care and end-of life issues were generally avoided.

Social isolation associated with the physical limitation of the patient's illness was a common concern of all participants. Their social and everyday life was controlled by how much the patient could endure, and their declining interest in things outside the home where they felt safe. The demands on the carer's role continued to escalate with decline of the patient's condition. The carers in this study adapted to the challenges of their role, but at the same time craved some respite from the relentless demands on their life, although none would have relinquished the care of their loved one.

Adding to the difficulties for the carer was the discordance and uncoordinated communication between different specialist services. The absence of coordinated discharge planning for example, meant communication to one patient's GP about current treatment plans was delayed by three weeks, by which time the patient required readmission. Communication anomalies between different specialist services were a cause of considerable anxiety for carers who tried to negotiate between services, and caused an exacerbation of the patients' suffering.

Conclusion

The metaphor 'living on the edge of a precipice' aptly conveys the phenomenon of living with advanced or end-stage heart failure. The precarious daily life of patients and their carers is marked by days of uncertainty as the patients decline in ability and motivation. New or refractory symptoms mark the patient's deteriorating condition and present new challenges for all concerned. Contributing to the dilemmas of managing patients' co-morbidities was the lack of convergent advice, which should not occur if specialist services worked collaboratively or at least consulted on treatment decisions. Only a few patients in this study had access to palliative care; others were not aware of the scope of this service and its holistic, family-centred approach. Palliative care services working collaboratively with cardiac services would contribute to better outcomes for patient and carer in terms of symptom management and psychosocial support.

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Recommendations

The findings of this study lead to the following recommendations. It is recommended that:

1. Communication between GPs and specialist service is promoted by use of technology such as email to hasten the process;
2. Communication between services is consistent through the utilisation of guidelines and discharge planning;
3. Access to comprehensive palliative treatment is an integral part of the treatment plan of advanced heart failure;
4. Guidelines for symptom management of advanced and end-stage heart failure should be implemented. For example, service provider can refer to *The National Heart Foundation of Australia, Guidelines 2006, Palliative Support section, p. 55-57*; and *Living Well With Chronic Heart Failure, 2007* should be accessible to patients and carers;
5. An information pamphlet for carers be developed about what to expect as the condition deteriorates to end-stage;
6. A single information pamphlet about how to access palliative and community support services and the range of services be developed;
7. Psychosocial support or counselling is accessible to patients and their carers;
8. The scope of palliative care services are introduced earlier and not just at the end or final stage of the disease;
9. A curriculum on the clinical management of advanced and end-stage heart failure is developed; and
10. Further studies should be undertaken to explore the lived experience of the carer during the final days.

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ATTACHMENT A

INTERVIEW GUIDE

Framework for questions

1. Participants'¹ understanding of their condition
2. Impact of the condition on their everyday life
3. Information needs
4. Attitudes toward service provision
5. Key worries and concerns relating to present and future

Instruction for interviewer:

Introduce self, state professional role, place of work and clarify your researcher role. Use the participant information sheet (PIS) to explain the purpose of the research, invite the participant to ask questions about the research.

Demographic details:

Participant identification number, eg. Use initials of interviewer and allocated sequential number of the participant, . Eg. DP-1, DP-2 DP-3 and so forth.

Gender

Marital Status

Next of kin

Primary carer at home (may be same as above)

Street address

Post code

How long living at this address

Current or previous employment

Other

Introduction to participants

Thank you for agreeing to help with our research. I would like to talk with you about how it is to have severe² heart failure and to manage at home. I am interested in your story, how your illness affects your day-to-day life, how you manage, who helps you at home, that sort of thing. I have prepared a few questions, but mostly I will let the

¹ Participant may include the patient with AHF and their family carer

² The term 'severe' will be used rather than 'advanced or end-stage heart failure' to minimise the impact of confronting the patient with their prognosis.

interview/conversation be guided by what you say. The interview will mostly focus on what you say but contribution from your family member or carer will also be welcomed.

The aim of this research is to make recommendations that improve community services and palliative care for patients like you who are dealing with severe heart failure and living at home.

With your permission I would like to record our interview on an audiotape recorder. I may also need to make brief notes during our conversation to avoid forgetting key points. The information you provide in the interview will be confidential to the research team and you will not be identified by name in my notes or the transcribed interviews notes.

You are free to withdraw from the interview without consequence to your health care or treatment, or the relationship with your treating hospital.

Inform participant they may stop the interview if it is becoming too arduous or tiring.

Questions

1. Participants' understanding of their condition

Suggested questions:

The intention of this section of the interview is to determine what the patient knows about their heart condition and current treatment.

The interviewer may simply ask, What can you tell me about your illness?

Or use questions such as:

When were you first told you about your heart condition?

How did you feel about the diagnosis?

How did you live before your illness?

How are you getting on with your heart condition?

What do you understand about the severity of your heart condition?

1.1 Physical symptoms

What kind of symptoms do you have now?

How would you describe your symptoms?

What treatment are you having for your symptoms?

Which symptoms trouble you the most?

Do you have any particular way of managing your symptoms?

Do you need help with any tasks that you could manage before your illness?

2. Impact of the condition on their everyday life

How do your symptoms affect your day-to-day life?

How does your heart condition affect your life at home?

Who helps you manage at home?

What helps you to cope?

What outside services do you use to help you manage at home, for example community nurses, meals-on-wheels, respite care, etc.?

3. Information needs

Do you have enough information about your medications and illness?

Are you satisfied with the information you have been given?

What has been the most useful information for you at this time?

Was there any information that was not useful to you?

Do you know about any community services that may help you and your family manage your illness at home?

What would you like more information about?

4. Attitudes toward service provision

Have you experienced any difficulties in contacting health care services?

Do you feel there are sufficient services to support you and your family to manage at home?

Which services would or do you find most helpful?

5. Key worries and concerns relating to present and future

If you could change something about the type of care or services you receive, what would you like to change?

What troubles you most at the moment?

How would you describe your quality of life at this time?
Or, how do you feel today?

The reasons for this interview is to gain information about how patients with severe heart failure are dealing with their situation while living at home and to find out what resources/ services are or could be helpful to them and their family.

Do you think you have been able to talk about this with me? Are there other things you would like to talk about or add to what has already been said?

Close the interview by thanking the participant(s) and ask if you may do a follow-up visit to either clarify points raised in the first interview or check that you have accurately recorded the participant's comments and meanings.