Abstract

Background

Women who live alone are becoming an increasing proportion of our population, yet few studies have examined the experiences that these women have during recovery from an acute cardiac event.

Objectives

This study aims to describe women's experiences of recovering alone from acute coronary syndrome (ACS).

Design

Women attending cardiac rehabilitation were interviewed 3-9 months following ACS using a Life History approach to address their personal/social background, professional life and work related processes and an in-depth narrative of their recovery from illness in relation to this background.

Subjects

The sample included 11 women aged from 44 to 82 years who lived alone.

Results

Being on my own was the pervasive theme, with independence being both required and valued. One subtheme included the complexity of social support arrangements women needed for their recovery. This was particularly important because women felt vulnerable when they were alone, particularly if they had experienced a sudden cardiac event or recurrent symptoms. Recurrent cardiac symptoms were an important subtheme because of the pervasive influence on women's lives, including their ability to work and plan ahead. Finally, the work and financial issues subtheme was a central concern for women, firstly because work was an important source of

income and enjoyment, but secondly, because loss of work meant loss of income. For some women this meant selling their home and/or having to move to another house.

Conclusions

Women who live alone are an increasing proportion of cardiac patients. Although they share many similar issues with other female patients and men who live alone, they appear to have unique concerns related to vulnerability, recurrent cardiac symptoms, social support, work and finances.

Introduction

Many women die from coronary heart disease (CHD) due to acute coronary syndrome (ACS) events such as myocardial infarction and unstable angina pectoris, however a high proportion survive and seek support during recovery[1,2]. It is not surprising that recovery for women has received increasing attention from researchers[3,4,5,6,7]. Most of this research doesn't differentiate the recovery experiences of women who live alone and increasingly, women are living alone due to circumstances or choice.

Many factors have contributed to the increased proportion of women living alone. The aging population and women's longer life expectancy result in more widowhood. In addition, social changes have also resulted in more women who have never married, have divorced, have not had children or have smaller numbers of children[8]. Importantly, living alone doubles the risk of recurrent events following myocardial infarction[9]. This may be due to a number of reasons including less social support, also a key predictor of quality of life for women following cardiac events[10,11]. Unpartnered women and men have been found to lack the monitoring and encouragement that enduring partnered relationships offer during recovery[12]. In their study of women recovering from myocardial infarction, Worrall-Carter, Jones and Driscoll[13] found that participants also seek the physical presence of their supporter. Women who normally live alone, therefore have to manage this need or adjust their circumstances.

A number of similar themes have been uncovered from the literature on women's experiences when living with CHD, including survival relief, loss, going on with domestic duties and the

desire for independence[13-16]. Although women who lived alone were frequently included in study samples, their experiences were seldom differentiated[13-15,17].

Only one of these studies investigated the experiences of women who live alone[16]. In this study, Robinson interviewed 12 older women, all widows, recovering from coronary artery bypass graft surgery. The women in this study described their feelings of facing possible death during surgery, their fears of recurrence and their gratitude that they had the good luck to survive. As women continued their recovery, they began to deliberately avoid or deny the underlying heart problem. Instead, within the theme of 'going on' they took up their daily routine, often from a sense of obligation or duty, facing each day as it came. Conversely, they became more cautious about the physical activity and emotions they experienced, which meant self-imposed limitations in their lifestyle. They described a sense of loss for their old life, but also attributed some of this loss to normal aging. Interestingly, women in two of the studies described their preference for living alone because of the freedom they had, so any independence they regained was considered important[14,16]. The addition of a partner is not presumed to be helpful because an unsupportive partner means women sacrifice their own needs during recovery[14]. Consequently single and/or widowed women may have been better off than those women who felt obliged to provide support for others.

In the study by LaCharity[15], one single woman described the importance of, and pride in, managing on her own after her heart attack. In contrast, others described their fear of being alone when they had recurring cardiac symptoms. While partner support featured for partnered women, friends also featured independently as an important source of support[13,15]. In contrast to Helpard

& Meagher-Stewart[14] and Robinson[16], the studies by LaCharity[15,17] and Worrall-Carter et al[13] included several women who worked, and women's responses to work during recovery varied. Some women found returning to work outside the home a source of self esteem, while others needed to negotiate new arrangements appropriate to their recovery, or were concerned about the impact of the stress of their work. However, some women were concerned by loss of energy and the balance between getting support at work versus being independent, with some women choosing not to return to work. In the study on younger women,[17] work featured more in their responses as a financial necessity, but also as a source of enjoyment, identity and independence. Some women were troubled by lack of energy at work, but women who were unable to return to work because of continuing symptoms were also distressed. For younger women, the additional theme of the shock of the diagnosis was evident and the lack of sexual counseling. It is clear that women view recovery from their cardiac event in the context of their whole lives.

In summary, women who live alone may be particularly vulnerable during recovery from acute cardiac events. Only one study was found that reported women's experiences of living alone after a cardiac event and this study was confined to older widows who had coronary artery bypass grafts[16]. Although many studies on women's cardiac recovery include women who live alone, their experiences are seldom sought or reported. This study aims to contribute to our understanding of the experience of women who live alone during recovery from a cardiac event.

Method

This study formed part of a larger study of women's experiences of recovery from an ACS event, specifically unstable angina and myocardial infarction, in the context of their whole life story.

The Life History approach was used to help women generate a personal narrative, as a way of gaining a subjective perspective on, and understanding of, the gendered experiences of women. In this study, the Life History approach helped define the woman's place in the social order of things, and how this impacted on her experience of recovery from a life threatening illness such as a cardiac event[18]. The advantage of this method over other qualitative techniques is that participants situate their experiences in the full context of their lives as women; including their work, family and relationships, rather than focusing on physical or emotional recovery for instance. As women expressed their stories it became clear that women who lived alone had many shared experiences of recovery and a special story to tell. This paper describes what women reported under an overall theme of recovering alone.

Participants

Following Institutional Review Board approval, a convenience sample of 20 women who had a recent ACS event were recruited from cardiac rehabilitation programs at two tertiary level metropolitan hospitals in Sydney, Australia. Potential participants were identified by cardiac rehabilitation staff if they had a diagnosis of ACS (unstable angina pectoris or myocardial infarction); were self-caring with no co-morbidities that impact on routine cardiac rehabilitation; and English-language literacy. Participants who met the inclusion criteria were given an introductory letter, information sheet, and consent form with a reply-paid envelope. Interviews were arranged with the participant following informed consent to coincide with late recovery (12 weeks post event), when women were no longer attending cardiac rehabilitation. Eleven of the 20 women who participated in the original study were identified as living alone, forming the sample

for this paper. The sample was culturally and linguistically diverse, although the majority were English-speaking and Australian-born.

Interviews

Participants were interviewed 3 – 9 months following their ACS event in their own home, by three experienced cardiac nurses who had training in conducting interviews using the Life History approach. Semi-structured interviews using a Life History approach were used, allowing the researcher to focus on broad areas of interest, whilst allowing the respondent to tell their story[19,20]. The Life History approach addresses personal/social background, professional life and work-related processes, and an in-depth illness narrative in relation to this background. Participants were also asked about their cardiac health history, general health history, cardiac risk factors and their life during recovery from their ACS event. None of the topics specifically addressed living alone, and audit of the transcripts demonstrated that no questions were asked on this topic. Interviews were audio-taped and transcribed verbatim.

Analysis

A general inductive approach to analysis was applied to these data[21]. Two researchers (RG and AM) closely read the 20 interviews and identified major themes arising from these data. Major categories were subsequently discussed and refined. Coded data from each researcher was compared for similarities and differences. Differences were discussed and relevant data were coded as agreed. This approach to data analysis improved the rigor of the analysis[21].

During the process of in vivo coding it became apparent to both researchers that a clear difference in the experience of recovery was being uncovered for those recovering alone, compared to those who were living with another person/s. Consequently data from the 11 participants who were recovering alone were isolated and analysed, again using a process of inductive coding. The final sample included 11 women whose ages ranged from 44 to 82 years as detailed in Table 1. The women were either divorced (7) or widowed (4) with most women working outside the home (7), 2 of whom performed substantial unpaid work and 2 women who would like to work but were unable to do so due to recurrence of cardiac symptoms such as angina.

Results

Discussion of the results of this study focuses on the overall theme of being on my own, which represented living alone during recovery. Subthemes included the complexity of social support, vulnerability, the impact of recurrent cardiac symptoms on women's lives and recovery, work and finances. Direct quotes illustrate the women's narratives within each theme, using pseudonyms.

Being on my own was the pervasive theme women raised when they discussed their life since their cardiac event. Living alone meant that these women had to be independent and had to cope with aspects of their lives, including the issues related to their recovery and adjustment. For Patricia, who had been widowed 18 months before, this was very tiring and she would do things when and how she could.

> When you live on your own you do everything. Everything is up to me, whether the house is clean and the rubbish goes out, whether food gets bought, everything, and I find that sometimes tiring.

However, most women had learnt the value of being independent from their life experiences, which they then applied to their recovery. Despite their tiredness and other symptoms, they continued to strive for independence during recovery. For Izzy and Margaret, this included surviving a traumatic divorce or widowhood and solo parenting.

> I have brought up two children on my own since they were babies; I have struggled through other operations so I get up and do things. I have never had anyone running after me so I get up and do it.

> You learn to become resilient and you somehow learn that although you've had a big loss in your life, nobody is going to help you but you have to move on. So I think that was a big lesson in my life and I think that's why I am so independent now.

Complexity of social support. The need for women living alone to be independent and resilient was present regardless of the extent and closeness of relationships with lovers, family or friends. Interestingly, these women often took the initiative in arranging their support and described quite complicated management processes to gain the support they needed. For Sandra, a 45 year old in full-time work, this meant scheduling a different friend every night.

> Basically I worked through all my friends. I had one here every night, two weeks worth of a different person every night.

For many women the most appropriate support lived at a distance (including overseas), so complex arrangements were made to ensure some live-in help was available in the first week at home. This was often followed by the woman traveling to family in later recovery. For Ellen, a widow with two daughters, this meant a roster of family members and extensive travel by her supporters and herself.

> My daughters both came up from Melbourne and then they did relays and they came to (my brother's place) twice with their families…because they both work. But they would come up and down. Stay a few days and go back.

After the acute phase, support was provided on the supporter's terms. Again, for Ellen, whose family roster included a stay with her brother, this meant support could be withdrawn when relationships floundered.

> My brother couldn't take it any more, which is really hurtful. He asked me there in the first place and then he couldn't take it.

Not surprisingly, some women preferred to avoid the stress related to these arrangements and/or having incompatible or inappropriate support in their homes. For Elizabeth this meant choosing not to have supporters stay with her so that she could recover at her own pace.

> Well my youngest daughter offered to sleep over and everything but to tell the truth I prefer to be on my own. I really like being on my own… she can't cook and she'd be untidy. I love her dearly but she'd not be the best of nurses. On the whole she would have just buggered about and irritated me and kept my blood pressure up.

Most women mentioned other women such as daughters, friends, mothers and sisters as their supporters. Other women found that due to their life circumstances including unsettled relationships with their children, that they had few supporters at all and no-one who would take over. For Patricia, a recent widow, this meant feeling very alone and unsupported.

> Yeah, quite alone. So my support network has dwindled…That's probably the biggest impact of being on your own is that there is no-one to ring and say "Darling can you go home and get me this?

Vulnerability. In addition to living alone, any time that women were on their own enhanced their sense of vulnerability, particularly if they had experienced a sudden event. Women did not physically feel safe, they felt they could no longer trust their heart to function normally. That another event might happen and if they were alone they could not get help immediately. Their concern with being alone was not confined to home but included any circumstance when they could be on their own including exercising, at work, using public transport, going out, and even when they were asleep. For Sandra, Margaret and Patricia this meant being prepared for emergencies, for example:

> I was really, really afraid, scared. I didn't want to be alone. I was just terrified that I was going to die. In terms of the way I live, I now keep my mobile always charged up and right next to my bed so that it is there if something happens and I can ring. I have a key downstairs under one of the bricks in case the ambulance needs to come.
>
> ...even if I did ring him to come over it would still take 15 or 20 minutes even in the middle of the night. So when you hit this button (MedicAlert) they respond you know. At the moment, of the three people who are on my list, two of them are overseas. So, if anything happens I just hit this and I'm fine.
>
> So it was a bit frightening being on my own anyway so I thought I'm not going to the doctor on my own in case I have a chest pain on the way to the doctor. So I waited for my friend to come.

Impact of recurrent cardiac symptoms on women's lives. Persistent symptoms, such as angina significantly influenced women's lives, particularly their ability to plan ahead including return to work. The impact was worse if no cause could be found and treatment was not effective. For Patricia this meant increasing her existing feelings of vulnerability and frustration in relation to lost work opportunity. This was in contrast to the feelings of physical vulnerability and mortality described in the previous theme, as the experiences of vulnerability in this case focused on life-planning and financial issues. In the following quote she explains her feelings in relation to her work.

> Well, it makes me realize how vulnerable we are. Especially now the problem hasn't been fixed. It is just very frustrating. (crying)

> I had the opportunity to work … and I just had to say no. which is a bit of a pity, but I just can't commit to even looking for a job let alone taking one on… I just feel my life is going nowhere right now. I can't commit to getting a job until this gets sorted out. At the moment I am in limbo. I'm totally, utterly in limbo.

Recovery, work and finances. Even when women did not have recurrent symptoms, return to work and financial issues occurred during recovery. When women were ready to return to work, some employers were reluctant, particularly if women were working outside of normal business hours and with new workplace rules for occupational, health and safety. For Elizabeth this meant extended leave from work.

> Yes, and I haven't been able to work. Or at least my supervisor was so worried that she wouldn't let me go back to work.

Many women were already juggling finances to repay loans and support family members. For Hannah, who had no sick leave because she was in casual work, this meant having to return to work early and handling the consequences.

> I had to be at work because I only get paid as I work. I had no sick leave or anything so I was a little bit stressed because I couldn't go to work. So I tried to get back to work and probably I went back too soon.

Whereas, for several other women, including Izzy, their work capacity ultimately decided if they could remain in their current home or have to sell it to provide a source of income.

> So it's up to me and I have to manage and I don't have anyone to help me manage money and I don't like managing money terribly well…when I stop work I have to move.

Work, however, whether paid or voluntary, was important to women not just for the important source of income but for the social contact. For Ellen this meant a welcome distraction.

> I think it was good to go back to work because when you live alone you can be too self-focused. So it is good to be focused on someone else. I enjoy my job. I get very tired, but I still love it.

Discussion:

The central theme raised by women during recovery from ACS was being on my own, because living on their own raised special challenges. As an increasing number of cardiac patients are women who live alone it's important that we help women meet these challenges. Women's feelings of vulnerability to further cardiac events have been reported in older women who live

alone[16] as well as with others[15,17]. However, it was clear that women were most afraid of these events recurring when they were alone and help was not available. Many women had detailed contingency plans in anticipation of another crisis. The fear of being alone included home, recreation and work settings and was heightened with recurrence of any cardiac symptoms. It was clear that the physical presence of another person was considered the best solution for most and may explain this preference noted by Worall-Carter et al.[13] Some women worked through friends and family to achieve this.

The desire to regain independence was central to women's recovery. Robinson[16] also reported that women valued independence because of the freedom it gave them. Using the Life History approach in our study helped women consider their recovery in the context of their life experiences. As a result, women described their recovery as just another challenge they had to face. As they had faced and overcome situations before, they would do so with their cardiac event. Many women did so by facing realities one day at a time. Indeed, some women clearly enjoyed living by themselves because they could face these realities in the way they chose. For these women, the prospect of inappropriate support or having to also manage their supporter's needs was not worth the care and physical presence they may gain.

The process of attaining and maintaining the support needed by women who lived alone during recovery was surprisingly complex. Although Helpard & Meagher-Stewart[14], LaCharity[15] and Worrall-Carter et al.[13] had previously noted that live-in partners were not necessarily supportive or what women needed, some women in our study mourned the loss of the ongoing instrumental support that a person who shares their home could provide. No previous study has described the

complex arrangements women and their families must make when traditional family support such as daughters, work and live at a distance. Some women described the important role of friends, which La Charity[15] had also described in older women.

The same demographic and social influences that increase the number of women living alone also support the increase of women in paid work. Very few studies have examined the recovery experiences of women who live alone, and even fewer, these experiences in relation to work. Similar to LaCharity[15,17], returning to work outside the home was an important step in recovery for the women in our study, providing an essential source of income, enjoyment, identity and independence for women. Our study clearly demonstrates the centrality of work for women living alone and regardless of age. Only women aged over 70 years were not working or not intending to work when symptoms were managed. Loss of work had serious consequences for many women in our study, beginning with loss of income, but also for some women, impending loss of their current residence and savings. For women who had an overcautious employer or recurrent cardiac symptoms, this meant a serious financial loss in their lives.

The impact of recurrent cardiac symptoms was a major obstacle to women's recovery, which has not been reported previously. Return of symptoms meant enforced lifestyle limitations, lost work opportunities, additional investigations and hospitalizations. Most important, women felt they could not make plans or have any control of their future.

The results of this study may be limited to women who begin cardiac rehabilitation, given the recruitment technique. This is an important limitation, as women's participation rates in cardiac

rehabilitation are low (32%), and non participants may have additional issues that prevented them from attending cardiac rehabilitation, which may also impact on their adjustment and recovery. These issues may include advanced age, comorbidities and social isolation due to lack of transport[23]. Importantly, given the support that cardiac rehabilitation provides, it is likely that our study may underestimate the difficulties that women face when they live alone and don't attend cardiac rehabilitation. Interestingly, few of the women in our study specifically raised the social support provided by cardiac rehabilitation, although one woman did describe an individual practitioner's support. This absence may reflect the passage of time since the women had completed or been able to participate in cardiac rehabilitation, which was an average of three months. However, further exploration of the experiences of women who do not participate in cardiac rehabilitation is justified, as is an exploration of women's perceptions of the support that cardiac rehabilitation provides, to gain a more detailed insight into how nurses may best support women.

Another limitation of the study is that although the participants in this study were culturally and linguistically diverse, only women who were competent in the English language could participate. This means that the experiences of many women from non-English speaking backgrounds have not been explored and these experiences may be quite different.

Conclusions and Implications

This first study of women's experiences of living alone during recovery from ACS is important because women who live alone are an increasing proportion of cardiac patients. The study contributes to nursing knowledge by identifying some of the challenges women face including

managing feelings of vulnerability and social support while returning to independence, work and financial issues and the impact of recurring cardiac symptoms. As living alone is also a predictor of recurrent cardiac events this information may help inform interventions that not only help women recover but also lessen their risk. The development of interventions that help women manage recurrent cardiac symptoms is crucial, so that they may return to work and make plans for their lives. As these symptoms either recurred after cardiac rehabilitation was complete or prevented participation, an alternative method is required to identify women at risk and select appropriate interventions.

Nurses, in their many roles are ideally placed to provide assessment and treatment for women living alone. Currently the literature in this area is extremely limited, although follow-up provided by advanced practice nurses shows promise[24,25]. The necessity for thorough assessment of individual women's life circumstances pre-discharge is required to determine the level and appropriateness of support health professionals need to provide for the individual woman in a way that supplements and supports their strengths. This assessment would also help hospital nurses identify, stimulate and organise appropriate support from family members and friends, during hospital admission. As these circumstances are dynamic, referral processes and follow-up will be necessary. The ideal timing and context for follow-up and referral would occur when women are attending cardiac rehabilitation, therefore any strategy that helps women engage with cardiac rehabilitation programs should be implemented. However, nurse practitioners working alongside family physicians are ideally placed to identify, treat and follow-up women when cardiac rehabilitation participation is completed or women are either unable or choose not to

attend. Finally, social support may be supplemented through the use of group strategies, which would support women without diminishing their valued independence.

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Table 1. Summary of Participants' Demographic and Clinical Data

	Participant										
	2	**3**	**6**	**7**	**8**	**10**	**13**	**14**	**15**	**16**	**19**
Age (years)	45	44	56	70	54	61		82	69	68	67
Marital status											
Divorced or separated	x				x	x	x	x	x	x	
Widowed		x	x	x							x
Work after ACS event											
Not seeking work				x				x			
Working	x		x		x		x		x	x	x
Wish to work but unable due to persistent symptoms		x				x					
ACS events or procedures											
Myocardial Infarction	x		x	x	x		x		x		
Coronary angioplasty/stent	x	x		x	x	x	x	x		x	x
Recurrent symptoms		x			x	x		x			