

A cardiac rehabilitation program to enhance the outcomes of older women with heart disease: Development of the Group Rehabilitation for Older Women (GROW) program

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ABSTRACT

Background: Heart disease in older women commonly manifests as acute coronary syndromes (unstable angina pectoris, or acute myocardial infarction) and heart failure (HF). These conditions are major causes of morbidity and mortality in

Australia and internationally. Following an acute cardiac event, women have poorer outcomes including higher mortality rates, and incidence of complications together with greater psychological morbidity compared with men. Traditionally cardiac rehabilitation programs have not specifically targeted the needs of older women.

Aim: To document the systematic development processes of a nurse-facilitated intervention to improve the outcomes of older women with heart disease.

Method: A critical literature review, supported by consumer and key informant consultation, was undertaken to develop an interactive program focussing on the use of goal setting, provision of information, and use of cognitive behavioural strategies in older women.

Findings: On the basis of the critical literature review, consumer consultation and key informant workshops, the research team concluded that the key strategies to be incorporated in the 8 week evidence-based, secondary prevention intervention (GROW program) are: (1) provision of succinct and clear information to participants; (2) facilitation of group interaction; (3) establishment of guidelines for referral to experts for management of anxiety, depression, complex social issues and clinical deterioration; (4) minimisation of participant burden with evaluation materials; (5) use of consistent information across the care continuum; (6) facilitation of self-care strategies; (7) an emphasis on cognitive-behavioural strategies to enhance self-management; in particular communication and strategies to promote self-efficacy; and (8) information, support and resources to assist nurses in facilitating the intervention.

Conclusions: It would appear from a critical literature review, consultation with consumers and clinical experts that an intervention focusing on psychological and social issues is likely to not only improve psychosocial morbidity but also improve risk factor adherence and secondary prevention strategies.

Key words: heart disease, older women, cardiac rehabilitation.

Burden of illness

Cardiovascular disease, manifest as acute coronary syndrome (unstable angina pectoris, or acute myocardial infarction) and heart failure (HF) are major causes of morbidity and mortality in industrialised society. Australians over age 60 years account for 70% of AMIs, 61% of percutaneous coronary interventions (PCI) and 73% of coronary

artery bypass surgery (CABG) (Australian Institute of Health and Welfare 2002). These rates are significant given that this age group represents only 16% of the population. These high rates of morbidity and cardiac procedures in elderly Australians demand interventions that facilitate their recovery and rehabilitation. Although it is commonly believed that heart disease is primarily a male problem (Arnstein, Buselli & Rankin 1996, Robinson & Sloan 2000), it is the major cause of death in women (Manson, Shlipak & Wenger 2001) and it has been reported that women have worse outcomes than men (Halm et al. 1999). The incidence of coronary heart disease (CHD) in women older than 75 years of age exceeds that of men (Davidson et al. 2003). Heart disease among women is characterised by a poorer prognosis, greater disability, and a higher rate of morbidity and early death after myocardial infarction (MI) compared with men (Oparil 1998). Of note, in Australia over the last 20 years the life expectancy of men has risen by 7.4% (from 71.2 to 76 years), while women's longevity has only increased by 4.6% (from 78.3 to 81.9 years) (Australia's Health 2002).

Reasons for poor outcomes of women with cardiovascular disease

Women are diagnosed less promptly and are treated more conservatively than men (Arnstein et al. 1996; Manson et al. 2001). Women tend to delay seeking medical attention for their cardiac symptoms compared with men, often attributing their symptoms to other causes (e.g. indigestion). Although they experience chest pain as often as men do, their increased likelihood of co-existing illnesses (e.g. arthritis, peptic ulcer, chronic lung disease) can make it more difficult to diagnose heart disease (Robertson-Malt et al. 1999). The symptoms associated with these co-morbidities may contribute to delays or a missed diagnosis when a heart attack has occurred (Arnstein et al. 1996). Therefore, one of the reasons that women have inequitable access to treatments and diagnostic tools is that often they do not experience the stereotypical symptoms of males. The literature on diagnosis and treatment of CHD tends to focus on men, so that physicians may lack the necessary information to diagnose women with cardiac conditions (Robertson-Malt et al. 1999). In addition, many diagnostic tools are specific to men with CHD and insensitive to the differing physiology of women, which may partly explain why women remain symptomatic yet are not diagnosed with a heart condition (Kwok et al. 1999).

In summary, women's tendency to delay seeking medical advice, misdiagnosis and more conservative treatment are likely to result in poorer outcomes in women that cannot be attributed only to their tendency to be older and have co-existing illnesses. The differences in women's presentation and outcomes with heart disease indicates the need for interventions targeting the assessment and management of women, particularly in those of advanced years. Adverse outcomes in women are

reflected in high rates of hospitalisation, less adherence to recommended treatment regimens and poorer quality of life compared to men (Halm et al. 1999). Encouragingly, growing evidence in the HF literature demonstrates that targeted interventions can improve individual and organisational outcomes (McAlister et al. 2001).

Psychological and social factors

Women are more likely to experience greater psychological morbidity than men with cardiac conditions (Davidson et al. *In press*). For instance, women frequently report experiencing denial, guilt and shame during cardiac episodes, which could influence their experience of symptoms and partly explain their tendency to misinterpret the meaning of the symptoms (Halm et al. 1999). Some women feel isolated in their experience because it is commonly perceived that heart disease is a condition of males (Lisk & Grau 1999). Women are also more depressed and anxious compared with men with heart disease (Brezinka & Kittel 1995; Moser et al. *In press*; Daly et al. 2001).

The experience of social isolation and lack of quality social support are independent risk factors for heart disease onset and prognosis (Brunker et al. 2003; National Heart Foundation Guidelines 2003). Older women may be at greater risk of social isolation because heart disease tends to occur in women who are older, and at a time when they are more likely to be widowed. Premature deaths and hospital readmissions are more likely to occur in women without spouses (Chin & Goldman 1998; Young & Kahana 1993). Krumholz et al. (1998) found that lack of emotional support prior to admission was a strong predictor of cardiac events in the year after admission in patients with heart failure, but only in women. Lisk and Grau (1999) found that many women in their study reported that support groups, family and friends were an important outlet for their concerns.

Women's roles as homemakers and caregivers also interfere with their cardiac rehabilitation, sometimes to the point of being readmitted to hospital as a result of performing home duties instead of following their physician's recommendations (Mackenzie 1993). Research has found that many women find it difficult to allow others to take on the role of primary caregiver and to accept help from others (Lisk & Grau 1999). Changing social norms as a result of both parents working means that the responsibility for child-care often falls on grandparents. Consequently, many older women with heart disease may find themselves in roles of caregivers to dependants.

Thus, older women with these conditions are less likely to have the most common source of social support (a spouse), and are more likely to be physically dependent due to their co-morbidities and advanced age, increasing their health risk due to lack of social support. It is difficult to generalise the

research on the physical and psychosocial impact of CHD to women because women make up only a small percentage of participants in these studies. Even fewer studies have included older women, who may have differing needs to younger women due to their increased risk of co-morbidity and social isolation. This situation is concerning when one considers that women have higher mortality rates, higher incidence of complications, less favourable responses to common treatments, greater psychological morbidity and are more likely to reinfarct, compared with men (Halm et al. 1999).

Health benefits from cardiac rehabilitation

Cardiac rehabilitation has been shown to reduce health costs due to decreased use of health care services and increased likelihood of return to work (National Heart Foundation of Australia 1994). It has been estimated that savings are approximately \$40 AUD per patient occasion of service (Goble & Worcester 1999). A Cochrane systematic review conducted by Jolliffe and colleagues (Jolliffe et al. 2002) demonstrated that comprehensive cardiac rehabilitation, addressing broader psychosocial aspects rather than exercise alone, significantly reduced mortality, but not non-fatal myocardial infarction. However, as the participants in these studies were predominately male, middle aged and low risk, the very participants who may have benefited most from the intervention were excluded from the trials on criteria of age, sex or co-morbidity.

Why do women have lower participation rates in cardiac rehabilitation programs than men?

Although 40% of cardiac events occur in women, only 20% of participants in structured cardiac rehabilitation programs are women (Moore 1996). This is partly explained by the tendency for women to be older with more severe pathology, a group that is less likely to participate (Moore 1996). Physicians are also partly responsible for the low rates: they tend to refer women less than men (Moore 1996). Women have also reported difficulties in attending due to lack of transport (Moore 1996). Their lower attendance rates may also be a function of their unwillingness to prioritise their health because of their role as caregiver (Hawthorne 1993). That is, they may perceive that they are unable to attend CR because they are caring for either a spouse or grandchildren and have home duties to attend.

Another possible reason for the lack of participation of women in CR programs is that the programs are targeted at men and not tailored to the specific needs of women (Arthur, Wright & Smith 2001). CR programs have been traditionally designed for men, with a predominant emphasis on physical aspects such as exercise (Dafoe & Huston 1997). Female patients also have less self-efficacy with regard to exercise and have lower tolerance levels for physical activity than men (Cochrane 1992). This problem is even greater in older women who have the lowest rates of aerobic exercise (Lee 1993). Some research

suggests that older women with cardiac disease prefer to set their own goals and not to exercise to the point of fatigue and/or pain (Moore 1996). As physical inactivity is a major risk factor for heart disease that increases with age in women (Lavie & Milani 1995), older women need to be encouraged to participate in exercise while at the same time instilling confidence in their ability for physical activity.

When one considers the benefits of CR and the importance of targeted secondary prevention strategies, it is a concern that women have lower participation rates. The evidence that women with heart disease experience greater psychosocial morbidity (Australia's Health 2002; Moser et al. In press; Frazure-Smith et al. 1997) indicates that CR programs targeted for women need to have a stronger psychosocial emphasis and be customised to their needs. Research also suggests that women's primary rehabilitative need may be support, particularly from women with similar experiences (Lisk & Grau 1999; Dafoe & Huston 1997). This has the potential to be provided in a group-based CR program designed for women.

The need to develop interventions to target the needs of older women

It is obvious that further research is needed to develop and evaluate CR programs designed specifically for older women, particularly as women have been found to experience more cardiac and psychological complaints one year following the event (Janz et al. 1999) and that CR programs have been found to decrease the risk of death by around 25% in cardiac patients (Lieberman, Meana & Stewart 1998), and a 67% reduction of major adverse cardiovascular events (Sdringola et al. 2003). The benefits of increased longevity pay a penalty of a greater number of years living with reduced functioning. In Australia, this period is an average of almost ten years (73.3 expected healthy years and longevity of 82.1 years), underscoring the importance of specific rehabilitation strategies. Gallagher and colleagues (2003) have demonstrated that a telephone counselling (TC) intervention did not decrease depression and anxiety scores in women (n=196) recently discharged from hospital and randomised to usual care or the TC intervention. In this study the mean age was 67 years and predictors of poor psychosocial outcomes for women were identified as being unemployed or retired, having poor psychosocial adjustment to illness at baseline, having readmission, or experiencing a stressful, personal event during follow-up. Interestingly, in this study being less than 55 years of age was also predictive of worse psychosocial adjustment.

Clark and colleagues conducted a series of studies (Janz et al. 1999; Clark et al. 2000; Janz et al. 2001) to develop, refine and evaluate the effects of a heart disease management program on physical and psychosocial outcomes in older women. Together these findings suggest that CR programs specifically designed for older women, based on their expressed

needs, are effective in improving the physical functioning and symptom status of participants. Clark and colleagues recommend that future interventions should have a greater psychosocial emphasis. It is imperative the intervention described in this paper be systematically tested given the growing evidence for psychological morbidity contributing to adverse outcomes. The failure of large well-designed randomised controlled trials, such as the ENRICH study to decrease mortality, yet the strong association between psychosocial morbidity and adverse outcomes, beg exploration of the fundamental constructs underpinning psychosocial interventions in CHD (Writing Committee for the ENRICH Investigators 2003). This is crucial when one considers the costs not only in economic terms, but in quality of life for those individuals and families it affects (Schulman 1992). These costs will only increase as women continue to have longer life spans as the population ages.

Summary of literature review

A literature review demonstrated that older women present with symptoms that are different from men and there is a scarcity of data related to evaluation of interventions tailored to the needs of women and specifically older women who bear the greatest burden of disease. (Davidson et al. In press). Key findings from the literature review include not only that older women compared with men have a poorer prognosis and experience greater disability but also they are at a greater risk of psychological and social problems, have a greater need for instrumental support and social support and have an altered perception of the risk of heart disease. We concluded from this problem that there is a need to develop and evaluate intervention studies that better meet the needs of older women with heart disease. Particular emphasis needs to be on psychosocial aspects, given evidence that identify these as major concerns for women.

Genesis of the Group Rehabilitation for Older Women (GROW) Program

A critical literature review supported by key informant consultation was undertaken to develop the GROW Program. This program will focus on goal setting, communication skills, such as negotiating, and anxiety and depression management. The GROW program is an 8 week evidence-based, secondary prevention, interactive cardiac rehabilitation program for older women focusing not only on education and exercise, but on the use of self-management techniques facilitated by cognitive behavioural interventions. This program will not only provide social support for older women with heart disease but simultaneously employ strategies to improve knowledge regarding secondary prevention and facilitate self-management strategies. This GROW program has several novel components. Firstly, it addresses many of the needs of women around role conflict (balancing care of themselves and families) and recognition of symptoms and access to care.

Secondly, it seeks to implement an intervention, informed by cognitive behavioural techniques and specialist training, that can be delivered by nurses. Thirdly, it incorporates a specially developed manual clearly describing strategies and techniques to ensure replication; and finally, it formalises the importance of psychosocial support as a specific intervention for older women with heart disease.

Key informant consultation

A key informant approach was used to glean the views and opinions of cardiac rehabilitation personnel. It was considered that this approach would increase the acceptability of the proposed intervention to health professionals as well as older women. The research team represented at the key informant consultation were two professors of nursing, and two psychologists. The key informants consisted of 8 nurses from a cardiovascular background. Nurses were 2 clinical nurse consultants, 4 clinical nurse specialists working in cardiac rehabilitation, a representative of the Heart Foundation, a research nurse and a cardiac rehabilitation coordinator. The nurses represented three Area Health Services in NSW Australia, which meant that recommendations were based not on just one centre's experiences of rehabilitation practices. Approval for this study was received from the University of Western Sydney and South Eastern Sydney Area Health Service (Southern Section).

The Consultation Workshop

In order to facilitate the development of an evidence-based intervention, the researchers presented and discussed a summary of the literature to key informants regarding the specific physical, psychological and social consequences of heart disease for older women. They also presented research on the rehabilitative needs of older women, as well as the latest National Heart Foundation (NHF) secondary prevention guidelines for cardiovascular events in people with heart disease. It was noted that for the first time the guidelines specify that depression, social isolation and lack of social support are significant risk factors for coronary heart disease. The workshop also presented and discussed a rehabilitation program that has been specifically designed for older women with heart disease, entitled the "PRIDE" program, developed by a group of researchers in the United States of America. The content and format of the "PRIDE" program were discussed such as to determine what aspects were relevant to the "GROW" program.

Following the literature review, secondary prevention guidelines, and "PRIDE" program presentation, the research team reached consensus on both general issues related to the format and implementation of the program, as well as content, summarised below.

Pragmatic issues

The group reached consensus on the following issues: supervision, training, guidelines, use of monitoring forms and format of the program/program.

(i) Supervision

The facilitator's manual should contain guidelines relating to clinical supervision and professional boundaries. The facilitator should receive peer support and clinical supervision, particularly as the role can be potentially emotionally burdensome.

- There is a need to maintain a professional relationship with participants and ensure participants do not develop dependency on the facilitator.

(ii) Characteristics of facilitator and training

For the purposes of sustainability, the intervention should be nurse-led, as it is unlikely that funding or availability would exist for allied health staff to conduct particular sessions. Furthermore, it may interfere with continuity and cohesiveness to have different facilitators.

- The facilitator should undergo a 'Train-the-trainer' course, particularly to learn about facilitation, group dynamics and group rules.
- A psychologist with expertise in cognitive behavioural techniques (CBT) be engaged to run a training course on CBT

Key informants suggested that the facilitator needs to be encouraging, foster group dynamics and use all opportunities to increase the GROW participants' self-efficacy.

(iii) Program Guidelines

The group facilitator should be a cardiac rehabilitation nurse specialist who is able to recognise symptoms, such as angina or significant cardiac arrhythmia. They should have current certification in cardiopulmonary resuscitation and knowledge of emergency procedures. A detailed manual will be provided to the facilitators. In addition to information the manual will state appropriate protocol to follow for issues such as:

- Recognising clinical depression or anxiety disorder and referring to appropriate specialist; and
- Managing chest pain incidents and referring to patient's cardiologist or physician for follow-up.

(iv) Requirements of participants in terms of monitoring forms

It was agreed that the burden on participants should be minimised, so it was not advisable to request participants devote significant time between sessions to completing monitoring forms/logs/diaries.

However, it was agreed there is a need for participants to set goals and monitor their behaviour in an informal way. This will be done in conjunction with the facilitator and with opportunities to feedback to the group.

(v) Interactive, supportive group format

It was agreed that the program format should follow an interactive, discussion group format rather than didactic presentation of information. Support is often the major reported benefit of such groups by participants, so use of a 'mutual-aid' model was supported. In a mutual aid framework, the group leader helps clients to help each other. Schulman's framework recognises a coalition of individuals who require each other in varying degrees to work on certain common problems. The need to depend on each other is useful in creating helpful relationships that are a vital ingredient to the group dynamic (Schulman 1992). The group recommended that the information and resources provided be simple and succinct as there is a tendency for participants to feel overloaded with information. It was suggested that a video in the first session may serve as an ice-breaker and prompt discussion about concerns of the group in relation to their heart condition. Key informants recommended that the manual contain resources such as overheads, to add humour and increase enjoyment and learning of the group.

Content of the GROW program

The intervention that key informants decided to implement can be described as a group, mutual-aid model to improve knowledge regarding secondary prevention and empowerment of self-management strategies in elderly women. Participants help one another in achieving goals and feeling confident about changing behaviours. The GROW program intervention is an 8 week, nurse-coordinated program based upon affirmation, empowerment through knowledge and development of an individualised, behavioural change intervention. A care plan will be developed after the initial assessment and given to the patient's general practitioner to ensure co-ordination and continuity of care.

Key components to the intervention determined by the key informants and research team are described below, and summarised in Table 1.

Information about heart disease: The program will commence with the provision of information about women and heart disease, discussing the unique symptomatology of women, and the particular risks and problems they face. In particular, key informants felt that there was a need to emphasise that many women experience symptoms despite the inability to provide a diagnosis. Common concerns of women with heart disease will be presented as a prompt for discussion. The three main areas shown to decrease symptoms of heart disease and improve day-to-day functioning (diet, exercise, medication) will be discussed, as well as how managing heart disease effectively means changing some behaviours.

Table 1 showing summary of content of the GROW Program

Week	Topic	Concept
1	Introductions Heart disease and women	<ul style="list-style-type: none"> Cardiovascular information: Risk factor modification, issues related to delay in presentation of symptoms Behavioural change issues, secondary prevention pharmacological strategies
2	Coping with multiple and changing roles	<ul style="list-style-type: none"> Role integration, stress and satisfaction Social support Need to use negotiation
3	Adjusting and coping to your diagnosis of heart disease	<ul style="list-style-type: none"> Coping with lifestyle adjustment Adhering to treatment regimen Self efficacy - achievement of therapeutic goals
4	Activity and exercise - combining an activity program in your daily schedule with practical demonstration	<ul style="list-style-type: none"> Adaptation to exercise Time management Strength training for prevention of osteoporosis
5	Depression and anxiety: knowledge and awareness of the signs	<ul style="list-style-type: none"> Recognition and management of depression and anxiety Self-talk as a technique, diary monitoring
6	Coping with challenging and stressful situations	<ul style="list-style-type: none"> Relaxation Conflict resolution
7	Women's health	<ul style="list-style-type: none"> Awareness and monitoring of potential sites of malignancy eg breast self-examination, PAP smear, skin cancer Management of menopause symptoms Clarifying issues around HRT
8	Communicating effectively	<ul style="list-style-type: none"> Importance of understanding what is being said to you and importance of being understood Benefits of communicating effectively Communicating to gain information about treatment regime Negotiating in order to meet your needs

Psychosocial aspects: Psychosocial topics such as coping with changing and multiple roles will be discussed. For example women may experience roles such as caregiver, home duties and a person with a heart condition. Other topics to be included in discussions are: conflicts between managing home duties and making their own health a priority following heart disease; increasing tendency for older women to care for grandchildren which can impact on their rehabilitation; stress and lowered self-esteem due to reduction in independence and control as a result of not being able to perform their role as homemaker; reluctance to accept help from others and guilt experience when family members help with home duties; the need to express one's needs and for self-preservation in order to manage their heart condition. Tips to conserve energy will also be provided. Key informants also felt that it was important for participants to discuss the issue of dealing with mortality around them (friends, family). Recognising symptoms of depression and anxiety as well as strategies for managing these responses will also be discussed.

Social and instrumental support: Participants will be asked to identify sources of instrumental and emotional support and realise the need to accept assistance during the rehabilitation period. The program will also increase participants' awareness of community groups that may provide both instrumental and emotional support. The use of negotiation skills will be applied to situations where increased support is desired. Key informants felt the need to emphasise that if self-preservation occurs there will be more energy to care for others. The link between receipt of instrumental support from family members and improved mood, satisfaction with life, and security will be discussed as well as the value of support groups, family and friends as an outlet for concerns and types of community support groups will be discussed. In order to enhance role integration, the program will also organise HomeCare when applicable (eg cooking, cleaning, washing) to reduce the stress related to women's role of homemaker).

Self-efficacy: Belief in one's own capacity as a concept to cope with heart disease will be discussed and used as a tool for enhancing self-management of particular target behaviours. Participants will be taught how to self-regulate by selecting specific behaviours they wish to target (eg diet, exercise, medication, stress management). Goal-setting through the use of graphs showing targets will be used to increase self-efficacy and encourage self-management. Throughout these sessions the nurse leading the group will provide encouragement to participants in order to maximise participants' self-efficacy, affirming their ability to effectively manage their heart condition.

Anxiety and depression: Cognitive-behavioural techniques (CBT) such as changing irrational or negative self-talk, relaxation and time management will be included in the program. Group facilitators will be trained in CBT techniques by a qualified therapist. This will occur simultaneously while the nurse

undertakes a 'Train-the-trainer program' that provides skills in group facilitation. A protocol to refer participants for expert assessment has been developed in the event of suspicion or evidence of significant psychological morbidity.

Physical activity: Aspects such as combining a physical activity program in participants' daily schedule will also be addressed, with a particular focus on individual supervision of exercise activities. Motivational techniques such as use of pedometers will also be used. Women's health issues, related to reproductive health, osteoporosis and increase in fall injury risk will be discussed.

Communication Skills: This session will discuss the importance of understanding what is being said and the importance of being understood; the benefits of communicating effectively in terms of preventing unnecessary worry and stress; constructive strategies for better communication based on participants' experiences; the use of 'I' language instead of 'you' (examples of aggressive, passive and assertive statements); and communicating effectively with one's doctor and other health professionals. The use of role plays will be used to demonstrate techniques. Negotiation skills that can be applied to personal situations where there are unmet needs will also be discussed.

Although the intervention has a structured content, participants will be encouraged to discuss any issues as they arise, as the social support derived from group interactions may be the most valuable reported aspect of the program (Lisk & Grau 1999). Prompts and reminders (eg fridge magnets), and monitoring mechanisms via telephone home visit or outpatient visit will occur in order to maximise the benefits of behaviour change strategies. Participants will be provided with handouts summarising class discussions.

Summary and concluding remarks

This paper has described the key processes in the development of a nurse-facilitated intervention to improve the outcomes of older women with heart disease. The GROW program has been developed following a critical literature review, supported by consumer and key informant consultation. This program is a participant, interactive program focusing on provision of information, exercise, and self-management through the use of cognitive behavioural intervention strategies. The research team will implement this program using a randomised controlled trial to determine the efficacy of the program in reducing physical and psychosocial morbidity, as well as reducing health care costs.

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