



GREATER SOUTHERN
AREA HEALTH SERVICE
NSW HEALTH

HEARTY HEALTH FOR RURAL WOMEN

**An examination of issues identified by women
living in Greater Southern Area Health Service with
Heart Disease**

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MAIN MESSAGES

- Heart disease is a women's health issue (one in five women die from heart disease).
- Early identification of heart disease in women will improve long term outcomes which is particularly important because women are living longer but frequently in poorer health.
- Family history of heart disease is common in women and could be easily assessed as an early indicator of potential risk reducing the mortality and morbidity experienced by women.
- Women have uncharacteristic symptoms of heart disease which are sometimes mistaken for other illnesses or old age.
- The effects of gender on women's experiences of heart disease shows women are concerned about the impact of their heart disease on family and the community and their ability to fulfill roles and responsibilities adding to the distress of not only having a serious illness but not being able to stay involved in routine daily activities.
- There is a requirement to educate women and the community about signs of heart disease in women and if any symptoms are present encourage them to seek advice. Health workers should offer services that are responsive to their needs for example: cardiac rehabilitation programs and exercise programs exclusively for women.

EXECUTIVE SUMMARY

The aim of this research study is to examine issues identified by rural women living in Greater Southern Area Health Service (166,000 square kilometers of southern NSW) with heart disease. Ten women volunteered to participate in this study and were asked to answer eight questions in an in-depth interview which was then recorded. The study was based on individual women's experiences and perceptions and was descriptive in design.

A qualitative methodology was used in an attempt to provide a social framework and increased understanding of the diversity of women's experiences. From a feminist perspective women's health is a pattern of interwoven positive and negative experiences which is best understood using a holistic framework that includes social, cultural and political factors. A range of issues emerged from the interviews and are summarized below.

What they knew about heart disease and how it affected women?

Many of the women did not know much about heart disease and women and associated heart disease with men. Women often had a family history of heart disease mostly on their father's side.

What type of heart disease do they have?

Atherosclerosis was the most common diagnosis of heart disease though two women had atrial fibrillation, one had cardiomyopathy and the other a leaking mitral valve.

How were they diagnosed with heart disease?

Half the women in the study were diagnosed in hospital following a sudden episode where they had collapsed whilst undertaking a routine daily activity. One third of women were diagnosed by a General Practitioner (GP) and two had been referred to a specialist for more in depth investigations.

How long did it take to reach a diagnosis of heart disease?

Many of the women were diagnosed in one to five days, one woman was diagnosed in a couple of weeks and the remaining four women took between one and three months to receive a diagnosis.

What symptoms did they experience?

Epigastric or chest pain was the most common symptom reported. Other symptoms included shortness of breath or becoming tired easily, some women experienced other pain (mostly in the back and neck) others reported palpitations and light headedness.

What impact did the diagnosis have on them?

Most of the women reported that they had to slow down and were unable to continue carrying out usual tasks (cleaning windows, removing cobwebs, community and church commitments) and one woman could no longer continue caring for an adult child with a

disability). Most of them felt guilty because they were unable to fulfill commitments to family and friends and did not want to be a burden on their children.

How did they feel about the care they received?

Many women were very satisfied with their care, some thought the care was reasonable, some had difficulties accessing specialist care due to large geographic distances and few services. One woman had problems with access to transport to go to appointments and described traveling long distances in a community transport vehicle.

Did they talk with other women with heart disease about their experiences'?

Most participants reported that they did not know any other women with heart disease and commented about the absence of women in cardiac rehabilitation programs. Several women commented on the fact that they did not discuss their health concerns with anyone and were often too busy to think about it.

The findings indicate that health service providers and women themselves do not see heart disease as an issue that affects women. As a result symptoms are frequently misdiagnosed and the seriousness of their illness fails to be taken into account.

Even though heart disease is the leading cause of death in women it is still considered to be a disease that only affects men. This creates difficulties for women in recognizing symptoms of heart disease and for service providers trying to deliver an appropriate gender specific response to women's symptoms. If women do not recognize symptoms as those of a heart attack they are more likely than men to ignore the symptoms and delay seeking help (Women's Health Bureau 2001:3).

A further compounding problem for women regarding heart disease is that women are still not being included in large enough numbers in research studies. Frequently data is aggregated and does not provide a comparison between women and men. Follow up care and management and treatment options to address the needs of women and men are based on research conducted only on men.

A REVIEW OF THE LITERATURE

It is commonly believed that heart disease is primarily a male problem though it is the major cause of death in women. National data suggests that women are five times more likely to die from heart disease as breast cancer. (1)

Women were believed to be protected from developing heart disease due to the presence of oestrogens. This belief was reinforced by the findings of the Framingham study. (2) The study showed a dramatic acute onset of heart disease in men in their mid forties and a slow insidious onset ten years later in women. It also demonstrated that the overall prevalence of heart disease was much higher in men than in women implying it was a male disease.

A lack of recognition of heart disease in women has reinforced the perception that it is not a women's health issue and therefore does not require further investigation.(3) Women have been excluded from trials due to a range of complicating factors for example: hormonal changes, risk of pregnancy, length of time required to undertake research and cost. (4)

Commonly heart disease is under diagnosed in women. This is due to a lower rate of symptom reporting, less specific angina like symptoms and difficulty in identifying specific symptoms experienced by women. (5)

Routine investigations used to diagnose heart disease for example: the conventional stress test give a high rate of false positive or inconclusive results in women and can lead to inaccurate diagnosis. (6)

These factors have created barriers to the inclusion of women in research and have perpetuated a gap in the evidence base leading to a lack of knowledge of preventative strategies, diagnostic testing and responses to medical and surgical treatments specifically for women. (7)

Women have significantly poorer outcomes than men following a heart event as they tend to be older and frequently present with a range of other co- existing health problems for example: diabetes, arthritis and peptic ulcers. They are more likely to be hospitalized following a cardiac event and once in the medical system may experience additional barriers to therapeutic and diagnostic services. (8)

Search Terms

A range of sources have been used to provide the information contained in the literature review for example: Medline search (key words, heart disease, gender differences in heart disease, women and heart disease, cardiac rehabilitation) Cinahl, meta-analysis and peer reviews.

National and international policy documents and reports have also been used to inform the literature review.

Issues in the Literature

While there is a growing evidence base about heart disease and women there are still a number of large gaps in the evidence about specific issues for women. Some of the reasons for an absence of information are related to issues of gender and the physical differences between women and men. There is a clear gender bias in the diagnosis and management of heart disease mainly due to the exclusion of women from research studies.

The Impact of Gender on the Diagnosis and Management of Heart Disease.

Gender refers to the values, norms and expectations that society attributes to being female or male. Gender is a social construction of the female and male identity that goes beyond the biological differences between women and men (known as 'sex'). (4)

Gender is related to a number of complex social, political, cultural, and economic factors that influence health and illness; for example, women as principal care givers, women's education and employment status, and cultural background. Traditional gender roles might be an obstacle to cardiovascular health as some women find it difficult to participate in health improvement activities because of a range of care giving responsibilities.

Women's lives are heavily influenced by social rather than clinical factors. In most cases women have the main responsibility for family food preparation and will not change their family's diet if their own diet has to change but will prepare separate food for themselves. If the father or husband's diet has to change, however, then the diet of the whole family tends to change. (6) Women often put the needs of others first and report not wanting to worry anyone as the reason for not seeking help. (7)

The roles, responsibilities and expectations associated with being female may lead to inequities in health; influencing women's access to services, how practitioners treat women, and even the health status experienced by women. There tends to be a lower rate of symptom reporting by women with heart disease and women are more likely to delay seeking help. (8)

Gender stereo typing can have an influence on clinical decision making as health professionals may attribute women's health problems to emotional rather than physical causes or to biological impacts caused by menopause. (8) Health care providers are influenced by the interaction of psychological symptoms and patient's female gender, there tends to be under diagnosis and under referral of women presenting with CHD symptoms in the context of stressful life events. (9) Gender differences in the treatment of heart disease have a significant impact on the outcomes and mortality for women. (10) Delays or misdiagnosis of heart disease in women contributes to higher mortality rates, higher incidence of complications, less favourable responses to common treatments and greater psychological morbidity. (11)

The literature indicates that more research on women is needed so that we do not miss the effects of the interaction of gender and pathology on clinical presentation, symptoms, treatments, and outcomes in all patients with coronary artery disease. ⁽¹²⁾ Moreover, from a quality and equitable care perspective, it appears that renewed efforts are required to incorporate gender sensitivity into cardiac health care. ⁽¹³⁾

An Absence of Evidence Concerning Women and Heart Disease

A lack of recognition of heart disease in women has reinforced the perception that it is not a women's health issue. Coupled with a gap in the evidence base about women and heart disease, there is a lack of knowledge of preventative strategies, diagnostic testing and responses to medical and surgical treatments specifically for women.

Women have been excluded from research studies due to a range of barriers for example: hormonal changes, risk of pregnancy, length of time required to undertake research and cost. Research has found that men are up to 10 times more likely to be referred to heart specialists and are more likely to be treated earlier in the course of the disease and undergo therapeutic interventions than women.

White middle aged men have been the subjects and models in most cardiac funded research trials with the assumption that irrespective of the results the same findings would apply for women. ⁽¹⁴⁾

Symptoms of heart disease in women are less likely to be investigated as thoroughly compared with men causing a delay in diagnosis and treatment. ⁽¹⁵⁾ Women are still less likely to receive certain drugs such as beta blockers on hospital admission for a myocardial infarction or to be referred to additional tests and cardiac procedures. ⁽¹⁶⁾

This has a significant effect on both physical and psychosocial health outcomes for women contributing to higher mortality rates and less favorable responses to common treatments.

Differing Presentations of Heart Disease in Women and Men

The differing presentation of heart disease in women and men have several implications for women as current diagnostic investigations and treatments for heart disease have been developed based on research involving men. There are various sex related differences in cardiovascular systems between women and men. ⁽¹⁷⁾ As a result women experience less specific angina like symptoms than men.

Research has revealed differences in various aspects of heart failure between men and women including risk factors, pathophysiology, clinical manifestations and responses to treatment. ⁽¹⁸⁾ Women are less likely to complain about pain in the chest and tend to describe pain located in the back, stomach, neck and chin and more likely to report higher levels of pain intensity accompanied with symptoms of dyspnea, dizziness, palpitations and irritability. ⁽¹⁹⁾

Women experience heart disease at a later age and present with different symptoms when having their first coronary event. (20) There is a greater difficulty in identifying specific symptoms in women which can complicate reaching an accurate diagnosis. Women confirmed to have anterior myocardial infarction tend to have more atypical symptoms at presentation than do men, including abdominal pain and dyspnea. (21)

Presenting symptoms of women and men with heart disease may be similar (approximately 70% experience chest pain), atypical symptoms are more common in women and not necessarily related to obstructive coronary disease or ischaemia. (22)

There are several risks for women in the stereotyping of cardiovascular disease as 'male'. Health care professionals may not recognize or may dismiss early signs of heart disease in women and women may not think they are at risk of developing heart disease. (23)

Women need to be especially educated that they may be more likely than men to experience atypical symptoms such as breast or back pain associated with a heart event. Women need to be told that heart disease is not a male disease, and that they too, are at risk of developing heart disease.

Efficacy of Treatments

Routine investigations used to diagnose heart disease for example: the conventional stress test give a high rate of false positives or inconclusive results in women and can lead to inaccurate diagnosis.

There are several factors that complicate the identification and appropriate treatment of heart disease in women. These include: a higher incidence of chest pain (may not be as a result of coronary artery disease CAD in women) a lower detection rate in women using traditional methods (women may not have a 50% reduction in the diameter of the coronary artery the standard diagnostic result for CAD) lower rates of interventional procedures and differences in the pathophysiology of heart disease between women and men (women have a higher incidence of endothelial dysfunction instead of narrower blocked arteries found in men with heart disease). (24)

The use of diagnostic imaging (echocardiography) can improve accuracy of stress testing in women though is problematic for women as they have a smaller left ventricle and breast attenuation which can interfere with imaging of the left coronary artery. (25)

The presence of co-existing health problems increases the risk of developing heart disease. Women tend to be older when diagnosed with heart failure and more often have hypertension and diabetes than men. (26) They are more likely to delay seeking medical treatment for their symptoms and have poorer outcomes following a heart event.

Women are less likely to undergo invasive cardiac procedures such as cardiac catheterization, revascularization and cardiographic artery bypass graft (CABG) due to age and the presence of other health related illnesses. (27)

The evidence suggests that women experience greater morbidity and mortality from heart disease than men. There are various reasons for the disparity related to the age at which women develop heart disease, differing risk factors and clinical presentations, as well as a perception that heart disease affects men rather than women.

Summary

After reviewing the literature on women and heart disease it is evident that there are disparities between the diagnosis and management of heart disease in women and men. Gender is a significant contributing factor for this difference and increased efforts are required by the health care system to understand the broad context of women's lives.

Delays or misdiagnosis of heart disease in women contributes to higher mortality rates, higher incidence of complications, less favourable responses to common treatments and greater psychological morbidity. Standard medical and surgical treatments are not as effective for women and quality of life can be substantially reduced.

Rationale

Heart disease has earned a male stereotype which contributes to the idea that women don't get heart disease. This is largely due to the fact that in most age groups many more men than women experience heart disease and premature death as a result of heart disease. Cardiovascular symptoms in women are less thoroughly investigated and less vigorously treated promoting a belief within the healthcare system and among women and their families that heart disease is not a women's health issue.

There is also the related issue of the absence of women in medical research on heart disease. Male subjects have been the focus of most studies of disease, diagnostic procedures, treatment therapies and management strategies. Frequently in situations where women have been included in research studies, results have been discarded as they did not conform to patterns based on the results from men. This has led to an assumption that the normal body is not subject to hormonal influences and that therapies will work for women in the same way they do for men.

There are a wide diversity of symptoms and presentations of heart disease in women. Women are more likely to experience epigastric and back pain, abdominal pain, palpitations and shortness of breath. These symptoms may be mistaken as gastrointestinal or musculoskeletal in origin and can contribute to delays in diagnosis.

The uncharacteristic nature of presenting symptoms in women needs to be more widely documented to educate women about heart disease and to reinforce the importance of seeking advice early. The health care system also needs to improve its response to

women complaining of uncharacteristic symptoms and consider that it may be as a result of heart disease or heart failure.

Frequently women have significantly poorer outcomes than men following a heart event as they tend to be older and commonly present with a range of other co-existing health problems for example: diabetes, arthritis and peptic ulcers. This combination of factors has a major impact on their health and wellbeing and perceived ability to fulfill their roles and responsibilities.

Some women experience additional fear and anxiety as a result of being unable to maintain their previous lifestyle due to their heart disease and increased worries about who will take care of things if anything happens to them.

Study Aim

The aim of this research study was to examine issues identified by rural women living in Greater Southern Area Health Service (166,000 square kilometers of southern NSW) who have heart disease. The study was based on individual women's experiences and perceptions and was descriptive in design. The principles of grounded theory ⁽²⁸⁾ were used to guide data generation and analysis as it was considered the most appropriate way to reflect women's individual experiences.

METHODS

Theoretical Perspective

Symbolic interactionism is the broad theoretical social philosophy that underpins grounded theory. It was originally described by George Herbert Mead (1863-1931). Mead was particularly interested in understanding the human self, especially the social self and believed language to be central to self. Individuals communicate through symbols and language and this is how individuals develop a sense of self in the course of their interaction with other people, hence the term symbolic interactionism. (29)

A qualitative methodology was used in an attempt to provide a social framework and increased understanding of the diversity of women's experiences. From a feminist perspective women's health is a pattern of interwoven positive and negative experiences which is best understood using a holistic framework that includes social, cultural and political factors.

Characteristics of Participants

Interviews commenced in June 2008 and were completed in October 2008. Ten women participated in the study with ages ranging from 52 years to 83 years. Their backgrounds were varied and all except two had lived within Greater Southern Area Health Service all their lives. One was born of Scandinavian heritage and migrated to a small town on the Murray River thirty years ago and the other was born in the ACT and moved to the south coast fifteen years ago.

Sampling

The focus of this study was rural women living in Greater Southern Area Health Service. Women were invited to participate in the study by using flyers and word of mouth. The flyers were placed in a broad range of community settings such as GP surgeries, local community sporting and social clubs and through the Country Women's Association. Additional recruitment occurred through hospitals, community health centres and women's health services as it became difficult to recruit enough women into the study (a minimum of ten were required).

Inclusion criteria required participants to be women aged over 45 years living in Greater Southern Area Health Service with a diagnosis of heart disease or primary risk factors for developing heart disease for example hypertension, high cholesterol, overweight or obese.

Initially women with a family history were excluded from the study to prevent participants from having a preexisting knowledge of heart disease prevention and therefore engaging in early intervention initiatives for example: Monitoring cholesterol levels and blood pressure measurements at an earlier age.

Women volunteering to participate in the study telephoned to express their interest and were selected based on the inclusion criteria and phone interview. Several requested copies of the interview questions to prepare for the interview which in most cases was

carried out in their homes. Two interviews took place at the community health centre and one in the grounds of the hospital. Written informed consent was obtained from the participants prior to commencing the interview they also received a participant information sheet about the study as well as the researcher's contact details if they had questions after the interview. Participants were also invited to provide contact details if they wished to receive a copy of the report.

Data collection and analysis

In-depth interviews were carried out using set questions that included some prompts and probes to elicit a broader response. The interviews were audio taped and field notes were written during the interviews to gain more information. The tapes were transcribed following the interviews and explored for common themes. Themes that emerged were followed through into the next interview though each interview was slightly different and most of the analysis occurred after the final interview

A process of coding was undertaken to organize the data from the interviews. A mind mapping diagram was created to document the content of the discussions and to assist with the development of themes and codes. The transcriptions and field notes were used to provide some more complex interpretation of the data. An attempt was made to clearly listen to what women said during the interview and provide an accurate reflection of their words "in and on their own terms" ⁽³¹⁾ as it can be difficult to clearly capture in the research process.

Confidentiality has been maintained according to the NH&MRC guidelines, audio recordings have been removed and filed notes and transcripts kept in a locked filing cabinet in the researcher's office.

Concern was taken at the end of the interviews to ensure the participants were comfortable and feeling safe with the interview process. Follow up support was offered with local community services.

Ethics approval was given by the Greater Southern Area Health Service HREC (Appendices A - research flyer, B - participant information sheet, C - research questions and D – participant consent form).

RESULTS

The themes and ideas that emerged from the data are discussed in the remainder of the report and provide insight in to heart disease and women, the impact heart disease has on women and it's implications for women's health.

Women do not associate heart disease with women

Women were asked in the interview to comment on what they knew about heart disease and how it affected women. More than half the women did not consider heart disease to affect women commonly believing it was a male problem. Many had fathers who had died suddenly from a heart attack or had strokes or histories of suffering from angina providing their association with heart disease and reinforcing the stereotype of heart disease as male.

Some of the women described different types of heart disease in their responses and thought it might affect women differently to how it affected men. A few suggested contributing factors to developing heart disease for example too much stress and overwork and again associated this with men engaging in hard physical work on farms or high pressured jobs working long hours. Essentially though, the majority of responses were that they did not know much about the specific effects on women. *"I did not realise it can affect women, we get different pains in different areas I think they have concentrated all the information that has been on men and their approach to it"*.

Family history is common

When asking women to discuss what they knew about women and heart disease many talked about having a family history of heart disease. Predominantly it was a paternal relationship where their fathers or male siblings had experienced heart disease in the form of a sudden death from a heart attack or had a stroke and required significant care.

A few of the women had mothers and female siblings with arthrosclerosis and several had significant risk factors for developing heart disease for example high blood pressure and were taking anti hypertensive medication. There were also concerns expressed about siblings with Type 2 diabetes who were overweight which contributed to high levels of distress for the women in relation to fears about them developing long term health problems.

Women are not aware of other women with heart disease

The final question in the interview related to talking to other women with heart disease about their experiences to provide information about the scope of heart disease among women. Overwhelmingly the response was that they didn't know other women with heart disease.

An older women in the study described not feeling comfortable to discuss her health problems with other people except her husband, not even her children. Another woman responded by saying *"women don't consider themselves and don't talk about their*

health problems". One woman stated that women are less inclined to talk about themselves and don't have time to think too much about themselves.

In a cardiac rehabilitation program at the Cooma Hospital only three of the nine participants were women, frequently men outnumber women in cardiac rehabilitation programs following a coronary event. This is reported to be due to women's roles as primary care givers and their reluctance to prioritise their own health needs by participating in a structured program. (33)

How the diagnosis was reached

The second question in the interview asked women to talk about their heart disease. More than half the women had been diagnosed with atherosclerosis and four of those had had a coronary event and surgery. Commonly the diagnosis occurred in hospital following a sudden episode where they had collapsed or needed to rest whilst participating in a routine daily activity.

One woman had an incident undergoing a bowel operation where her heart stopped beating. She had previously been advised by her doctor that the symptoms she was complaining of were related to indigestion and when she had a negative ECG she also dismissed any further symptoms as being heart related.

Of the remaining four women three had been referred by their doctor to a specialist service for further investigations, two had been diagnosed with atrial fibrillation and the third cardiomyopathy. The fourth woman has a leaking aortic valve and a significant degree of heart failure contributing to a poorer quality of life. *"I don't get out as much as I used to and often feel lonely and like I don't contribute much to my community any more"*.

Frequently identified symptoms

All of the women in the study had experienced uncharacteristic pain, palpitations and numbness and tingling in their fingers over a period of time, shortness of breath and fatigue. Many became tired and unable to complete daily tasks that were usually easily accomplished and lost their motivation for involvement in community activities, continuing to participate out of a sense of obligation. *"Well I had a sort of bubbling in my chest for years and doctors in my home town said there is nothing wrong, it was like it was pushing on a vent"*.

Several women talked to their doctor about their symptoms and had preliminary investigations. The result of the tests were negative and even though they still didn't feel well they explained the symptoms as *"getting older I'm bound to feel a few more aches and pains"*.

Length of time to reach diagnosis

For half the women interviewed it took one to three days to diagnose their heart disease mostly due to the sudden and urgent nature of how it occurred. Three women had investigations over several months before an accurate diagnosis could be provided and

one took six years before being told she had a leaking aortic valve. During that time her physical and emotional health deteriorated considerably and has caused irreversible damage to her heart.

Family is a major concern

Many of the women interviewed described how they delayed telling their families about their heart disease or minimized the seriousness of it as they did not want to worry them, particularly one woman whose sons aged seven and nine had witnessed their grandmother drop dead as she was minding them *“I did not want them getting to deterred about it so I really tried to play it down, also my son was turning twenty one and having a party and I did not want to spoil it for him and the rest of the family”*. Another woman talked about feeling distressed by not being able to play with her grandchildren like she used to and hearing one of her grandchildren telling their mother that *“Grandma’s only good for cake now”*.

Today many older women have caring responsibilities for their parents because people are living longer. This can be a physically demanding role for women who may themselves be elderly and have heart disease and an extra stress they want to protect their aging parents from. One woman provides respite care for her mother who lives some distance away near her sister *“I try to go once a month and spend a few days there to give my sister a bit of respite but I find it hard going now since my operation and I feel sad that I can’t do more for Mum”*.

There were times during several interviews where women became teary when talking about their worries in relation to the impact of their heart disease on their families and fears they had for the future. One elderly woman has an adult child with a severe physical and intellectual disability who spent two years making the decision to place her in care *“so that if I die I know she will be looked after, I can rest better now”*.

DISCUSSION

This section highlights some of the findings from this research project and issues already identified in research about women and heart disease. The findings are similar to those of other research studies and fall into a few broad categories relating to the impact of gender, the lack of evidence about women and heart disease and atypical signs and symptoms experienced by women.

The literature suggests that there is a clear gender bias in the diagnosis and management of heart disease mainly due to the exclusion of women from research studies. In studies where women have been included the data is aggregated and does not provide a picture that represents women. Treatment and management options are based on the experience and relevance to men.

The roles, responsibilities and expectations of being female may have a negative impact on the health of women due to gender stereo typing. It may influence the way health service providers' make clinical decisions as problems may be attributed to emotional rather than physical causes or the biological effects caused by menopause.

Gender may also influence women's access to services as many are engaged in a range of care giving responsibilities and unable to participate in health improvement activities.

The symptoms women experience when having a heart attack are sometimes confused with other medical conditions like indigestion or shortness of breath related to fatigue. Women are more likely to delay seeking help as their symptoms are not perceived to be serious or related to heart attacks or they do not want to disrupt their family through illness.

There are some limitations to this study in that it involved a small number of participants (ten in total). Whilst it was valuable to hear women's stories which largely reflected the findings of other research studies it would have also been of additional value to interview health service providers to find out what perceptions and understandings they have about women and heart disease.

CONCLUSION

It is evident from the available literature and results from the study that a gendered approach to cardiovascular health is required in the diagnosis and management of heart disease. The findings indicate that health service providers and women themselves do not see heart disease as an issue that affects women. As a result symptoms are frequently misdiagnosed and the seriousness of their illness fails to be taken into account.

There is an imperative to encourage women to seek help early to avoid delays in diagnosis as well as a desperate need to include women in heart disease research studies and clinical trials to provide a better understanding of symptoms experienced by women and improve treatments for women.

Awareness raising in the community and education of health service providers about risk factors for women and heart disease, will assist in providing earlier identification of heart disease in women. Together these strategies will reduce long term negative health outcomes experienced by women.

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APPENDICES

Appendix A



WOMEN and HEART DISEASE

Are you a woman aged 45 years or older living with heart disease?

I am looking for rural women to take part in a small research project to find out about women's experiences of living with heart disease.

If you would like to share your experience please contact:

Annie Flint

**44724544 (Bateman's Bay
Community Health Centre)**

0419422168

or

email: annie.flint@gsahs.health.nsw.gov.au

This research project is being conducted by Annie Flint A/Women's Health Coordinator Greater Southern Area Health Service as part of a rural research scholarship program.

The program is funded by NSW Health in partnership with the NSW Institute for Rural Clinical Services and Teaching and Greater Southern Area Health Service.

Appendix B



Women and Heart Disease Research Project

Rural Women's Experiences of Living with Heart Disease

Participant Information

This research project is being conducted by Annie Flint A/Women's Health Coordinator for Greater Southern Area Health Service as part of a rural research scholarship program.

The program is funded by NSW Health in partnership with the NSW Institute for Rural Clinical Services and Teaching and Greater Southern Area Health Service.

Annie is seeking your consent to participate in a one to one interview lasting approximately 60 minutes. The research project aims to examine issues identified by rural women from small towns in Greater Southern Area Health Service (GSAHS) with heart disease.

If you agree to the interview you will be asked to describe your thoughts about heart disease as a women's health issue and how living with heart disease affects your life, how you manage your heart disease and the impact it has on your family life and relationships. The interview will also ask you to compare your experience of living with heart disease with that of other women living with heart disease.

All the information from this research will be kept under lock and key and computer password protected only those working on the research project will have access to it. With your permission the interview will be recorded and transcribed. No publications from this research will identify any individuals.

Your participation would be very helpful, but there is no pressure on you to take part and your access to services will not be affected if you decline. If you agree to the interview you are free to stop the discussion or withdraw at any time.

If you have any comments about this research project, please contact:

Annie Flint
A/Women's Health Coordinator

GSAHS
44724544, 0419422168

Should you have any concerns about this research project please contact:

GSAHS HREC
Albury
PO Box 3095
Albury NSW 2640

Appendix C



Women and Heart Disease Research Project

Rural Women’s Experiences of Living with Heart Disease

CONSENT FORM

I..... (name in block letters) have read the participant information and any questions I have asked have been answered to my satisfaction.

I agree to participate in the research study, knowing that I may withdraw at any time. I agree that research data gathered for the study may be published, provided my name is not used.

.....
(Signature of Participant)

.....
(Date)

.....
(Signature of Researcher)

.....
(Date)

If you would like a copy of the Final Report from this study, please indicate with your name and address.

.....
.....
.....

Appendix D



Interview Questions

1. Can you tell me what you know about heart disease and how it affects women?
2. Can you tell me about your heart disease?

Prompt: What type of heart disease do you have?

3. Can you tell me about how you first found out about your heart disease?

Prompt: When you were first diagnosed?
Was that at the doctors or hospital?

Probe: How did you feel when you were first told?
Do you remember what your first thoughts were?
Tell me what your family said about your diagnosis?

4. How long did it take to diagnose your heart disease?

Prompt: What impact did the diagnosis have on you?

5. Do you remember if you experienced any symptoms before you were diagnosed?
6. How are you feeling about your heart disease now?

Prompt: Do you feel differently now to how you felt when you were initially told?

7. Can you tell me how you feel about the care you are receiving for your heart disease?
8. Have you talked to other women with heart disease about their experiences?