“I don’t have the spoons for that…”

The views and experiences of younger ACT women (aged 18 to 50 years) about accessing supports and services for chronic disease

Amber Hutchison

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Acknowledgements

Thank you to all the women who chose to share their limited supply of ‘spoons’ and participate in this research by completing the consultation survey, being involved in an interview, or participating in a focus group. It is your valuable insights and sharing of your life experiences that inform our work and help us to influence change in health services and support so that they are responsive to the needs of all ACT women. We thank you for your stories and hope that this report will highlight and influence the need for improvements that might have a real and lasting impact on your lives.

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About Women’s Centre for Health Matters Inc.

The Women’s Centre for Health Matters Inc. (WCHM) is a community based organisation which works in the ACT and surrounding region to improve women’s health and wellbeing. WCHM believes that the environment and life circumstances which each woman experiences affects her health outcomes. WCHM focuses on areas of possible disadvantage and uses social research, community development and health promotion to provide information and skills that empower women to enhance their own health and wellbeing. WCHM undertakes social research and advocacy to influence systems’ change with the aim to improve women’s health and wellbeing outcomes. WCHM is funded by ACT Health.

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Executive summary

Chronic disease is long lasting and debilitating. It has a large personal and societal cost,[1] and affects a growing number of people in the ACT. This is particularly so for women.

Women live longer so are more likely than men to live with disability and chronic conditions.[2] [3] Women are also more likely to have unique health concerns and issues that relate to their gender and their life roles which will impact on their conditions.[4] [5] This means they will use health services and medicines more frequently, and over a longer period of time, increasing the demand on the health system and expenditure on health care costs. [6] [7]

At the moment the ACT health care system focusses on acute care in response to acute needs and episodic health issues, and many of these are aimed at meeting the needs of older people or very young people with chronic conditions. There is a gap in understanding of how the experience of chronic conditions might differ between men and women, and in understanding the needs of women who are experiencing the onset of chronic conditions in early adulthood. In addition, there is a need to address the co-morbidities of physical and mental health,[8] and to focus on chronic diseases that are not caused by preventable 'lifestyle' factors.

It is important to consider gender in future health services planning in the ACT, and to address barriers for younger women to accessing the health care system.[9] Women are more prone than men to conditions that are complex and misunderstood. They often have symptoms that are 'hidden', which have no easily visible physical characteristics, have no known cause, and symptoms that don't fit together.[10] [11] Younger women who present with diseases that are usually found in older patients, such as arthritis, report not being believed by health professionals, leading to poor patient outcomes.[12]

A quote from a study about women with lupus explains what living with a chronic disease is like, and how it effects every aspect of their life:

> *"the context of daily life was framed by uncertainty, fatigue, and pain, which interfered with the most routine aspects of family life, altered their sense of self, and, in many cases, threatened their financial security."*[13]

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[1] C Walker, 'Multiple conditions: exploring literature from the consumer perspective in Australia', *Health Expectations*, vol. 18, pp. 166-176.

[2] Australian Institute of Health and Welfare 2012. Australia's Health, 2012. Australia's health series no.13. Cat. No AUS156. Canberra: AIHW

[3] Australian Institute of Health and Welfare 2016. Australia's health 2016. Australia's health series no. 15. Cat. no. AUS 199. Canberra: AIHW

[4] NSW Ministry of Health, *NSW health framework for women's health 2013,* North Sydney, 2013.

[5] Department of Health and Ageing, *National women's health policy 2010*, Canberra, 2010.

[6] NSW Ministry of Health, *NSW health framework for women's health 2013,* North Sydney, 2013.

[7] Department of Health and Ageing, *National women's health policy 2010*, Canberra, 2010.

[8] Department of Health, *Primary health care advisory group final report better outcomes for people with chronic and complex health conditions*, Canberra, 2016, retrieved on the 26th of September 2017: https://www.health.gov.au/internet/main/publishing.nsf/Content/76B2BDC12AE54540CA257F72001102B9/$File/Primary-Health-Care-Advisory-Group_Final-Report.pdf

[9] Health Care Consumers Association, *Primary health care in the ACT: Consumer Experiences*, Canberra, 2014.

[10] S Stone, 'Must disability always be visible?, the meaning of disability for women', *Canadian Women Studies*, vol.13, no. 4, 1993, pp. 11-13.

[11] R Epstein et al., 'Physicians' responses to patients' medically unexplained symptoms' *Psychosomatic Medicine*, vol. 68, 2006, pp. 269 –276.

[12] M Moradi et al., 'Impact of endometriosis on women's lives: a qualitative study', *BMC Women's health*, vol. 14, no. 123, 2014, pp. 1-12.

[13] C Mendelson, 'Managing a medically and socially complex life: women living with lupus', *Qualitative Health Research*, vol. 16 no. 7, 2006, pp. 982-997.

It is important to ensure that ACT women have access to appropriate prevention and health management support that enable them to have better long-term health, more productive years, engagement with community and prevention of comorbidity. For women aged 18 to 50 years, this can have a significant impact due to the number of years they will be living with a chronic disease.

Women in our research told us that:

- Many of the chronic diseases appeared in women's younger reproductive years;
- They experienced not being believed by health professionals, which often delayed diagnosis and treatment;
- Many of them had to manage pain and fatigue on a daily basis while trying to maintain their traditional roles as mothers, partners, carers, friends and employees;
- Their chronic disease/s impacted on or prevented them from carrying out normal daily activities such as domestic duties, employment, education, child rearing and health promoting activities;
- They experienced long waiting times for some essential services as well as gaps in availability of services;
- Cost was a major barrier, especially for those with multiple chronic health issues who needed to see many specialists who each focussed on a single condition;
- Some of them needed to travel interstate to access treatment from specialists; and
- They needed more integrated care that took into consideration multiple and co-existing chronic diseases.

The research found that:

- The top three conditions reported were mental health conditions, autoimmune conditions, and musculoskeletal disease, all of which are unlikely to be due to lifestyle factors.
- Seventy one percent of the younger women with chronic disease self-rated their health as fair, poor, or very poor.
- Sixty one percent of the respondents had more than one chronic disease.
- Those that had more than one disease rated their health as poorer than those with only one disease.
- There are a lack of supports and services in the ACT health system and in the community that understand and adapt to the needs of younger women with chronic diseases, including providing access at different opening hours, more integrated and affordable treatment options and easily navigated system.
- There is a risk to the continued employment of younger women, and thus a potential economic cost to the ACT, of not adapting responses to their different needs in the early years.
- The women bear a high cost for health care which impacts on their ability to afford the full range of treatments needed to keep them healthy.
- Women-led self-help groups are important to women managing chronic disease as well as life roles as mothers, partners, students and employees.

- The ACT health system response does not deal holistically and in an integrated way with the physical, social, and emotional needs of these women.
- There is a negative impact from the early onset of chronic disease symptoms and medication use on younger women's ability to successfully manage their health behaviours without support.

The findings of this report are consistent with the ACT's *Chronic Conditions Strategy 2013-2018,* which identifies the need for:

- "*the right care, in the right place, at the right time from the right team*";
- Supporting the management of daily life, including continuing in paid work;
- An integrated system, which does not focus on single disease treatment;
- Increasing community support for people with chronic diseases (including young people and adolescents), and the benefit from targeted self-management courses;
- People with chronic diseases to have all the information they need, and to know where and what services to access; and
- Acknowledging barriers to health care such as affordability, location, length of disease, vulnerable groups, complexity of disease and multi-morbidity.[14]

This research identified the need to support ACT organisations and services to understand how to cater for young women with chronic diseases, and the need to inform improvements in service delivery and in policy planning in relationship to the suitability and life-stage appropriateness. WCHM will advocate and work with ACT policy makers, health care professionals, the Capital Health Network, and community-based services to consider changes that improve services for younger women with chronic diseases.

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[14] ACT Health, *ACT chronic conditions strategy- improving care and support 2013-2018*, Canberra, 2013, retrieved on the 12th of January 2018; https://www.health.act.gov.au/sites/default/files//Policy_and_Plan/Chronic%20Conditions%20Strategy%202013%20-%202018.pdf

Recommendations

1. WCHM to work with ACT Health to inform their Territory-wide Services Framework to influence the way services are delivered for younger women so that they are age appropriate and life stage appropriate.
2. WCHM to work with ACT Health to identify the need for future investment in community-based options to reduce the need for acute hospital system care for younger women with chronic disease.
3. WCHM to provide input to the design of the ACT Office for Mental Health to ensure the needs of younger women with mental health issues associated with multiple chronic diseases are understood.
4. WCHM to work with the Capital Health Network about how they might respond to the results of the research and consider how they might support GPs to better support and understand the increase in chronic disease and their impacts on younger women aged 18-50 years.
5. WCHM to work with community-based health organisations so that they understand the need to adapt their services and supports for chronic disease so that younger women have access to age appropriate and life stage support.
6. WCHM to work with ACT Health to reinforce the importance of support for women led peer support groups for younger women with chronic disease.
7. WCHM to conduct further research on how local health promotion campaigns and responses for healthy eating and physical activity can take into account the barriers experienced by women with chronic diseases aged 18 to 50 years.

A note on the title

The title of this report – “*I don’t have the spoons for that…”* - comes from the the spoon theory of Christine Miserando, which is used to explain the sudden and unexpected loss of energy that is common in many people who have a chronic disease. [15]

The idea is that most people without chronic disease start the day with a seemingly unlimited amount of energy to do what they want, but people with chronic disease only have a limited supply of energy - ‘spoons’ - available each day, and each basic task or action uses a number of them. The harder the task, the more spoons are used. This requires a different approach to planning their time.

The phrase "running low on spoons" has been adopted as a useful way of communicating the need for rest to others. This analogy was used by some of the women involved in our research as a way of helping other people to understand the impact the invisible symptoms of their chronic disease had on their energy levels.

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[15] C *Miserandino, '"The Spoon Theory". But You Don't Look Sick', 2003, retrieved on the 10th of January 2018: https://butyoudontlooksick.com/articles/written-by-christine/the-spoon-theory/*

Terminology

Common concepts and terms that appear throughout this report are described briefly here.

Comorbidity: The presence of two or more diseases in a person at the same time.

Multi-morbidity: The coexistence of multiple chronic diseases and medical conditions in the same individual, which are often long-term and require complex and ongoing care.

Mental health conditions: These are conditions that can affect an individual’s mood, thinking and behaviour, including depression and anxiety.

Autoimmune disease: These are illnesses that occur when the body’s own immune system attacks healthy tissue by mistake. It can affect any place on the body and occurs predominantly in women. Common autoimmune diseases include rheumatoid arthritis, lupus, multiple sclerosis, Sjogren’s syndrome and ankylosing spondylitis.

Musculoskeletal conditions: These are conditions of the bones, muscles and connective tissues, and include various forms of arthritis, back pain and problems, osteoporosis and gout.

Endocrine disorders: These are disorders related to the endocrine system of the body which are the glands that produce and release hormones. They include Diabetes Type 1 and 2, Endometriosis, Addison's Disease, Cushing's Syndrome, Graves' Disease, and Hashimoto's Thyroiditis.

Gastrointestinal conditions: These are conditions involving the gastrointestinal tract (the oesophagus, stomach, small intestine, large intestine, liver, gallbladder, and pancreas. They include Celiac disease, Chrone’s disease and ulcerative colitis.

Neurological disorders: These are disorders of the brain, spine and the nerves that connect them. They include epilepsy, Alzheimer disease and other dementias, cerebrovascular, multiple sclerosis, and Parkinson's disease.

Respiratory diseases: these are diseases of the airways and the structures of the lung. They include chronic obstructive pulmonary disease (COPD), emphysema, and asthma.

Endometriosis: Endometriosis is a condition that affects a woman's reproductive organs, and occurs when cells similar to those that line the uterus are found in other parts of the body

Myalgic encephalomyelitis: Myalgic encephalomyelitis (ME) is commonly referred to as chronic fatigue syndrome (CFS). It is characterised by multiple symptoms including profound fatigue, and muscle and joint pain.

Cardiovascular disease: These are a group of conditions that affect the heart and blood system. They include coronary artery diseases, stroke and heart failure/cardiomyopathy.

Genetic disorders: These are disorders that are caused by an abnormality in an individual's DNA. They include cystic fibrosis; haemophilia; and muscular dystrophy.

Cancers: Cancer is a diverse group of several hundred diseases in which some of the body's cells become abnormal and begin to multiply out of control. There are many different types of cancer, and usually they are named for the organ or cell type of the primary cancer.

Chronic kidney and urinary disorders: Kidney and urinary tract disorders can involve one or both kidneys, one or both ureters, the bladder, or the urethra. Chronic kidney disease, also called chronic kidney failure, describes the gradual loss of kidney function.

Blood and metabolic disorders: Metabolic disorders occur when a defective gene causes an enzyme deficiency, or when the liver or pancreas do not function properly. Blood disorders include anaemia, bleeding disorders such as haemophilia, blood clots, and blood cancers such as leukemia, lymphoma, and myeloma.

Lipoedema: This is also known as Painful Fat Syndrome and it is a progressive condition that occurs mostly in women. The disease mainly affects the legs, although arms and other parts of the body can be affected.

Person Centred Care: A strategy to increase patient outcomes by ensuring that the patient is the director of their own care. It is about treating the person receiving the care in the way they want to be treated. ACT Health’s focus is “*the right care, in the right place, at the right time from the right team*” to encourage person centred care.[16]

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[16] ACT Health, *ACT chronic conditions strategy- improving care and support 2013-2018*, Canberra, 2013, retrieved on the 12th of January 2018; https://www.health.act.gov.au/sites/default/files//Policy_and_Plan/Chronic%20Conditions%20Strategy%202013%20-%202018.pdf

Introduction

In 2016, WCHM identified that there appeared to be an increase in the number of younger ACT women being diagnosed with autoimmune disease in the ACT. Anecdotally, WCHM was aware that this cohort of women experienced difficultly locating information, services, and supports which were relevant to their life stage and that services struggled to make and sustain contact with them.

Literature showed that women were more susceptible to developing autoimmune disease, particularly during childbearing years, and accounted for 75-80 percent of individuals diagnosed across all age groups. [17] [18] [19] These diseases are increasing in prevalence and have lasting and persistent effects on a person, not only physically and emotionally but on their overall quality of life, economic stability and future opportunities.[20]

A scoping study was conducted by WCHM to help identify whether there was evidence of the need for further social research into the issues raised by these women. The scoping study consisted of a series of focus groups with women living in the ACT aged 18 to 30 years who had autoimmune diseases. Focus groups were also held with service providers and advocacy groups. This enabled feedback from both groups to be voiced and identify if there was a need for further research. They identified that they had trouble accessing the type of care or support necessary for their condition. One of the issues frequently raised during the focus groups was that services and support were not age appropriate, in that they were not suitable for women who were younger than retirement age or had family caring responsibilities in addition to managing their own health.

It was determined that further research was needed to investigate the experiences of younger ACT women with chronic diseases, and whether there were age and gender appropriate responses suitable for their life roles.

The age group for younger women was expanded as many women aged 30 to 50 years also expressed interest in participating in research, as they also felt that services for women with chronic disease in the ACT were not suitable for women in their age group or life roles. They experienced similar issues because chronic diseases were seen as only impacting on older people and not those under 50.

A literature review confirmed that younger women with other chronic diseases, not just autoimmune diseases, also have barriers to accessing services, supports, courses and information. It also indicated there may be gaps in knowledge about younger women with chronic diseases.

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[17] Office on Women's Health in the Office of the Assistant Secretary for Health 2012, 'Autoimmune diseases fact sheet', *U.S. Department of Health and Human Services* website, retrieved on the 10th of January 2018: https://www.womenshealth.gov/a-z-topics/autoimmune-diseases.

[18] S Amur, A Parekh, & P Mummaneni, 'Sex differences and genomics in autoimmune diseases'*, Journal of Autoimmunity*, vol. 38, issue. 2-3, 2012,pp. J254-J265.

[19] S Kivity, & M Enthrenfeld, 'Can we explain the higher prevalence of autoimmune disease in women?', *Expert Review of Clinical Immunology*, vol. 6, no. 5, 2010, pp. 691-694.

[20] A Lerner, Jeremias P, & Matthias T, 'The World Incidence and Prevalence of Autoimmune Diseases is Increasing', *International Journal of Celiac Disease*, vol. 3, no. 4, 2015, pp. 151.

The study also identified the need to support ACT organisations and services to understand how to cater for younger women with autoimmune diseases, and ways to inform improvements in service delivery and in policy planning in relationship to the suitability and life-stage appropriateness for this group.

A decision was made early in the research that the definition of chronic diseases to be used is the Australian Institute of Health and Welfare definition. The Australian Institute of Health and Welfare describes chronic disease as lasting for six months or more.

> *'Chronic disease applies to a group of diseases that tend to be long-lasting and have persistent effects. Chronic diseases have a range of potential impacts on a person's individual circumstances, including quality of life and broader social and economic effects. Chronic diseases also have a significant impact on the health sector.'*[21]

This definition of chronic disease encompasses both physical and mental health which are different, but each can be debilitating.

WCHM set out to explore:

- Younger women's knowledge and experiences of ACT government and non-government programs, courses and services available to provide information and support to those with chronic disease;
- Which information, services and support were relevant to younger women living with chronic disease – including their suitability and the age-appropriateness for younger women with chronic diseases; and
- The gaps and barriers that might exist and ideas to facilitate and improve younger women's access to and involvement in responses that assist them to manage their condition in their life stage.

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[21] Australian Institute of Health and Welfare, 'Chronic disease definition of chronic diseases', Canberra 2017, retrieved on the 26th of September 2017 https://www.aihw.gov.au/reports-statistics/health-conditions-disability-deaths/chronic-disease/about

Literature review

Introduction

A literature review was undertaken to better understand existing knowledge of the impact of chronic disease on younger women aged 18 to 50 years, and it's effect on their access to services, supports and information.

Chronic disease

Chronic diseases are the leading cause of illness, disability and death in Australia.[22] It has been estimated that at least half of Australians have a chronic disease, and 20-30% have more than one chronic disease.[23] [24] [25] There is no current published data on the number of women in the ACT who have a chronic disease. Nevertheless, we do know that one in five women in the ACT have a disability.[26]

There is a National Strategic Framework for Chronic Conditions (2017–2025) which is the overarching policy document that provides guidance to States and Territories for the development and implementation of policies, strategies, actions and services to reduce the impact of chronic conditions in Australia. The Framework recognises that:

- "Chronic conditions are occurring earlier in life and Australians may live for longer with complex care needs.
- This means individuals require more services from a range of providers across the health system over extended periods of time.
- Change must occur to deliver a sustainable health system that responds more effectively to chronic conditions."[27]

The ACT's *Chronic Conditions Strategy 2013-2018* aims to improve care and support for people with chronic disease in the ACT.[28] The strategy encourages a person-centred approach, which means that patients should receive "*the right care, in the right place, at the right time from the right team*". It focuses on the need for the person's involvement in the care process, and advocates for the use of a care plan to manage complex cases. The strategy encourages management of daily life, including continuing in paid work. It aims for an integrated system, steering clear of single disease treatment. It suggests increasing community support for people with chronic diseases, and identifies young people, adolescents, and new parents as groups that may benefit from

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[22] Australian Institute of Health and Welfare, *Australia's health in brief 2016*, Canberra, 2016, retrieved on 1st of November 2017: https://www.aihw.gov.au/getmedia/7752644b-e6f0-4793-b4e0-74ef3093c589/19748-ah16-ib.pdf.aspx?inline=true

[23] Australian Institute of Health and Welfare, *1 in 5 Australians affected by multiple chronic diseases*, Canberra, 2015, retrieved on 6th of July 2017: http://www.aihw.gov.au/media-release-detail/?id=60129552034

[24] C Harrison et al., 'The prevalence of complex comorbidity in Australia', *Australian and New Zealand Journal of Public Health*, vol. 40, no. 3, 2016, pp. 239-244.

[25] C Harrison et al., 'The prevalence of diagnosed chronic conditions and multimorbidity in Australia: A method for estimating population prevalence from general practice patient encounter data' *PLoS ONE*, vol. 12, no. 3, 2017, pp. 1-13.

[26] The Legislative Assembly for the Australian Capital Territory, *The ACT Women's Plan 2016-26*, 2016, pp. 4. (ABS *National Health Survey 2004-05)*

[27] Australian Health Ministers' Advisory Council, *National Strategic Framework for Chronic Conditions*, Australian Government, Canberra, 2017.

[28] ACT Health, *ACT chronic conditions strategy- improving care and support 2013-2018*, Canberra, 2013, retrieved on the 12th of January 2018; https://www.health.act.gov.au/sites/default/files//Policy_and_Plan/Chronic%20Conditions%20Strategy%202013%20-%202018.pdf.

targeted self-management courses. The strategy discusses the need to ensure that people with chronic diseases have all the information they need, and to know where and what services to access.[29] It aims to have patients treated as a person and not just as a single disease, while acknowledging barriers to health care such as affordability, location, length of disease, vulnerable groups, complexity of disease and multi-morbidity. [30]

Multi-morbidity

In Australia and other western countries multi-morbidity is becoming the "rule rather than the exception".[31] [32] Those with multi-morbidity have less access to health services and experience poorer quality care, have higher health care costs and have poorer quality of life than those with one, or without, chronic disease.[33] [34] [35] [36] Although numerous studies have researched multi-morbidity in Australia and overseas, none address the gender differences between Australian women and men, let alone younger women, that we are aware of. In a nationwide study in Scotland about gender and age differences in multi-morbidity, the researchers found that women, were more likely to be living with multi-morbidity, and more likely to have a combination of mental and physical health chronic conditions.[37] Turner et al. hypothesised that people dealing with a chronic disease often also suffer from mental health conditions because the emotional impact from loss of self can lead to depression.[38] Findings from a large Australian study, in which most of the participants were female, reported that depressive symptoms were more likely to be present in persons with multiple chronic conditions. Those with physical limitations or poor self-rated health were more prone to depressive symptoms.[39]

Self-rated physical health has been researched extensively and has been found to be a predictor for mortality, morbidity, and increased health service utilisation.[40] [41] [42] [43] However, few studies specifically explore women and self-rated health, and even fewer focus on younger Australian women with chronic disease. An older longitudinal study that looked at Australian women of all

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[29] ACT Health, *ACT chronic conditions strategy- improving care and support 2013-2018*, Canberra, 2013, retrieved on the 12th of January 2018; https://www.health.act.gov.au/sites/default/files//Policy_and_Plan/Chronic%20Conditions%20Strategy%202013%20-%202018.pdf.

[30] Ibid.

[31] M Fortin et al., 'Prevalence of multimorbidity among adults seen in family practice', *Annals of Family Medicine,* vol. 3, 2013, pp. 223-228.

[32] C Harrison et al., 'The prevalence of diagnosed chronic conditions and multimorbidity in Australia: A method for estimating population prevalence from general practice patient encounter data' *PLoS ONE*, vol. 12, no. 3, pp. 1-13.

[33] M Fortin et al., 'Multimorbidity and quality of life in primary care: a systematic review', *Health and Quality of Life Outcomes*, vol. 2, no.51, 2004, pp.1-12.

[34] J Marlowe, M Maeyer & J Greer, 'Complex chronic illness: an essential target in health cost management', *World at Work Journal*, Third Quarter 2009, pp. 47-56.

[35] L M Hunt, M Kreiner & H Brody, 'The changing face of chronic illness management in primary care: a qualitative study of underlying influences and unintended outcomes', *Annals of Family Medicine*, vol. 10, no. 5, 2012, pp. 552-560.

[36] Y Jeon et al., 'Economic hardship associated with managing chronic illness: a qualitative inquiry', *BMC Health Services Research*, 2009, vol. 9, no. 182, pp. 1-11.

[37] K Agur et al., 'How does sex influence multimorbidity? Secondary analysis of large nationally representative dataset', *International Journal of Environmental Research and Public Health*, vol. 13, 2016, pp.1-13.

[38] J Turner, 'Emotional dimensions of chronic disease', *Western Journal of Medicine*, vol. 172, 2000, pp. 128-130.

[39] J M Gunn et al., 'The association between chronic illness, multimorbidity and depressive symptoms in an Australian primary care cohort', *Social Psychiatry and Psychiatric Epidemiology*, vol. 47, no. 2, 2012, pp. 175-84.

[40] M Jylha, 'What is self-rated health and why does it predict mortality? Towards a unified conceptual model', *Social Science and Medicine*, no.69, 2009, pp. 307-316.

[41] M Bopp, J Braun, F Gutzwiller & D Faeh, 'Health risk or resource? Gradual and independent association between self-rated health and mortality persists over 30 years', *PLoS One*, vol. 7, issue 2, 2012, pp. 1-10.

[42] J Sundquist & S Johansson, 'Self-reported poor health and low educational level predictors for mortality: a population based follow up study of 39 156 people in Sweden', *Journal of Epidemiology and Community Health*, vol. 51, 1997, pp.35-40.

[43] P M Smith, R H Glazier & L M Sibley, 'The predictors of self-rated health and the relationship between self-rated health and health service needs are similar across socioeconomic groups in Canada', *Journal of Clinical Epidemiology*, vol. 63, 2010, pp. 412-421.

ages observed change in self-rated health over time. Those with chronic diseases of more than four years in duration, who had changed their self-rating of health, were likely to rate their health as declining.[44] A more recent Australian non-gendered study that looked at 7,620 survey results from participants contacted through general practitioners found correlations between poor self-rated health and depressive symptoms.[45]

It is important that Australian governments address multi-morbidity when developing public health policy.[46] Recently, ACT Health released a draft health services framework for the ACT, which does not appear to address multi-morbidity.[47] Numerous studies have found that people with multi-morbidity have poor access to health care because primary health care is siloed into single diseases.[48] [49] Although there have been numerous studies on the impact of multi-morbidity, none have put forward a solution.[50] Walker stresses that to address the problem, there is a need for consultation with people that have multi-morbidity, as was done in her study.[51] Recommendations from that study included changing single disease guidelines to guidelines that address the complexity of disease interactions and multiple medication interactions.[52]

Chronic disease in younger women

Chronic disease does not only occur in older people. Increasingly younger women are also being diagnosed with long-term conditions. Diseases such as chronic fatigue syndrome, fibromyalgia, endometriosis, and autoimmune diseases occur far more in women than men with onset in younger adulthood.[53] [54] [55] [56] Women also experience more mental health conditions such as anxiety and depression, than men, which can have severe psycho-social impacts and affects their ability to live disability free.[57] [58] These diseases, physical and mental, are often hidden from view, where the patient may look well but in fact is not,[59] and often leads to failure to correctly diagnose, or poor recognition from the medical community.[60]

Women need to work hard to be a credible patient.[61] Werner and Malterud reported that women often are misdiagnosed, rejected, and ignored by healthcare professionals. The study reported

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[44] B Shadbolt, 'Some correlated of self-rated health for Australian Women', *American Journal of Public Health*, vol. 87, 1997, pp. 951-956.

[45] L Mewton & G Andrews, 'Poor self-rated health and its associations with somatisation in two Australian national surveys.' *BMJ Open*, vol. 3, 2013, pp. 1-8.

[46] C Walker, 'Multiple conditions: exploring literature from the consumer perspective in Australia', *Health Expectations*, vol. 18, 2012, pp.166–176.

[47] Health, 'Draft ACT Health territory-wide health services framework, 2017-2027', Canberra 2017, retrieved on the 16th of October 2017: https://www.health.act.gov.au/sites/default/files//Territory%20Wide%20Health%20Services%20Framework%20%28TWHSF%29-18Sept17-with%20draft.pdf

[48] D Mangin, I Heath & M Jamoulle, 'Beyond diagnosis: rising to the multimorbidity challenge' *BMJ,* vol. 344, 2012, pp.1-3.

[49] C Harrison, J Henderson, G Miller & H Britt, 'The prevalence of complex multimorbidity in Australia', Australian and New Zealand Journal of Public Health, vol. 40, no. 3, 2016, pp. 239-244.

[50] C Walker, 'Multiple conditions: exploring literature from the consumer perspective in Australia', *Health Expectations*, vol. 18, 2012, pp.166–176.

[51] Ibid.

[52] Ibid.

[53] L A Jason, 'A community-based study of chronic fatigue syndrome', *Archives of internal medicine*, vol. 159, 1999, pp. 2129-2137.

[54] H E Grape, 'Staying healthy from fibromyalgia is ongoing hard work', *Qualitative Health Research*, vol. 25, no. 5, 2015, pp. 679-688.

[55] M Moradi et al., 'Impact of endometriosis on women's lives: a qualitative study', *BMC Women's health*, vol. 14, no. 123, 2014, pp. 1-12.

[56] M J Harrison, 'Perspective on the impact and management of rheumatoid arthritis', *Arthritis and Rheumatism (Arthritis Care & Research)*, vol. 49, no. 6, 2003, pp. 846-852.

[57] Australian Bureau of Statistics, *National survey of mental health and wellbeing: summary of results*, Canberra, 2007, retrieved on the 13th of February 2018; http://www.ausstats.abs.gov.au/Ausstats/subscriber.nsf/0/6AE6DA447F985FC2CA2574EA00122BD6/$File/43260_2007.pdf

[58] Australian Institute of Health and Welfare, *Australian burden of disease study, Impact and causes of illness and death in Australia*, Canberra, 2011.

[59] S Stone, 'Must disability always be visible?, the meaning of disability for women', *Canadian Women Studies*, vol.13, no. 4, 1993, pp. 11-13.

[60] R Epstein et al., 'Physicians' responses to patients' medically unexplained symptoms' *Psychosomatic Medicine*, vol. 68, 2006, pp. 269 –276.

[61] A Werner & K Malterud, 'It is hard work behaving as a credible patient: encounters between women with chronic pain and their doctors', *Social Science & Medicine*, vol. 57, 2003, pp. 1409–1419.

situations where women were told they looked too young and healthy to have a chronic disease.[62] In the ACT, Moradi et al., found that an average of eight years (minimum three months, maximum 24 years) was taken to diagnose women who had endometriosis.[63] The group from the study were not listened to and told that their symptoms were “normal and not serious”.[64] Delayed diagnosis is one of the main reasons for dissatisfaction with health services.[65]

The effects of wait times on younger women with chronic diseases has yet to be studied in sufficient detail. However, amongst cohorts of mixed genders, prolonged wait times for patients who are in significant pain negatively affects their quality of life.[66] Hogg et al. discusses the importance of pain management clinics in Australia, but increasing demand and quality has meant that wait times are long.[67] A Canadian study found that for those in pain, waiting for longer than six months is “medically inappropriate”, as deterioration may occur within as little as five weeks from the onset of pain. [68]

People with chronic disease often have to spend a large amount of time on self-care mechanisms such as glucose monitoring, preparing medications, or attending appointments, and therefore time is scarce in their lives.[69] A qualitative study by Grape found that women who had fibromyalgia, but were in remission, required large amounts of effort and time to maintain health and wellbeing.[70] This is in addition to parenting and domestic duties, left little time for leisure activities, which negatively affected their health.[71] [72]

Wolkom, Loxton and Robertson found that women in Australia accessing health care struggled with costs. Participants discussed the ongoing cost of medications, GP visits, and complementary medicines as the most difficult. Women in their study mentioned that the number of medications they needed to take for their conditions and poor access to bulk billing compounded the costs.[73] Bulk billing in the ACT is the lowest in Australia, only 60.1% of GP visits are bulk billed compared to the national average 85.%.[74] Low rates of bulk billing are very likely to impact affordability of health care.[75] In a study on both genders, people with chronic diseases experienced hardship with ongoing health care, regularly skipping medications or accessing health care due to affordability.[76]

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[62] A Werner & K Malterud, ‘It is hard work behaving as a credible patient: encounters between women with chronic pain and their doctors’, *Social Science & Medicine*, vol. 57, 2003, pp. 1409–1419.

[63] M Moradi et al., ‘Impact of endometriosis on women’s lives: a qualitative study’, *BMC Women’s health*, vol. 14, no. 123, 2014, pp. 1-12.

[64] Ibid.

[65] A Andén, S Andersson & C Rudebeck, ‘Satisfaction is not all – patients' perceptions of outcome of general practice consultations, a qualitative study’, *BMC Family Practice,* vol. 6, no. 43, 2005, pp. 1-8.

[66] M E Lynch et al., ‘A systematic review of the effect of waiting for treatment for chronic pain’, Pain, vol. 136, issues 1-2, 2008, pp. 97-116.

[67] M N Hogg et al., ‘Waiting in pain: a systematic investigation into the provision of persistent pain services in Australia’, *Medical Journal of Australia*, vol. 196, no. 6, 2012, pp. 386–390.

[68] M E Lynch et al., ‘A systematic review of the effect of waiting for treatment for chronic pain’, Pain, vol. 136, issues 1-2, 2008, pp. 97-116.

[69] T Jowsey, L Yen & P Mathews, ‘Time spent on health related activities associated with chronic illness: a scoping literature review’, *BMC Public Health*, vol. 12, no. 1044, 2012, pp. 1-11.

[70] H E Grape, ‘Staying healthy from fibromyalgia is ongoing hard work’, Qualitative Health Research, vol. 25, no. 5, 2015, pp. 679-688.

[71] S P Fullagar & P R Brown, ‘Everyday temporalities: leisure, ethics and young women's emotional Wellbeing’, *Annals of Leisure Research*, vol. 6, no. 3, 2003, pp. 193-208.

[72] S Cartwright & P Warner-Smith, ‘‘Melt down’: young women’s talk of time and its implications for health, wellbeing and identity in late modernity’, *Annals of Leisure Research*, vol. 6, no. 4, 2003, pp. 319-338.

[73] E J Wolkom, D Loxton & J Robertson, ‘Cost of medicines and health care; A concern for Australian Women across the ages’, *BMC Health Services Research*, vol. 13, no. 484, 2013, pp. 1-9.

74 Australian Institute of Health and Welfare, My healthy communities; Web update: Medicare Benefits Schedule GP and specialist attendances and expenditure in 2015–16, Canberra, 2017, retrieved on the 15th of February 2018; http://www.myhealthycommunities.gov.au/our-reports/gp-and-specialists-attendances-and-expenditure/august-2017/web-update

[75] E J Wolkom, D Loxton & J Robertson, ‘Cost of medicines and health care; A concern for Australian Women across the ages’, *BMC Health Services Research*, vol. 13, no. 484, 2013, pp. 1-9.

[76] E J Callander, L Corscadden & J Levesque, ‘Out-of-pocket healthcare expenditure and chronic disease – do Australians forgo care because of the cost?’ *Australian Journal of Primary Health*, vol. 23, no. 1, 2017, pp. 15-22.

Jan, Essue & Leeder reported that there is an ongoing cycle of chronic disease and economic hardship whereby “poor health leads to poverty, which then leads to poor health.”[77] More-so with multi-morbidity, where each additional chronic disease may increase the likelihood of financial difficulties by 46%.[78]

Yeon et al. found people with chronic disease come across economic hardship both when receiving financial support from the government and when ineligible for subsidies. Economic hardship, Yeon et al. explains, occurs because money earned, or financial support were “insufficient to meet the costs of managing long-term illness over and above necessary daily living expenses,” furthermore it greatly reduced patient’s capacity to practice self-care techniques that may reduce potential further disease.[79]

In addition, location of health services can affect physical accessibility to services.[80]

Life roles

Chronic disease impacts everyday life. Mendelson revealed how women with lupus deal with their condition every day in a study that documented the women’s journey with the disease and their daily struggle of small tasks that require adaption and perseverance.[81] The women in that study expressed difficulty trying to fulfil their role as a mother or partner and reduced their ability to spend quality time with their family. [82] In a study by Moradi et al., women with endometriosis suffered with maintaining relationships and struggled with a sense of self. It was also demonstrated that the disease impacted on women’s education and financial situation.[83]

It is known that women generally have lower workforce participation rates, with a high number of women working in lower paying and insecure employment.[84] A study conducted in Melbourne examining data from the *Household Income and Labour Dynamics in Australia* (HILDA) survey found that women with chronic disease were far more disadvantaged than men with chronic disease.[85] Women were more likely to be employed in casual work without leave entitlements, and were not working the hours that they wanted because of their condition.[86]

The Australian Institute of Health and Welfare (AIHW) reported on workplace participation for people with chronic disease. They found that up to 60% of people with chronic disease were not participating in the workforce due to their illness.[87] Issues such as absenteeism, reduction in

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[77] S Jan, B M Essue & S R Leeder, ‘Falling through the cracks: the hidden economic burden of chronic illness and disability on Australian households’, The Medical Journal of Australia, vol. 196, no. 1, pp. 29-31.

[78] S Jan, B M Essue & S R Leeder, ‘Falling through the cracks: the hidden economic burden of chronic illness and disability on Australian households’, The Medical Journal of Australia, vol. 196, no. 1, pp. 29-31.

[79] E J Callander, L Corscadden & J Levesque, ‘Out-of-pocket healthcare expenditure and chronic disease – do Australians forgo care because of the cost?’ *Australian Journal of Primary Health*, vol. 23, no. 1, 2017, pp. 15-22.

[80] A Dobson et al., ‘Rural, remote and regional differences in women’s health: Findings from the Australian Longitudinal study on women’s health’, Newcastle, 2011.

[81] C Mendelson, ‘Managing a medically and socially complex life: women living with lupus’, *Qualitative Health Research*, vol. 16, no. 7, 2006, pp. 982-997.

[82] Ibid.

[83] M Moradi et al., ‘Impact of endometriosis on women’s lives: a qualitative study’, *BMC Women’s Health*, vol. 14, no. 123, 2014, pp. 1-12.

[84] M Baird, R Cooper & D Oliver, Down and Out with Work Choices: The Impact of Work Choices on the Work and Lives of Women in Low Paid Employment, The University of Sydney, Faculty of Economics and Business, 2007.

[85] S Werth, Women, work and chronic illness: an exploratory investigation of themes form HILDA, Griffith University, Queensland, 2010.

[86] Ibid.

[87] Australian Institute of Health and Welfare, *Chronic disease and participation in work*, Australian Government, Canberra, 2009.

hours, leaving the workforce, and discrimination often occur in relation to people with chronic disease.[88] [89] A report by Arthritis Australia reported that people with arthritis experience and fear discrimination in the workforce where they often find it difficult to ask for additional supports or modifications to equipment.[90] In a national study, people with mental health conditions also talked about their workplaces being “mentally unhealthy” as they experienced discrimination. The study identified that 50% of workplaces in the ACT/NSW were not “mentally healthy”.[91] Mental health conditions affect women’s ability to maintain employment, leading to many unemployed women that have had a mental health conditions which had affected them within the last 12months.[92]

Impacts on self-care activities

Currently in the ACT, health promotion is targeted towards the prevention and treatment of non-communicable disease that are preventable through lifestyle change.[93] However, this type of messaging is not effective for diseases that are not influenced by lifestyle change.[94] Diseases that have genetic, autoimmune or unknown cause can be impacted by self-care activities but need to be disease specific and highly individualised, therefore the current health promotion campaigns are likely to be unsuitable.[95]

Self-care activities such as physical activity, healthy eating and weight management are likely to be helpful in the management of chronic disease. However, even women in the general population report barriers to self-care activities such as life role transitions[96] and time constraints.[97] Furthermore, women with chronic disease are likely to experience similar barriers to undertaking self-care activities but at a greater degree due to the presence of chronic disease.[98] [99]

Another form of self-care is associating with people that share your experience. Peer-support groups have a positive role to play in chronic disease management.[100] Peer-support groups provide emotional and social support and helps attendees increase their confidence.[101] They can provide a platform for learning about and managing their illness and helps them become more active in engaging in self-management of their conditions.[102] Previous local research by WCHM has shown the benefit of peer-support groups for women. Women who had a mental health

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[88] Australian Institute of Health and Welfare, *Chronic disease and participation in work*, Australian Government, Canberra, 2009.

[89] Arthritis Australia, Submission on the Government’s consultation paper on Disability and Employment, Sydney, 2013.

[90] Ibid.

[91] TNS and Beyond Blue, State of Workplace Mental Health in Australia, Sydney, 2004.

[92] Australian Bureau of Statistics, *National survey of mental health and wellbeing: summary of results*, Canberra, 2007, retrieved on the 13th of February 2018; http://www.ausstats.abs.gov.au/Ausstats/subscriber.nsf/0/6AE6DA447F985FC2CA2574EA00122BD6/$File/43260_2007.pdf

[93] ACT Health, *Population Health Strategic Framework 2013-2017*, Canberra, 2013, retrieved on 1st of November 2017: https://www.health.act.gov.au/sites/default/files//Population%20Health%20Strategic%20Framework.pdf

[94] C Walker, ‘Multiple conditions: exploring literature from the consumer perspective in Australia’, *Health Expectations*, vol. 18, 2012, pp.166–176.

[95] Ibid.

[96] W J Brown & S G Trost, ‘Life transitions and changing physical activity patterns in young women’, *American Journal of Preventive Medicine*, vol. 25, no. 2, 2003, pp. 140-143.

[97] S Cartwright & P Warner-Smith, ‘‘Melt down’: Young women’s talk of time and its implications for health, wellbeing and identity in late modernity’, *Annals of Leisure Research*, vol. 6, no. 4, 2003, pp. 319-338.

[98] S Wilcox et al., ‘Perceived exercise barriers, enablers, and benefits among exercising and non-exercising adults with arthritis: results from a qualitative study’, *Arthritis & Rheumatism (Arthritis Care & Research),* vol. 55, no. 4, 2006, pp. 616–627.

[99] H E Grape, ‘Staying healthy from fibromyalgia is ongoing hard work’, *Qualitative Health Research*, vol. 25, no. 5, 2015, pp. 679-688.

[100] K Coppa & F M Boyle, ‘The role of self-help groups in chronic illness management: A qualitative study,’ *Australian Journal of Primary Health*, vol. 9, 2003, pp. 68–74.

[101] Ibid.

[102] Ibid.

condition were observed show improvements in mental wellbeing, and the peer-support groups also helped to reduce stigma and increased social connectedness.[103]

Conclusion

The literature and research presented indicates that younger women with chronic disease are likely to have barriers to accessing services, supports, courses and information. It also indicates that there are gaps in knowledge about the needs of younger women living in the ACT who experience chronic disease and in the local understanding of and responses to how they live their lives with a chronic disease.

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[103] L Pound, K Judd & J Gough, *Peer support for women living with mental health issues. The views of ACT women,* Women's Centre for Health Matters, Canberra, 2011, retrieved on the 9th of February 2018; http://www.wchm.org.au/wp-content/uploads/2015/02/Peer-support-for-women-with-mental-health-issues-The-views-of-ACT-women.pdf

Methodology

Findings from a scoping study carried out in 2016 by the WCHM found that there was a need to investigate the experiences of younger women with chronic disease accessing services, supports, information and courses in the ACT. WCHM used a mixed methodology by developing and implementing a survey and conducting two focus groups in early 2017. The aims of the survey were to collect quantitative and qualitative data from women in the ACT, and to recruit them to share their stories in a focus group setting. The aim of the focus groups was to explore in more detail the findings of the survey.

The survey was open for 24 days. There were 263 responses from women in the Canberra region, however only 161 responses were complete.

The online survey, developed in Survey Monkey, was distributed through WCHM's networks and through those of other community organisations, service providers, and Community Development Network. Advertisements were placed on the WCHM website, Facebook, and on RiotACT.[104] Although the survey was available in paper format in a few medical centres, no paper copies were completed. Flyers advertising the survey were given to a variety of GP clinics and pharmacies to increase awareness.

The survey contained two initial qualifying questions that required an answer of yes to continue:

1. Are you a woman who lives or works in the Australian Capital Territory (ACT) or surrounding area?
2. Do you have a chronic disease? (any ailment, mental or physical, that has persisted more than six months with an associated functional impairment or disability).

Responses to the survey that did not have the questions on self-rating mental and physical health and the demographic questions completed, were not included for final analysis.

The online survey provided all participants with information about the project and an indication that, by completing and submitting the form, they were consenting to their information being stored and used for the purposes of this research.

The online survey was also used to directly recruit participants for the focus groups. The final question asked women to indicate if they would like to participate, and if so to provide contact details. Eighty-five women expressed interest in participating in the focus group. Two focus groups were held, one in business hours and one outside business hours, to provide women with multiple participation options. Eighteen women in total attended the focus groups, and one woman was interviewed individually via skype as she was unable to attend the focus group due to her chronic disease. The focus group questions were developed to further inform the survey results as well as to explore areas that WCHM wanted to understand in more depth.

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[104] E Davidson, 'You're too young to have that', RiotACT, retrieved on the 11th of October 2017: https://the-riotact.com/youre-too-young-to-have-that/204225

Analysis of qualitative, open ended questions was coded and analysed using the qualitative data program NVivo11. Quantitative data was analysed using Microsoft Excel. Themes were built around the questions, and a literature review helped identify paradigms. The literature review involved searching a wide range of search engines, university databases and relevant published papers. Searches included broad terms such as ‘chronic disease’, ‘women’s experiences’, ‘younger women’, ‘services’, and more specific terms such as ‘barriers to health’, ‘self-reported health’, ‘co-morbidity’ and ‘multi-morbidity’.

As with all surveys conducted to date by WCHM, we used a non-probability convenience sample. This means that the survey was widely promoted and all women who met the qualifying criteria were welcome to participate. As a result, the number of women in our sample does not reflect the population of women in the ACT as a whole and is therefore not representative. Rather, the findings in this report provide an indication of the issues that exist for younger women in the ACT, as well as recommendations for actions that could be taken to address these.

Findings

Demographics of respondents

We received 161 completed responses for the survey and 18 participants attended the focus groups. There is currently no publicly available gender and age-disaggregated chronic disease data for the ACT, so we are unable to compare to the total ACT population of younger women with chronic disease. Table 1 shows the participants of each age bracket of women between 18-50 years old.

Age	Number	Percentage
18-24 years old	27	17%
25-34 years old	55	34%
35-44 years old	50	31%
45-50 years old	29	18%

Table 1: Age of surveyed women.

As seen in Table 2, 85% of the survey respondents (n=137) had a qualification at diploma level or above.

Highest education level	Number	Percentage
Year 10	6	4%
Year 12	18	11%
Certificate / Diploma	35	22%
University qualified	102	63%

Table 2: Highest level of education obtained by participants.

Figure 1 shows the high proportion of university qualifications for the respondents.

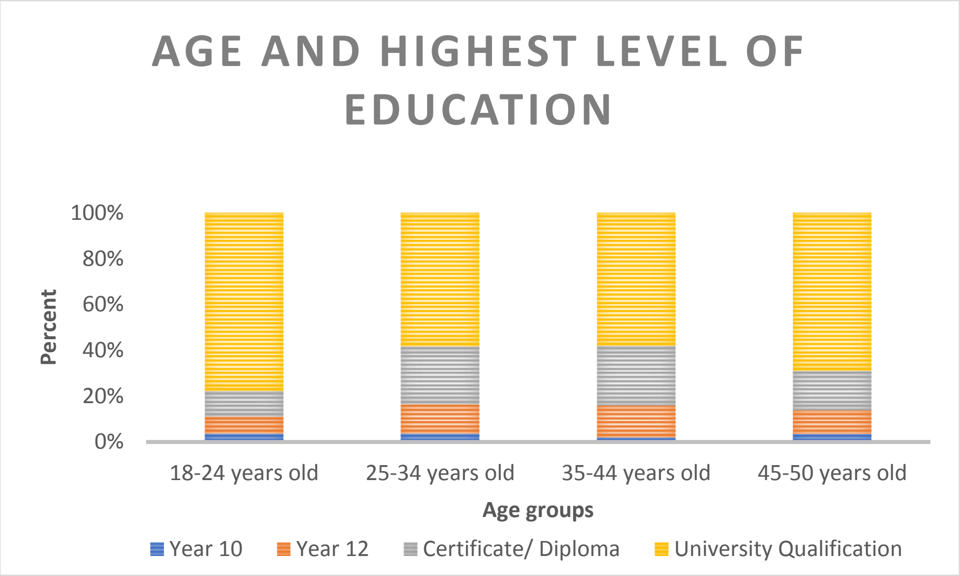

Figure 1: Age groups and highest level of education

As shown in Figure 2, the women who responded had a similar income to the population of women in the ACT of the same age group.[105]

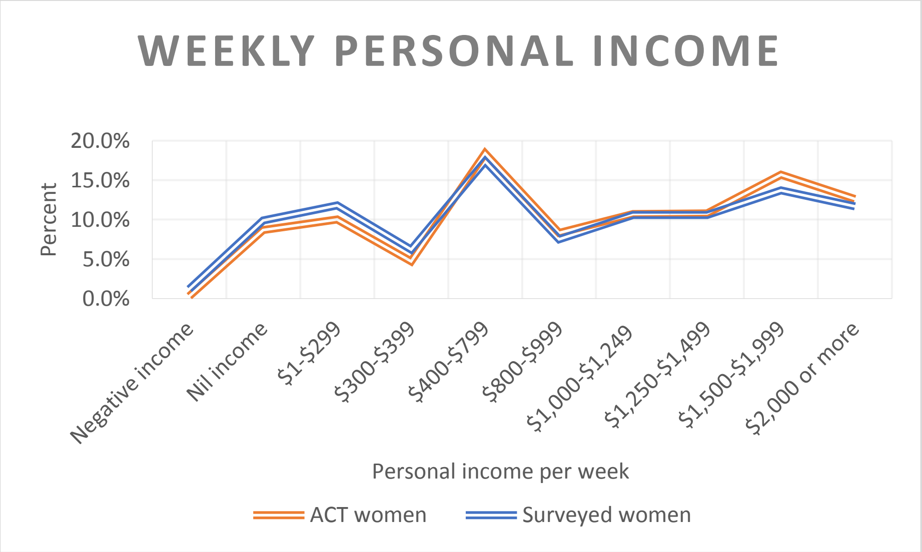

Figure 2: Gross weekly income of younger women with chronic disease compared to women of the same age in the ACT.

Survey respondents lived across the entirety of the ACT. Twenty three percent of women lived in Belconnen (n=37) and Tuggeranong (n=37), 21% lived in Central Canberra (n=34), 13% of survey respondents lived in Gungahlin (n=20) and Weston/ Woden area (13%, n=21). Seven percent (n=11) lived in Queanbeyan or NSW. This compared to data from the 2016 Census of Population

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[105] Australian Bureau of Statistics 2017, *Census of Population and Housing 2016*, TableBuilder. Findings based on use of ABS TableBuilder data.

and Housing, in which 24% of the women in the ACT in the relevant age groups lived in Belconnen, 19% in the Tuggeranong area, 22% in Central Canberra, 20% in Gungahlin, and 13% lived in Weston/ Woden area.[106]

Only one woman identified as of Aboriginal or Torres Strait Islander background and 17 participants were from culturally and linguistically backgrounds.

Self-rated physical and mental health

Survey respondents were asked to rate their physical and mental health. As presented in Figure 3, 77% of the women rated their physical health as fair to poor (n=124) and 4% as very poor (n=6). No participants identified themselves as having excellent physical self-rated health.

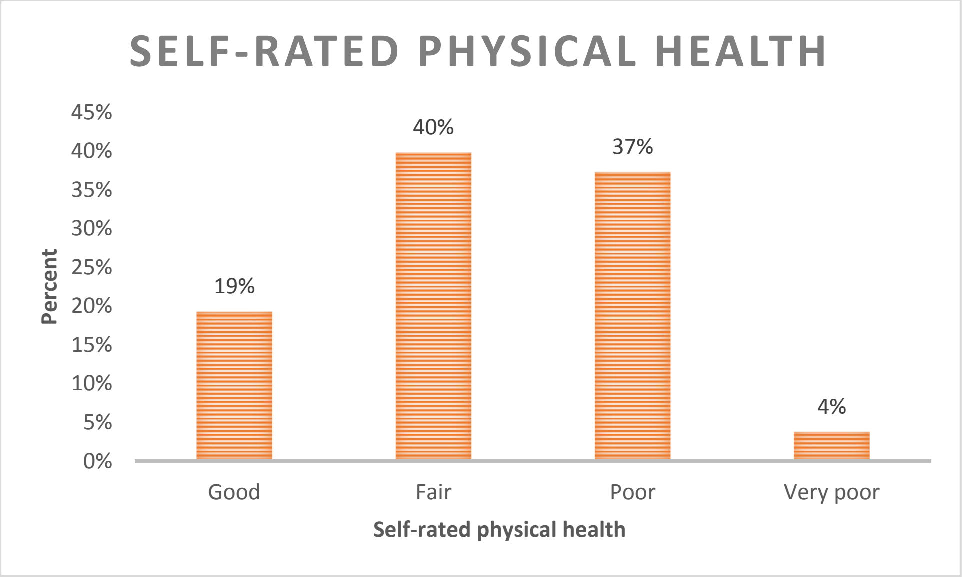

Figure 3: Percentage of respondents self-rated physical health.

As can be seen in Figure 4, 65% of respondents rated their mental health as fair to poor (n=105) and 6% as very poor (n=10).

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[106] Australian Bureau of Statistics, *Census of population: Age by sex by area – Australian Capital Territory*, 2017, retrieved on the 30th of July 2017: http://www.abs.gov.au/census

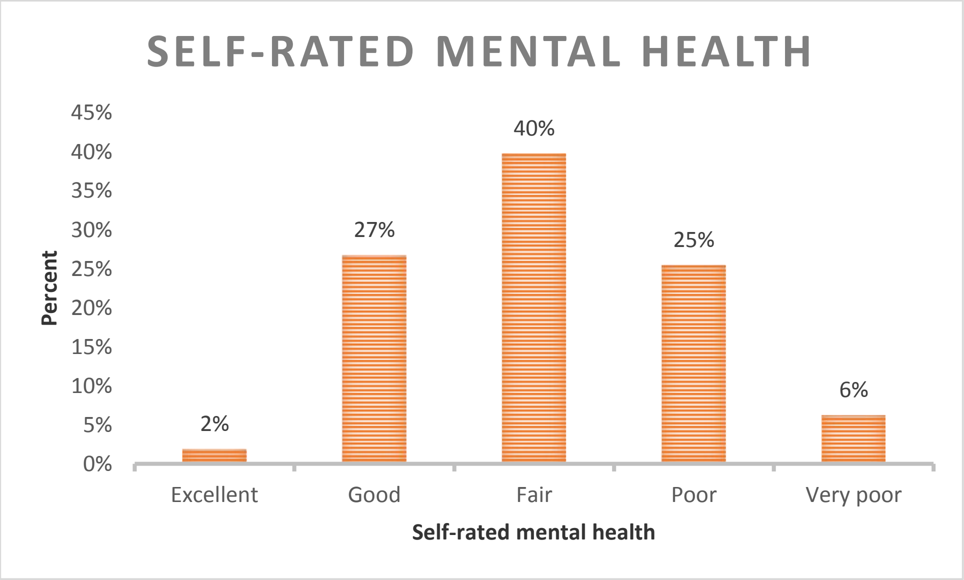

Figure 4: Percentage of respondents self-rated mental health.

Figure 5 demonstrates that women in the 45-50 years age group reported better physical health than any other age (good self-rated physical health, 55%, n=16). Compared to younger age groups, they also self-rated lower levels of fair (24%, n=7) and poor (17%, n=5) physical health.

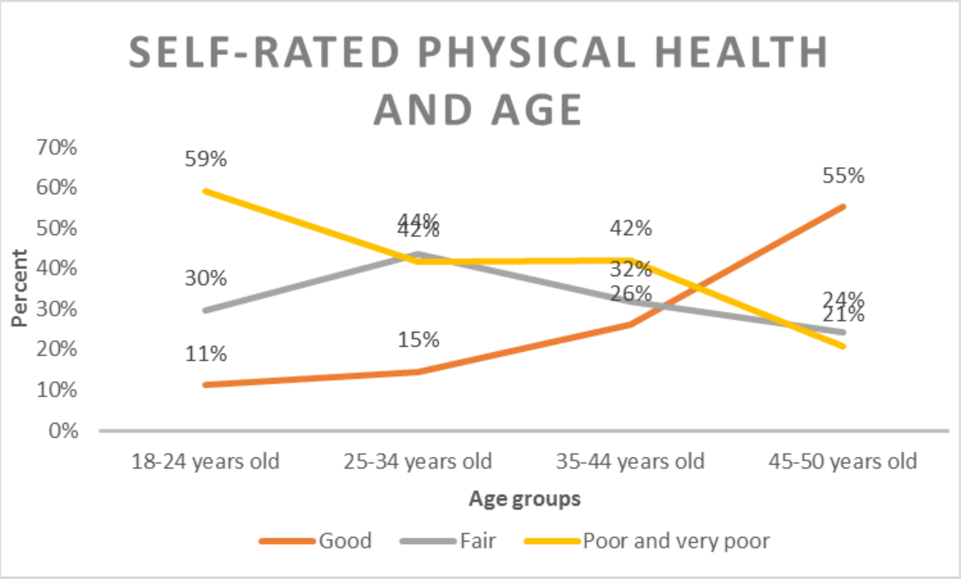

Figure 5: Percentage of self-rated physical health compared to age group.

As shown in Figure 6, respondents in the 18-24 years age group had the highest proportion of poor and very poor self-rated mental health (67%, n=18), whereas the 25-34 years age group mostly rated themselves as having fair mental health (53%, n=29). Respondents in the 45-50 years age group reported higher levels of excellent and good (52%, n=15) self-rated mental health. From this graph, self-rated mental health improved as age increased.

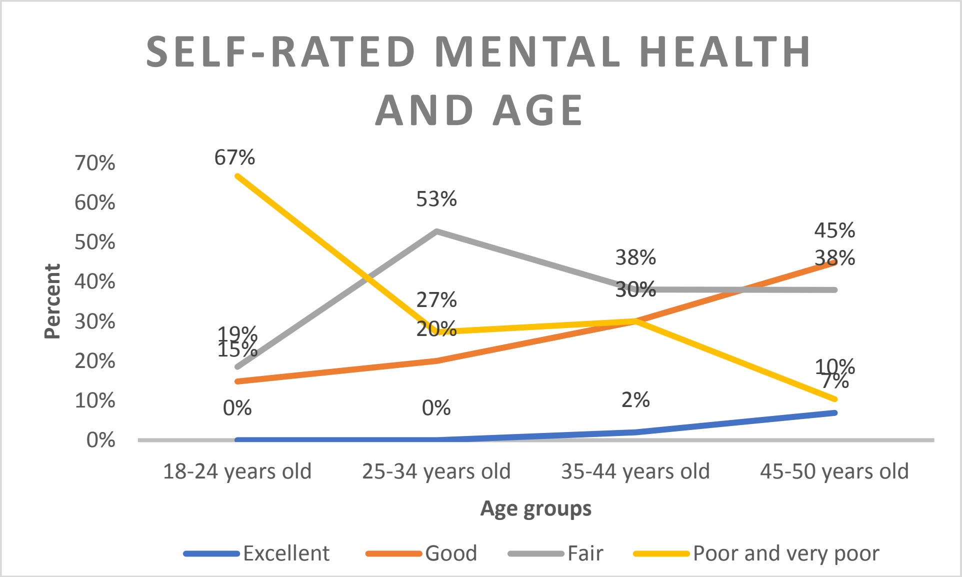

Figure 6: Percentage of self-rated mental health compared to age group.

Women in the study with good and excellent self-rated mental health were more likely to self-rate good physical health (37%, n=17) than other groups. On the other hand, women with poor and very poor self-rated mental health were more likely to have poor and very poor self-rated physical health (63%, n=32).

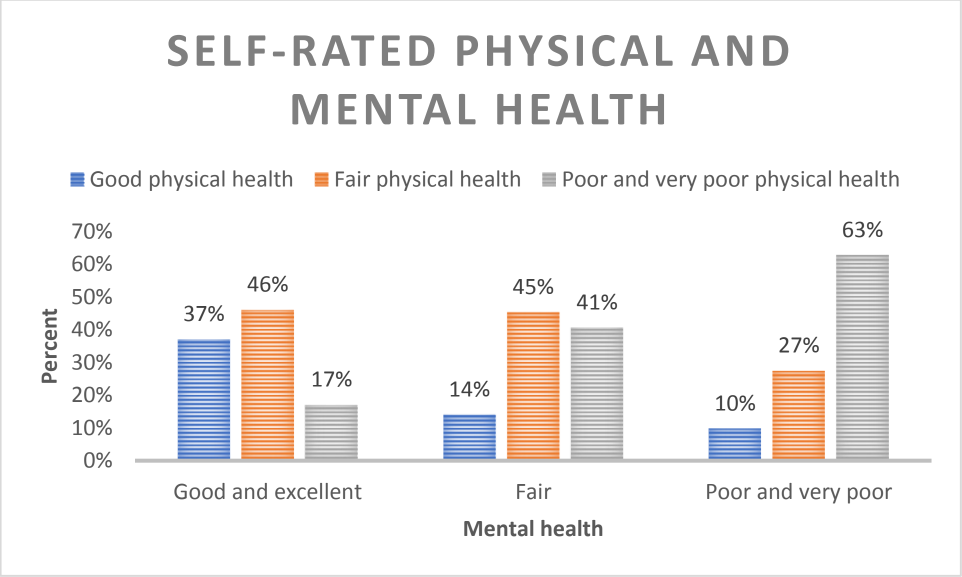

Figure 7: Percentage of respondents self-rated physical health compared to their self-rated mental health.

Types of chronic disease

Survey respondents were presented with a category list of chronic diseases from which they could select all that applied to themselves. It can be seen in Figure 8 that a large proportion of women who answered the survey reported having mental health conditions (40%, n=65), auto-immune diseases (39%, n=63), musculoskeletal conditions (39%, n=63) and endocrine disorders (29%, n=46). Other significant diseases included endometriosis (n=17), chronic fatigue syndrome and myalgic encephalomyelitis (CFS/ME, n=13).

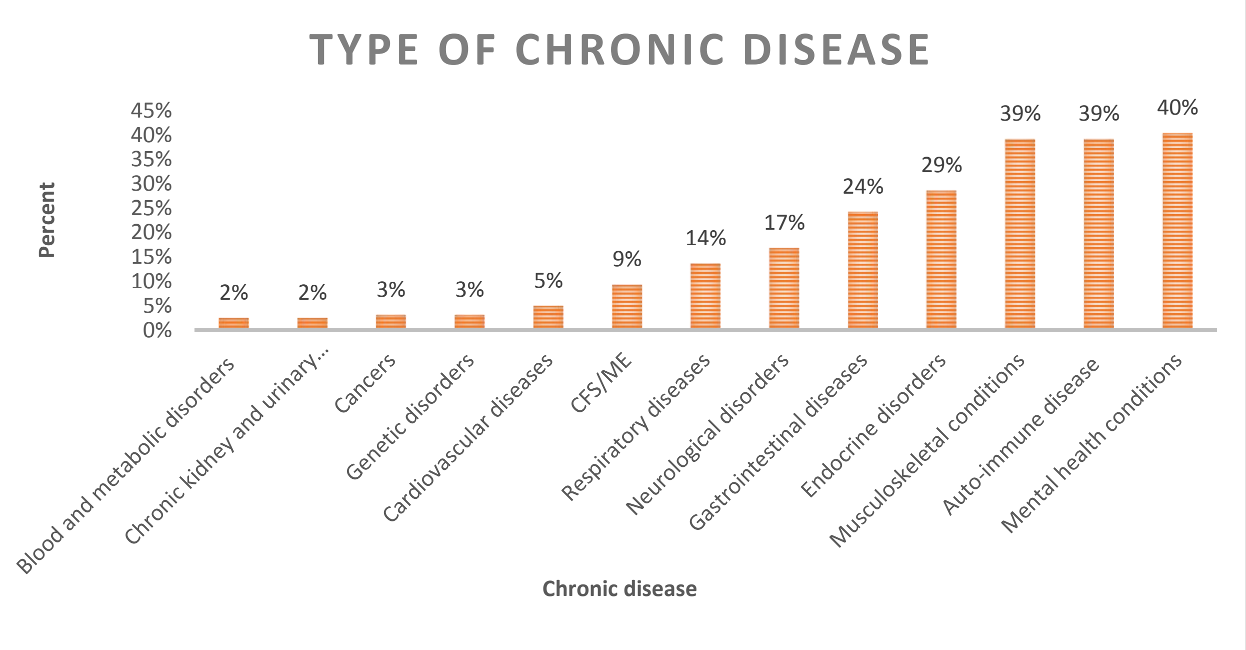

Figure 8: Types of chronic diseases experienced by participants in the research.

Table 3 reveals that 39% of women surveyed had one chronic disease (n=62), whereas 61% had more than one chronic disease (n=99).

Number of diseases	Number of women	Percentage of women
One	62	39%
Two	46	29%
Three	27	17%
Four or more	26	16%

Table 3: The percentage of women who chose one or more disease categories.

Women with one chronic disease self-reported far better physical health than those with more than one disease. As detailed in Figure 9, respondents who listed four or more diseases were more likely to self-rate their health as poor (62%, n=16). They had higher rates of very poor self-rated health (12%, n=3), and lower rates of good (4%, n=1) and fair self- rated health (23%, n=6), than respondents who listed three or fewer diseases.

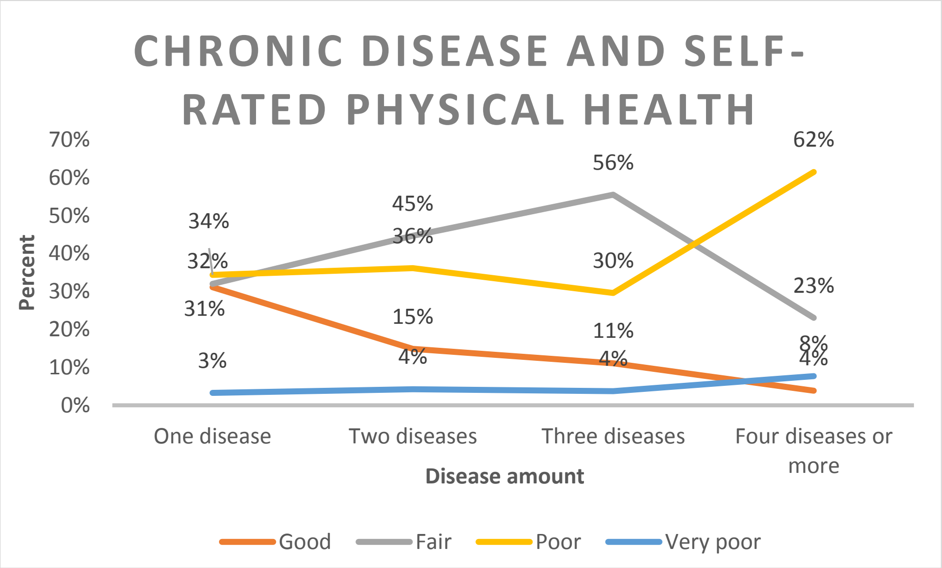

Figure 9: Comparing the percentage of chronic diseases per respondent to self-rated physical health.

Respondents that had more than one disease rated themselves with poor and very poor self-rated mental health (n=33, 33%), as shown in Figure 10.

Figure 10: Comparing the number of chronic disease per respondent to self-rated mental health

The 45-50-year-old group had more women with one disease (48%, n=14) compared to 18-24-year olds (19%, n=5).

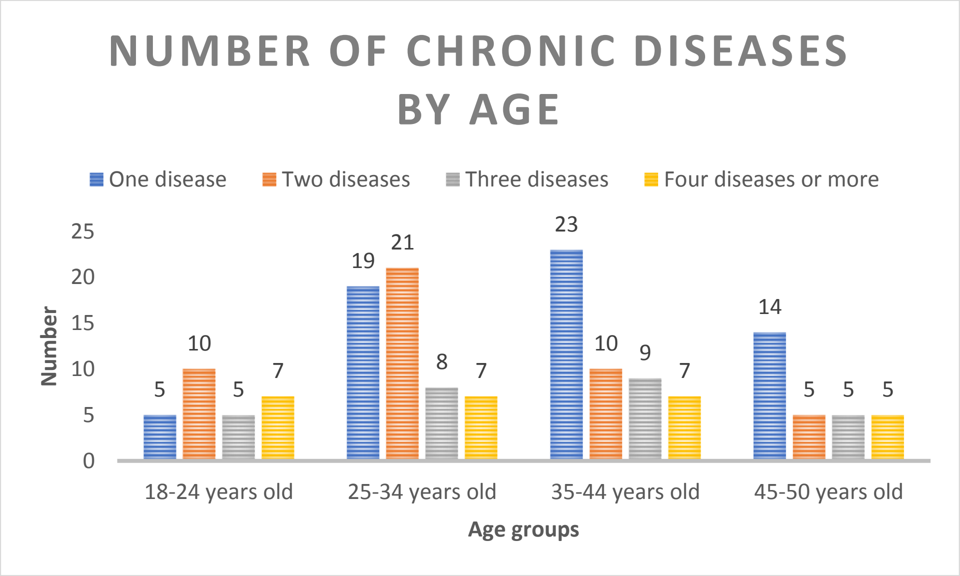

Figure 11: Comparing chronic disease amount by age group.

A higher percentage of women in the 18-24-year-old age category were reported having more than one chronic disease as shown in Figure 12 (81%, n=22).

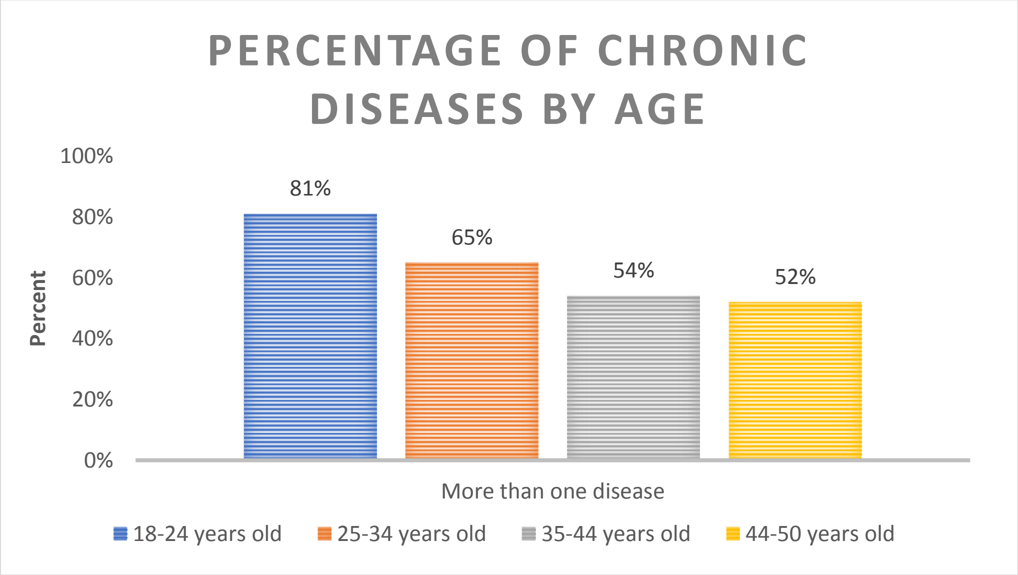

Figure 12: Comparing across age groups by percentage of respondents with more than one chronic disease.

Figure 13 illustrates that 86% of the respondents who reported having a mental health condition reported that they also have a physical health condition (n=56). The most prevalent chronic disease category that the women with a mental health condition listed was musculoskeletal (23%, n=27), followed by endocrine (17%, n=20) and auto-immune (16%, n=19). Only 6% of women (n=7) listed having a mental health condition with no other chronic disease.

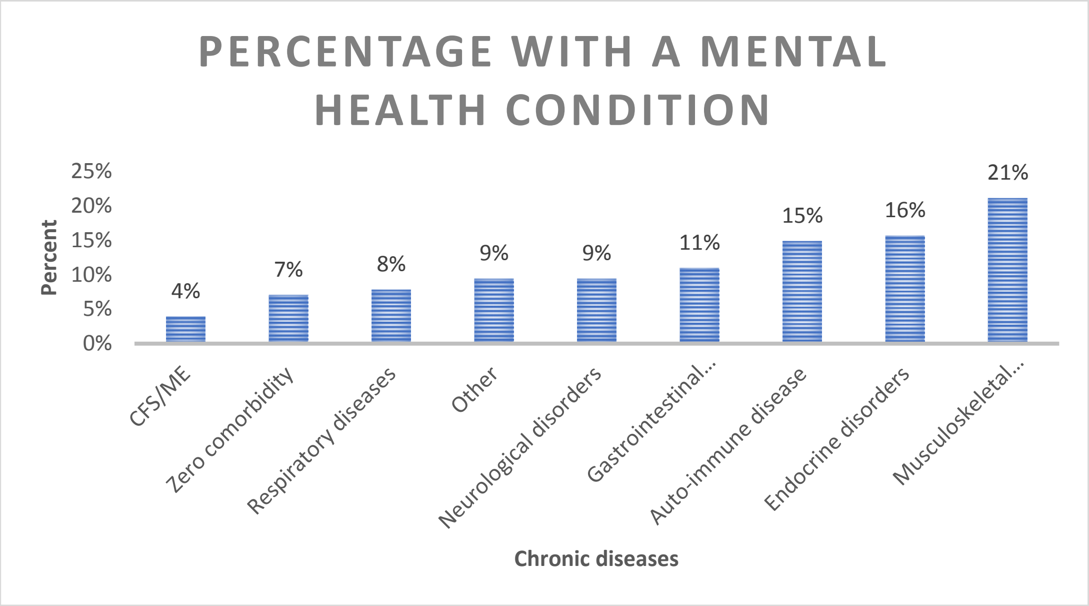

Figure 13: Percentage of respondents who reported having a mental health condition as one of their chronic disease.

Respondents who had more than one chronic disease were more likely to have a multi-morbid mental health condition (57%, n=56). Respondents with four diseases or more had the largest percentage of mental health multi-morbidity (65%, n=17).

Number of diseases	Number of respondents	Number of respondents with a mental health multi-morbidity	Percentage of respondents with physical and mental health multi-morbidities
One	61	9	15%
Two	46	27	59%
Three	27	12	44%
Four or more	26	17	65%

Table 4: Multi-morbidity of physical and mental health conditions by number of chronic conditions reported.

Figure 14 shows that 59% of participants in the 18-24-year-old age group reported a mental health condition (n=16), compared to 21% of 44-50-year olds (n=6).

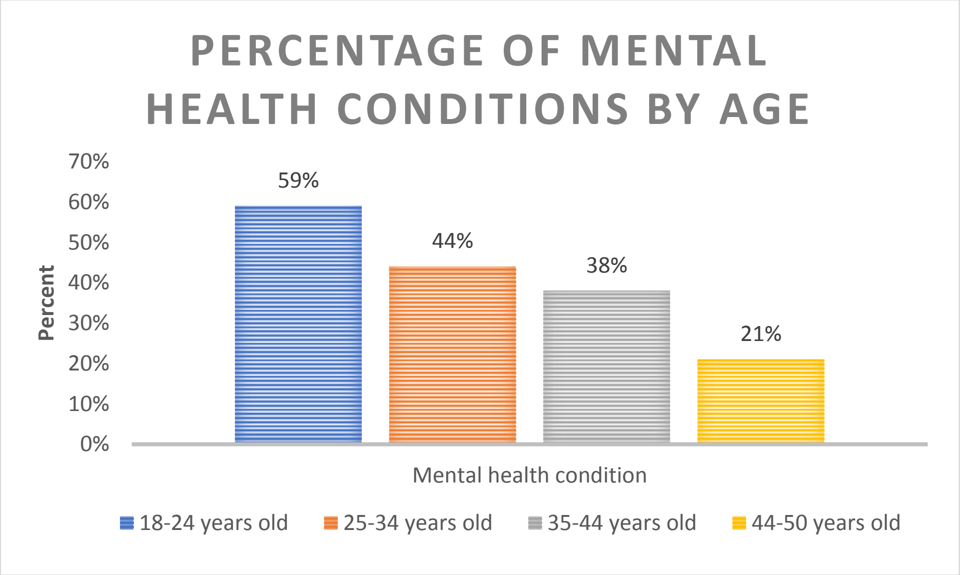

Figure 14: Percentage of women with a mental health condition by age group.

Table 5 demonstrates that 34% of survey respondents listed that they had a diagnosis of a chronic disease for 10 years or more (n=54).

Years since diagnosis	Number	Percentage
0-2 years	23	14%
2-4 years	29	18%
4-6 years	31	19%
6-10 years	24	15%
10 years or more	54	34%

Table 5: Number of years since diagnosis.

It is apparent from Figure 15 that women who reported that they had their disease for 10 years or more are more likely to have three or more diseases (42%, n=22).

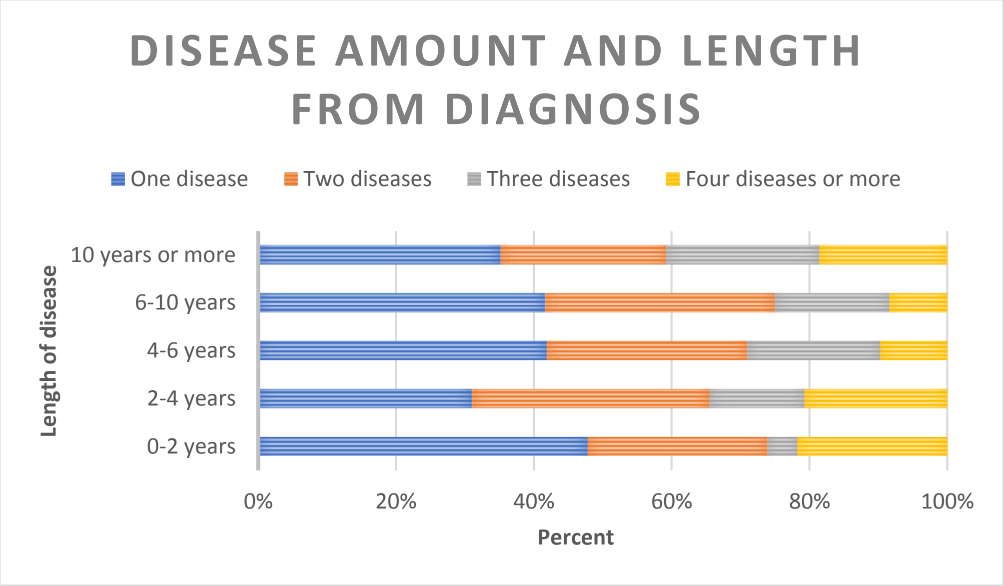

Figure 15: The percentage of participants by the number of disease they have and how long ago they were diagnosed.

Older age groups, 35-44 and 45-50 years old, had a larger number of women who reported having their chronic disease for 10 years or more as presented in Figure 16. The 18-24-year-old group had the largest number of women reporting having their chronic disease for 4-6 years (41%, n=11).

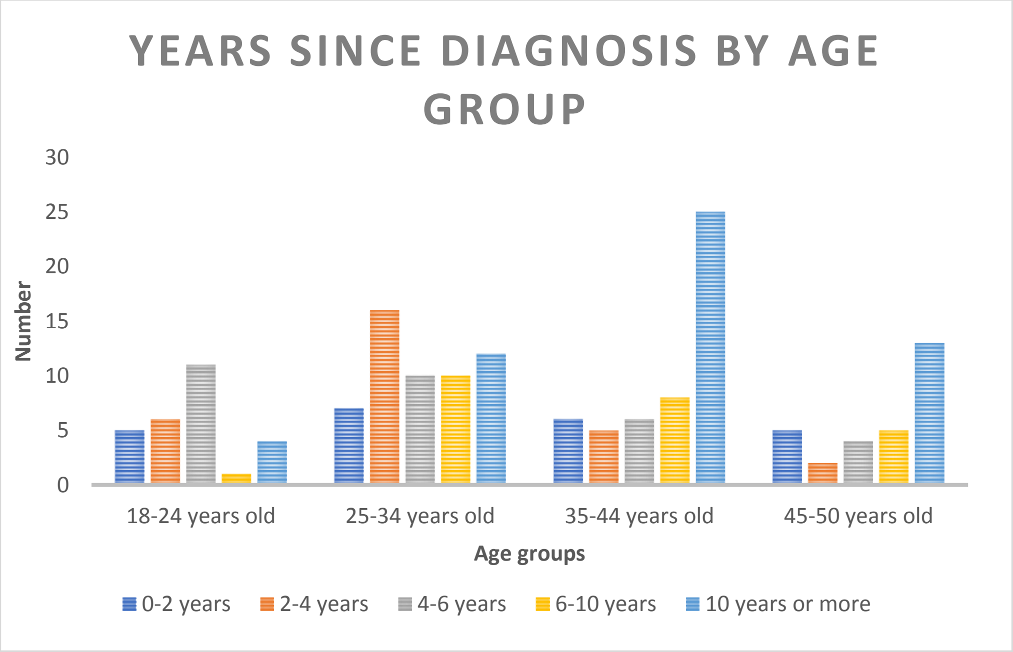

Figure 16: Length of years since diagnosis of disease by number of women in each age group.

Symptoms of chronic disease

Survey respondents and focus group participants said they experienced symptoms of their chronic disease that prevented them from carrying out normal daily activities such as domestic duties, work, child rearing, food preparations, and exercise.

Close to half of the younger women surveyed mentioned pain (n=76), many mentioning it multiple times. Figure 17 shows a “word cloud” which summarised the comments made by the women in the study on their chronic disease experience. Respondents discussed pain in relation to how they must organise their lives around it; limiting their contact hours with other people and choosing between activities to limit the amount of pain they will experience. Women who participated in the research raised their concern with how pain controlled their life.

Figure 17: The Word Cloud is an indication of the words linked to pain that women expressed from the research.

> *“Constant pain, fatigue and multiple medications. Means have enough energy to meet work commitments but little else.”*

> *“Unable to parent the way I used to. Lack of intimacy in relationship loss of friends due to constantly being sick. Unable to participate in social activities due to mobility and pain.”*

The women also expressed their frustration about their ability to get the help they needed even during times of extreme pain.

> *“The assistance you get for endometriosis is ludicrous. Majority of the time you will go into hospital in excruciating pain and be sent away as 'bad period pain.'”*

> *“I have had to miss multiple days of work, let alone having THREE weeks in hospital on ketamine before they decided that they should do surgery to identify the problem. I have never cried from pain until this point and NO ONE cared.”*

> *“I don't go to the ED for pain because I have heard so many horror stories about people who have been treated badly, not taken seriously, nurses and drs ignoring specialist instructions.”*

Chronic fatigue is not only a syndrome but a symptom of many diseases. Women in the survey and the focus group discussed fatigue impacting their daily lives (n=37). The term “spoons” was mentioned, and it is a theoretical way of explaining that because women only had enough energy for a number of things per day they often had to choose between them.

> *“I introduced it to my direct boss and then her boss because one day I was like, “If I don't leave now I’m not going to get home safely.” With chronic fatigue a big thing is I*

> *have to know how much energy I have to get through the day, and if I get to 11 o'clock and I've only got enough energy to drive home or I've got enough energy to do two more hours of work, if I do those two more hours of work I'm not going home. So introducing the boss to that and just went, "I'm out of spoons, I'm going home" and she was like, "What?" So got home, sent him the link, went to sleep and got an email back going, "Yep, that's fine, I understand now." So having this theory that you can say to people, "Read this, this is my life", all of a sudden they get you so much more."*

> *"And one of the things I was explaining to my GP and to my parents is that it's not just the walking from the carpark to the shop or whatever, it's the walking around, it's the standing around, it's bending down picking up things and by the time you get back and have to carry things back to your car you just want to cry. "*

The following quote expresses the difficulty of managing life and fatigue, where fatigue levels are variable.

> *"It is incredibly difficult to have chronic fatigue as a parent. School runs, cooking dinner, spending quality time - all of these things become impossible at time. The disease fluctuates in symptoms depending on how it is managed. During the worst times I have not been able to do school runs or cook. I have only recently started to understand how to manage CFS from an online program and this is helping but I have a long way to go. Carer/support services would be a fantastic help. Without family and friends I would not have been able to function at all - sometimes for long periods of time (many months)."*

Chronic disease effects on life roles

When women participating in the research were asked specifically how chronic disease affects their ability to carry out their life roles, 79% said that their role was affected (n=127). As shown in Figure 18, those women identified that chronic disease mainly affected their role as an employee (59%, n=75), as a mother (23%, n=29) and as a life partner (18%, n=24).

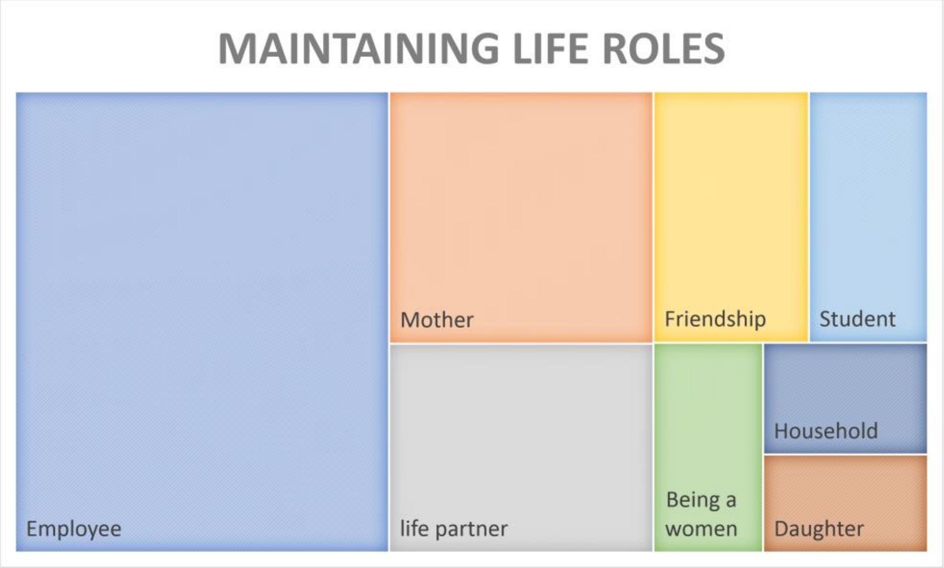

Figure 18: Percentage of life role themes reported being affected by chronic disease.

<u>Impacts on employment</u>

Of the 75 women who told us that chronic disease affected their employment, some mentioned that at times they could not complete work to a standard that they would like (n=19). Some reported having to leave employment (n=16), absenteeism (n=15) and being worried about or experiencing discrimination at work because of their chronic disease (n=15), while some had to reduce their working hours to casual or part-time work (n=10).

Women from the study explained their experiences with employment and their chronic disease.

> *“I regularly miss work due to pain and for 23 years I doubted my pain threshold and work ethic. This has also resulted in career opportunities being missed. I am fatigued often so spend evenings and weekends recovering from the work week which results in isolation as I have no energy to socialise or maintain the household cleaning/cooking/shopping.”*

> *“I can just manage to get up and go to work each day, which needs to be done to pay the bills. Most time I spend with my kids is curled up in bed because I dare not do much else. I am very lucky to have an understanding boss and a part time job. If I'm not dealing with the pain and issues associated with endometriosis I'm dealing with chronic fatigue.”*

> *"It would be great to have someone to support me at work. I have had no support from them at all and nobody to advocate for me."*

> *"… you know like there's no way you would self-identify as having any sort of problem you know like my career was pretty much over once I started having health problems. Not just because of the fatigue and the symptoms but just the stigma of having any kind of problem you know…"*

Participants in the research mentioned a fear of discrimination and some had chosen to not disclose their chronic disease. Women in the focus group discussed losing their jobs, and being poorly treated.

> *"As a young woman with a chronic illness, the biggest issue I faced is wanting to hide it in fear of being unemployed as a result. Many of the women I initially met felt nothing but regret at owning up to their illness, and all struggled with work as a consequence. As such, I have since stopped seeking support for fear it would circulate and get back to me and discriminate me from a job."*

Impacts on motherhood

Being able to effectively parent children is important to women, and all of the women who mentioned motherhood reported that it was difficult with their chronic disease. They missed out on activities and felt that they were unable to care for their children the way they wanted to.

> *"My kids can't go on school excursions or to events. When I collapse, my youngest cares for me, (since she was 3!) A teen now, the burden has got her down. She sometimes cuts herself and feels suicidal. So we are back 'banging on doors' for help. The upside to chronic illness is mindfulness and constant gratitude for the blessings I've got. Poverty has made me raise my kids under the motto, 'Carpe Diem', be alert, seize opportunities. Thus they've accessed scholarships and have done well from them. They are well-liked in the community as they are the kind of unselfish kids who step up to the plate."*

> *"I have been unable to effectively parent or attend work for several months. Increased pressure and responsibility on my partner has stressed our family financially and emotionally."*

Impacts on relationships

As a life partner, women in the research identified numerous issues that their chronic disease had had an impact on (13%, n=28). Some women felt that they were not able to be the wife, girlfriend, or partner they wanted to be (n=3). Respondents reported having to give up doing many household duties such as caring for children and household chores. Some had their partner undertake the role as their primary carer as well as taking on household responsibilities, and this put pressure on the partner (n=6). Some of the women reported that their relationship became strained (n=7) or that there were ongoing intimacy issues (n=3). Some women reported to staying single because relationships were too difficult (n=3).

> *“I'm so tired all the time that I don't get to be the best of any of my roles - mother, partner, employee. I find it very hard to keep up with housework and always feel overcommitted although I don't think I have a massive amount on my plate.”*
>
> *“this has been hard on both my husband and myself. A lot of what we used to do together is now him alone or with other mates. We rarely go out as a couple - it's just too tiring and painful.”*
>
> *“I've lost my career, my opportunity to have children and my independence as I can't even shop, cook, clean and some days dress myself. On the rare occasion we go out, my partner has to push me in a wheelchair. This is not how I planned my 30s, or the rest of my life.”*
>
> *“And it’s not just the physical aspect of it either because you then have the emotions that go with it like you have the guilt that you feel because your husband’s going out to work and he’s working long hours and then he’s coming home and he’s doing all this housework and the heavy stuff and then he’s taking care of the kids when you can’t and all the emotions that go with that and is he resentful? Well why not? He should be.”*

Impacts on life roles by age groups

Chronic disease appears to affect women’s life roles differently depending on age. Figure 19 reveals the two younger age groups 18-24 years old (33%, n= 10) and 25-34 years old (5%, n=5) listed their role as a student being affected by chronic disease, whereas the older two age group categories did not. In addition, the 18-24 year olds did not list being a mother as something that chronic disease affects. Chronic disease effects on being a mother increases in the older age categories. Chronic disease affected being an employee in all age groups, although less so in 18-24 age group, where being a student was affected more.

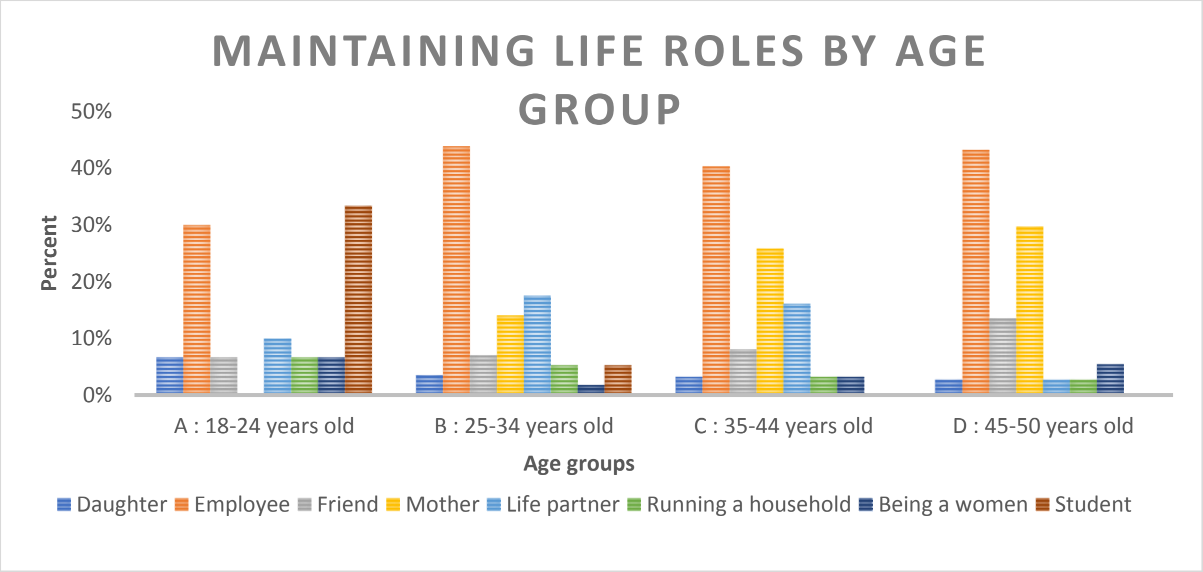

Figure 19: Percentage of life role themes reported as being influenced by chronic disease by age group.

A woman from the 18-24 age group described the impact on her as a student looking for work:

> *"Finding work and being a university student makes it really difficult. There's brain fog that can impact studies and sometimes transport is a pain. Also people don't care/ have an understanding of chronic/ invisible illness. I think mental health is getting better, but try to explain to someone you can't walk up stairs today so aren't come into uni because your leg as you slept on it funny."*

Women from the 45-50 age group described wider impacts:

> *"It impacts every aspect of my life. I am completely disabled and I am a single mother of two children. I have no supports, despite having a plan approved for NDIS 6 months ago, I haven't been able to access the funds, and I am still waiting for help. I can't work. I can't even walk. I had to buy my own wheelchair, but even so, I am largely housebound. I have no social life, and no formal or informal supports."*

> *"Where do I start? Every activity of daily life has been impacted. I have learned to make all sorts of accommodations: eg, driving a work car requires extra steps to fit my spinner knob, to cook or open a lock requires little "tricks." I have had employers make no extra time allowance for this adjustment--or simply not schedule me to do work that requires driving because that was "unfair" to make extra adjustments for me."*

Information, services, and support groups

Women's experiences of information, services, and support groups in the ACT for chronic diseases were explored in both the survey and focus groups. This included questions about information to assist in navigating the health system, information about their chronic disease or it's symptoms, services provided by ACT Health and by private service providers, support groups and community organisations.

Seeking services for chronic diseases

Women were asked to nominate the services they accessed or tried to access which were specific to their chronic disease, and to comment on their age-appropriateness, affordability, convenience of location, convenience of opening times, and whether the services addressed their needs. They could identify up to 4 different services.

Figure 20 shows that participants accessed a variety of different types of services - the most listed services were private specialists followed by ACT Health services. Seven women identified that they did not know of any services.

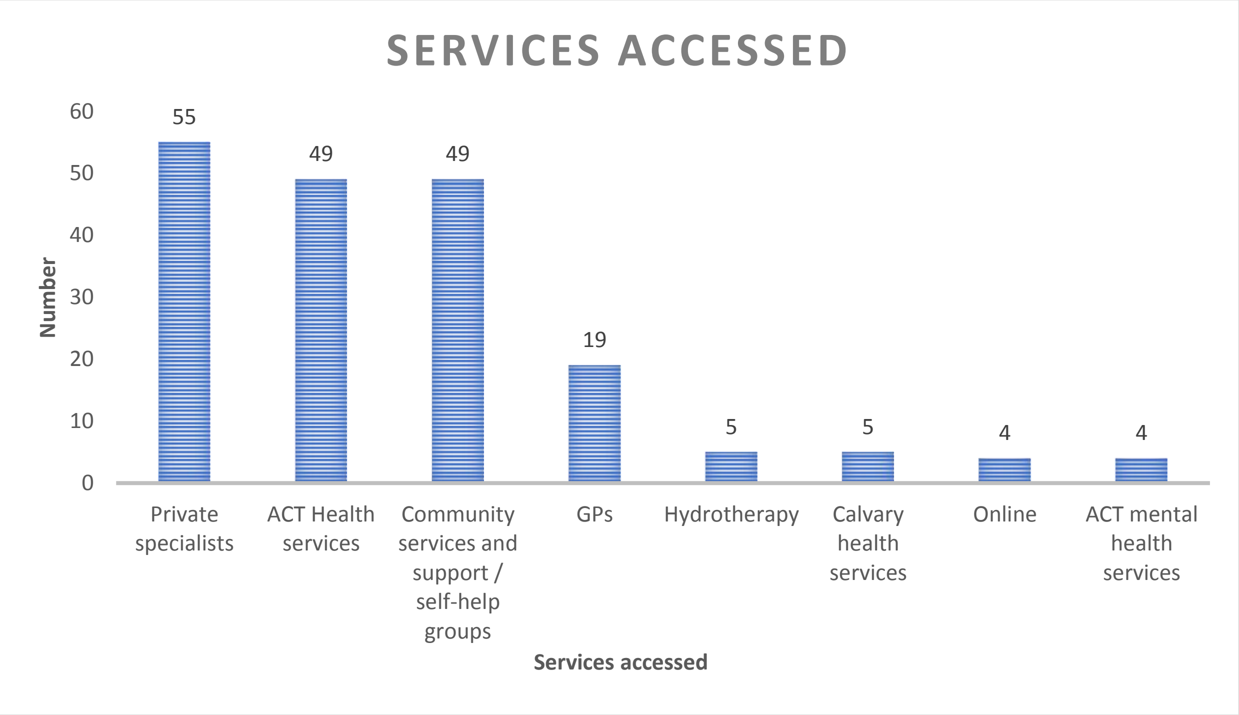

Figure 20: Types of services for chronic disease accessed in the ACT.

Age appropriateness of services

For each of the services identified women were asked to comment on the age-appropriateness of the service.

A few participants commented on hydrotherapy: "*Mostly older people." and "Felt uncomfortable being the youngest by about 40 years."*

All women accessing the Community Canberra Endometriosis Network said it was age appropriate.

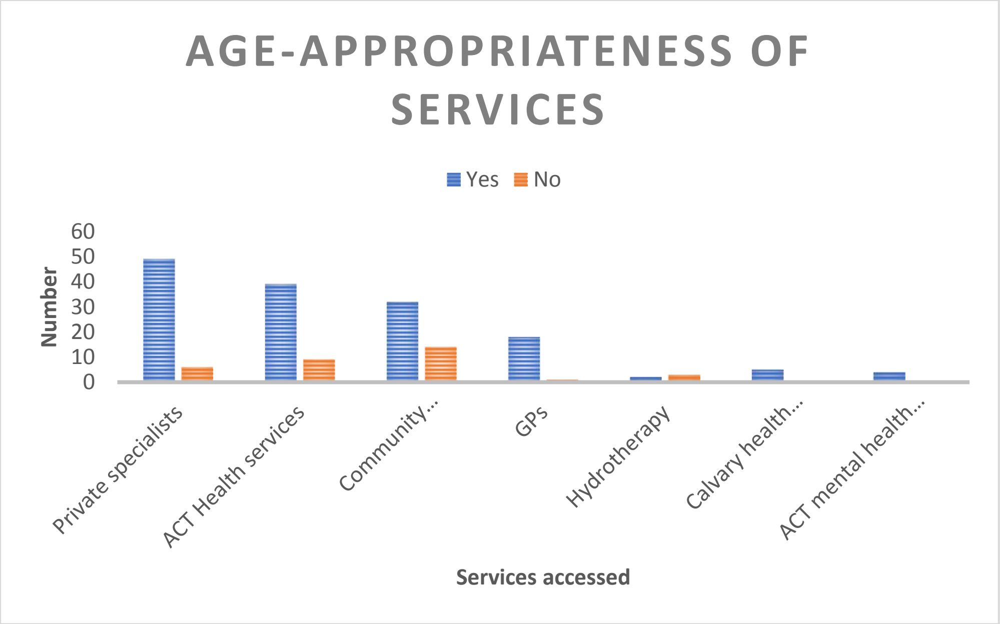

Figure 21: The number of age-appropriate services for chronic disease in the ACT.

Seven out of 15 women who mentioned Arthritis ACT reported that they were not age-appropriate for younger women with chronic disease. The women responded that Arthritis ACT was:

> "*Very much directed to older people*."
>
> *"They don't really exist for my condition. At 46 I am too old for the young people with arthritis group, and too young for the standard group, which are filled with people in their 70s with osteoarthritis."*
>
> *"directed to old people in retirement or children who don't have anyone dependent on them, they're not independent of their parents"*
>
> *"If you go to courses '– …City Mental Health sent me to courses in Belconnen and they're courses that were theoretically open to everyone, they're put up for everyone. Me and a bunch of retired men."*

Affordability of service

Women were asked to comment on the affordability of the services they accessed or tried to access. Respondents commented that many of the services were only affordable due to bulk billing or Medicare rebates, and two women reported that; if they were working then they could afford the service. When commenting on hydrotherapy, two out of five women said it was affordable:

> *"Would have visit more if slightly cheaper. $20 per visit."*

A large number of women reported private specialists were not affordable (n=41). When specific specialists were mentioned, eight rheumatologists were described as unaffordable.

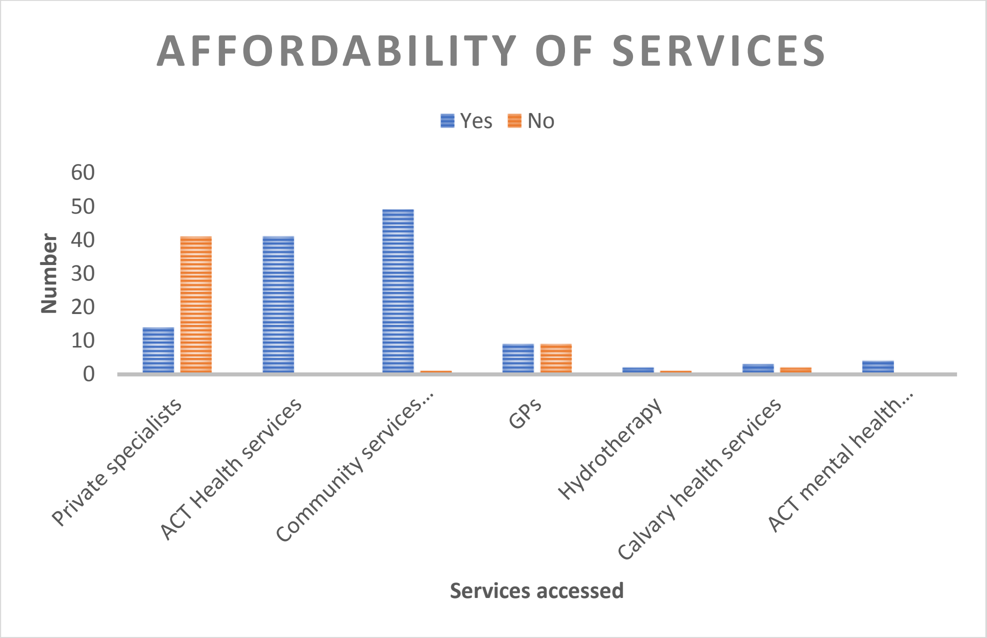

Figure 22: The affordability of services for chronic disease in the ACT.

Convenience of location

Respondents were asked if services were in convenient location. Almost half of the respondents that listed private specialists said they were not located in a convenient place*:*

> *"No, had to travel 20km from my home"*

Some identified that they had to go interstate after a long wait time:

> *"When having a flair I was unable to see anyone within 6 months in Canberra so I went to Sydney as I was able to get an appointment within a fortnight."*

Others commented on having to use buses to travel which added to the cost of the service.

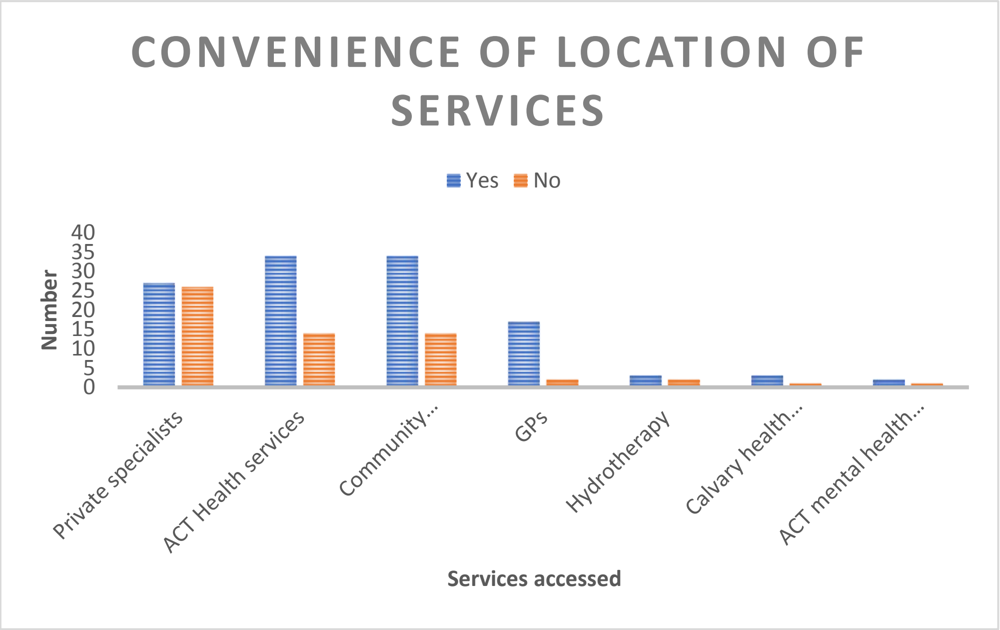

Figure 23: The convenience of locations of services for chronic disease in the ACT.

Convenience of times

There were two themes that were expressed when respondents were asked about convenience of times: appointment times and wait times. Respondents expressed difficulties in finding times that suited their lives and usually would have to work around the services' available times and wait times.

Private specialists had limited after hours appointments:

> *"No, no after hours appointments so I have to miss uni or work to go there."*
>
> *"Not really - had to change working hours to accommodate."*
>
> *"No during working hours."*

ACT Health services also had inconvenient times with 14 women responded yes and 18 said no, while others qualified their answers:

> *"Moderately - only available during the day and have to book months in advance, so often ends up clashing with a uni class"*
>
> "*Appointment times are very limited and there is an expectation you will take leave from work to attend appointments and courses.*"

Wait times for private specialists and ACT Health services were:

> *"Very long wait times and then only select days."*
>
> *"Definitely not [at convenient times]! Waiting more than 6 months for an initial appointment"*
>
> *"Long wait times, and then inconvenient availability - I often have to rearrange my life."*

> *“To people without jobs.*”
>
> “*Huge waiting list, not convenient.*”

Women also advised similar issues with hydrotherapy, 4 out of 5 said no;

> “*Most classes held during business hours. Only like 2 classes held after hours. And some held too soon after 5pm to get there in time. Needed more times after work or on weekend.”*

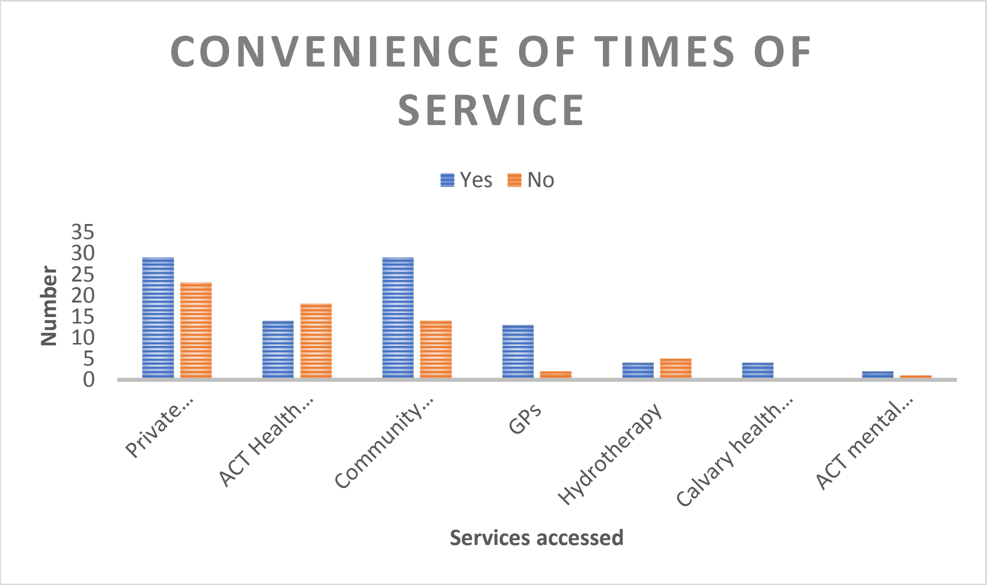

Figure 24: The convenience of times of availability of services.

Did the service address younger women’s needs?

Comments about community services implied that services could be better targeted at younger women’s needs:

> “*Targeted non working and older people.”*
>
> *“Was a small clicky group. Didn't feel that comfortable.”*
>
> *‘‘It would be great to have a class specifically for younger people suffering from inflammatory arthritis.”*

Women who attended ACT Health services, mentioned that waiting times, appointment times, and location meant that the services often did not address their needs:

> “*Haven't had appointment yet as hospital and waiting times are bad.”*
>
> *“Because of the time and location, I cannot access them as needed*.”

Women identified that they felt their needs weren’t being addressed as services weren’t integrated, they didn’t have the time to tell their story and everything was rushed:

> "*Sometimes, they are so busy and can really only do a cursory check up. There are different Registrars so one needs to go over the same thing again and again which is very frustrating and tiring when you have quite an in depth medical history."*
>
> *"Some are very good but some just do the basics and you don't feel heard.", "Getting any necessary paperwork done is a nightmare."*
>
> *"Yes though the service is rushed."*

When women mentioned private specialists, 25 women responded yes, and 20 said no to whether the services addressed younger women's needs. Negative comments were mostly related to affordability.

> "*Somewhat but I can't afford to take full advantage".*
>
> *"No too expensive. Private service for a chronic disease requiring continuous treatment very expensive and unaffordable in a long period of time."*
>
> *"No didn't understand the condition and made it worse. Didn't feel believed. Treated what fitted their paradigm not what was actually happening."*

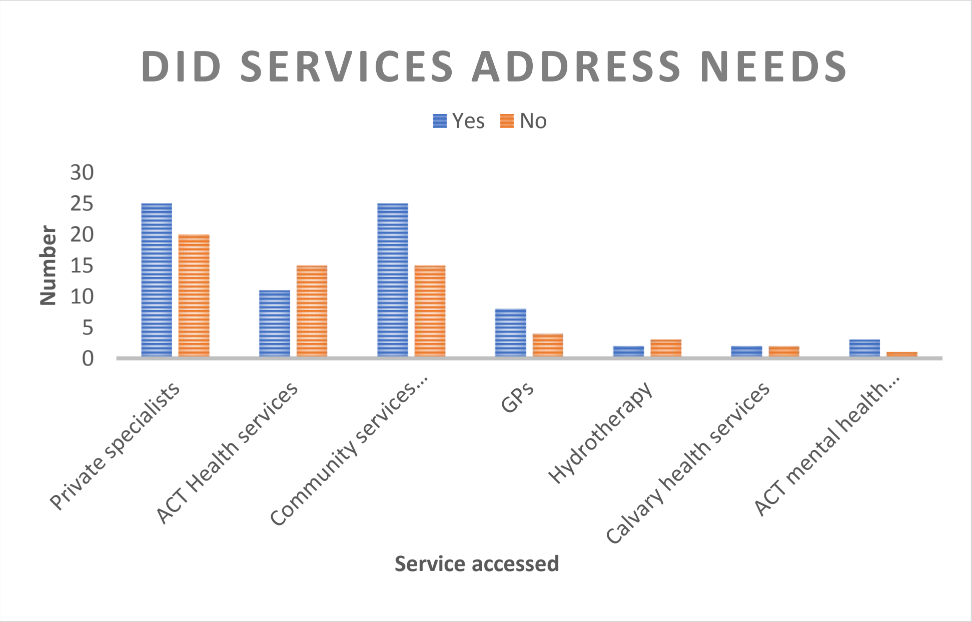

Figure 25: Whether services addressed the needs of respondents.

Seeking other information and support

Women were asked what other information and support they accessed to help them manage their chronic disease.

As presented in Figure 26, the three most commonly used information sources were:

- The internet - n=149;
- Relevant website to their chronic disease - n=141; and
- Pamphlets from doctor or other health provider - n=72.

The women could also list other sources of information and these included 23 women using Facebook support groups and online support groups, face to face support groups, and accessing peer reviewed articles.

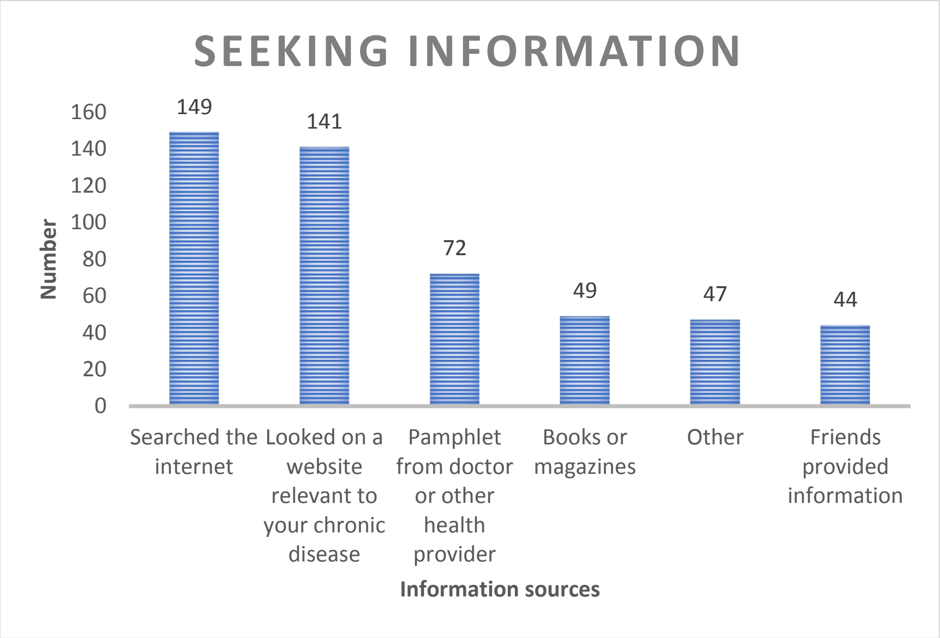

Figure 26: Seeking information about their chronic disease.

As shown in Figure 27, the sources of information were consistent across all age groups.

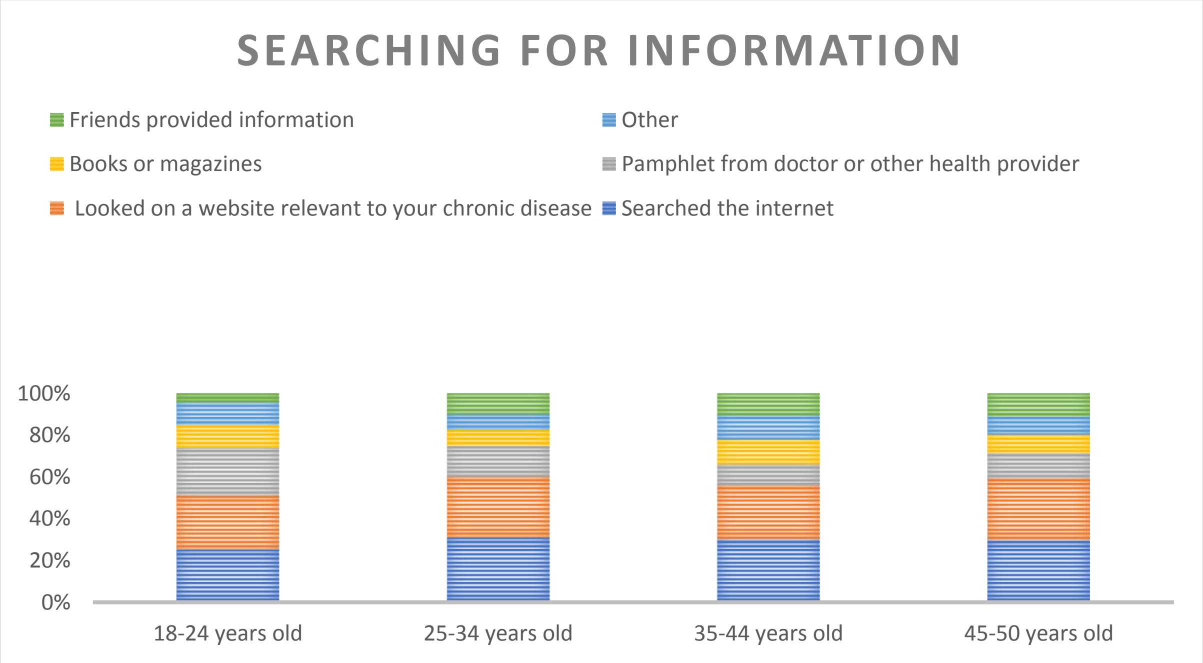

Figure 27: Women seeking information by age group.

Barriers to access to services, supports and courses in the ACT

When asked if they had experienced any difficulties or barriers when trying to access services in the ACT for their chronic disease, 83% of all respondents (n=134) reported that they had experienced barriers, with many listing that they encountered more than one barrier.

Eighty eight percent (n=87) of the women who had more than one chronic disease said they had barriers to accessing services, compared to 76% (n=47) of the women who had only one chronic disease.

Eighty two percent of women with mental health conditions experienced barriers to services and supports in the ACT.

The six main barriers identified by them were:

- Dissatisfaction with treatment by services (57%, n=76)
- Limited services available (38%, n=51)
- Affordability of services (37%, n=49)
- Time barriers (32%, n=43)
- Physical access and location of services (10%, n=14).
- Age-appropriateness of services (10%, n=13).

Dissatisfaction with treatment by services

Women with chronic diseases who participated in the research identified that the most prevalent reason for dissatisfaction of treatment with services were that their expectations of treatment by service providers were not met (n=76). Respondents expressed frustration that the service providers were often not well informed about their condition, and that they had an unwillingness to learn and were closed-minded.

> *"When one has only 1-2 hours of functional energy per day, one tries not to waste it on unproductive courses or get weighed down by the negativity of health professionals who can't conceptualise that someone who looks fit, has chronic illness. (Yes, I'm not obese. I look rosy because I force myself to exercise outside daily and eat healthily)."*

> *"Discrimination, assumptions about my illness that were untrue, lots of 'we can't help you', sexist and derogatory comments from male health practitioners, spoken to like a child, told i wasn't 'trying' hard enough, lack of clear answers, no follow up."*

> *"… health professionals who are interested in actually helping as opposed to just telling me to keep taking pain meds."*

> *"Being a lesbian makes it hard. The information in the services (including private doctors) makes it hard to be a lesbian with endometriosis. Everything is geared to maintaining fertility etc, and people can't seem to understand that my experience just doesn't cover that. Leaves you feeling invisible twice over..."*

Respondents spoke of how difficult this made their access, and that it often led to feelings of shame.

> *"How do you feel about going to get pain medications and you have to explain to the 16 year old behind the counter that you have a chronic health condition, "Please just give me my Panadeine." It's like you don't even know what it is and I have to explain to you."*

GPs were heavily relied on for diagnosis and management of the women's chronic disease, and 13% of the women (n=17) who reported they had barriers said they were dissatisfied with the treatment they received from their GP. They expressed frustration about not being believed or listened to, especially by someone from whom they were trying to access help.

> *"The Freudian legacy, 'if its female, it's hysteria', continues to dominate conventional medicine here and elsewhere. Thus I was dismissed or misdiagnosed for years. After diagnosis there was little help. … GPs treated me like an idiot, (I'm a trained nurse with extra tertiary degrees) or shook their heads, 'I've got nothing'."*
>
> *"Doctors know little about the neurological illnesses and do not understand the daily impact they have on my work nor their severity. This has made it difficult to get supporting letters from doctors to access specialised or disability services that may be of greater help."*
>
> *"At first told not to worry. Finally got referral "to put my mind at ease". Diagnosed after 10+ years of symptoms."*
>
> *"In my experience GPs manage chronic mental health conditions poorly, and are hesitant to refer to specialist (psychiatrist)."*

Specialists were also accessed for expert advice, and some research participants described being dissatisfied with their interaction (8%, n=10).

> *"Specialist doctors too concrete in thinking. Judging by age and therefore failing to diagnose problem for long period. Misdiagnosis, misinformed and not willing or able to collaborate with other specialities. Resulting in poor treatment, damage to my body, extended period of inpatient stay and prolonged recovery time."*
>
> *"…I have found the quality of care in some cases … has been so awful I am now unwilling to seek treatment…."*
>
> *'After diagnosis there was little help…. I tried them. Cost versus results didn't weigh up. And, when I had to withdraw from paid work, they became a wasteful extravagance.'*
>
> *"No knowledge of condition and a lack of specialists in area. Some of said specialists have no idea of my particular condition or have outdated information or views."*

The Pain Management Clinic at the Canberra Hospital was a service where six respondents reported they were not able to get the outcome that they desired,

> *"…they were very apathetic towards me and made my mental health worse (which in turn made my physical illness harder to cope with)…"*

> *"… the pain management unit took me off the waiting list, and I never got in!"*

Some women in the focus group found that because they did not have a definitive diagnosis of their condition, they had difficulties accessing services.

> *"And you don't have a real diagnosis that people are willing to take seriously, it's – and you know like I've been in this position – like I've had depression since childhood but I've had fibro since you know my early 30s and I'm now in my mid-40s you know so it's been sort of 15 or 16 years of just kind of floating around going will someone please help me? You know and just trying to you know get on Medscape and get on you know all those medical websites and just try and work it out myself"*

> *"…about not being diagnosed I'm experiencing a similar thing at the moment and it does make it hard to access groups where you've not got a particular condition and so I think there needs to be some kind of support network for young women that isn't focused on a particular disease, it's just focused on the fact that you've got a chronic illness. It might not cause you pain but there's other issues."*

Limited services available

Thirty eight percent of the women in the study listed that the limited number or availability of services was a barrier to accessing appropriate services, supports, courses and information in the ACT (n=51).

> *"There just aren't many services or support available that I am aware of. Feel very alone in this."*

When asked if there were any gaps in services or supports in the ACT for managing chronic disease, women identified different specialists who aren't currently available or are in short supply in Canberra (n=23), such as for endometriosis (n=4), rheumatoid arthritis (n=4), and mental health (n=5).

> *"No one here has heard of lipoedema and there are no specialists in it. I have been referred to a lymphoedema clinic who may be able to help, but it's very likely all they can do is look at me and say, "You're right! It's not lymphoedema!" I have to travel to Sydney to access a specialist there."*

> *"Need more mental health professionals & many many more rheumatologists. It isn't acceptable to wait 8+ months for an appointment."*

> *"Mental health services to deal with that aspect of being diagnosed with a chronic disease."*

> *"During the worst times with Chronic Fatigue Syndrome I need a Dr who does home visits because, getting out of the house and driving anywhere can be literally impossible. Finding a GP in Canberra who has a good understanding of CFS has been so difficult I no longer bother to look."*

Eight women reported having to access services in Sydney.

> *"I have to go interstate to see a specialist and for some tests. Canberra hospital always threatening to remove warm water pool. No assistance with biologic injections have had to pay privately. .. Support groups like arthritis ACT don't support people with ankylosing spondylitis."*

Because of the difficulty in finding services some women expressed the need for a centralised information source such as a website, advertising, or their doctor to provide information about services in the ACT.

> *"But I don't know how you find these people you know like you know I've been sick all these years, I've lived in Canberra my entire life and I'm stuffed if I don't know how to find these people."*

> *"And you go onto websites, I've tried searching through the government websites when I was having a really down year and they're just not easy to search through. The ACT government one is awful and it's ugly and it's just bad and so – and then if you do Google – like I found a couple of good online ones but they're not ACT-specific…."*

> *"It is very difficult to get information on services available in the ACT even via the internet. Advice on things like Chronic Disease Management Plans etc is buried away and GPs are often unfamiliar with them."*

Affordability of services

Thirty seven percent of respondents identified the barrier when trying to access services of affordability. The top affordability issue was general cost followed by the cost of doctors, tests and medications. Respondents who answered 'cost' or 'affordability' without being specific were grouped under the theme - general cost. Forty two percent (n=11) of the women with four or more chronic diseases listed affordability as the main barrier to accessing services in the ACT.

Affordability of services	Mentions	Percentage
General cost	18	36%
Cost of doctors, test, medications and surgery	11	22%
Private specialist fees	8	16%
Lack of eligibility NDIS	5	10%
Allied health expensive	4	8%
Lack of bulk billing	3	6%
Monetary support for episodic conditions	1	2%

Table 6: Affordability of services as a barrier to accessing services in the ACT.

Women responding to this question expressed that not only were GP visits unaffordable (20%, n=10), but the compounding effect of multiple visits per year, pathology and medical tests, extended sessions for care plan management and ongoing medications contributed to a greater financial impact. Women also mentioned the lack of bulk billing services as being a barrier to accessing services.

> *“Healthcare is SO expensive - Canberra has the lowest bulk-billing rate in the country, up to $60-70 out of pocket for a GP visit. I am not especially poor, so I don't get bulk-billed, but with my medications, regular GP/specialist visits, physiotherapy, hydrotherapy, etc, it really adds up. I spent nearly $12,000 last year on out of pocket medical expenses - after Medicare and private health insurance rebates.”*

> *“You know the one thing that is seriously lacking? Once you hit 16 if you are not an extremely low income earner you have to pay full cost for all of your medications until you hit pension age. If you have a husband or if you have a job and you earn over $25,000, $30,000 all of your medications are full cost. … I’m not fit enough to work so all of my meds cost 30 something dollars a script. We pay for my meds roughly $170, $180 a month.”*

Survey respondents also listed cost as a barrier speficically about specialists.

> *“The main barriers I've faced were financial. Seeing a neurologist for migraines can cost $200 per session. I can see a psychologist ten times per year for free via Headspace and the Mental Health Care Plan, but availability of sessions is limited and ten per year is not frequent enough for the severity of my condition. Seeing a private psychologist often costs at least $200 per session. These are large expenses on a limited student budget.”*

> *“Costs of private psychiatrists are a barrier as is waiting times to get in to see people. There aren't enough in the ACT. I tried to see someone as a preventative measure when*

> *I first arrived in Canberra just so I was on someone's books if things got worse but it $550 for the first session so I couldn't justify it as I was fairly well at that stage. Then when you are in crisis you can't see anyone. You have to have multiple expensive sessions with someone before start addressing issues. It may help deal with some stresses but adds financial strain."*

> *"With regards to services here in ACT outside of our specialists and our doctors/our GPs I find that allied health therapies are really expensive here compared to other states. When I'm on forums and people are saying, "If you've got a mental health plan it's free", it's not free here, the Gap is massive. And finding a good allied health professional like a physio who understands a complex body like mine is really difficult; we don't have enough of them. But I think we could work on our allied health access here."*

Time barriers

Time was listed as a barrier to access services in the ACT (32%). Women reported having to wait significant time to get an appointment, and often services were only available at inconvenient times. Time to access services took away from other tasks that women had to do such as working or looking after children, while wait times had a significant impact on their health.

> *"Waiting periods for services (even private) are too long. When something impacts on your daily life, a six month wait can feel like a lifetime."*

> *"…Lots of groups meet during the day, I have classes. I need things in the evening or on weekends, I can't make 2pm on Tuesday work."*

> *"Times suited to work. Appointments were scheduled and you were expected to be grateful for them no matter what the time. Doctors were rarely in time so a full day off work was often required to attend one 20-30 minute appointment. I went to Sydney in order to be diagnosed quicker as the waiting list for a rheumatologist in Canberra was 18 months. Arthritis courses, pain management classes, exercise classes specific to condition were all in the middle of the day during the week, I have a full time job so it makes it impossible to access these supports."*

> *"Things aren't available after work anyway usually. That is part of the difficulty with accessing services … is they're not available outside of hours"*

Specialists were mentioned six times regarding wait times, with some women reporting that they accessed services in Sydney for their chronic disease instead of enduring long wait time in the ACT.

Age-appropriateness of services

The term "age-appropriate" is used in this report to identify themes including not being diagnosed because of age, not feeling comfortable due to the general age of other members of support groups, or getting information about their condition that is not suitable for their age. Age-appropriateness was mentioned by 13 women, when they were asked about barriers when trying to access services in the ACT. In the focus group women spoke about some support groups that were not inclusive of their age, so they were unwilling to spend their limited time and energy to attend.

> *“No you’re too young to be ill.”*
>
> *“They are focused on elderly people and males. I find that they don't target people in my demographic so I don't want to waste what little energy I do have attending these programs.”*
>
> *“… once I turned 25 I could no longer see the counsellor who was already treating me there.”*

The age-appropriateness of services was also mentioned by 13 other women who had not mentioned it when asked what were the barriers to services in the ACT.

> *“Something for women my age with upper primary/high school age kids.”*
>
> *“I think a general support group for younger women with auto-immune conditions. Also perhaps support for managing chronic conditions while pregnant - felt very alone while I experienced that as well.”*

Women with chronic diseases who participated in the research reported that they often faced misdiagnosis or inability to access services due to their age.

> *“And that has – like that I think directly relates to like the pain management courses and all the support that is available, there’s none that is directed at young people who are trying to study and work and are expected to make a living and progress their life”*
>
> *“Yeah –…and one of the surprising things, I first went there a couple of months ago and it really shocked me that everyone was my parents’ age and older apart from one girl and I went straight to her and talked to her. …I don’t know about the rest of the spectrum but in arthritis in particular you’re stuck in the middle, there’s all the people who are 16 and under, the kids and lots of focus put on there because the kids, oh they’ve got arthritis – I’m not saying that it’s too bad for them but it is bad and then there’s people who are 60 etc and up, the osteoarthritis, the elderly, you have to look after them and you’re suspended in this little area.”*

Physical access and location of services

Physical access to and location of services as well as disability access was mentioned 14 times by women as one of the barriers to accessing services.

> *“Support groups were only held in south of Canberra at night and I didn't feel safe at the location walking from my car to the meeting.”*

> *"Physical issues such as services who have stairs, no wheelchair access and difficult parking meaning can't physically access those services. Had issues due to my age and conditions considered to 'only affect older people'…"*

Barriers by age groups

Participants in different age groups mentioned the barriers in varying amounts, however dissatisfaction with treatment by services and supports in the ACT was the biggest barrier in all age groups, as shown below in Figure 28.

Time barriers was the second largest barrier for the 18-24-year-old group (20%, n=7), whereas for the 25-34-year-old and the 35-44-year-old group second largest barrier was no known services. However, for the 45-50-year-old group, affordability was the second biggest issue.

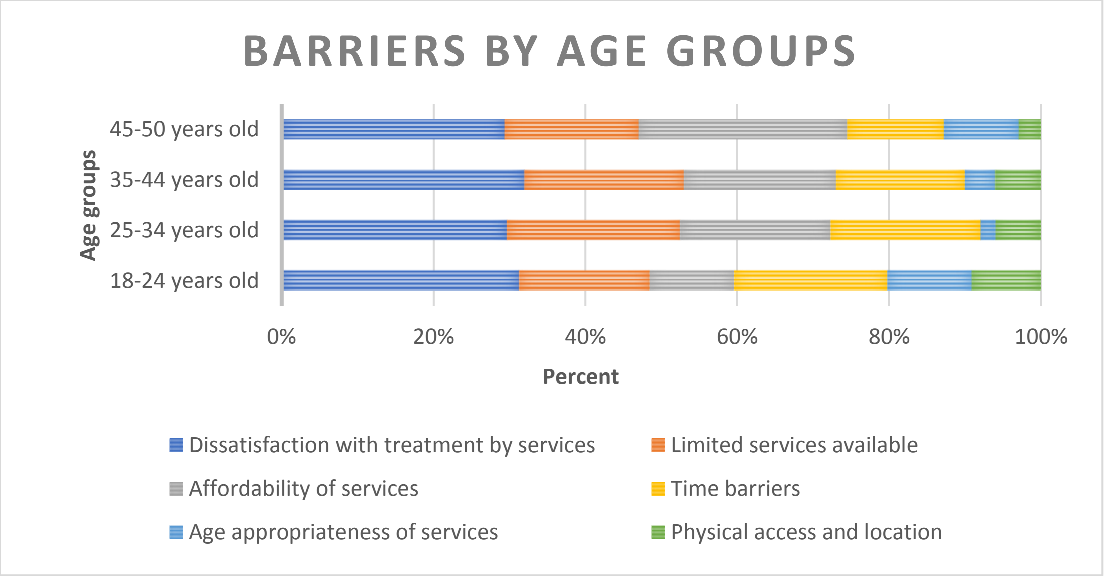

Figure 28: Barriers to ACT services and supports by age group.

Gaps in services

The participants were asked if there were any gaps in services or supports, in the ACT for managing their chronic disease. Participants identified the need for more support services for their condition (27%, n=30) including support groups for chronic disease management (n=7), support for their partners and exercise classes. The women in the focus group expressed how important it was to talk to people who understood what they were going through, other women who were dealing with the same life struggles, starting a family, finding employment and maintaining friendships, while having a chronic disease.

Peer support generally

Participants expressed the need to talk to other younger women about their experiences.

> *"Networks for re-establishing friendships and relationships after time away due to illness. Everyday support groups to go and chat as chronic illness is stigmatised and people isolate instead of seek support."*

> *“I really wish there was a group I could go to to meet other young people living with multiple chronic conditions.”*

> *“Lack of appropriate services, most seem targeted to older adults or to people newly struggling with their conditions. I don't need to relearn all the stuff about chronic pain etc, I know this as I've done programs in the past. I need better support programs targeted at emotional and physical support; eg. A young people's exercise group, a young people's support group.”*

Peer support for their chronic disease

Peer support for participants particular chronic disease was expressed.

> *“Youth groups for Crohn's and colitis.”*

> *“Group therapy with young people might be nice.”*

> *“I'm not aware of services or support available for young women with auto-immune disease in the ACT.”*

> *“I think a general support group for younger women with auto-immune conditions. Also perhaps support for managing chronic conditions while pregnant - felt very alone while I experienced that as well.”*

> *“More awareness, or support groups for young women experiencing gynaecological issues. More awareness in schools surrounding what is normal for a period and what is not- there are so many young girls I talk to that think having excruciating pain during a period is normal.”*

> *“They don't really exist for my condition. At 46 I am too old for the Young people with arthritis group, and too young for the standard group, which are filled with people in their 70s with Osteoarthritis. I have inflammatory arthritis, and our support body, Arthritis Australia, doesn't even seem to know the difference between inflammatory arthritis and degenerative arthritis, certainly the people at the ACT branch did not a few years ago when I approached them. They were so hopeless they turned me off seeking out any other support groups.”*

Peer support for disease management

A few women find it difficult to find services and support for their chronic disease and would like to have services to manage their condition.

> *“Multiple diseases require a myriad of appointments. Would be nice to have a multidisciplinary facility here.”*

> *“I struggle to find peer support and am sick of wading through the rubbish that exists on the internet. I work full time and like others with autoimmune conditions have other family members who also need my support. I hate it that I can't access services*

> *because they either don't exist or are hard to find outside of office hours. I am worried about my health and future as well as those who depend on me."*

Support to maintain a work life

Chronic disease affects participants ability to work, those that are still in the workplace have expressed a desire for have support to continue working.

> *"I want a women's support group for professionals. How to handle confronting conversations, when to disclose, how to get financial support etc."*
>
> *"It would be great to have someone to support me at work. I have had no support from them at all and nobody to advocate for me. Support groups with health professionals knowledgeable about the chronic diseases. Having help from others feeling the same, but also professionals who are empathetic and want to help."*

Partner support

Women also expressed the need for appropriate support for their partners, because of their dependence on their partners.

> *"My husband found that when I really sick with depression, he went to a carers' group 'cause I was you know really bad for a really, really long time but he just couldn't relate to any of the people there 'cause they were all parents of young people with schizophrenia and you know for him it was his wife with severe depression. And you know it was hard for him coming home and finding me you know in a very bad state and you know there was just no support for him at all.*
>
> *"Yeah. We just had to – 'cause the last few months or at the beginning of the year I was completely nutso on the drugs - having – we had to have some really like important conversations as I was taken off that 'cause I'm like look, you've been my carer, I want my husband back like you want your wife back, how do we do that? And yeah so a service of some sort or even just a support group where you can come and go okay, what – like there's lots of – I mean what does marriage look like with a chronic illness and you know for my partner as well, not just for me."*
>
> Partner given up job to care for me, I lost licence due to disease. I'm not working, physically and mentally limited. I have been rejected for DSP and NDIS. I find it difficult to navigate system, procedures etc. I feel let down. I have only just gotten chronic disease management plan as I didn't know they existed. I would love more help to understand what to do. I don't want to be so sick, alone and depressed."

Exercise classes

Fourteen percent of the gaps mentioned in survey responses listed exercise classes which were affordable and appropriate to their chronic disease (n=16) as a service they would like access for their chronic disease. Women in the focus group also discussed maintaining their health with the chronic disease.

> *“One-to-one support around managing exercise challenges and limitations. One-to-one support around managing the unpredictable nature of the disease (totally 'normal' for a week/s then suddenly crippled with fatigue and/or pain): particularly as this affects work and social relationships.”*

> *“I tried to get home help when I was a stay at home mum and at uni part time but was told it was only for the aged. Physio and massage for my condition. Exercise group specific for younger women with limitations…”*

A few participants in the survey that discussed exercise classes also mentioned that they need them to be on at appropriate times and suitable to their age.

> *“Hydrotherapy that actually takes place in the evenings and caters to those that work full time.”*

> *“A support group that met on weeknights and was more open to newcomers. Hydrotherapy classes catered to younger people. Exercise classes that cater to chronic conditions and younger people.”*

> *“Services and programs outside of work hours, rather than only during main business hours. Ie even private gyms run classes suited for people with arthritis during week days.”*

Positive aspects of accessing services in the ACT

Even though the women with chronic disease expressed their difficulties in accessing services, supports and courses in the ACT, they also reported positive experiences. They discussed how much they appreciated caring GPs, good experiences in hospitals, and health professionals who understood their complexities.

> *“I actually got in to see someone last week at the hospital and she actually treated me like a person, not a bunch of symptoms. It’s actually nice to have someone sit down and say okay, this is what we’re going to do, this is what we have, we might start you on methotrexate, blah, blah, blah, blah, blah, we’ll keep you currently on what you’re on but we want to try and eliminate some of that as well like finally, someone who actually treats me like I’m a person and not just oh you’ve got this, this, this, this and this. It was actually really refreshing.”*

The women in the focus group expressed the importance of being listened to and believed. They appreciated GP’s who were empathetic and proactive. It’s important to women that they feel cared for, especially when they are looking for answers.

> *“I found [a GP] who’s amazing and got the sort of mental health care plan and stuff. And found a psychologist who bulkbilled in Civic so that was sort of – I was like that’s my option, there’s no other – yeah so I’m in there and she was – she’s a very nice person, we didn’t click so that didn’t work fantastically but I just sort of found my way with the things I could get access to, I guess.”*

> *"… as soon as I walked in not only did she believe me but she also listened to what I wanted. It was a case of look, I am having these issues, I want the pain to go away and she's like okay well here are the kinds of meds we can put you on, we're also going to send you to this person and they might be able to set up another plan and here's a pain therapist for you and you can try and do some of the mental stuff as well. And I was like where have you been?"*

Chronic disease and self-care activities

Women were asked about their experiences in participating in self-care activities for preventative health, such as participating in physical activity, maintaining a healthy diet, and maintaining a healthy weight.

Participating in exercise

Seventy five of the women who responded (47%) reported that they they were able to meet the Australian Physical Activity Guidelines of at least 2.5 hours per week of moderate intensity.[107]

Eighty five women (53%) reported having difficulties in meeting the guidelines. Figure 29 shows the barriers they mentioned.

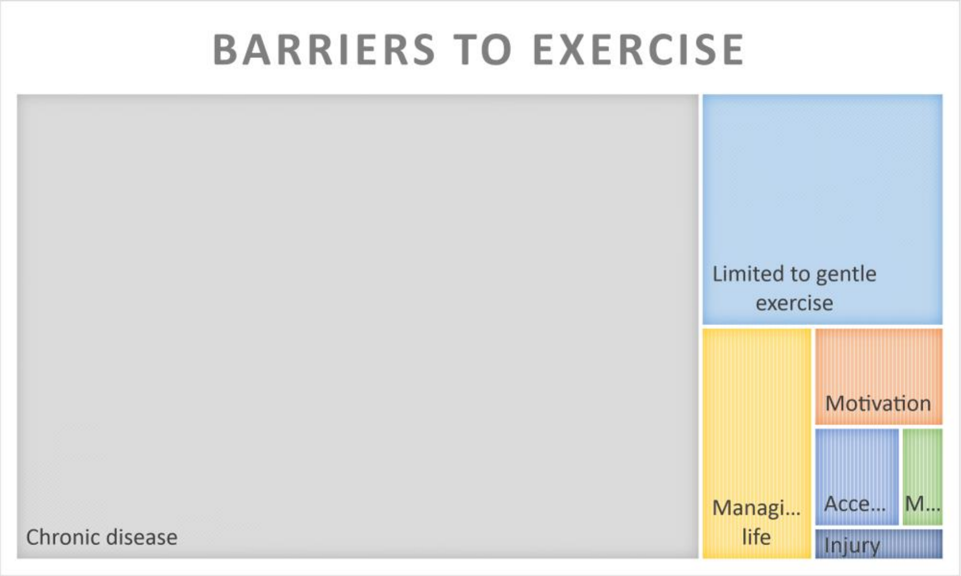

Figure 29: Barriers to exercise for women with chronic disease.

Women reported the following barriers in doing exercise:

- Chronic disease symptoms– symptoms such as pain and fatigue were extremely limiting.
- Limited to gentle exercise – maintaining some physical activity but unable to achieve moderate levels of activity.
- Managing life, family and work commitments.

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[107] Department of Health, *Australia's physical activity and sedentary behaviour guidelines*, Canberra, 2017, retrieved on the 6th of February 2018; http://www.health.gov.au/internet/main/publishing.nsf/content/health-pubhlth-strateg-phys-act-guidelines

- Motivation – difficulties with motivation.
- Accessibility – exercise barriers such as affordability and embarassment in public.
- Injury –injury unrelated to their chronic condition.
- Medication –reduced ability related to medication.

> *"If I walk more than 15 minutes at a fast pace I end up exhausted and in bed for 24 hours"*
>
> *"I can do a lot more hours of slow walking, but anything moderate intensity or higher causes pain in my legs which can last for days or weeks after the fact. I also have hypermobile joints and can easily injure myself while performing intense exercise, and have had to give up running due to this. This is a result of the lipoedema."*
>
> *"I am in too much pain. I can usually manage 10 minutes a day."*
>
> *"ME is characterised by abnormal physiological response to activity or exertion. Exertion makes the symptoms worse."*

The largest barrier for participating in exercise was the chronic disease itself for 86% of those with a barrier (n=73). Pain, fatigue, and other symptoms of their disease limited their ability to do any exercise at all, or meant that they could only do gentle exercise (15%, n=13).

Women in the focus groups also discussed the issues associated with maintaining exercise. Some said they were unsure of the types of exercise that they were able to do with their limitations, and others were not able to exercise due to pain and fatigue. Some women reported that physical activity was incompatible with their condition, and making it worse, while others said that exercise was beneficial in managing their condition.

> *"I am anaemic due to IBD and so have difficulty with exercise as I am often out of breath just by walking moderately faster. Also, I suffer from extreme fatigue from both chronic diseases which means that I often do not have enough energy to even consider exercising."*
>
> *"I walk for 10-60 minutes daily. I do heavy gardening when I can. If I'm doing something intellectually, physically, socially or emotionally demanding, I must rest the day before and the day after. I shine at events, collapse for days after."*
>
> *"I really struggle because I have got a very active toddler and some nights I'll be like I'm going to bed early, I'm getting a good night sleep, and then he doesn't get a good night sleep so I don't get a good night's sleep. Then you've got to go I'll push through and go to work today, and because I work part time as well I feel really bad having a day off. And then if my son gets sick or I get sick or whatever – so trying to fit in exercise is crazy but I try and do it, like I'll take him for a bike ride so expend some of his energy but it's a real struggle. By the time I get to the end of the day…"*

Across all ages, as shown below in Figure 30, women in the research expressed that their main barrier to maintaining exercise is their chronic condition.

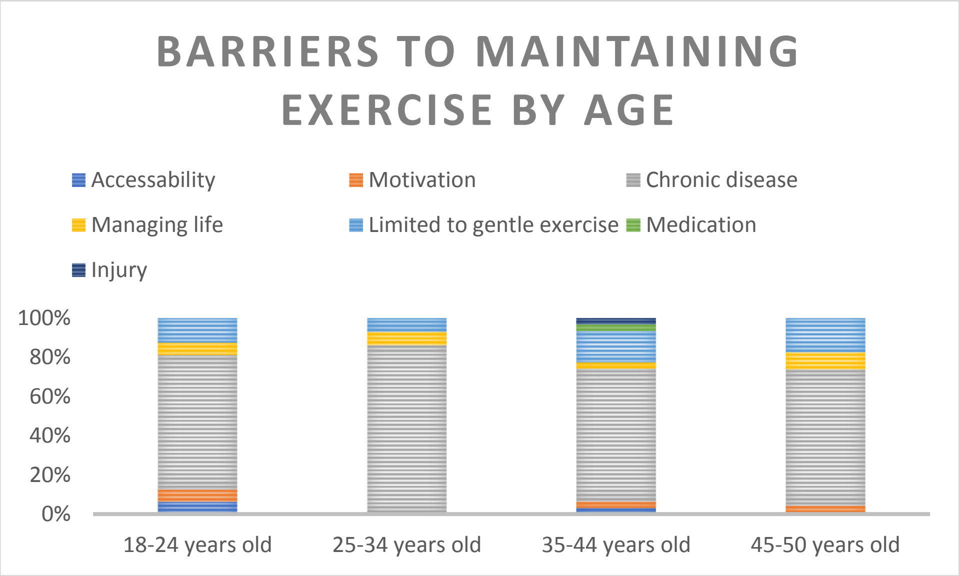

Figure 30: Barriers to maintaining exercise by age group.

Maintaining a healthy diet

One hundred and seventeen women reported that they were able to maintain a healthy diet (72%).

The main barriers that respondents listed that impacted upon their ability to maintain a healthy diet were:

- Chronic disease – symptoms such as pain and fatigue, food intolerances.
- Cost – the affordability of healthy food.
- Eating habits – comfort or stress eating, poor motivation.
- Managing life – juggling work and family.
- No control over food.
- Appetite – medication side effects.

Figure 31 shows that, of the 44 women who reported not being able to maintain a healthy diet 68% (n=30) identified the main barrier as their chronic disease.

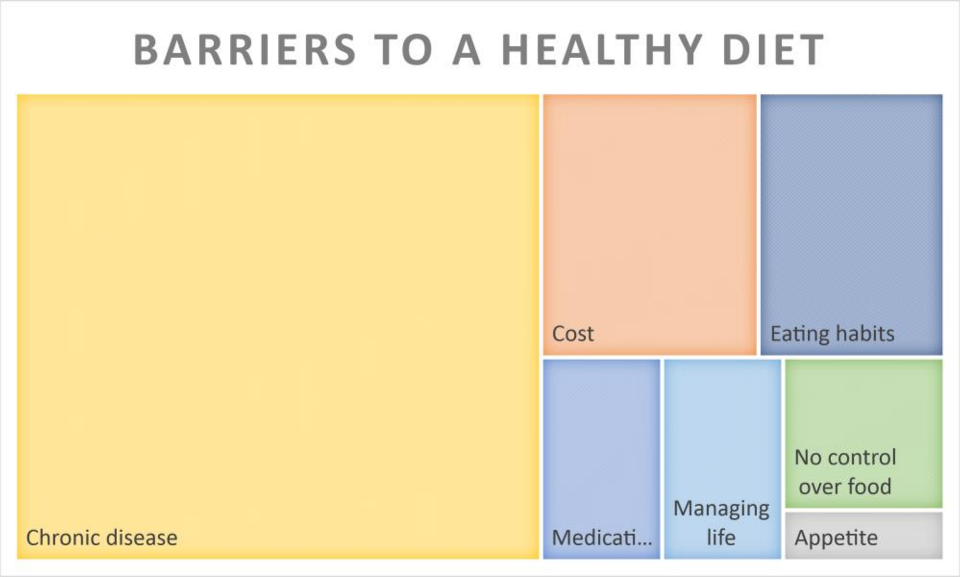

Figure 31: Barriers to a healthy diet for women with chronic disease.

> *"I know how and used to, but circle of depression, sleep and work issues has led to being time poor, energy poor and opting for quick and easy over healthy. I try to minimise unhealthy by eating frozen Healthy Choice etc meals"*
>
> *"It's mostly healthy, but due to gut issues and trouble getting proper treatment and affording medication, I often stop eating for days to reduce the impact of my health conditions or I eat unhealthy food such as yoghurt or ice cream as the only meal I eat during a day as it's easy to get down and stay down. I also have trouble doing grocery shopping so cannot buy and transport home the food I need."*

Figure 32 below reveals the differences in the barriers to maintainin a healthy diet by age group. Notibly, eating habits was not a barrier to healthy eating for the 45-50 year olds and only the 25-34 years old listed that appetite was a barrier.

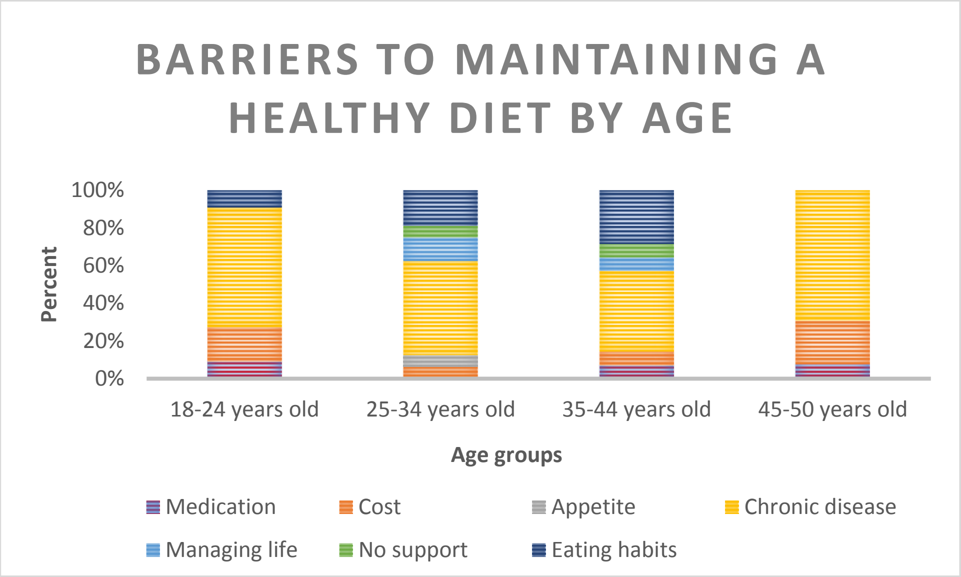

Figure 32: Barriers to maintaining a healthy diet by age group.

Maintaining a healthy weight

Seventy one respondants (44%), reported they were able to maintain a healthy weight. Ninety women (56%) reported having difficulty in maintaining a healthy weight.

The women listed the following barriers to maintaining a healthy weight:

- Limited exercise – not being able to exercise due to a variety of reasons such as limited access to appropriate exercise classes, and chronic disease symptoms like pain and fatigue that limits ability to exercise.
- Medication – side effects such as weight gain.
- Chronic disease – symptoms of disease such as pain and fatigue, as well as conditions that have a metabolic effect (polycystic ovary syndrome, thyroid disease).
- Eating poorly – poor diet, or poor eating due to disease effects.
- No reason – some women just reported on the amount of weight they needed to lose.
- Other – combination of metabolism, medication, and quitting smoking.

As shown in Figure 33 below, the main barriers listed were limited exercise (32%, n=36), medication (21%, n=23) and the impacts of their chronic disease (19%, n=21).

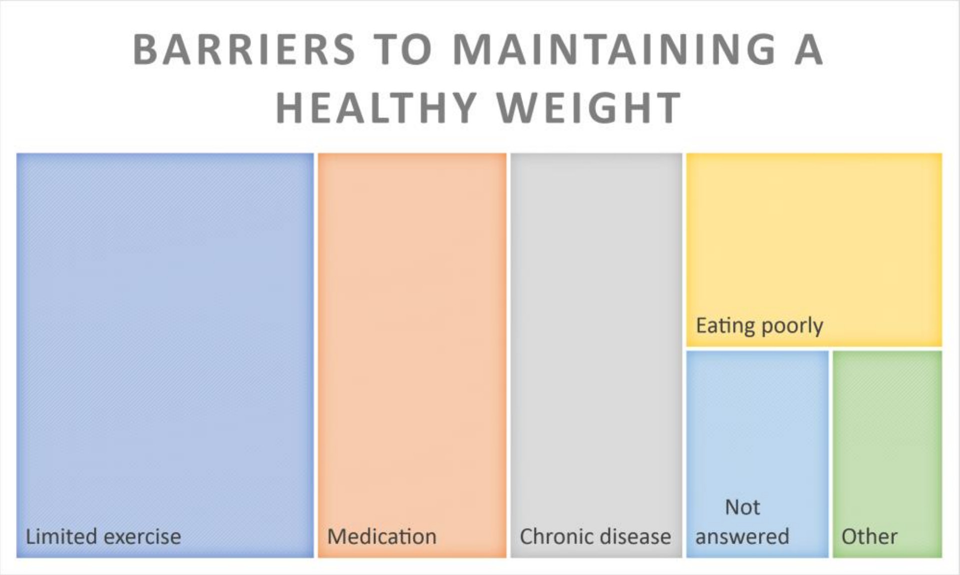

Figure 33: Barriers to maintaining a healthy weight.

Table 7 shows the differences in barriers to a healthy weight between the age groups.

Age groups	Number of women by age who had difficulty maintaining a healthy weight	Percent of women by age who had difficulty maintaining a healthy weight
18-24 years old	10	37%
25-34 years old	30	55%
35-44 years old	29	58%
45-50 years old	21	72%

Table 7: Percentage and number of women by age who had difficulty maintaining a healthy weight.

In three of the age groups - 18-24, 25-34 and 45-50 year olds - women reported that limited exercise was the largest barrier to maintaining a healthy weight, as displayed in Figure 34 below. In the 35-44 year old age category, women reported impacts of their chronic disease as the largest barrier to maintaining a healthy weight weight.

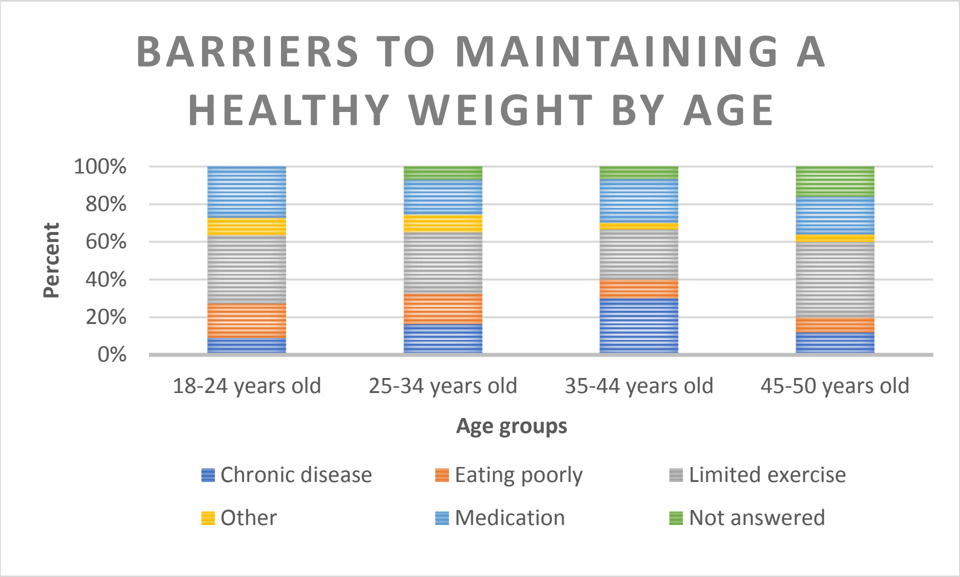

Figure 34: Barriers to maintaining a healthy weight by age group.

> *"I put on weight extremely easily and find that despite my best efforts, I cannot always stick to the optimum amount of exercise/ healthy diet due to fatigue or mental health issues."*

> *"Prior history of severe obesity. Even at my lowest weight (85kgs) I looked 'sick' due to the weight loss and excess skin despite still being considered obese. Also stress eat and eat as a result of psychiatric medication."*

Public health campaigns

Participants in the focus groups were asked about health promotion messages from public health campaigns, who admitted they felt angry and frustrated. Most agreed that losing weight would be of benefit, but their conditions were not preventable, and impacted upon their ability to meet the expectations of those messages. They did not understand where they would get the time and energy to do that.

> *"… a lot of our conditions here, they're not preventable you know they just come you know come upon you. In terms of the exercise stuff you know my condition's a little bit different in that you know I have periods where I can't do anything you know like I live in a two-storey house and I just need my husband to get anything I need from upstairs but then I have times when I'm fantastic you know and I can you know walk the dog for an hour and then I can come home and get on the exercise bike and you know like I'm absolutely fine and fit and whatever. And then I have a flare again you know and it's you know nothing in the public domain around you know exercise actually helps someone with this kind of condition manage that variability, you know? I've still after all these years not nailed how do I exercise when I feel well without bringing on a flare?"*

> *"It does nothing. Like they keep on saying to me you need to lose weight and it's like… 'How?'"*

> *"It's frustrating, it's like you need to lose weight and it's like okay, have you got a miracle cure 'cause you know I'm trying but nothing's working?"*

Participants in the focus groups said that they found the messages intolerable, especially when they struggle with the activities of daily living. They also found the messages too general and not applicable to their lives.

> *"I have to [be on a special diet] to keep my Crohn's disease under control, and even the other week with my housemate he was saying, 'Chickpeas are so healthy' and I went, 'They actually make me really ill' and he's like, 'Nah they're great for you'. It is not one fits all. Your healthy food campaign does not apply to everybody."*

> *"I think that comes from social awareness of chronic illnesses. When I first fell really ill I couldn't sleep and all these terrible symptoms [and] everyone tells me, 'Go exercising, you just need more exercise' and only later on after I struggled for about two or three years I realised I should not have exercised. The more I exercised the lower my adrenaline production and the worse I get, and actually during those two years my condition worsened because I thought I needed to exercise… I have another issue with my weight because I literally put on 10 kilos in the first week of taking antidepressant to help with sleeping and the thing is not everyone who are overweight are because they have bad diet or lazy, it could be from a complication but people don't really realise that, they say, 'All you need to do to get better is exercise, eat better and sleep well' but it's not easy when you actually have a chronic illness."*

Discussion

Our findings show that younger women with chronic disease are experiencing barriers to accessing services and support to help maintain their health in the ACT. These are different to the barriers experienced by older people with chronic disease, yet much of the health system response to chronic disease is focussed on older people. Moreover, much of the response is also focussed on the chronic diseases caused by lifestyle behaviours, whereas the diseases which these younger women described were related to genetic, hormonal or infectious factors.[108]

Most women in this study reported multi-morbidity, which impacted how they rated their health and which they identified as affecting every part of their life. They expressed frustration in trying to maintain their roles as an employee. And even though many women in the study were highly educated, they identified how their work-life was interrupted by periods of treatment and recovery from their chronic disease resulting in absenteeism, concerns about discrimination because of their illness, the need to reduce working hours. It impacts on the quality of work, the need to cease employment, and the resulting financial and familial repercussions. Their role as a partner, a mother, and/or student was also impacted upon by their chronic disease.

The younger women described facing barriers when accessing health care such as not being listened to or believed, which often impeded correct diagnosis or timely access to appropriate treatment and support. This shows that there are still remnants in the present day of 'female hysteria' which dates back 4000 years, and was a common diagnosed condition in women.[109] Women are still experiencing being distrusted about their own bodies.[110] The difficulties women face are often due to symptoms from chronic diseases which look different in women compared to men.[111] Diseases that are more prevalent in women than in men are often over looked. [112] In addition, clinical trials are mostly always on men which places limitations on treatment options for females who are biologically, genetically and hormonally different.[113] We found that the diseases themselves impacted on the ability of some women who had difficulty with maintaining self-care activities such as healthy eating, exercise, and a healthy weight. As a result, some women identified that health promotion messages were not suitable and inappropriate for them - the most common reason for compromised participation in self-care activities was the chronic disease itself.

As younger women, the chronic disease also impacted on their life roles – as employees or students, as partners or mothers, or friends.

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[108] D Fairweather & N R Rose, 'Women and Autoimmune Diseases', *Emerging Infectious Diseases,* vol. 10, no. 11, 2004, pp. 2005-2011.

[109] C Tasca et al, 'Women and hysteria in the history of mental health', *Clinical Practice & Epidemiology in Mental Health*, vol. 8, 2012, pp. 110-119.

[110] S Werth, Women, work and chronic illness: an exploratory investigation of themes from HILDA, Griffith University, Queensland, 2010.

[111] G Baggio et al., 'Gender medicine: a task for the third millennium', *Clinical Chemistry and Laboratory Medicine*, vol. 51, no. 4, 2013, pp.713–727.

[112] S Werth, Women, work and chronic illness: an exploratory investigation of themes from HILDA, Griffith University, Queensland, 2010.

[113] K A Liu & N A Dipietro Mager, 'Women's involvement in clinical trials: historical perspective and future implications', Pharmacy Practice, vol. 14, no. 1, 2016, pp. 708.

Multi-morbidities

More than half the women in the present study had more than one chronic disease. Research shows that in Australia and other OECD countries, multi-morbidity is the "rule rather than the exception".[114] [115] In addition, women have more multi-morbidity, and more often than men.[116] Sixteen percent of women surveyed had four or more conditions, and this level of multi-morbidity is often strongly associated with functional decline.[117] Moreover, 74% of the women in our research, who had four or more chronic diseases, rated themselves as having poor or very poor physical health. Multiple chronic diseases increase and add complexity, and is depicted by poor self-rated health, and poor quality of life, in addition to morbidity and mortality.[118] [119] [120]

Eighty seven percent of women in the research who had more than one disease reported that they also had barriers to accessing services and supports. People with multi-morbidities are at risk of poor quality care, as they have complex care needs which are impacted by having to interact with multiple health care providers.[121] [122] Some women in the present study felt that this contributed to the mismanagement of multi-morbid chronic diseases. One women said of a service provider, *"they were very apathetic towards me and made my mental health worse (which in turn made my physical illness harder to cope with)."*

Although multi-morbidity was seen in all age groups in this research, the groups with the highest amount was the 18-24 year old and the 25-34 year old's with 81% and 65%, respectively. This has significant implications for the individual women over a lifetime, as the financial burden of multi-morbidity is greater than that for single conditions of which multi-morbidity can cost two and a half times more to the individual than a single disease.[123] *"When I was diagnosed with epilepsy as a 17 year old woman ... Barriers were long term. … needing medication for life and the long-term cost..."*

These ages can also be a vulnerable stage in their lives, where they are trying to establish themselves, completing their studies, starting a career or starting a family.[124]

ACT Health's draft Territory-wide health services framework aims to integrate health services in the ACT. The aim is to make the health system easier to navigate by grouping hospital and

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[114] M Fortin et al., 'Prevalence of multimorbidity among adults seen in family practice', *Annals of Family Medicine,* vol. 3, 2013, pp. 223-228.

[115] C Harrison et al., 'The prevalence of diagnosed chronic conditions and multimorbidity in Australia: A method for estimating population prevalence from general practice patient encounter data' *PLoS ONE*, vol. 12, no. 3, 2017, pp. 1-13.

[116] K Agur et al., "How does sex influence multimorbidity? Secondary analysis of large nationally representative dataset', *International Journal of Environmental Research and Public Health*, vol. 13, 2016, pp.1-13.

[117] E A Bayliss et al., 'Predicting declines in physical function in persons with multiple chronic medical conditions: what we can learn from the medical problem list' *Health and Quality of Life Outcomes*, vol. 2, no. 47, 2004, pp. 1-8.

[118] M Fortin et al., 'Multimorbidity and quality of life in primary care: a systematic review', *Health and Quality of Life Outcomes*, vol. 2, no. 51, 2004, pp. 1-12.

[119] O McDaid et al., 'The effect of multiple chronic conditions on self-rated health, disability and quality of life among the older populations of Northern Ireland and the Republic of Ireland: a comparison of two nationally representative cross-sectional surveys', *BMJ Open*, vol. 3, no. 6, 2013, pp. 1-11.

[120] M Rijken, 'Comorbidity of Chronic Diseases: Effects of Disease Pairs on Physical and Mental Functioning', *Quality of Life Research*, vol. 14, no. 1, 2005, pp. 45-55.

[121] M Fortin et al., 'Multimorbidity and quality of life in primary care: a systematic review', *Health and Quality of Life Outcomes*, vol. 2, no.51, 2004, pp.1-12.

[122] J Marlowe, M Maeyer & J Greer, 'Complex Chronic Illness: An essential target in health cost management', *World at Work Journal*, Third Quarter 2009, pp. 47-56.

[123] J Rogowski, L A Lillard & R Kington. 'The financial burden of prescription drug use among elderly persons', *Gerontologist*, vol. 37, no. 4, 1997, pp. 475–482.

[124] A Steel et al, 'Women's health in NSW – a life course approach: a rapid review', Sydney, 2013.

community-based services for particular conditions in their own "Centres".[125] The issue that still needs to be thought through in the framework is the management of people with multi-morbidity, particularly where their diseases would not be treated at a single "Centre". A single disease focus results in fragmented care and potentially poorer patient outcomes for those with multi-morbidity.[126] [127]

Mental health conditions and multi-morbidity

Sixty-five women in our research had a mental health condition. Compared to men, women have more mental health conditions when discounting for substance abuse.[128] Mental health conditions have the largest number of healthy living years lost (disability- adjusted life year, DALY's).[129] [130] Of the women who responded to the survey, the younger groups 18-24 and 25-34 year olds, had higher rates of mental health conditions than the older ages.

Eighty six percent of women who said they had a mental health condition also had a chronic physical disease. Women experience multi-morbidity differently to men, as they often experience a mix of physical and mental health conditions.[131] Those with chronic disease must adjust to life with limitations regarding aspirations, lifestyle, and employment.[132] Feelings of loss and sadness may turn into depression and anxiety for some.[133] The women surveyed who had multi-morbidities were far more likely to have a mental health condition, and this is consistent with current literature.[134] In addition, physical limitations or poor self-rated health have been associated with depressive symptoms.[135] Multi-morbidity with depression tends to worsen the health of the person compared with depression alone.[136] Mental health conditions have been found to be a predictor of other conditions, such as cardiovascular disease, where higher levels of cortisol negatively impact heart health.[137] [138]

Eighty two percent of women with mental health conditions experienced barriers to services and supports in the ACT. Borba et al. found women with serious mental illness experienced affordability as a barrier to health services.[139] Women in Borbas et al. study said at times they

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[125] ACT Health, 'Draft ACT Health territory-wide health services framework, 2017-2027', Canberra 2017, retrieved on the 16th of October 2017: https://www.health.act.gov.au/sites/default/files//Territory%20Wide%20Health%20Services%20Framework%20%28TWHSF%29-18Sept17-with%20draft.pdf

[126] K Agur et al., 'How does sex influence multimorbidity? Secondary analysis of large nationally representative dataset', *International Journal of Environmental Research and Public Health*, vol. 13, 2016, pp.1-13.

[127] D Mangin, I Heath & M Jamoulle, 'Beyond diagnosis: rising to the multimorbidity challenge' *BMJ,* vol. 344, 2012, pp.1-3.

[128] Australian Bureau of Statistics*, National survey of mental health and wellbeing: summary of results*, Canberra, 2007, retrieved on the 13th of February 2018: http://www.ausstats.abs.gov.au/Ausstats/subscriber.nsf/0/6AE6DA447F985FC2CA2574EA00122BD6/$File/43260_2007.pdf

[129] Department of Health and Ageing, *National women's health policy 2010*, Canberra, 2010.

[130] Australian Institute of Health and Welfare, *Australian burden of disease study, Impact and causes of illness and death in Australia*, Canberra, 2011.

[131] K Agur et al., "How does sex influence multimorbidity? Secondary analysis of large nationally representative dataset', *International Journal of Environmental Research and Public Health*, vol. 13, 2016, pp.1-13.

[132] J Turner, 'Emotional Dimensions of Chronic Disease', *Western Journal of Medicine*, vol. 172, 2000, pp. 128-130.

[133] Ibid.

[134] J A Swartz & I Jantz, 'Association between nonspecific severe psychological distress as an indicator of serious mental illness and increasing levels of medical multimorbidity', *American Journal of Public Health*, vol. 104, no. 12, 2014, pp. 2350-2358.

[135] J M Gunn et al., 'The association between chronic illness, multimorbidity and depressive symptoms in an Australian primary care cohort', *Social Psychiatry and Psychiatric Epidemiology*, vol. 47, no. 2, 2012, pp. 175-84.

[136] Moussavi et al., 'Depression, chronic diseases, and decrements in health: results from the World Health Surveys', *The Lancet*, vol 370, 2007, pp. 851-858.

[137] Wilkinson R & Marmot M (eds), *Social Determinants of Health: The Solid Facts, 2nd edn*, World Health Organization, Geneva, 2003.

[138] M Prince et al., 'No health without mental health', *Lancet*, vol. 370, 2007, pp. 859–77.

[139] C P C Borba et al., 'A qualitative study examining the perceived barriers and facilitators to medical healthcare services among women with a serious mental illness', *Women's Health Issues,* vol. 22, no. 2, 2012, e217–e224.

could not access services as they weren't able to pay for even the small co-payment, and likewise in our research, women expressed frustration with the cost of services;

> *"The main barriers I've faced were financial. Seeing a neurologist for migraines can cost $200 per session. I can see a psychologist ten times per year for free via Headspace and the Mental Health Care Plan, but availability of sessions is limited and ten per year is not frequent enough for the severity of my condition. Seeing a private psychologist often costs at least $200 per session. These are large expenses on a limited student budget."*

Women living with mental health conditions who participated in the focus group in research from the WCHM, reported also having significant affordability barriers to health care in the ACT, limiting their opportunities to help themselves.[140]

Financial impacts

The ACT's Chronic Conditions Strategy 2013-2018 recognises that:

> *'People with chronic conditions can experience cost barriers associated with managing single or multiple chronic conditions, multiple pharmacotherapies, and accessing a range of health services, including those for which there is little or no rebate available. Accessing some services may require travel, accommodation or other support services and can result in additional out-of-pocket expenses.'*[141]

The cost of living with a chronic disease is such that the healthcare demands are sometimes unaffordable when all aspects of managing the condition are factored in. This includes medication, specialised food, doctors, different types of specialists, medical equipment such as inhalers or glucose testing machines and other health care costs.[142] [143] [144] [145] And even with universal coverage, out of pocket costs can be high.[146] Woman described the ongoing financial cost of chronic disease which was a common view amongst women in this research;

> *"… the cost of treatment, medications, frequent hospitalisations and not being able to work impacts financially and limits or prevents attending appointments, accessing physio, therapies and medication."*

Some women reported that it was incredibly difficult to keep afloat financially, and others said that they sometimes would put off doctor's visits or tests as they couldn't afford to go. ACT has the

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[140] A Carnovale & E Carr, *It goes with the Territory! ACT women's view about health and wellbeing information*, Women's Centre for Health Matters, Canberra, 2010.

[141] ACT Health, *ACT chronic conditions strategy- improving care and support 2013-2018*, Canberra, 2013, retrieved on the 12th of January 2018; https://www.health.act.gov.au/sites/default/files//Policy_and_Plan/Chronic%20Conditions%20Strategy%202013%20-%202018.pdf

[142] V Tran et al., 'Taxonomy of the burden of treatment: a multi-country web-based qualitative study of patients with chronic conditions', *BMC Medicine*, vol. 13, no. 115, 2015, pp. 1-15.

[143] L M Hunt, M Kreiner, H Brody, 'The changing face of chronic illness management in primary care: a qualitative study of underlying influences and unintended outcomes', *Annals of Family Medicine*, vol. 10, no. 5, 2012, pp. 552-560.

[144] Ibid.

[145] Y Jeon et al., 'Economic hardship associated with managing chronic illness: a qualitative inquiry', *BMC Health Services Research*, 2009, vol. 9, no. 182, pp. 1-11.

[146] A Kemp et al. 'How much do we spend on prescription medicines? Out-of-pocket costs for patients in Australia and other OECD countries,' *Australian Health Review*, vol. 35, no. 3, pp. 341-9.

lowest rates of bulk billing in the country[147] which is likely to impact the affordability of services and reduce access to treatment for women.[148] Chandler, Corscadden and Levesque have found that skipping out on health care due to cost is a regular occurrence for some people with chronic disease.[149]

> *"The fact that I have to rely on what the hospital can provide because I have no income and no HCC as my husband is over the limit.... when someone suffers from multiple chronic debilitating and degenerative diseases, it's very expensive. I often go without scans, medications etc due to the guilt I have. I will wait u til the hospital can do a scan....multiple times it has been well over 12 months for a scan or an ultrasound."*

People with chronic disease come across economic hardship both when receiving financial support from the government and when ineligible for subsidies. [150] Which was also true for women in the research:

> *"I've spent years on welfare, which was the only thing keeping me from starving at the time, and I needed it, because I was too sick to work. We still struggle every week with making ends meet; getting all the bills paid, getting the rent paid, getting enough good food to keep us from getting sicker, getting enough of the meds we need to keep us from getting sicker, and so on."*

> *"There seems to be an assumption that people who are employed have access to a bottomless pit of money to fund all the ancillary services required to manage their condition - like physio, exercise physiology, exercise (swimming; fitness classes) etc. The cost of that, and medication, is prohibitive. Often it's a choice of one or the other, and sometimes, neither."*

Multi-morbidity is expensive, the more conditions a person has, the more services they are likely to need depending on the types of disease. Research suggests the health system is not setup to deal with the presence of multi-morbidity, therefore requiring patients to use many services, rather than just one or two that suit their needs.[151] van der Aa et al. list "discontinuity of the process, insufficient time allotted, understaffing, and facilities that are not sufficiently adapted to their needs" as reasons why patients with multi-morbidity have greater health burden.[152]

> "Even without the cost of specialists potentially the increased number of sick days or increasingly having to travel and pay for parking because you're not well enough to walk to the bus stop or stuff like that, it adds up a lot."

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[147] Australian Institute of Health and Welfare, My healthy communities; Web update: Medicare Benefits Schedule GP and specialist attendances and expenditure in 2015–16, Canberra, 2017, retrieved on the 15th of February 2018; http://www.myhealthycommunities.gov.au/our-reports/gp-and-specialists-attendances-and-expenditure/august-2017/web-update

[148] E J Wolkom, D Loxton & J Robertson, 'Cost of medicines and health care; A concern for Australian Women across the ages', *BMC Health Services Research*, vol. 13, no. 484, 2013, pp. 1-9.

[149] E J Callander, L Corscadden & J Levesque, 'Out-of-pocket healthcare expenditure and chronic disease – do Australians forgo care because of the cost?' *Australian Journal of Primary Health*, vol. 23, no. 1, 2017, pp. 15-22.

[150] E J Callander, L Corscadden & J Levesque, 'Out-of-pocket healthcare expenditure and chronic disease – do Australians forgo care because of the cost?' *Australian Journal of Primary Health*, vol. 23, no. 1, 2017, pp. 15-22.

[151] M J van der Aa, et al., 'Patients with multimorbidity and their experiences with the healthcare process: a scoping review', *Journal of Comorbidity*, vol. 7, no. 1, 2017, pp. 11-21.

[152] Ibid

Impacts on education and study

Tertiary education allows people with chronic disease to access greater employment opportunities.[153] Thirty seven percent of the women from the 18-24 year old group in our research reported that chronic disease affected their education. The women commented on having to reduce their study workload due to fatigue, pain, and energy levels, and some were unable to work part time. Students experience significant levels of stress completing a degree[154] in the presence of a chronic disease.[155] One woman from the study said that she had to withdraw from university as she wasn't well enough to continue. Students with chronic diseases have a hard time arranging appointments around their schooling, transitioning from adolescence to adult care, reported poor quality of life regarding social activities, and poor management of their condition.[156] The difficulty in getting a qualification and maintaining employment is described by this quote:

> *"I've had some form of chronic disease since I was 11 (I'm 40 now) and it has interfered with every single aspect of my entire life. I did not finish high school. I struggled with holding down any sort of full-time job, or even part-time. I struggled to finish a part-time University degree (as a mature age student) and only completed it with the help of understanding lecturers who got me through."*

Impacts on family life and relationships

Many of the women discussed how symptoms of chronic disease impacted their family life and relationships. In research that focused on women with lupus, women described how distressing it was that they weren't able to fulfil their role as a mother, partner, or to spend quality time with the family.[157] Similarly, for some of our respondents the debilitating nature of symptoms like pain and fatigue meant that it was difficult to maintain their life role. Women discussed having no energy to look after the family after a work day and feeling inadequate because of it. It has been shown that pain and fatigue significantly affect the ability of women to do housework, care for their children, and look after their family.[158] And compared to men, women are more likely to experience chronic pain, and if the chronic pain interferes with women's daily activities it has a strong impact on self-rated health.[159]

> *"I can just manage to get up and go to work each day, which needs to be done to pay the bills. Most time I spend with my kids is curled up in bed because idant do much*

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[153] K E Jung, 'Chronic illness and educational equity: the politics of visibility', *NWSA Journal*, vol. 14, no. 3, 2002, pp. 178-200.

[154] M Mcallister, 'Staff experiences of providing support to students who are managing mental health challenges: A qualitative study from two Australian universities', *Advances in Mental Health*, vol. 12, no.3, 2014, pp. 192–201.

[155] V Wilson, 'Students' experiences of managing type 1 diabetes', Paediatric Nursing, vol. 22, no. 10, 2010, pp. 25-28.

[156] V Wilson, 'Students' experiences of managing type 1 diabetes', *Paediatric Nursing*, vol. 22, no. 10, 2010, pp. 25-28.

[157] C Mendelson, 'Managing a medically and socially complex life: women living with lupus', *Qualitative Health Research*, vol. 16, no. 7, 2006, pp. 982-997.

[158] S Demain et al., 'Living With, Managing and Minimising Treatment Burden in Long Term Conditions: A Systematic Review of Qualitative Research', *PLOS One*, vol. 10, no. 5, 2015, pp. 1-18.

[159] F M Blyth et al., 'Chronic pain in Australia; a prevalence study', *Pain*, vol. 89, 2001, pp. 127-134.

> *else…. If I'm not dealing with the pain and issues associated with endometriosis, I'm dealing with chronic fatigue."*

Chronic diseases can have detrimental effects on relationships.[160] In our research, some women also told us that sexual intimacy and social interaction was lost between themselves and their partner due to pain and fatigue:

> *"it has placed incredible stress on my relationship with my partner. We can't go out spontaneously, I can't enjoy sex".*

Age appeared to have a significant impact on whether women experienced that chronic disease affected their role as a life partner. Between 25 and 44 years old, an age group where child rearing is most prevalent, women in our research reported that chronic disease impacted their role as a life partner. A few women told us how they now needed to rely on their partner as their primary carer which also had significant impacts on their relationship.

> *"More support to my partner would be appreciated. He is the one that has look after me when I flare and he also has to look after everything else for the house."*

Time barriers

In the focus groups, women discussed the relationship between the time taken to attend appointments and the number of "spoons" they had to expend. Those with chronic disease were found to have significant time demands with constant treatment burden.[161] The women in the focus groups also reported on the inconvenience of appointment times with some occurring during business hours. They also mentioned the time it took to attend appointments:

> *"Times suited to work. Appointments were scheduled and you were expected to be greatful for them no matter what the time. Doctors were rarely in time so a full day off work was often required to attend one 20-30 minute appointment..."*

> *"I had no time to ever access anything…in the end I left my job".*

One women reporting having to take half the day off work because she had to catch the bus to attend the appointment:

> *"I had to have an employer who would give me half a day off a week to go to this course 'cause I had to bus up and then bus down and by the time I got back it was 1:00."*

Women already have reduced available time compared to men, as they often take on more of the child rearing and household responsibilities.[162] Australian research shows that there is a limit to

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[160] M Moradi, 'Impact of endometriosis on women's lives: a qualitative study', *BMC Women's health*, vol. 14, no. 123, 2014, pp. 1-12.

[161] A Sav et al., 'Treatment burden among people with chronic illness: what are consumer health organizations saying?', *Chronic Illness*, vol. 9, no. 3, 2012, pp. 220–232.

[162] S P Fullagar & P R Brown, 'Everyday temporalities: leisure, ethics and young women's emotional wellbeing', *Annals of Leisure Research*, vol. 6, no. 3, 2003, pp. 193-208.

the number of hours of work, paid or unpaid, that can be performed each week before it has a negative impact on health.[163] The constant juggling of work and family commitments has also been shown to have a negative impact on the health of a woman.[164] The stress of the constant time pressure can increase the incidence of sickness and lead to additional chronic diseases.[165]

Appropriateness of ACT supports and services

Women in our research reported that many services and supports seemed to be targeted at older people or people who are not working. The women discussed the desire to access services that could help with their chronic disease but that were suitable for their life-stage. Accessing courses or community-based services was not easy, as they were on at times that were inaccessible to them or they were scheduled during the morning where pain can be at its worst for some chronic diseases:

> *"the accessibility is also a big problem … like first thing in the morning for an arthritis group."*

The women reported feeling that the support groups and courses weren't for people who are still in the workforce and questioned why they should try to access them.

> *"Services seem to focus on people who don't work rather than helping those who are continuing to try and work. There's very little clear information on what you should do, outside of direct medical intervention."*
>
> *"Lots of groups meet during the day, I have classes. I need things in the evening or on weekends, I can't make 2pm on Tuesday work. Nowhere to find out what services exist, means you don't know what's available to you and what you could be using. Frustrating."*
>
> *"Arthritis courses, pain management classes, exercise classes specific to condition were all in the middle of the day during the week, I have a full-time job, so it makes it impossible to access these supports".*

Women also spoke of the lack of age-appropriate responses in primary health care services, with many women experiencing stigma and not recognised as having a chronic disease because of their age and being told they were too young or looked too healthy to be sick.

> "*No you're too young to be ill*".

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[163] H Dinh, L Strazdins & J Welsh, 'Hour glass ceilings: work-hour thresholds, gendered health inequities' *social science and medicine*, vol 176, 2017, pp. 42-51.

[164] N Skinner & B Pocock, *The persistent challenge: living, working and caring in Australia in 2014*, the Centre for work and life, University of South Australia, 2004.

[165] L Bryson et al, 'Managing the work–life roller-coaster: Private stress or public health issue?', *Social Science & Medicine*, no. 65, 2007, pp. 1142-1153.

> *'Lack of understanding. Lack of relevant services that understand the condition, are age-appropriate'.*

Werner & Malterud's research shows that the women's younger age was "used against them" when seeking medical attention, resulting in misdiagnosis and barriers to accessing the right treatment.[166]

Treatment by health services

Women must work particularly hard to be a credible patient. Trying to make the symptoms that they experience visible and real so they don't look "too strong, too weak, too healthy or too sick, or too smart or too disarranged".[167] Women in this study have said they were sometimes told "*you don't look sick"*, and this perception of wellness may mean lack of investment from healthcare professionals.

> *"People don't believe me when I say I'm really sick and have all this stuff going on with my body. They (including some doctors) don't think a 23 year old can be this sick."*
>
> *"Specialist doctors too concrete in thinking. Judging by age and therefore failing to diagnose problem for long period. Misdiagnosis, misinformed and not willing or able to collaborate with other specialities. Resulting in poor treatment, damage to my body, extended period of inpatient stay and prolonged recovery time."*

The women described their condition as 'waxing and waning', where at times they could not get out of bed. Therefore, when they presented at the doctor, they were not at their worst. There are a number of chronic diseases that are 'hidden',[168] are poorly diagnosed, or that the medical community doesn't recognise and are considered too difficult to treat.[169] Doctors need to believe in the patient, particularly when dealing with these diseases.[170]

Twenty nine percent of the women that mentioned they were dissatisfied reported not being listened to or believed. Werner & Malterud's research shows that women had to struggle and assert themselves constantly for their condition to be recognised.[171]

> "*The medical profession has spent most of its time either ignoring me or actively trying to dissuade me from the notion that I am sick".*
>
> "*Also attitude towards the illness. I have been treated as the illness not as a person with the illness*."

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[166] A Werner & K Malterud, 'It is hard work behaving as a credible patient: encounters between women with chronic pain and their doctors', *Social Science & Medicine*, vol. 57, 2003, pp. 1409–1419.

[167] Ibid.

[168] S Stone, 'Must Disability always be visible? The meaning of disability for women', *Canadian Women Studies*, vol.13, no. 4, 1993, pp. 11-13.

[169] R Epstein et al., 'Physicians' responses to patients' medically unexplained symptoms' *Psychosomatic Medicine*, vol. 68, 2006, pp. 269 –276.

[170] B Sabo, M R Joffres & T Williams, 'How to deal with medically unknown symptoms', *Western Journal of Medicine*, vol. 172, 2000, pp. 128-130.

[171] A Werner & K Malterud, 'It is hard work behaving as a credible patient: encounters between women with chronic pain and their doctors', *Social Science & Medicine*, vol. 57, 2003, pp. 1409–1419.

> *“Had issues due to my age and conditions considered to 'only affect older people'. Not being believed, being dismissed, discriminated against and questioned. This by both doctors and medical professionals as well as some services.”*

Even when accessing prescribed medications for their chronic disease, women reported feeling the shame of not being believed. As one woman commented about her difficulty in filling a prescription of anti-depressants.

> *“I feel like you should just give me my drugs so I can go home and be less sad about my life”.*

If patients are not believed or listened to, their situation is likely to get worse, and they may become more ill.[172] Moreover there needs to be trust both ways: if a person is not believed, how can they trust that they will be getting the correct treatment that meets their needs and is not going to cause them harm?[173]

> *“On top of the exhaustion of living every day with chronic illness, I also now have a huge mistrust of the medical health industry. I don't have the energy (physical or mental) to keep proving how sick I am to people, so I've stopped trying, even if it means having less access to resources.”*

These results match those observed in a study by Johansson et al., which demonstrated women’s lack of faith in doctors as their requests for diagnosis and treatment were ignored, disregarded, and rejected.[174]

Historically, women have not been taken seriously about their pain, and this can lead to delays in treatment, incorrect treatment, and under-diagnosis.[175] This can cause women to feel that their pain is not recognised as legitimate.[176] The women reported that their pain was not validated.

> *“The constant and often severe pain that I feel is also not recognized.”*

Women in the survey expressed frustration when they were unable to get the help that they needed, even when they were in extreme pain.

> *“The assistance you get for endometriosis is ludicrous. Majority of the time you will go to hospital in excruciating pain and be sent away as ‘bad period pain”.*

This may prevent access to adequate and timely pain information and treatment. Participants in a study conducted by the Health Care Consumers Association (HCCA) in Canberra expressed frustration with GPs not taking their chronic pain seriously. They felt they were not believed and

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[172] B Sabo, M R Joffres & T Williams, ‘How to deal with medically unknown symptoms’, *Western Journal of Medicine*, vol. 172, 2000, pp. 128-130.

[173] H Rainey et al., ‘The role of patients and their relatives in ‘speaking up’ about their own safety – a qualitative study of acute illness’, *Health Expectations*, vol. 18, 2013, pp.392–405.

[174] E E Johansson et al., ‘”I’ve been crying my way” -qualitative analysis of a group of female patients’ consultation experiences’, *Family Practice*, vol.13, no. 6, 1996, pp. 498-503.

[175] D E Hoffmann & A J Tarzian, ‘The girl who cried pain: A bias against women in the treatment of pain’, *Journal of Law, Medicine & Ethics,* vol. 29, 2001, 13-27.

[176] A Werner & K Malterud, ‘It is hard work behaving as a credible patient: encounters between women with chronic pain and their doctors’, *Social Science & Medicine*, vol. 57, 2003, pp. 1409–1419.

were often labelled as a "drug seeker".[177] This was also mentioned by women in our research. Pain has a very negative impact on women's lives. Not being able to access the right care due to health care providers not taking women's pain seriously significantly damages their lives.[178]

Women from WCHM's research recognised when they have a good GP, because of their many negative experiences. Some women recounted good experiences when they told their GPs about their pain. Their GPs listened to and acknowledged their chronic pain experience, investigated further, and provided referrals where necessary. They recognised and validated their experiences, even if it was difficult to find the cause for the pain.

Misdiagnosis was a common thread for women in our research when accessing health care. Women spoke about being misdiagnosed, referred to the wrong specialists, and misinformed. Anden, Andersson and Rudebeck found that dissatisfaction with services can result from not knowing why you are sick. They point out that it isn't the only thing that makes a doctor's appointment successful, but it is an important part.[179]

One explanation is that practitioners do not consider gender differences. The most common account of this is Yentl Syndrome, whereby women are less likely to receive medical attention for a heart attack because the symptoms are often different to men's.[180] Barriers to correct diagnosis and treatment for women can occur when the majority of medical research about a disease is gender insensitive, which can give the impression that it is a "man's disease".[181] Women in our research reported that some health care professionals were misinformed or lacked expertise in diagnosing or treating their disease.

> *"(they) had no experience with my condition and refused to treat me as they didn't understand it. Nor did they refer me on."*

Women also told us about the lack of support for specific groups:

> *"Being a lesbian makes it hard. The information in the services (including private doctors) makes it hard to be a lesbian with endometriosis. Everything is geared to maintaining fertility etc, and people can't seem to understand that my experience just doesn't cover that. Leaves you feeling invisible twice over..."*

Wait times

Twenty three women in our research identified the lack of specialist services and some said they then had to access services outside of Canberra. When they looked for specialists in the ACT,

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[177] Health Care Consumers Association, 'Primary health care in the ACT consumer experiences, 23 January 2014', Canberra, 2014.

[178] M Moradi et al., 'Impact of endometriosis on women's lives: a qualitative study', *BMC Women's health*, vol. 14, no. 123, 2014, pp. 1-12.

[179] A Andén, S Andersson & C Rudebeck, 'Satisfaction is not all – patients' perceptions of outcome of general practice consultations, a qualitative study', *BMC Family Practice,* vol. 6, no. 43, 2005, pp. 1-8.

[180] G Baggio et al., 'Gender medicine: a task for the third millennium', *Clinical Chemistry and Laboratory Medicine*, vol. 51, no. 4, 2013, pp.713–727.

[181] J C Frich, K Malterud & P Fugelli, 'Women at risk of coronary heart disease experience barriers to diagnosis and treatment: A qualitative interview study', *Scandinavian Journal of Primary Health Care*, vol. 24, 2006, pp. 38- 43.

some mentioned that their books had closed, or that long wait times impacted timely access. As a result, 8 women said they had to go to Sydney specifically to get treatment.

> "*…just Googled and went with the first one I saw which happened to be in Sydney, and drove myself up and back that day."*

> *"I went to Sydney in order to be diagnosed quicker as the waiting list for a rheumatologist in Canberra was 18 months."*

The HCCA also found that some of their participants went interstate to gain access to a service in a suitable time frame. [182] Some women said it was cheaper to access services in Sydney as bulk billing was more available. If the option of travelling was not available, some women continue to access unsuitable services.

Wait times of longer than six months have a substantial impact on the individual. During that 6-month period, "significant deterioration of health related quality of life and psychological wellbeing" is experienced by the patient.[183] Pain management clinics across the world have excessive wait times[184.] Data from 2012 in Australia shows that the average wait time was 150 days.[185] Hogg et al reported that 54% of pain management clinics in Australia don't meet the pain management standards.[186]

> *'Waiting periods for services (even private) are too long. When something impacts on your daily life, a six month wait can feel like a lifetime.'*

> *"Currently I am waiting to see a surgeon for an initial consultation. So far I have waited 9 months. I am in chronic pain."*

Impacts on employment

Almost half of the women in our study mentioned employment as an area of their life that had been negatively affected by chronic disease. Sixteen percent reported having to reduce their hours or give up work altogether, faced discrimination, and many have mentioned that it has negatively affected their family. One women reported she almost became homeless. Eighty seven per cent of the women in the study have attained certificates/diplomas or university degrees. Therefore, lower levels of education do not reduce workforce accessibility in women with chronic disease - it's the chronic disease that impacts their ability to work.

People with chronic disease face challenges in the workplace such as absenteeism, discrimination (perceived and actual), reduced hours, and needing to leave the workforce altogether.[187] [188]

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[182] Health Care Consumers Association, 'Primary health care in the ACT consumer experiences, 23 January 2014', Canberra, 2014.

[183] M E Lynch et al., 'A systematic review of the effect of waiting for treatment for chronic pain', *Pain*, vol. 136, issues 1-2, 2008, pp. 97-116.

[184] S R Fashler et al., 'Systematic review of multidisciplinary chronic pain treatment facilities', *Pain Research and Management*, vol. 2016, 2016, pp. 1-19.

[185] M N Hogg et al., 'Waiting in pain: a systematic investigation into the provision of persistent pain services in Australia', *Medical Journal of Australia*, vol. 196, no. 6, 2012, pp. 386–390.

[186] M N Hogg et al., 'Waiting in pain: a systematic investigation into the provision of persistent pain services in Australia', *Medical Journal of Australia*, vol. 196, no. 6, 2012, pp. 386–390.

[187] Australian Institute of Health and Welfare, *Chronic disease and participation in work*, Australian Government, Canberra, 2009.

[188] Arthritis Australia, Submission on the Government's consultation paper on Disability and Employment, Sydney, 2013.

Absenteeism was a significant worry for women in the current study. Sick leave is not used only for days when they are unwell, but also for scheduled medical treatments to maintain functionality.[189] Some health services are only available during office hours, and so may be inaccessible to someone in paid work. There is a correlation of up to 60% between the number of sick days used and early mortality, particularly those that are using sick leave for mental health conditions.[190] Women are more likely than men to work part time in casual or contract positions which have no entitlement to paid annual leave,[191] and women with disabilities are more likely to work part time (with reduced leave entitlements) than full time.[192] It is likely that women are forced into casual work for the flexibility.[193] Moreover, women in general already have lower workforce participation rates, with a higher number of women working lower paying and unstable work than men.[194] A large number of women in the present research reported that their employment opportunities were impaired, and some said that it led to consequences for their ability to afford GP visits, medications, specialists, and other types of treatment.

Some women reported having to be financially dependent on loved ones:

> *"I am a single, childless 45-year-old woman who lives at home, can't live in my own house because my employment options are now greatly reduced and the money I earn isn't enough to pay my mortgage."*

Ten percent of younger women in our research reported having to leave employment. Women with a chronic disease, like fibromyalgia, reported how brain fog and concentration problems have reduced their ability to work effectively.[195] They reported 'confusion, forgetfulness and disorientation' which have led to them leaving their job.[196] According to a report by the Australian Institute of Health and Welfare (AIHW), as many as 60% of people with chronic diseases were not participating in the workforce due to their illness.[197] Women in the our research also worried about their reduced ability to work effectively. This shows the complexity of their situation, where it's not just a problem of 'ability to work the hours' but their desire to have a successful and satisfying working life. Women have been found to be employed at lower levels, have poorer career opportunities, are paid less, and having less satisfying jobs than women without chronic illness.[198] With some chronic diseases being 'hidden', it makes it difficult to ask for time off, workplace modification, or change in hours.[199] Varekamp et al reported that employees with chronic disease

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[189] Y Jeon et al., 'Achieving a balanced life in the face of chronic illness', *Australian Journal of Primary Health*, vol. 16, 2010, pp. 66-74.

[190] J E Ferrie et al., 'Diagnosis-specific sickness absence and all-cause mortality in the GAZEL study', *Journal of Epidemiology and Community Health*, vol.63, no.1, 2009, pp.50.

[191] Australian Bureau of Statistics, 2017, Labour Force, Australia, Detailed, Quarterly, May 2017, cat. no.6291.0.55.003, viewed 22 June 2017, http://www.abs.gov.au/Ausstats/abs@.nsf/mf/6291.0.55.003

[139] Commonwealth of Australia 2017, Senate Question on Notice Number 449, viewed 30 June 2017, http://www.aph.gov.au/Parliamentary_Business/Chamber_documents/Senate_chamber_documents/qon

[193] S Werth, Women, work and chronic illness: an exploratory investigation of themes form HILDA, Griffith University, Queensland, 2010.

[194] M Baird, R Cooper & D Oliver, Down and Out with Work Choices: The Impact of Work Choices on the Work and Lives of Women in Low Paid Employment, The University of Sydney, Faculty of Economics and Business, 2007.

[195] V A Crooks, 'Exploring the altered daily geographies and lifeworlds of women living with fibromyalgia syndrome: A mixed-method approach', *Social Science & Medicine,* vol. 64, 2007, pp.577–588.

[196] Ibid.

[197] Australian Institute of Health and Welfare, *Chronic disease and participation in work*, Australian Government, Canberra, 2009.

[198] S Werth, Women, work and chronic illness: an exploratory investigation of themes from HILDA, Griffith University, Queensland, 2010.

[199] Arthritis Australia, Submission on the Government's consultation paper on disability and employment, Sydney, 2013.

may not have the skills to suitably solve problems in the workforce which are specific to their chronic disease, for example negotiating work accommodations.[200]

Women in our research spoke of discrimination or the fear of discrimination as an employee is affected by chronic disease. Arthritis Australia lists one of the main barriers to employment as fear of discrimination and lack of understanding by employers.[201] Some women who answered the survey discussed the perception of being sick.

> *"My boss doesn't understand how sick I am and tells me my medical appointments interfere with my ability to work, which they don't"*.

Many women told us they felt unsupported at work, and often faced stigma:

> *"People take you at face value – you're considered lazy when you are most likely fatigued from the disease".*

These women were already fatigued and had limited "spoons" so fighting stigma was another burden of having a chronic disease. In some cases, women spoke of trying to decide if they should tell their workplace even though they may face discrimination, or not disclose their chronic disease and risk being labelled as lazy anyway.

> *"Trying to hold down full time work and being able to function physically and mentally is so challenging and also not having to tell everyone what is wrong. Especially when you're in pain and tired."*

> *"For me it makes me hugely anxious in the workplace to disclose, not disclose".*

> *"As a young woman with a chronic illness, the biggest issue I faced is wanting to hide it in fear of being unemployed as a result. Many of the women I initially met felt nothing but regret at owning up to their illness, and all struggled with work as a consequence. As such, I have since stopped seeking support for fear it would circulate and get back to me and discriminate me from a job (as mine is not severe enough to be a disability, but an issue enough to cause problems)."*

Women in the focus groups discussed the limitations they faced with their workplace regarding the stigma of mental health.

> *"As soon as you're identified as having some sort of problem you're on the outer".*

The stigma of mental health in the workplace is widely known, however the problem is complex. Not wanting to disclose is common. Studies have shown discrimination by colleagues and employers, although stigma can also be self-reflective.[202] [203] [204] However, it is not just the problem

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[200] I Varekamp et al., 'Facilitating empowerment in employees with chronic disease: qualitative analysis of the process of change', *Journal of Occupational Rehabilitation*, vol. 19, 2009, pp.398-408.

[201] Arthritis Australia, Submission on the Government's consultation paper on disability and employment, Sydney, 2013.

[202] K Wheat et al, 'Mental illness and the workplace: conceal or reveal?', *Journal of the Royal Society of Medicine*, vol. 103, 2010, pp. 83–86.

[203] B A Pescosalido et al., '"A disease like any other"? A decade of change in public reactions to schizophrenia, depression, and alcohol dependence', *American Journal of Psychiatry*, vol. 167, no. 11, 2010, pp. 1321–1330.

[204] S E Hanisch et al., 'The effectiveness of interventions targeting the stigma of mental illness at the workplace: a systematic review', *BMC Psychiatry*, vol. 16, no. 1, 2016, pp. 1-11.

of the employee. Workplaces (that are not mentally safe) that are inconsiderate and unsupportive to those with mental health problems have employees that take more mental health leave. Research by Beyond Blue shows that 50% of workplaces in ACT/NSW are not mentally safe.[205]

Paid work is not just important for income, it also affects individual wellbeing and quality of life.[206] Some women in this study felt disempowered because the chronic disease took away their autonomy, and when they could no longer work they were stripped not just of the financial benefit but of independence.

> *"… not being able to work any longer … affects my self-esteem, causes guilt and financial hardships and lack of social interaction which was essential for me."*

Not being able to work severely shrinks their world, reducing their access to social contact, lost feeling of contributing to society, and money for social situations.[207] Charmez described the loss of self in people with chronic disease, who described their experiences of their former self reducing. The research showed that they suffer from "leading restricted lives, social isolation, being discredited and burdening others."[208] This phenomenon was mirrored in the women in the present study.

Women also told us about the difficulty of getting through the working day and having energy to spend time with children.

> *"Has impacted on number of family activities ie severely reduced on weekends as they are now spent sleeping and or recovering so as to be able to work the following week."*

Limited services available

Fifty-one women mentioned that they had difficulty accessing services, as they were unaware of services or believe there are insufficient services in the ACT.

> *"There just aren't many services or support available that I am aware of. Feel very alone in this."*
>
> *"Even now I have a formal diagnosis there's no where to go to get help. I rely on Facebook support group experiences of where and what to do."*

Many of the younger women in our research reported that their knowledge about services, particularly support groups and other types of programs in the ACT, was limited:

> "*I've lived in Canberra my entire life, and I'm stuffed if I can find these people".*

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[205] TNS and Beyond Blue, State of Workplace Mental Health in Australia, Sydney, 2004.

[206] A Chorus et al., 'Labour force participation among patients with rheumatoid arthritis', *Annals Rheumatic Diseases*, vol. 59, 2000, pp. 549–554.

[207] V A Crooks, 'Exploring the altered daily geographies and lifeworlds of women living with fibromyalgia syndrome: A mixed-method approach', *Social Science & Medicine,* no. 64, 2007, pp. 577–588.

[208] K Charmez, 'Loss of self: a fundamental form of suffering in chronically ill', *Sociology of health and illness*, vol. 5, no. 2, 1983, pp. 168-195.

Women from the focus group and in the survey identified the need for a centralised place to find information. Participants in a study from HCCA discussed how finding information is difficult and how they often had to use the internet to look up services. [209] And likewise women in past WCHM research also relied heavily on the internet as information and also expressed *“the need for better navigation about the range and scope of available services for women in the ACT.”*[210]

GPs

As GPs are the providers of referrals and prescriptions, they are looked upon as the gateway to services. Some women reported difficulty accessing referrals to other services, as their GP was reluctant to refer them on as they either didn’t believe the patient’s condition or had poor understanding of the impact it had on the patient.

> *“At first told not to worry. Finally got referral "to put my mind at ease". Diagnosed after 10+ years of symptoms.”*
>
> *“Not enough doctors know about it. Needs more research and support in medical. Took me till I was 49 to be diagnosed and that was only because of Facebook and me researching. I than had to find a GP to refer me to a geneticist to confirm that it was EDS. I would have seen a dozen GP's in my lifetime to get help. I was belittled, refused to be seen again, sent to psychiatrist, felt like giving up.”*

Moradi et al. also found, in a group of women with endometriosis in Canberra, that GPs didn’t take their concerns seriously and so didn’t refer them to the appropriate specialist.[211] The HCCA reported that people look to their GPs for provision of information and services when trying to navigate the health system. However, patients with complex needs said that their GP fell short particularly with provision of information as they lacked the relevant knowledge and skills to manage complex conditions.[212]

> *“Sometimes I have no confidence in my doctor. I am not sure how knowledgeable my doctor is. I rely on a Facebook patient group to get the most updated information, not the doctor, so I am a little bit disappointed.”*

The consequence of inadequate referral and unhelpful direction is lack of appropriate treatment. Some women in the study reported significant delays to access specialists which impacted on their wellbeing and financial situation.

> *“I asked for a referral to a gynaecologist that specialises in endo by the GP, and didn’t get an appropriate referral. I am still travelling back to Melbourne to see my prior one…”*

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[209] Health Care Consumers Association, ‘Primary health care in the ACT consumer experiences, 23 January 2014’, Canberra, 2014.

[210] A Carnovale & E Carr, *It goes with the Territory! ACT women’s view about health and wellbeing information*, Women’s Centre for Health Matters, Canberra, 2010.

[211] M Moradi et al., ‘Impact of endometriosis on women’s lives: a qualitative study’, *BMC Women’s health*, vol. 14, no. 123, 2014, pp. 1-12.

[212] Health Care Consumers Association, ‘Primary health care in the ACT consumer experiences, 23 January 2014’, Canberra, 2014.

One women expressed difficulty accessing treatment as there was poor integrative care;

> *"My doctors, particularly specialists, don't speak to each other. So currently I have chronic conditions with my kidney, heart, endocrine system and central nervous system which may all be related but we don't know because doctors don't share information."*

Peer-support groups

Peer-support groups have a positive role to play in chronic illness management.[213] Thirty women in the study expressed the need for peer-support groups. Some women expressed the need for peer-support groups specific for their chronic disease. Coppa & Boyle reported the benefits of peer-support groups for particular conditions in their qualitative research. [214]

> *"I struggle to find peer support and am sick of wading through the rubbish that exists on the internet.".*

Women particularly benefit from peer- support groups, which is likely to be due to socio-cultural influences.[215] Mijais, Gill and Spigelman found that peer-support groups helped younger women with disabilities to increase their self-confidence where the group fostered a sense of belonging as well as provide necessary information on disability management.[216] Women in the research commented on the need for peer-support groups targeted at their age, life roles and their requirements (such as for knowledge of disease, or support and understanding).

> *"It's actually really good talking to other people face-to-face, it feels really good to just talk to other people who have the same problems and – or similar problems and the whole mental health issue as well because there is the depression that quite often comes with all this rubbish."*
>
> *"There's nothing like that, it's just we all support each other."*

Research shows that GPs may also find these types of services useful, although they continue to be underutilised,[217] and in the ACT it appears that many of these groups have dissolved.

Chronic disease and maintaining healthy activities

Women with chronic diseases have many barriers to maintaining healthy activities, such as physical activity, healthy eating, and maintaining a healthy weight. When looking at people with multi-morbid chronic diseases, factors such as 'compounding effects of conditions, physical

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[213] K Coppa & F M Boyle, 'The role of self-help groups in chronic illness management: A qualitative study,' *Australian Journal of Primary Health*, vol. 9, 2003, pp. 68–74.

[214] Ibid.

[215] F O Okoro & D J Barksdale, 'The influences of gender on peer support in chronic illness self-management: an overview', *The ABNF Journal*, vol. 28, no. 2, 2017, pp. 1-10.

[216] N J Mejias, C J Gill & C Shpigelman, 'Influence of a support group for young women with disabilities on sense of belonging', *Journal of Counselling Psychology*, vol. 61, no. 2, 2012, pp. 208-220.

[217] C E Young et al., 'Investigating referral pathways from primary care to consumer health organisations' *Australian Journal of Primary Health*, vol. 16, 2010, pp. 260–267.

limitations, medications, financial constraints and low self-efficacy or sense of loss of control' limit their ability to carry out self-care activities.[218]

Fifty three percent of younger women with chronic diseases had barriers with engaging in physical activity. The largest barrier is in fact the symptoms of the chronic disease such as pain and fatigue, with the women reporting *"chronic pain affecting mobility. Fatigue that wipes me out for days, often unable to do more than get out of bed."*

Exercise has been shown to be both beneficial as well as a source of pain, which can be difficult for a person with chronic disease to overcome.[219] Bee et al. found that even if exercise may be beneficial for chronic pain, uptake is hampered by patients' view that pain can be caused by movement. Patients have a higher chance of continuing with exercise programs if the program is individualised, and factors such as illness and treatment options are considered.[220] Some women in our research mentioned that they can only do gentle exercise rather than 2.5 hours of moderate physical activity per week as recommended in the Australian Guidelines to Physical Activity. A few women have reported that moderate physical activity has a negative impact, as it flares up their symptoms, so only gentle exercise is beneficial: *"At the moment fast paced walking will cause me insomnia, irritable bowel symptoms and other health issues. I can only handle 10-15 minutes gentle walk each day."*

Jerrant, von Fiederichs-Fitzwater & Moore discovered that people with chronic diseases are limited by the amount of time in which they can stand or walk around which can profoundly affect their social engagements and employment opportunities.[221] Managing work and family while dealing with chronic disease and its symptoms means that some women in the present study were unable to participate in physical activity. Women with dependents already have limited time to spend on themselves, as they often take on more of the domestic and child rearing responsibilities.[222] In addition, functional decline is likely to occur in those with multi-morbidity[223], so it is remarkable that 47% of the women in the study do not have any barriers to physical activity.

A smaller number of women in our research had barriers to maintaining a healthy diet than physical activity, with only 27% reporting that they had difficulty. As with physical activity, participants reported that their chronic disease was their main barrier to a healthy diet. Most women who reported barriers said that it was due to mobility, pain, and fatigue: *"Difficult to manage healthy eating and cooking when I'm so tired and in pain".* Women said that pain, fatigue, and mobility reduced their ability to shop for produce, chop and prepare food, and consume food. Some women reported that affordability was a barrier to healthy eating habits, with a few saying they would often choose paying for treatment over food. In a study that looked at women in

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[218] E A Bayliss et al., 'Descriptions of barriers to self-care by persons with comorbid chronic diseases', *Annals of Family Medicine*, vol. 1, no. 1, 2003, pp.15-21.

[219] S Wilcox et al., 'Perceived exercise barriers, enablers, and benefits among exercising and non-exercising adults with arthritis: results from a qualitative study', *Arthritis & Rheumatism (Arthritis Care & Research),* vol. 55, no. 4, 2006, pp. 616–627.

[220] P Bee et al., 'Managing chronic widespread pain in primary care: a qualitative study of patient perspectives and implications for treatment delivery', *BMC Musculoskeletal Disorders*, vol. 17, no. 354, pp. 1-11.

[221] A F Jerant, M M von Fiederichs-Fitzwater & M Moore, 'Patients' perceived barriers to active self-management of chronic conditions', *Patient Education and Counselling*, vol. 57, 2005, pp. 300-307.

[222] SP Fullagar & PR Brown, 'Everyday temporalities: leisure, ethics and young women's emotional wellbeing', *Annals of Leisure Research*, vol. 6, no. 3, 2003, pp. 193-208

[223] E A Bayliss et al., 'Predicting declines in physical function in persons with multiple chronic medical conditions: what we can learn from the medical problem list' *Health and Quality of Life Outcomes*, vol. 2, no. 47, 2004, pp. 1-8.

Australia accessing health care, participants noted that it was a constant juggle between the cost of health care and other important costs like food.[224] Interestingly, the age group that reported the biggest concern with affordability of healthy eating was the 44-50 year-olds: *“Affording healthy food every week is sometimes not possible. If I have a lot of medical expenses I will buy cheaper less healthy options.”*

Women in the focus group expressed frustration in weight reduction messages: *“It does nothing. Like they keep on saying to me you need to lose weight and it’s like, how?”*

Fifty six percent of women in the present study reported that they had barriers to maintaining a healthy weight. Most listed a combination of factors such as exercise, unhealthy eating, and medication. The women from the study seemed to know the complexity of weight management but appeared to be perplexed on how to overcome the barriers. As with other preventative health behaviours, maintaining a healthy weight can be difficult.[225] Some women discussed healthy weight as something they have managed before and no longer can: *“I'm a few kilos overweight. It's hard to shake it off when I can no longer play active sports.”*

There was a small number of women who did not list a barrier at all, but made comments such as *‘Give me a break’* or *‘I am overweight’*. This shows how sensitive this issue is and how much stigma there is around weight.[226]

> *“Motivational quotes and the current trends for healthy living further strengthen this idea, that all is possible if you work hard. I'm in no way saying there is no hope, rather that my path is significantly different, and most do not realise”*

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[224] E J Wolkom, D Loxton & J Robertson, ‘Cost of medicines and health care; A concern for Australian Women across the ages’, *BMC Health Services Research*, vol. 13, no. 484, 2013, pp. 1-9.

[225] A F Jerant, M M von Fiederichs-Fitzwater & M Moore, ‘Patients’ perceived barriers to active self-management of chronic conditions’, *Patient Education and Counselling*, vol. 57, 2005, pp. 300-307.

[226] S Lewis et al., ‘How do obese individuals perceive and respond to the different types of obesity stigma that they encounter in their daily lives? A qualitative study.’ *Social Science & Medicine*, vol. 73, no. 9, 2011, pp. 1349-1356.

Conclusion

Younger women aged 18 to 50 years with chronic disease in the present research experience barriers to accessing services, support, and information in the ACT.

Multi-morbidity impacts women’s lives negatively as they have higher health care costs, poorer health in general, and many are affected by a mental health condition as well as a physical health condition. ACT Health will need to take multi-morbidity into consideration when designing the framework for health services in the ACT, so as not to contribute to the disadvantages faced by these individuals.

Women with chronic disease in this age group also struggle to manage the impact of their chronic disease on their education, employment, ability to provide care to family, and maintain social relationships. Reducing stigma and discrimination in education and employment, and increased support for peer support groups, may help these women. There is an economic benefit to the ACT of supporting these younger women to stay in the workforce and stay out of the hospital system.

Self-care activities such as maintaining physical activity, healthy eating, and maintaining a healthy weight are affected by disease symptoms including pain and fatigue, affordability, and stigma. Health promotion programs aimed at improving rates of physical activity and healthy eating need to take into account that women with chronic diseases may be experiencing these barriers to participation, and provide useful information or support to overcome these barriers.

> *“I find it difficult to navigate system, procedures etc. I feel let down. I have only just gotten [a] chronic disease management plan as I didn't know they existed. I would love more help to understand what to do. I don’t want to be so sick, alone and depressed.”*

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