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Exploring androcentricity in medicine, medical research and education, and the impacts on the experiences of female patients

> Considering how common illness is, how tremendous the spiritual change that it brings, how astonishing, when the lights go down, the undiscovered, what wastes and deserts of the soul a slight attack of influenza brings to view, what precipices and lawns sprinkled with bright flowers a little rise of temperature reveals, what ancient and obdurate oaks are uprooted in us by the act of sickness. (Woolf, 1926/2002)

Dr. Lea Merone MBChB (Hons) PGCert MPH&TM MSc FAFPHM

For the degree of Doctor of Philosophy in the College of Healthcare Sciences, James Cook University, June 2022

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Abstract

Women live longer than men but notably experience poorer health outcomes such as higher rates of morbidity and disability. This disparity is in part attributable to socioeconomic gender inequalities, rooted in a patriarchal society. As a societal structure, medicine is also patriarchal and has a long androcentric history in terms of the medical workforce, medical research and attitudes towards female patients. In this thesis, I assess the current sex and gender gaps in medicine, medical research and education, and explore the experiences of female patients that are potentially related to identified gaps.

A systematic scoping review of the literature revealed that females remain broadly under-represented in the medical literature, and that sex and gender sub-analyses were infrequently explored. A cross-sectional analysis of 88 studies published over a 1-year period was used to explore the current gender gap in health research in Australia. This analysis revealed that, overall, women represented 55% of research participants; however, when sub-analysed by specialty, women were significantly under-represented in cardiology and nephrology studies and over-represented in psychiatry, care of the elderly and orthopaedic studies. Only 9% of studies analysed their results by sex or gender.

Medical research is used to guide clinical practice and education. Analysis of the sex and gender gaps in Australian medical school curriculum guidelines, online course outlines and recommended clinical textbooks ascertained that there are currently no fixed or explicit requirements to include women’s health in medical school curricula. While most medical school online course outlines referred to a rotation in obstetrics and gynaecology, there was no other mention of women’s health. Clinical textbooks did not account for sex and gender differences in disease presentation, assessment and management.

It is possible that the observed sex and gender gaps in research affect the experiences of female patients. A quantitative survey determined the median time to diagnosis and proportions of re-diagnoses in a sample of Australian females with chronic conditions. This analysis revealed that it takes on average 6 months for women to be diagnosed; however, almost half of all women were re-diagnosed later. The median time to re-diagnosis was 4 years. Semi-structured qualitative interviews explored the experiences of women with chronic conditions, determining several key themes including physical and emotional suffering, difficulties obtaining a diagnosis, and feeling dismissed or disbelieved by doctors, and identifying a need for healthcare providers to obtain more knowledge about chronic conditions.

The findings of the studies in this thesis suggest that androcentricity in medicine and medical research may adversely affect the experiences of female patients. There is a need for further research, including comparison with the experiences of males with chronic conditions and improved education for healthcare providers surrounding women’s health and chronic conditions.

Statement of Sources Declaration

I declare that this thesis is my own work and has not been submitted in any form for another degree or diploma at any university or other institution of tertiary education. Information derived from the published or unpublished work of others has been acknowledged in the text and a list of references provided.

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I would like to offer enormous thanks to my husband, Andrew Daltry, who proofread my work, helped me format tables, fixed my technology (and patiently showed me how to use most of it), and supported me through the most challenging hours.

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My parents, Sue and Leon Merone, have been endlessly understanding and supportive throughout my entire career and I can see no more perfect place than to thank them in my PhD thesis. I would not have accomplished any of my achievements in life without their kindness, patience and love.

Finally, I would like to dedicate this thesis to the friends I’ve lost along the way. Amy, my best friend in the whole world, you are missed and I hope I have made you proud. Lucy, I am sorry your adventure was cut short and I wish we could have had more time together. Rainy, your spoons ran out but your memory is eternal. Sarah, I’m sorry the changes in the system are coming too late for you. Sam, forever missed, paradise will never be the same. Thank you for sharing your journey with me.

Statement of Contribution in Publications

Chapter details and publication status	Authors' contributions
Chapter 1: Historical Overview. Provides a background on the history of patriarchy and the androcentric history of medicine. Commentary piece: "Sex and Gender Gaps in Medicine and the Androcentric History of Medical Research". Published *ANZJPH* June 2021 https://doi.org/10.1111/1753-6405.13139	Lea Merone (LM) wrote the first draft. Subsequent drafts were revised by Cate Nagle (CN), Komla Tsey (KT) and Darren Russell (DR) prior to thesis submission. Proofread by Andrew Daltry (AD).
Chapter 2: Methodology. Outlines the research aims and situates the thesis within feminist epistemologies. Not published.	LM wrote the first draft and CN, KT and DR revised subsequent drafts. Proofread by AD.
Chapter 3: Enhancing Evidence-Based Medicine: A Feminist Critique. Outlines the problems with the methods used for evidence-based medicine from a feminist perspective. A commentary piece: "Evidence-based Medicine: Feminist Criticisms and Implications for Women's Health", has been accepted for publication in *Women's Health Reports*.	LM wrote and structured the first draft, CN, and KT then revised subsequent drafts. LM prepared the included manuscript for publication. This was reviewed by CN, KT, DR and AD. All the work in this chapter was proofread by AD.
Chapter 4: Assessing the Sex and Gender Gap in Medical Research in Australia. The first half of this chapter provides a systematic review of the literature on current research into sex and gender gaps in global medical research and identified several papers displaying signs of misogyny. An original paper, "Sex Inequalities in Medical Research: A Systematic Scoping Review of the Literature", was published January 2022, *Women's Health Reports*, https://doi.org/10.1089/whr.2021.0083 The second half of this chapter examines, via cross sectional analysis, the current sex and gender gap in a sample of Australian health research. "Mind the Gap: Reporting and Analysis of Sex and Gender Health Research in Australia, A Cross-Sectional	LM collected the data for both studies, and screening of articles was reviewed by KT. Following the initial drafting of the papers by LM, they were revised by CN, KT and DR prior to submission for publication. All the work in this chapter was proofread by AD.

Chapter details and publication status	Authors’ contributions
Study” has been published in *Women’s Health Reports,* https://doi.org/10.1089/whr.2022.0033. Together, these studies highlight ongoing inequities in health research.	
Chapter 5: Representation of Women and Women’s Health in Australian Undergraduate Medical Education. Building on the work of chapter 4, this chapter explores the sex and gender inequities presented in medical school online course outlines and commonly recommended clinical textbooks. An original paper, “Representation of women and women’s health in Australian medical school course outlines, curriculum requirements and selected core clinical textbooks” has been submitted for publication with the *Australian Journal of Clinical Education.*	LM designed the data collection tool and collected and analysed the data. Drafts that were written by LM were revised by CN, KT and DR prior to submission for publication. All the work in this chapter was proofread by AD.
Chapter 6: Experiences of Australian Women with Chronic Conditions. This chapter explores the sex and gender gap in Australian healthcare from the perspectives of female patients and incorporates a survey of time to diagnosis and proportions of re-diagnosis, followed by the findings from semi-structured qualitative interviews with females with chronic disease in Australia. An original paper, “Self-Reported Time to Diagnosis and Proportions of Re-Diagnosis in Female Patients in Australia” has been published with *Women’s Health Reports,* https://doi.org/10.1089/whr.2022.0040 AND “I Just Want to Feel Safe Going to a Doctor”: Experiences of Female Patients with Chronic Conditions in Australia” has also been accepted for publication with *Women’s Health Reports.*	LM designed the survey and interview questions, with input and advice from CN, KT, DR and AD. LM then drafted both papers, which were reviewed prior to submission for publication. All the work in this chapter was proofread by AD.
Chapter 7: Discussion, Conclusions and Recommendations. A presentation of the thesis discussion, conclusions and recommendations for further research and translation.	LM constructed the initial draft of the chapter, which was read and revised by CN, KT and DR. All the work in this chapter was proofread by AD.

Chapter details and publication status	Authors’ contributions
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Statement of Contribution of Others

Assistance	Contributors
Supervision	Primary advisor: Professor Cate Nagle, James Cook University Co-advisors: Professor Komla Tsey, James Cook University, and Professor Darren Russell, Cairns Sexual Health Service
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Data collection and analysis	Pacific Transcriptions—transcription of qualitative interviews Professor Rhondda Jones—guidance on statistical analysis of a survey
Editorial assistance (manuscripts and thesis)	Professor Cate Nagle Professor Komla Tsey Professor Darren Russell Dr Andrew Daltry
Editorial assistance (thesis)	This thesis was edited by Elite Editing

List of Publications Included in This Thesis

Four publications in peer-reviewed journals have been published. These papers are in Chapters 1, 4 and 6:

- Merone, L., Tsey, K., Russell, D., & Nagle, C. (2021). Sex and gender gaps in medicine and the androcentric history of medical research. *Australian and New Zealand Journal of Public Health, 45*(5), 424–426. https://doi.org/10.1111/1753-6405.13139
- Merone, L., Tsey, K., Russell, D., & Nagle, C. (2021). Sex inequalities in medical research: A systematic scoping review of the literature. *Women's Health Reports,* 3(1), Article 49059. doi:10.1089/whr.2021.0083.eCollection
- Merone, L., Tsey, K., Russell, D., & Nagle, C. (in press). Mind the gap: Reporting and analysis of sex and gender in clinical trials in Australia. *Women's Health Reports,* 3(1), https://doi.org/10.1089/whr.2022.0033
- Merone, L., Tsey, K., Russell, D., Daltry, A., & Nagle, C. (2022). Self-reported time to diagnosis and rates of re-diagnosis in female patients with chronic conditions in Australia. *Women's Health Reports,* 3(1), https://doi.org/10.1089/whr.2022.0040

Two publications have been accepted for publication by peer-reviewed journals. These papers are in Chapters 3 and 6:

- Merone, L., Tsey, K., Russell, D., Daltry, A., & Nagle, C. (in press). Evidence-based medicine: Feminist criticisms and implications for women's health. *Women's Health Reports*.
- Merone, L., Tsey, K., Russell, D., & Nagle, C. (2022). "I just want to feel safe going to a doctor": Experiences of female patients with chronic conditions in Australia.

One publication has been submitted to peer-reviewed journals and is currently under review. This paper is in chapter 5:

- Merone, L., Tsey, K., Russell, D., & Nagle, C. (2022). *Representation of women and women's health in Australian medical school course outlines, curriculum requirements and selected core clinical textbooks*. Manuscript submitted for publication.

List of Presentations Resulting from This Thesis

Five presentations based on the results and findings from this thesis have occurred in a variety of settings:

- January 2020, *Mind the Gap*, local presentation, Tropical Public Health Services, Cairns
- June 2021, *Mind the Gap*, Far North Queensland Lady Doctors Association, Rainbow Conference
- December 2021, *Self-Care During your PhD—Achieving the balance*, James Cook University Nursing and Midwifery Research School
- February 2022, *Exploring Androcentricity in Medical Research and the Potential Impacts on the Experiences of Female Patients*, Tropical Australian Academic Health Centre, Community of Practice, Women's Health Seminar
- May 2022, *Exploring Androcentricity in Medical Research and the Potential Impacts on the Experiences of Female Patients*, Cairns Hospital and Health Service Medical Grand Rounds
- August 2022, *Exploring Androcentricity in Medical Research and the Potential Impacts on the Experiences of Female Patients,* Department of Women's Health, Monash University

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Glossary

- Acute conditions: medical problems that are sudden in onset and often severe
- Allergy: an inappropriate immune response to a substance such as food, pollen, fur
- Androcentricity: dominated by masculine points of view or placing a man at the centre of importance
- Angiography: a medical imaging technique used to examine the inside of arteries
- Anxiety: the body’s natural response to stress, a feeling of fear and apprehension. Also, an abbreviation for an anxiety disorder
- Anxiety disorder: excessive fear, nervousness or anxiousness that affects daily living
- Asthma: a condition characterised by swelling of the airways, coughing and wheezing
- Autoimmune disorder/disease/conditions: a collection of conditions where the body’s immune system mistakenly attacks healthy organs
- Bourgeoisie: according to Marx, the capitalist class who own most of the wealth in society
- Cancer: a disease caused by uncontrolled division of cells
- Capitalism: an economic and political system whereby a country’s trade is controlled by private owners for a profit
- Cardiac re-synchronisation therapy (CRT): a treatment used to correct abnormal heart rhythms
- Cardiomyopathy: a disease of the heart muscle
- Cervical intraepithelial neoplasia (CIN): A pre-cancerous lesion of the cervix, characterised by abnormal cells
- Chronic conditions/disease: an umbrella term long-lasting conditions with persistent and ongoing effects

- Chronic kidney disease (CKD): gradual loss of kidney function over time, leading often to kidney failure
- Chronic obstructive pulmonary disease (COPD): a condition that causes constriction of the airways
- Chronic pain: persistent or recurrent pain lasting 3 months or longer
- Chronic regional pain syndrome (CRPS): excess pain and inflammation following an injury, usually to an arm or leg
- Chronic tonsillitis: recurrent or ongoing swelling of the tonsils due to bacterial infection
- Clinical acumen: the skill and experience applied to form a judgement and make the correct clinical decisions
- Coronary heart disease (CHD): a condition that is characterised by thickening of the arteries in the heart and associated with chest pain and myocardial infarctions (heart attacks)
- COVID-19: an infectious disease caused by the SARS-Cov-2 virus
- Cystic fibrosis: an hereditary disorder causing thick mucous and blockage of the pancreatic ducts
- Depression: a mental health condition that causes persistent feelings of sadness and loss of interest
- Diagnosis: identification of the nature of a condition through examination of symptoms and/or test results
- *Diagnostic and Statistical Manual of Mental Disorders* (DSM-V): a diagnostic resource for mental health conditions
- Disability: impairments of the body structure or function that limit activities
- Duhem–Quine thesis: states that in science it is impossible to test one theory in isolation

- Dysautonomia: a group of medical conditions caused by problems with the autonomic nervous system
- Endometriosis: a painful condition whereby the endometrial tissue appears outside of the uterus
- Enlightenment movement: a philosophical and intellectual movement that was popular in Europe in the 18th century. The focus was on ideals such as progress, tolerance and separation of the church from the state
- Encephalitis: inflammation of the brain caused by infection or an autoimmune response
- Epilepsy: a neurological disorder characterised by seizures, loss of conscious or sensory disturbance, and associated with abnormal brain activity
- Evidence-based medicine (EBM): a systematic approach to medicine utilising the best available evidence from clinical research to make decisions regarding individual patient care
- Feminism: advocacy for the rights of women on the grounds of equality between the sexes
- Feudal period: the early and central Middle Ages, 5th–12th century A.D.
- Foreign accent syndrome: a speech disorder caused by traumatic brain injury
- Fibromyalgia: a condition that causes widespread pain and tenderness to touch
- First World War: A period of conflict between 1914 and 1918, fought mainly in Europe
- Functional conditions/disease: an umbrella term for medical conditions that impair normal functioning but currently have no differentiating test results
- Functional neurological disorder (FND): medical conditions related to how the brain functions, rather than damage to a structure in the brain
- Gitelman’s syndrome: a kidney disorder that causes an imbalance of ions in the body, with loss of potassium, magnesium and calcium

- Haemophilia: a medical condition that is characterised by a reduced ability of the blood to clot, leading to risk of severe bleeding
- Heart failure: a condition whereby the heart muscle does not pump effectively
- Hemiplegic migraine: a rare condition whereby sufferers experience a headache and unilateral weakness of the body
- Hidradenitis suppurativa: a skin condition whereby small, painful bumps form under the skin
- Hysteria: an outdated term for a psychological disorder characterised by somatisation and changes in self-awareness
- Idiopathic thrombocytopenia: a blood disorder whereby platelets are reduced
- Implantable cardiac defibrillator (ICD): a small electronic device connected to the heart to correct abnormal heart rhythms
- Inflammatory bowel disease: a group of conditions characterised by intestinal inflammation
- Inguinal hernia: a hernia that occurs in the groin
- Inorganic (or non-organic) conditions/disease: a condition with symptoms but currently no known disease process or test results to support the diagnosis
- Intersectional feminism: an inclusive form of feminism that acknowledges women’s different experiences and identities, such as race, sexuality and disability
- *International Classification of Diseases 10* (ICD-10): a book and online resource that is used to code health conditions
- Irritable bowel syndrome (IBS): a common disorder of the large bowel
- Iron deficiency anaemia: a condition characterised by reduced red blood cells due to insufficient iron

- Left ventricular assist device (LVAD): a device implanted into the chest to assist the heart in pumping blood
- Long-COVID: persistence of the symptoms of COVID-19, particularly fatigue, for months following infection with the SARS-Cov-2 virus
- Long QT Syndrome: a heart condition characterised by fast, chaotic heartbeats
- Lupus: an umbrella term for systemic lupus erythematosus (SLE), cutaneous lupus, neonatal lupus and drug-induced lupus. These are multisystem autoimmune conditions
- Matrilocal: a marriage custom whereby the husband goes to live with the wife’s family or community
- Mast cell activation syndrome (MCAS): a condition of the immune system that causes recurrent allergic symptoms
- Medically unexplained symptoms (MUS): ongoing symptoms for which there is no discernible pathology by current testing standards and guidelines
- Mental illness: is also known as mental health disorders; an umbrella term for disorders that affect mood, thinking and behaviour
- Mesopotamian society: an ancient civilisation that included the Sumerian, Assyrian, Akkadian and Babylonian civilisations
- Middle Ages: 500–1500 B.C., the period from the collapse of the Roman Empire to the Renaissance
- Migraine: a severe, throbbing or pulsing headache that is usually unilateral
- Misdiagnosis: receiving an incorrect diagnosis
- Misogyny: aversion to, or prejudice against, women
- Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS): a disabling condition characterised by fatigue, post-exertional malaise and a myriad of other symptoms

- Myasthenia gravis (MG): an autoimmune condition that affects the communication between nerves and muscles, causing muscle weakness
- Myocyte: cardiac muscle cell
- Narcolepsy: a chronic sleep disorder characterised by daytime sleepiness and sudden attacks of sleep
- Neolithic period: the period of time from the beginning of agriculture to the bronze age, around 10,000 B.C.
- Observational studies: experiments that draw inferences from a sample to a population
- Obsessive-compulsive disorder (OCD): a psychological disorder that is characterised by unwanted patterns of thought, obsessions and repetitive behaviours
- Oophorectomy: surgical removal of the ovaries
- Osteoarthritis: a common form of arthritis characterised by loss of the cartilage that lines the bones at the joints
- Osteopenia: a condition where there is loss of bone density and weakened bones
- Organic conditions/disease: health conditions with an observable and measurable disease process
- Patriarchy: a societal or government system where men hold the power and women are largely excluded from it
- Patrilocal: a marriage custom whereby the wife goes to live with the husband’s family or community
- Pelvic congestion: enlarged veins in the pelvic area that cause chronic pelvic pain
- Peptic ulcer: an ulcer in the lining of the stomach or oesophagus
- Postural orthostatic tachycardic syndrome (POTS): a condition that causes a rapid heartbeat on standing, light-headedness and fainting

- Post-traumatic stress disorder (PTSD): a psychiatric disorder experienced by people who have witnessed a traumatic event
- Post-viral syndrome: synonym for ME/CFS
- Proletariat: the collective name for working-class people
- Pseudoseizures: real clinical events that resemble epileptic seizures but there is no discernible abnormal brain activity
- Psoriasis: a skin disease characterised by red, scaly patches
- Psychoanalysis: a type of psychological treatment based on the theory that our present is shaped by our past
- Psychogenic conditions/disease: often used synonymously with non-organic, functional or MUS conditions. This term pertains to any disorder that cannot be attributed to an organic condition and is believed to be due to psychological factors
- Psychosomatic: an outdated term referring to physical symptoms caused by psychological distress
- Randomised controlled trials (RCT): an experimental design that assigns participants to either a treatment group or control group
- Re-diagnosis: Diagnosing a previous condition as a different condition, usually in the event of misdiagnosis
- Renal calculi: kidney stones
- Research paradigm: the philosophical framework that research is based on
- Rheumatoid arthritis (RA): an autoimmune disease affecting the joints
- Scheuermann’s disease: a condition causing rounding, or kyphosis, of the spine
- Seizure: sudden uncontrolled electrical disturbance in the brain, leading to loss of consciousness, changes in movement, changes in behaviour or changes in sensation
- Sexism: prejudice or discrimination against women

- Supraventricular tachycardia (SVT): an abnormal heart rhythm that causes a rapid heart rate
- Thoracic outlet syndrome: a group of disorders caused by compression of the vessels or nerves between the collarbone and first rib (the thoracic outlet)
- Type 1 diabetes mellitus (T1DM): an autoimmune condition whereby the pancreas produces insufficient insulin
- Type 2 diabetes mellitus (T2DM): a chronic condition that affects the way the body processes sugar
- Ulcerative colitis: an inflammatory bowel disease
- Underdetermination: for every scientific theory, there will always be an alternative theory that can be logically maintained
- Western civilisation: the heritage of social norms, values, traditions and beliefs of the Western world
- VACTERL syndrome: a multisystem congenital disorder
- Vesicovaginal fistula: a hole that can form between the bladder and the vagina following an obstructed labour
- Vulvodynia: a condition with no identifiable cause that causes pain or discomfort around the opening of the vagina

Abbreviations

A.D.	Anno Domini
B.C.	Before Christ
CHD	coronary heart disease
CIN	cervical intraepithelial neoplasia
CKD	chronic kidney disease
COPD	chronic obstructive pulmonary disease
CRT	cardiac resynchronisation therapy
DSM	*Diagnostic and Statistical Manual of Mental Disorders*
EBM	evidence-based medicine
FND	functional neurological disorder
GFR	glomerular filtration rate
HFwPEF	heart failure with preserved ejection fraction
HFwREF	heart failure with reduced ejection fraction
HREC	Human Research Ethics Committee
IBS	irritable bowel syndrome
ICD-10	*International Classification of Diseases 10*
LVAD	left ventricular assist device
MCAS	mast cell activation syndrome
ME/CFS	myalgic encephalomyelitis/chronic fatigue syndrome
MG	myasthenia gravis
MUS	medically unexplained symptoms
NIH	National Institutes of Health
OCD	obsessive compulsive disorder
POTS	postural orthostatic tachycardic syndrome

PTSD	post-traumatic stress disorder
RA	rheumatoid arthritis
RCT	randomised controlled trial
SLE	systemic lupus erythematosus
SVT	supraventricular tachycardia
T1DM	type 1 diabetes mellitus
T2DM	type 2 diabetes mellitus
UK	United Kingdom
US	United States

Prologue

I was raised a feminist by my parents near Liverpool, United Kingdom (UK), and grew up during the 1990s when it was still common for females from my background to marry and have children early. My parents raised me to value my independence, career and education, and this was normal for my family, although many of my school peers commenced their own families not long after leaving high school.

I did not become a conscious feminist, however, until I had completed my medical degree and began working as a junior doctor in hospitals in West Yorkshire, again in the UK. During this time, I unfortunately became increasingly unwell with what was ultimately and eventually diagnosed as systemic lupus erythematosus (SLE), an autoimmune disease. I was visiting hospital as a patient and learning to manage a chronic condition while, at the same time, endeavouring to maintain work as a junior doctor. I began to notice that some of the medics I encountered did not seem to believe me or listen to me when I described my symptoms, and that I would often need the validation of my then-boyfriend (now husband), who is also a doctor. This had significant impacts upon my care-seeking behaviour as a patient. I recall one incident where I was in the emergency department with abdominal pain; the doctor who treated me did not perform a full set of investigations and sent me home with a humiliating letter to my GP about how my symptoms were psychosomatic. I did not see a doctor for 6 months following that, until I was admitted to hospital as an emergency and within 24 hours was diagnosed with an autoimmune disease.

While this significant illness was occurring in my private life, I was starting to notice how female patients were cared for on the wards by colleagues. One shift, I was working as a resident medical officer and carrying the emergency pager. I was called to an emergency on the surgical ward; a young woman of my age (24 years) was having a seizure on the patient bathroom floor. We secured her airway with a nasopharyngeal tube; about the diameter of a finger, this tube is inserted through a nostril and into the back of the throat to maintain a patent airway. The patient did not flinch. After she was stabilised, I discussed the case with a senior doctor, asking what might have caused her seizure. He told me there was nothing wrong with her, that it was not a real seizure, and it was ‘in her head’. I felt uncomfortable. Just because a cause was not immediately apparent did not mean this was not a ‘real seizure’. She had not yet had any investigations to seek a cause. I started to notice a pattern of dismissal, particularly for young female patients, and it was paralleled with my own personal experiences.

I then began exploring the literature on the care of female patients and learnt that most medical research has historically been conducted on male bodies and applied to females. The idea developed to formally investigate the research gap and the potential impacts on the experiences of female patients in Australia. I read well-informed accounts of personal illnesses by authors such as Gabrielle Jackson (*Pain and Prejudice*), Maya Dusenbery (*Doing Harm*) and Katerina Bryant (*Hysteria*). I connected with other feminists on social media and learnt more about the background of the patriarchy. Strikingly, whenever others enquired as to the nature of my doctoral research, every woman seemed to have her own story of how she was dismissed by her doctors, only to later learn she had a serious health condition.

As the COVID-19 pandemic progressed throughout 2020–21, I noticed a group of patients with ‘long-COVID’—a cluster of ongoing, severe symptoms that have an astonishing resemblance to myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), a disabling disease of unknown aetiology that disproportionately affects women. It is interesting to watch the new long-COVID epidemic unfold, as men and women appear equally affected and research surrounding post-viral fatigue syndromes is increasing, which will potentially benefit ME/CFS patients. Notably, when this condition affected mostly women, research seemed to be under-funded and little progress made.

Throughout this research, I have gained an understanding not only of women’s health and health inequality, but also of the chronic disease and disabled community. I have watched women struggle for clear diagnoses and treatment plans, and their suffering has spurred on this research to educate medical colleagues about the sex and gender gaps in medicine and hopefully inspire other medics to respond and reflect on their own biases to improve women’s health.

Introduction

Thoughts on My Sick-Bed

And has the remnant of my life
Been pilfered of this sunny Spring?
And have its own prelusive sounds
Touched in my heart no echoing string?

Ah! say not so—the hidden life
Couchant within this feeble frame
Hath been enriched by kindred gifts,
That, undesired, unsought-for, came

With joyful heart in youthful days
When fresh each season in its Round
I welcomed the earliest Celandine
Glittering upon the mossy ground;

With busy eyes I pierced the lane
In quest of known and unknown things,
—The primrose a lamp on its fortress rock,
The silent butterfly spreading its wings,

The violet betrayed by its noiseless breath,
The daffodil dancing in the breeze,
The caroling thrush, on his naked perch,
Towering above the budding trees.

Our cottage-hearth no longer our home,
Companions of Nature were we,
The Stirring, the Still, the Loquacious, the Mute—
To all we gave our sympathy.

Yet never in those careless days
When spring-time in rock, field, or bower
Was but a fountain of earthly hope
A promise of fruits & the splendid flower.

No! then I never felt a bliss
That might with that compare
Which, piercing to my couch of rest,
Came on the vernal air.

When loving Friends an offering brought,
The first flowers of the year,
Culled from the precincts of our home,
From nooks to Memory dear.

With some sad thoughts the work was done.
Unprompted and unbidden,
But joy it brought to my hidden life,
To consciousness no longer hidden.

I felt a power unfelt before,
Controlling weakness, languor, pain;
It bore me to the Terrace walk
I trod the Hills again; —

No prisoner in this lonely room,
I saw the green Banks of the Wye,
Recalling thy prophetic words,
Bard, Brother, Friend from infancy!

No need of motion, or of strength,
Or even the breathing air;
—I thought of Nature's loveliest scenes;
And with Memory I was there.

(Wordsworth, 1832)

Introduction

This introductory chapter outlines the aims of the research presented in this thesis, provides an overview of the thesis structure, and offers the definitions of sex and gender utilised throughout this doctoral work. The content of this thesis is based on seven manuscripts. There are two manuscripts in Part One; the initial commentary and background piece is presented in Chapter 1 and an analysis of evidence-based medicine (EBM) from a feminist perspective is contained in Chapter 3. The studies for Part Two are contained in Chapters 4 and 5. The two studies for Part Three are presented in Chapter 6. Chapter 7 provides a discussion and subsequent conclusions and recommendations from this doctoral study. Table 1 presents a publication plan demonstrating how the papers relate to the thesis chapters and objectives.

Research aims and objectives

The androcentric history of medicine has potentially created a sex and gender gap in medical research, and this remains largely undocumented in Australian medical research, education and patient experience. This research aims to explore whether sex and gender gaps in medical research may affect the experiences of female patients in Australia via the following objectives:

1. To explore if there are current or ongoing sex and gender gaps in the current health research literature, with a focus on Australia.
2. To establish if any gaps in the medical literature possibly translate into gaps in medical school curriculum guidelines, course outlines and recommended clinical textbooks.

3. To explore the experiences of female patients with chronic conditions in the Australian healthcare system.

Thesis overview

Exploring contemporary androcentricity in medicine, medical research and education and the potential impact on female patients involves multiple studies. At the time of writing, four papers are published, two papers are accepted for publication and one manuscript is under review.

There are three parts to this doctoral thesis. Part One incorporates a background to the development of the patriarchy and discusses medicine as a patriarchal structure. An overview of the development of feminism and feminist ideology is also given. Exploration of feminist methodologies in relation to the research presented throughout this thesis is provided, with a focus on feminist criticisms of EBM. Part Two includes three research papers that investigate recent and ongoing sex and gender gaps in contemporary health research and medical education. Data were collected via systematic review of the literature, cross-sectional analysis of the contemporary published literature in Australia, and a sex- and gender-based analysis of curriculum accreditation standards, medical school course outlines and selected recommended clinical textbooks. Part Three investigates the experiences of Australian female patients with chronic conditions via a quantitative survey and a series of semi-structured qualitative interviews. This doctoral thesis does not attempt to prove the experiences of female patients are related to any sex and gender gaps observed in the research literature and medical educational system. This thesis endeavours to highlight any ongoing discrepancies in the care of female patients and explore the impacts this may have on patient care, as experienced by female patients.

Table 1

Publications, thesis chapters and research objectives

Phase and thesis chapter	Paper title	Journal and publication status	Research objective
Part One, Chapter 1	Sex and Gender Gaps in Medicine and the Androcentric History of Medical Research	*Australia and New Zealand Journal of Public Health*, published 2021	1
Part One, Chapter 3	Evidence-Based Medicine: Feminist Criticisms and Implications for Women's Health	*Women's Health Reports*, accepted for publication	1
Part Two, Chapter 4	Sex Inequalities in Medical Research: A Systematic Scoping Review of the Literature	*Women's Health Reports*, published 2022	1
Part Two, Chapter 4	Mind the Gap: Reporting and Analysis of Sex and Gender in Health Research in Australia: A Cross-Sectional Analysis	*Women's Health Reports*, published 2022	1
Part Two, Chapter 5	Representation of Women and Women's Health in Australian Medical School Course Outlines, Curriculum Requirements and Selected Core Clinical Textbooks	*Australian Journal of Clinical Education*, under review	2
Part Three, Chapter 6	Time to Diagnosis and Proportions of Re-Diagnosis in Female Patients with Chronic Conditions in Australia	*Women's Health Reports*, published 2022	3
Part Three, Chapter 6	"I Just Want to Feel Safe Going to a Doctor": Experiences of Female Patients with Chronic Conditions in Australia	*Women's Health Reports*, accepted for publication	3

Defining sex and gender

Sex and gender are related but distinct entities; sex refers to the biological qualities that define an individual as female, male or intersex, whereas gender is societally constructed, particularly during development of the patriarchy during the English restoration and eighteenth century (McKeon, 1995), and refers to the roles, behaviours and activities of an individual, encompassing a range of identities beyond woman and man (Sex and Gender Sensitive Research Call to Action Group et al., 2020). Gender is multidimensional and can be considered in terms of gender identity (considering oneself to be a woman, man or someone who does not fit the binary) and gender expression (behaving in ways appropriate for a woman or man as deemed by society; Lips, 2018). Sex and gender interact to affect health outcomes that are not yet fully understood and are still largely overlooked. Both sex and gender also intersect with ethnicity, age, socioeconomic status and sociocultural factors that further impact upon health outcomes. Symptoms such as pain, are influenced by not only physiological factors such as hormones and metabolism, but socio-cultural factors such as acceptability of pain-reporting (Stefanick, 2020). Owing to such interactions, it is difficult to dissect sex and gender entirely, and this is reflected throughout this doctoral thesis.

Part One: Background and Methodological Approaches

Chapter 1: Historical Overview

They Shut Me Up in Prose

They shut me up in prose-
As when a little girl
They put me in the closet-
Because they liked me "still"-

Still! Could themselves have peeped-
And seen my brain – go round-
They might as wise have lodged a bird
For treason – in the pound-

Himself has but to will
And easy as a star
Look down upon Captivity-
And laugh – No more have I-

(Dickinson, 1862)

1.1 Introduction

This chapter provides a descriptive overview of the history of patriarchy and describes how medicine as an institution is a structure of patriarchy. An overview of the history of feminism is provided with explanation of the different feminist ideologies. This chapter creates the setting for discussion of feminist methodologies and criticisms of evidence-based medicine (EBM), discussed in Chapters 2 and 3.

1.2 The history of patriarchy

The term patriarchy literally means the rule of the father and was originally used to describe the male-dominated family— a large household that included women, children, and slaves or servants under the rule of the dominant man. As times have progressed, the term has taken on a wider meaning to refer more generally to male domination and the systemic power relationships that men exert over women (Sultana, 2011). Thus, the concept of patriarchy has been defined by different thinkers in different ways. Feminists use the word to describe the imbalanced power relationship between men and women (Patil, 2013). Some use it to refer to social systems built upon the historical exchange of women, and others to define the social structures and institutions that simultaneously exploit and oppress women (Sultana, 2011). One may define patriarchy as a set of hierarchical social relations between women and men that enable men to dominate women. The ideology of patriarchy exaggerates biological determinism, which states that women and men are naturally different because of their biology and therefore are assigned different social roles, and ensures that men remain dominant. This has historically been achieved via institutions, such as the Christian church and their understanding of the family, that justify and emphasise the subordination of women to men (Sultana, 2011).

Advocates for maintaining tradition believe that men were born to dominate and women to be subordinate to men, and that this hierarchy has always existed and will continue to exist (Sultana, 2011). The origins of patriarchy are closely related to the development of gender roles (Lerner, 1986). Some feminists argue that patriarchy and associated gender roles are socially constructed (Buckley, 1986). In reality, patriarchy is more of a theory, and this concept can be utilised to understand women's realities (Sultana, 2011).

The patriarchy was created over a period of almost 2500 years by men and women (Lerner, 1986). Many of the Western arguments for the inferiority of women originate from Aristotle (384–322 B.C.), who referred to males as 'active' and females as 'passive' and defined women as 'mutilated males' (Horowitz, 1976; Sultana, 2011). It was Aristotle who first described the female body as a deviation from the norm of the male body, characterising femininity as a lack of maleness (Horowitz, 1976). It took a further 2000 years after Aristotle's one-semen theory that embryos are derived from semen alone for scholars to investigate the role of the ovary and ovum in reproduction (Horowitz, 1976). Aristotle legitimised the patriarchal household—ideas that have prevailed for centuries before and since. His justification lay in his belief of the mental and biological superiority of free men over both women and slaves (Horowitz, 1976).

Sixteenth century philosopher Robert Filmer authored the book *Patriarcha*, centred on his belief that the state was a family, the first king was a father, and submission to the patriarchy was an obligation of all society, dictated by God (Filmer, 1680). As Filmer wrote, the basic unit of patriarchy is the patriarchal family, and the roles and behaviour deemed appropriate to each sex (viewed as binary female and male) were expressed through social norms, laws, values and customs (Lerner, 1986). The development of patriarchy, however, dates back thousands of years. Women were commodified as a resource during the Neolithic period, long before the establishment of Western civilisation, where tribal exchanges of women coincided with the development of agriculture. Agriculturists who traded women utilised the labour of children to increase production and accumulate a surplus, thus rendering women a valuable resource. Women were exchanged in marriages between tribes or enslaved when battles between tribes occurred. The knowledge that women could be enslaved led to the later enslavement of men that lasted for centuries in the Western world (Lerner, 1986). Enslavement of women and then men pre-dates the development of class systems and subsequent oppression of the lower social classes. In ancient Mesopotamian society, the second millennium Before Christ (B.C.), girls from lower socioeconomic backgrounds were frequently sold into marriage or prostitution to enhance the economic position of their family (Lerner, 1986).

The commodification of women, American feminist historian Professor Lerner believed, may be the earliest example of the accumulation of private property (Lerner, 1986). The first sex-defined social role of women was exchange in marital transactions. The class position of women was determined via their sexual relations, whereas the class of men was based on their means of production; those who could produce commodities dominated over those who could not. Forced control over sex and reproduction has been a major feature of patriarchal social domination in every society (Lerner, 1986). This continues in modern times, observed in recent restrictions in access to abortion and planned parenthood in the United States

(US) (Planned Parenthood, 2022). Reducing a woman’s worth to her reproductive potential is a form of oppression and violence against women. Reproductive oppression is defined as control and exploitation of females through control of their bodies, sexuality, labour and reproduction (Manes, 2017). Reproductive oppression cannot be disentangled from other oppressions, nor from social, mental, economic, societal and familial wellbeing (Manes, 2017). Radical-libertarian feminist Shulamith Firestone (1970) is famously quoted as stating “women cannot be free until released from the tyranny of reproduction” (p213), severing the tie between femininity and the body. French feminist philosopher Simone de Beauvoir (1949/2015) believed that female biology laid the foundation of social oppression (Mackay, 2020). In this sense, the development of contraception and reproductive freedom have been landmark moments in the history of feminism.

Western civilisation draws many of its metaphors and definitions of gender and morality from the Christian Bible, in particular the book of Genesis from the Old Testament. The book of Genesis was heavily influenced by Sumerian, Babylonian, Canaanite and Egyptian cultural materials alongside laws and cultural practices of the people living at that time. The writing of the book of Genesis spanned approximately 400 years, from the tenth century Before Christ (B.C.) to the fifth century B.C. (Lerner, 1986). The patriarchal period of history outlined in the Bible dates to around the first half of the second millennium B.C. The stories in the book of Genesis provide insight into the transition from matrilocal family organisation, where the new husband moved in to reside with the family of his wife, to patrilocal family organisation, where the new wife moved in to reside with the family of her husband. Matrilocal marriage allowed women greater freedom, including the right to divorce, which was then forbidden under the later-established patrilocal marriage. The dominant family structure referred to in the Bible is the patrilocal family (Lerner, 1986). The earliest patriarchs of the Old Testament had absolute control over their family; the wife would call her husband ‘ba’al’, which translates to master. The wife was considered a possession of the husband, alongside any servants and livestock. Initially, a man could legally sell his daughters into slavery or prostitution; however, this was later forbidden (Lerner, 1986).

In the patriarchal families of the second millennium B.C. (Frymer-Kensky, 1981), inheritance would fall to the eldest son. If the family had no sons, it would fall to the eldest daughter, who would have to marry within the tribe to ensure the wealth was not transferred out. All sons and their wives would live within the father’s household until his death. The dowry for a daughter marrying into other families would serve as their portion of inheritance (Frymer-Kensky, 1981; Lerner, 1986). Men enjoyed complete sexual freedom outside of their family. Women, however, were expected to be virgins at marriage and provide complete sexual fidelity. Punishment for adultery was death of both adulterating parties. By the time of the patrilocal marriage, divorce was only the right of the husband and came with significant economic penalty. Jewish law forced the man to marry a woman he raped and specified that divorce was unobtainable for both parties in that circumstance (Lerner, 1986). In the marital unit, the wife was expected to provide offspring, particularly sons. Failure to produce sons was considered to be barrenness and was not only a disgrace, but also legitimate grounds for a divorce (Lerner, 1986).

It is not adequate to view patriarchy as simply the rule of the father or husband; rather, we need to understand the formalised patriarchal rules such as inheritance, child obedience, marital arrangements, sexualisation and the obedience of women (Gruber & Szoltysek, 2012). Patrilocal residence is strongly associated with patriarchy as a representation of the power relations that favour men over women (Gruber & Szoltysek, 2012). Examining the ancient civilisations described in the book of Genesis, we observe that the oppression of women is grounded in economic disadvantage and the regulation of women’s sexuality alongside double-standard law codes surrounding sex and family relations (Lerner, 1986). In the Old Testament, women are ‘upgraded’ to mothers (Lerner, 1986). The fifth commandment states children are to honour the mother and the father equally (Lerner, 1986), however, the book of Ephesians in the New Testament states that a wife should submit to her husband as the head of the household (Zonderfan, 2017). In this way, the church and the state co-developed as patriarchal institutes, with the Christian church aiding the formation of gender inequality and upholding it to this day (Wood, 2019). While the church and state developed together, establishing male dominance, economic and political factors also helped to progress patriarchy.

The Marxist socialist feminist account for the origin of patriarchy is based in the development of capitalist economic structures, as highlighted by Friedrich Engels (1884). Engels believed that the patriarchy originated with the development of private property alongside division of the classes. Engels drew parallels between the patriarchal family presented in the Bible and the modern-day bourgeois family. He believed that the establishment of male supremacy was first demonstrated in the patriarchal family (Engels, 1884). The patriarchal household formed the transitional stage between the matriarchal family and the single family of the modern world (Engels, 1884). Marx believed that the modern family originated from ideologies of slavery and serfdom (Engels, 1884). Indeed, the patriarchal household community coincided with cultivation of the land, agriculture and later development of private property (Engels, 1884). The patriarchal family and the later single family brought a change in community; the household management was no longer concerned with society, but became a private service with the wife as the head servant, excluded from participating in social production until large-scale industry opened this up again, but only to the proletarian wife (Engels, 1884). The modern individual family, Marx and Engels believed, was founded on the slavery of the domestic wife (Engels, 1884). Engels believed that patriarchy and capitalism were co-constructed with the development of animal agriculture; men gained control of the tribe’s animals and then later a surplus of animals constituted an accumulation of wealth. As men’s value in production grew in importance, the value of women’s production decreased and, with it, their status in society (Tong & Fernandes Botts, 2018). At this point, society transitioned from matrilocal to patrilocal; men took control of the household and denigrated women to servant status. The husband ‘ruled by virtue of his economic power’ (Tong & Fernandes Botts, 2018).

For Engels, the shift to private property and capital explained the development of the monogamous family, or single family unit. To ensure biological fatherhood of any offspring, men imposed the institution of heterosexual monogamy upon women, ensuring the family was based on economic rather than natural conditions (Engels, 1884; Tong & Fernandes Botts, 2018). Engels believed that the emancipation of women was therefore dependent upon their becoming economically independent of men by reintroduction of women into public industry and socialisation of housework and child-rearing.

Examination of class is just one way of examining the history of patriarchy. Firestone (1970), defined patriarchy as the systematic subordination of women and claimed this to be rooted in the biological inequality of the sexes. Firestone believed that Engels and Marx were so focused on economic drivers of patriarchy that they ignored what she termed ‘sex class’ (Firestone, 1970). For Firestone, reproductive relations rather than production were the driving forces of patriarchy, concluding that women’s liberation would require a ‘biological revolution’ whereby women must obtain control of means of reproduction to eliminate the sex class system (Firestone, 1970; Tong & Fernandes Botts, 2018). Firestone believed that the roots of patriarchy are pre-social in that the oppression of females can be traced back to the animal kingdom; women are at the mercy of their biology—menstruation, pregnancy and menopause—and the biology of their offspring because human babies take longer to mature than animals and are consequently dependent on their mother for an extended period of time. Thus, the mother–child interdependency shapes the psychology of every mature female and the natural reproductive difference between the sexes led to the first divisions of labour (Murray, 1995).

The two-system feminist explanations of patriarchy and the oppression of women combine socialist (Marxist) feminist accounts with radical-libertarian theory. Socialist feminist Juliet Mitchell (1940-) proposed a two-system explanation. In her book *Women's Estate,* she suggests how a woman's position is related to an interplay of her role in production, reproduction, socialisation of children and sexuality (Mitchell, 2015). Mitchell noted that despite women being equally qualified as men for high-paying, prestigious jobs, owing to lack of progress in the areas of women's production and socialisation of children, women continue to be mostly confined to low-paying and low-status jobs (Mitchell, 2015). Mitchell argued that even if the family as an economic unit ceased to exist, women would still not be equal to men until society is liberated from the idea that women are less valuable than men (Mitchell, 2015; Tong & Fernandes Botts, 2018). American philosopher Alison Jagger similarly defines a two-system explanation of women's oppression; however, she identifies not capitalism as the root cause, but patriarchy itself, as an oppressor of both women's identity and their activity (Tong & Fernandes Botts, 2018).

Interactive-system feminists argue that socialist feminists incorrectly causally link feminism with capitalism and overlook the fact that in socialist countries, women are still equally oppressed (Tong & Fernandes Botts, 2018). Political theorist Iris Marion Young states that class is gender blind and advocates for a sexual-division-of-labour analysis. Young reasons that patriarchy should not be considered a separate system from capitalism and that class and gender structures are heavily interconnected; a feudal system of gender relations accompanied a feudal system of class arrangements. Ultimately, most seem to agree that by one mechanism or another, social relations of class and gender developed together into the capitalist nuclear family (Tong & Fernandes Botts, 2018; Young, 1981). Capitalism developed following the fall of feudalism.

1.3 From feudalism to feminism

Feudalism refers to the medieval European (5th–12th centuries Anno Domini [A.D.]) political system and was structured around three concepts: lord; vassel (land); and serf (Sweezy & Dobb, 1950). A lord would grant the serf vassels in exchange for military service, and all land was ultimately owned by the King. Capitalism, on the other hand, is structured around privately owned production and distribution of products for a profit (Berend, 2015).

Most accounts of the origin of patriarchy appear to hinge, at least in part, on the development of capitalism and social class as a causal or co-factor. In her book *The Law of the Father? Patriarchy in the Transition From Feudalism to Capitalism,* Professor Mary Murray (1995), discusses the relationship between class and patriarchy, critiquing the work of Engels, largely on the basis that women's oppression is not specifically explored in Engel's theses, and neither is the extent to which patriarchal relations affect class relations. Murray attempts to analyse the relationship between class and gender across a period of English history, arguing that the social relationships of class and patriarchy contained each other and formed each other. Murray believes that during the feudal time period, it is impossible to understand class and patriarchy as independent.

By the seventh and eighth centuries A.D., consolidated social hierarchies had evolved and a feudal economy was emerging in England, evidenced by the social classes of kings, lords, peasants and slaves. Lords began to exploit their land and labour, renting their land to men who would have to not only pay rent but also contribute agricultural labour (Murray, 1995). Development of an advanced administrative system with taxation, currency and law led to the second phase of feudalism (1000 to 1300 A.D.), which observed a large population increase alongside agricultural and industrial growth. In feudal societies, peasants were the leading and direct producers of both subsistence and surplus produce. It was the surplus produce that created class division.

In the 14th and 15th centuries, the feudal system began to break down with a collapse of large-scale feudal agriculture and international trade, prefaced by plague and population decrease. Feudalism had laid the foundations for capitalism. Capitalism began to accelerate as a response to the crisis of feudal power (Federici, 2004) and in development with colonialism and the subsequent rapid influx of capital and precious metals from overseas, utilising labour as a commodity (Murray, 1995). Marxism states the basis of capitalism is an exploitive relationship between the property-owning capitalist class and the ‘free’ wage labourers (labourers that sell themselves and trade as a commodity). Free wage labourers differ from serfs and servants in their freedom to enter into contracts to sell their labour power, rather than being owned (Murray, 1995). The labourer is, however, forced to sell labour power as they are property-less. By the seventeenth century much of the land in England was owned by capitalist farmers who produced for a commodity-based free market and employed wage-labour as primary producers. Two key events in the seventeenth century, the Civil War and the Industrial Revolution, spurred the capitalist society forward from its feudal beginnings. Following this, in the eighteenth century, the American and French revolutions, alongside the English Industrial Revolution, sealed capitalism as triumphant (Murray, 1995).

In pre-industrial Europe and America, the household was the central unit of production, with men at the head of the household and women as caretakers of the family and producers of goods. The Industrial Revolution (1760–1860) (Nardinelli, 2019) changed the roles of working-class women, forcing them into factory or farm work, while still maintaining pressure to undertake child-raising duties (Taylor, 2020). Throughout the Industrial Revolution, women received on average a third of the salary of a man (Workplace Gender Equality Agency, 2019), and typical women’s jobs such as printing and spinning could be easily learnt at home and were highly profitable for exploitive employers (Foundations of Western Culture, 2016). Early feminist movements began to grow to fight for equal pay for women. From here, women began to campaign for increasing societal rights as workers in their own right, including the right to vote, led by suffragettes worldwide (Foundations of Western Culture, 2016).

1.4 The patriarchy: an Australian perspective

For Australia, the patriarchy, colonialism and issues with ethnicity, social class, age and sexuality are inextricably linked and are the products of an imperialist, capitalist and white supremacist society (Baldry, 2015). Australia was colonised in 1788, as the patriarchy across Europe was developing, and consequently a similar political and economic model was constructed in Australia (Murray, 2012). Aboriginal and Torres Strait Islander women are at the intersection of race, sex and gender and exemplify colonial and neo-colonial oppression in their notable disadvantage compared with non-Indigenous people in Australia (Baldry, 2015). Aboriginal and Torres Strait Islander women are over-represented in systems of control, particularly the penal system. The entwinement of colonialism and patriarchy is particularly important when endeavouring to understand Aboriginal and Torres Strait Islander women's perceptions of feminism, and according to Moreton-Robinson (2000), white feminist movements have historically concealed the colonisation process. Baldry and Cunneen (2014) argue that the ongoing influence of colonial patriarchy continues to enhance Aboriginal and Torres Strait Islander women's disadvantage and incarceration rates. Consequently, throughout this thesis there is consideration for the historical context and differing circumstances for Aboriginal and Torres Strait Islander women,

1.5 Medicine as a patriarchal structure

Medicine as a profession holds significant social power and often reflects the moral standings of the era (Foucault, 1973). Medicine has a long androcentric history, dating back to

Ancient Greece, where Plato developed theories of the womb wandering lustfully through the bodies of women, causing illness and hysteria (Adair, 1995). Despite this, female healers date back to ancient history; Isis the Egyptian goddess of medicine, had temples built in her honour, and priestesses of Isis were women healers who were believed to obtain their power from the goddess (Wynn, 2000). Egyptian women could study at the medical school in Heliopolis as early as 1500 B.C., and imagery of women performing surgery is common in Egyptian tombs and temples, indicating that female doctors were a norm in this ancient civilisation (Wynn, 2000). In Ancient Greece and Rome, in spite of the misogynistic attitudes of Plato and fellow philosophers, women doctors taught medicine, cared for patients, performed operations, delivered babies and provided general obstetric care (Wynn, 2000).

In medieval times, as the church became increasingly oppressive towards women, the medical education of women declined significantly. Then, as witch-hunts dominated Europe during the Middle Ages, many female healers, even midwives, were executed as women were not allowed to study medicine, and therefore, any skill was believed to have been derived from the devil (Wynn, 2000). Medicine became dominated by men, who fiercely resisted the attempts of women to study medicine and become physicians, claiming them to be too affected by menstruation or physically weak (Jefferson et al., 2015). Indeed, it was believed and postulated by many male physicians that studying would lead a woman to develop hysteria, as her smaller, inferior brain would be using energy that would otherwise be utilised by her reproductive organs (Cleghorn, 2021).

While recently female admissions have overtaken male admissions into medical school in the UK (Jefferson et al., 2015), US (Association of American Medical Colleges, 2019) and Australia (Medical Deans, 2018), the UK only allowed women to enter medical school in the late 19th century owing to a loophole that allowed American medical graduate Dr Elizabeth Blackwell to practise medicine in the UK in 1858 (Jefferson et al., 2015). Blackwell had been the first female medical student in the US just a decade earlier in 1847. It was only in 1885, after Sydney Medical School allowed the entry of women, that Australian medical schools began admitting women (Stanley, 2020). Today, senior positions in both medicine and academia remain dominated by men, and women and people of colour are significantly under-represented (Teede, 2019).

Additionally, ethically and morally, medicine has a questionable history, including experimentation on enslaved women in the 19th century that informed gynaecological advances (Shahvisi, 2019). James Marion Sims is widely acknowledged as the father of modern gynaecology, accredited with developing the curative surgery for a vesicovaginal fistula. Sims's technique, however, was developed on enslaved African American women, with neither their consent nor an anaesthetic. Following perfection of the technique, Sims then performed it—using anaesthetic—on consenting white women (Wall, 2006). Jean-Martin Charcot, a 19th century Parisian neurologist, delivered a series of lectures featuring vulnerable, unwell female patients, who were often diagnosed with hysteria. While not a feminist, Charcot did advocate against the oophorectomy as a treatment for hysteria (Goetz, 1999). However, Charcot also paraded and exploited the women in his care theatrically in front of audiences and photographically, despite many women expressing the trauma of prior sexual abuse and rape. The visual observation of symptoms was at the centre of Charcot's diagnostic approach and came at the expense of direct and confidential patient interaction and treatment (de Marneffe, 1991).

The diagnosis of hysteria itself can be used as a marker of the patriarchal and misogynistic history (and present) of medicine. Hysteria comes from the Greek word for uterus *hystera*, when female maladies were attributed to a 'wandering womb', and marriage and regular copulation were the only cures. One Hippocratic medical text from the fifth century B.C. stated that 'the womb is the origin of all diseases in women'—a concept that persisted for millennia (Dusenbery, 2017). Treatment for hysteria included placing strong-smelling items at the vagina or mouth to encourage or drive the uterus back into place, respectively (Shetty et al., 2020). During the medieval period, theories regarding the cause of hysteria changed; in line with the witch-trials and supernatural beliefs of the time, the hysterical woman was bewitched and under the influence of the devil. Such women were tortured and often executed (Dusenbery, 2017). By the 18th century, hysteria was no longer linked directly to the womb and was also diagnosed in males. Women, however, were considered far more vulnerable to the condition owing to their 'weak constitution of the spirits' and small brains, and hysteria remained a stereotypical female disease (Dusenbery, 2017).

The specialty gynaecology emerged in the 19th century, and the hysteria diagnosis and treatment became the rope in a tug of war between gynaecology and neurology—each laying claim to the disorder until Freud emerged with psychoanalysis (de Mota Gomes & Engelhardt, 2014). Gynaecologists would treat hysteria with intra-uterine injections, leeches on the vulva, cauterisation of the cervix and oophorectomies. When neurologists laid claim to hysteria, they opted for electrotherapy, drugs, arsenic, opiates and the famous 'rest cure' as described in the short story *The Yellow Wallpaper*, which confined women to strict bedrest for months at a time (Gilman, 1892). Hysteria was even at the centre of why women were unable to pursue careers considered to be mentally taxing, such as medicine. The reproductive organs had too much influence on the brain and the female body could easily be thrown into 'dangerous disorder' (Dusenbery, 2017). Dr Edward H. Clarke, a professor at Harvard Medical School, during a dispute in 1843 on whether to admit female medical students, stated that higher education would lead to atrophy of the womb in such women.

In the 1800s, Dr Sigmund Freud entered the hysteria debate, abandoning neurological and gynaecological causes in favour of psychological aetiology, arguing that psychological conflict was 'converted' into physical symptoms. Freud argued that hysteria arose when traumatic memories that had been repressed in the unconscious found symbolic expression in the body. Later, he would decide that fantasies of sexual abuse could produce the same conflict and conversion disorder (Dusenbery, 2017). Freud developed psychoanalysis as a treatment for hysteria, believing that consciously recalling the distress would cure the condition (Dusenbery, 2017).

Although now considered outdated, Freud's theories laid the foundations for many female-dominated conditions and theories of their aetiology observed in medicine today. While hysteria as a diagnostic label is no longer recognised, multiple synonyms exist in the discourse today. Conversion disorders are one such example, still listed in the *Diagnostic and Statistical Manual of Mental Disorders Fifth Edition* (DSM-V) (American Psychiatric Association, 2013) under the new titles 'somatic symptom disorder', 'functional neurological symptom disorder' (FND) and 'illness anxiety disorders' (Shetty et al., 2020). The *International Statistical Classification of Diseases and Related Health Problems* (ICD-10) lists similar conditions as dissociative disorders, somatoform disorders and hypochondriacal disorders (World Health Organization, 2016). These conditions are still actively diagnosed today; as author Katerina Bryant describes in her autobiography *Hysteria*, her non-epileptic seizures were initially diagnosed as conversion disorder. A brief Google search on her part led her down a rabbit hole of hysteria and the experiences of hysterical women through history (Bryant, 2020).

Somatisation, a term coined by Viennese psychoanalyst Wilhem Stekel in the 1920s, describes a 'process by which neurotic conflicts appear as physical disorder' (Dusenbery, 2017). This idea was strongly related to Freud's ideas of conversion, and as Freud's influence on the American medical education system peaked, a subspecialty of 'psychosomatic medicine' developed (Dusenbery, 2017). At its peak, diseases considered to be psychosomatic, or at least have a strong psychological component, included asthma, hypertension and ulcers

(Dusenbery, 2017). Medically unexplained symptoms (MUS) are still judged to be psychosomatic, or of psychological cause (Mobini, 2015).

More recently still, diseases are referred to as organic, having a known physical or pathological origin, or non-organic/functional/psychogenic, having no known physical cause and being attributed to a largely psychological origin (Bell et al., 2020). The term ‘functional’ originally described a condition with a lack of discernible cause; however, it has become a contemporary term for psychosomatic (Dusenbery, 2017). There are concerns that the terms functional and psychogenic have ‘loaded social meanings’ and there is potential for patient disempowerment in their utilisation (Bell et al., 2020). Functional/MUS disorders are currently believed to have a female predominance (Clareus & Renstrom, 2019), and this may be a result of the patriarchal history of medical research and medicine and the over-representation of females in psychiatric research (Merone, Tsey, Russell, & Nagle, in press).

1.6 Sex and gender gaps in medicine and androcentric history of medical research

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Sex and gender gaps in medicine and the androcentric history of medical research

Lea Merone,[1,2] Komla Tsey,[3] Darren Russell,[1,4] Cate Nagle[5]

1. School of Public Health, James Cook University, Queensland
2. Poche Centre for Indigenous Health, University of Queensland
3. College of Arts, Society and Education, James Cook University, Queensland
4. Cairns Sexual Health Service, Queensland
5. College of Healthcare Sciences, James Cook University, Queensland

> *The truth will set you free, but first it will piss you off* – Gloria Steinem[1]

Women live longer than men, however, despite this, women experience poorer health outcomes including higher rates of morbidity and disability.[2] This disparity has been attributed to, at least in part, societal gender inequalities such as the employment and pay gap, making women more likely to have a lower socioeconomic status than men.[2] Lower socioeconomic status (SES) and lower educational attainment have been linked to oppression[3,4] and poor physical health.[5] In Australia, women are more likely than men to be assaulted by an intimate partner. Between 2014 and 2015, 2,800 women and 560 men were hospitalised following an assault by a partner or spouse.[6] One woman per week and one man per month were murdered by a current or former partner between 2013 and 2015.[6] In addition to physical violence, sexual abuse against women is more prevalent than it is against men.[7] These inequities may be a modern manifestation of the historical imbalance of power between the sexes.[8]

Sexual abuse is an ongoing public health issue, highlighted in recent years by the #MeToo movement, where women shared their stories of sexual assault and advocated for change.[9] Statistics from the domestic violence advocacy body White Ribbon Australia reveal that one in every five Australian women have experienced sexual abuse and 85% of women have been sexually harassed.[10] Violence and sexual abuse have clear physical and psychological health impacts on women, contributing to women's general disadvantage and often their lower SES and homelessness.[11] The employment and pay gap contribute significantly to the disadvantage experienced by women.

Gender gaps are observed in societies throughout the world. Caroline Criado Perez notes in her book *Invisible Women*[12] that even town and transport planning display a gender gap and everything in everyday life is built around the needs and lifestyles of males in society. Perez argues that societal gender gaps place women's lives at significant risk.[12] In Australia, women represent 47% of the workforce but only 17% of leadership positions and 30% of management positions. The sex and gender pay gap is 23% and almost 72% of female workers are employed part-time.[13]

Gender gaps in medical research and medicine

Sex and gender inequalities in medicine and medical research are drawing increasing media attention[14,15] and subsequently there is a call for Australian researchers to proportionally increase female representation in medical research.[16] To measure any improvement, sex and gender must be clearly defined. Sex refers to the biological and physiological characteristics that define humans as male, female or intersex.[17] Gender, however, is a societal construct that refers to roles, activities and behaviours, and encompasses a wide range of identities beyond male, female and intersex.[18]

Historically, women have been excluded from clinical trials and biomedical research because researchers considered the presence of menstruation rendered the biological processes within female bodies too variable to glean reliable results,[19] and/or because of fears of harming the prospects of a future pregnancy.[20] Thus, most research data have been collected from males and generalised to females, intersex people, transgender people or gender nonconformists.[18,21] The medical research literature largely excludes gender nonconformists, outside of their sexual, reproductive and psychological health.[22] While academia has been dominated by male researchers, the clinical literature has been dominated by research on male participants and the female body considered to be that of a 'small male', discounting biological differences outside of sexual organ diversity.[23] Subsequently, the differences in male and female health have been largely excluded from the curricula of medical schools,[24] which may have significant consequences for the care of the female patient.

Females and males experience different patterns of illness, different life spans, different metabolic responses to medications and different manifestations of disease.[23] Observational studies of hospital cohorts have shown that women generally wait longer than men for a diagnosis and acute pain relief and are more likely to be discharged or misdiagnosed during serious medical events.[25-27] This is particularly marked in cardiovascular diseases, which have historically been considered to be diseases affecting males more frequently than females. However, statistics demonstrate that heart disease was the leading cause of death in both women and men in Australia in 2018[28] and heart disease rates and mortality are actually increasing in young women.[29]

Women respond differently to medications than men.[30] Differing responses to treatment can be dangerous for female patients, who may experience more significant or potentially life-threatening side effects.[31] Further, women who respond differently to medications may be more likely to be labelled by their doctors as 'difficult'.[32] The perception of females as 'difficult' is embedded within societal, cultural and historical misogyny.[33] 'Difficult' may be considered synonymous with hysteria – a modern manifestation of the hysterical discourse. This can impact on the time it takes to diagnose and treat female patients experiencing pain. Somatoform disorders may be misdiagnosed before the eventual identification of a pathological source of pain.[34,35] Women wait on average 6.7 years from presentation to diagnosis and treatment with the painful gynaecological condition endometriosis.[36] Young et al. (2018) investigated practitioners' perceptions of women with endometriosis; interviews with four general practitioners and eight gynaecologists revealed that archaic ideas of hysteria persist, particularly when women's symptoms are challenging to treat. Physicians expressed opinions that women with endometriosis were "difficult", had become "consumed" by their condition and were sometimes "mad".[37] These findings demonstrate the persistence of the archaic Freudian 'hysterical discourse' – the idea that women are hysterical and emotional beings. The hysterical discourse is heavily intertwined with the 'Yentyl syndrome'; in order to be taken seriously by medical professionals, a woman must prove herself as unwell as a male counterpart.[38] This is a well-documented cause of delayed or inappropriate care for some female patients.[39-41]

Medicine as a patriarchal institute

The focus of women's health on their reproductive organs serves to reinforce the ideas of the patriarchal society that a woman's sole purpose is reproduction.[31] This is underpinned by stories of women with painful gynaecological conditions being refused hysterectomies despite life-limiting disease.[42] Contrasting this situation is the practice of the forced sterilisation of marginalised women such as ethnic minorities, disabled women and women of low socioeconomic status, often following procedures such as abortion or caesarean section.[43] The Disabled People's Organisation of Australia reports that forced sterilisation of disabled women is an ongoing practice that remains legal but is against human rights.[44,45] Imperialism, capitalism and the patriarchy influence the socioeconomic standards by which people and particularly women and their fertility are valued.[46]

Medicine holds social power, and patriarchal values are reflected in the institutional structures,[31] where women currently dominate the ground-level workforce but continue to be under-represented in leadership and senior roles.[47] Barriers to female advancement in the profession are largely owing to the 'unconscious (gender) bias' existing at systems and policy levels as well as the individual level.[48] Upholding inequality results in unconscious bias against the female patient, where the testimony of suffering by the female patient is often deemed incredible, and knowledge of female health is inadequate. These factors combine to potentially reduce the outcomes and experiences of female patients. In circumstances where research has focused on women's health, outcomes have improved, as observed in breast cancer, where research on the molecular and cellular level has combined with clinical trials to produce measurable improvements in outcomes and quality of life.[49]

The future of women's health

For women's health to improve, it is imperative that the research gap be addressed alongside addressing the culture of dismissing women as 'difficult'. Not only may including more women in clinical research improve patient outcomes but systematic review and meta-analysis has also demonstrated that simply participating in research significantly improves the health of female participants compared with those who do not participate.[50] It is important that the extent of the research gap in Australian published literature is ascertained and that women are not only included in medical research but that results are also analysed by sex and gender. Additionally, there needs to be greater inclusion of gender nonconformists in clinical trials. The real-life impact of the gender gap in research must be quantified and analysed. Aspects of the 'hidden curriculum' may be addressed within medical schools by incorporating awareness and feminist theory into the curriculum.[24]

If women are to truly become equals in modern society, sex and gender gaps need to be thoroughly explored and addressed. As collaborative professionals, medics and public health specialists must unite to learn about the gender gap, consider the underlying culture that perpetuates the gender gap and the consequential adverse outcomes for female patients, and finally advocate for the closure of the gap.

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Correspondence to: Dr Lea Merone, James Cook University, 383 Flinders Street, Townsville, QLD 4810; e-mail: lea@doctors.org.uk

1.7 Concluding comments

This thesis draws upon several schools of feminist thought. It is assumed that differences in healthcare and research representation between women and men are based on medicine as an oppressive patriarchal power structure, but also that there are fundamental biological differences between women and men that may affect their healthcare. Modern feminism embraces intersectionality that recognises the important differences between women, such as race, culture, socioeconomic class, disability and sexual orientation, and this is reflected in the work in this thesis.

This chapter has highlighted the background and development of patriarchy and centred medicine as an androcentric institution. It has also discussed the progression of feminism and medical feminism in the modern era. Chapter 2 discusses the feminist methodology behind this research, including defining epistemology, ontology and methodology and a discussion on the importance of reflexivity in feminist research.

Chapter 2: Methodology

The Lilies
When I learned I might have cancer,
I bought fifteen white lilies. Easter was gone:
the trumpets were wilted, plants crooked with roots
bound in pots. I dug them into the garden,
knowing they would not bloom for another year.
All summer, the stalks stood like ramshackle posts
while I waited for results. By autumn, the stalks
had flopped down. More biopsies, laser incisions,
the cancer in my tongue a sprawling mass. Outside,
the earth remained bare, rhizomes shrunken
below the frost line. Spring shoots appeared
in bright green skins, and lilies bloomed
in July, their waxed trumpets pure white,
dusting gold pollen to the ground.
                                                            This year,
tripled in number, they are popping up again. I wait,
a ceremony, for the lilies to open, for the serpentine length
of the garden to bloom in the shape of my tongue’s scar,
a white path with one end leading into brilliant air,
the other down the throat’s canyon, black
and unforgiving. I try to imagine
what could grow in such darkness. I am waiting
for the lilies to open.

(Wood, 2001)

2.1 Introduction

This chapter discusses the importance of ontology and epistemology for developing the research methodology and methods used, and outlines the aims of this research while situating the work within feminist epistemology. The concept of ‘womanness’ is explored, including definitions of woman and the implications this has for medical practice. Feminist research is complex, and the issues of reflexivity and power imbalances between the researcher and researched are discussed here. Finally, an overview of the ethical issues arising from the research is provided.

2.2 Ontology, epistemology and methodology

A research paradigm consists of four components: ontology, epistemology, methodology and methods (Scotland, 2012). Ontology is the study of being, concerned with the structure of reality, the nature of existence, and what it is possible to know about the world (Crotty, 1998). Ontology centres on objectivism, the idea that reality exists independently of our understanding or beliefs—it can be observed directly, and constructionism, the theory that external reality exists but is only understood through socially constructed meanings and there is no shared reality, only a series of individual constructions (Al-Saadi, 2014). Epistemology is defined as the assumptions we make about the nature of knowledge (Richards, 2003) and is associated with positivism. Positivist epistemology assumes that facts are distinct, and the world is unaffected by and independent of the researcher. Interpretivist epistemology assumes that the researcher and world affect each other and facts are not distinct (Al-Saadi, 2014). Epistemological assumptions are associated with how we can acquire, create, and communicate knowledge (Scotland, 2012).

Each research paradigm is based upon ontological and epistemological assumptions held by the researchers (Scotland, 2012), which then guide the choice of methodology (Al-Saadi, 2014). This thesis situates its investigations within feminist empirical, standpoint and social constructivist epistemologies—allowing women to tell their stories within projects designed, developed, implemented, and analysed by women. Feminist epistemologies recognise women’s experiences as legitimate and valid sources of knowledge, and feminist methodologies endeavour to eliminate sex and gender bias from research by finding ways to amplify female voices (Campbell & Wasco, 2000). Feminist scholar and author Rebecca

Campbell (Campbell & Wasco, 2000) states that feminist research contains the following four characteristics:

1. includes both qualitative and quantitative methods;
2. connects a variety of women for group-level data collection;
3. facilitates trust and disclosure by reducing hierarchies between researchers and participants; and
4. recognises and reflects upon the emotional aspects of women’s lives.

In social research, methodology is concerned with procedures for validating knowledge and connecting the understanding people produce about social life with reality (Curd et al., 2013). Methodology and methods are frequently confused. Methodology concerns the underpinning theory and rules that specify the approach to a social investigation. These rules can provide criteria by which we can judge between competing knowledge claims (Ramazanoglu & Holland, 2002). Method is the approach to research, the techniques used to explore social reality and produce evidence. Methods may include focus groups, interviews, questionnaires, and clinical trials.

2.3 The feminist movement: A brief history of feminism

Feminism generally refers to the advocacy of female rights; however, in the 21st century, the meaning has expanded to incorporate theories of male dominance, political relationships between women and men (and other genders), and the general political struggles of women (International Women’s Development Agency, 2018; Ramazanoglu & Holland, 2002). However, this definition may be an over-simplification. Feminism is an interdisciplinary approach that incorporates gender studies and women’s studies (Woodward & Woodward, 2015) to address issues surrounding equity and equality pertaining to gender, gender expression, gender identity and sex. Feminist notions of social change are grounded in experiences of gender subordination and incorporate judgements on what is deemed to be unjust. Feminism depends on determining firstly that women as a category exists, secondly that women do have common conditions of their gendered existence despite the social and cultural divisions of intersectionality, and finally that justice and injustice can be clearly and universally defined with criteria (Gunnarsson, 2011). Failing to acknowledge intersectionality has previously left feminism open to the criticism that it seeks to incorporate all women into Western values and categories; however, women's movements have developed at different times, in different languages, in different cultures, and consequently in different ways than simply those within the Western paradigm. Despite the multitude of women's movements, there has never been a unified theory of gender oppression or male dominance, of justice or liberation or approach to epistemology (Ramazanoglu & Holland, 2002).

Feminism should be intersectional in that it includes addressing inequalities in all women, representing women of colour, disabled women, and women from all social backgrounds and of all sexualities (Day, 2016). Feminism emerges in its different guises in specific social and cultural conditions and may be different across cultures (Karimi et al., 2020).

As a social movement, feminism commenced in the 1840s and spanned through World War I, with a focus on women's right to vote and the activism and work of suffragettes such as Emmeline Pankhurst and Emily Davison, who famously sacrificed herself to her cause by stepping out in front of King George V's horse at the 1913 Derby (Fisher, 2018). While the suffragettes were fierce fighters for the right to vote, this was not their only cause. Other demands included equality in marriage, ending of censorship regarding women's writing and lecturing, equal access to education, and economic independence (Sharlach, 2009).

In the 1960s in the context of the United States of America civil rights and anti-war movements, which led to an increasing social consciousness in minority groups globally, feminists were becoming increasingly radical and focused on reproductive rights and issues of sexuality. Women famously burned their bras, protested beauty pageants, and promoted an inclusive sisterhood that included women of colour and those from varying social class backgrounds (Rampton, 2019). Typically, feminine items that defined women by their looks, such as bras and high-heels, were considered tools of oppression (Hillman, 2013). In this period, Gloria Steinem (2019) spent some time undercover in a Playboy nightclub writing of her various experiences, including being measured, being physically and intimately examined, and lengthy shifts in uncomfortable and revealing outfits. Naomi Wolf (1993) wrote *The Beauty Myth,* a book that centred on the patriarchal use of beauty as a tool of oppression against women, linking increasing social powers of women with increasing pressures, particularly from the mass media, to attain unrealistic beauty standards. This compromised the ability of women to be both accepted and successful in society (Wolf, 1993). Women began to connect more with their menstrual and other nature cycles, and the ecofeminism school of thought was developed (Rampton, 2019).

Informed by post-modernist thought, feminists in the 1990s de-constructed and destabilised many of the previous beliefs, such as the ideas of universal womanhood, gender and heteronormativity. Young women reclaimed the accessories previously deemed to be such as lipstick, bras and high-heeled shoes, stating it is possible to simultaneously be beautiful and intellectual (Rampton, 2019). Feminine beauty became defined by women, rather than men (Rampton, 2019). Many women refused to identify with the term feminist because of negative perceptions and stigma.

Modern feminists focus on intersectionality and acknowledgement of the need to understand the oppression of women through consciousness of other capitalist and patriarchal issues: racism, ageism, ableism, classism and sexual orientation (Rampton, 2019). As feminist thinking has expanded, there has been significant development of feminist ideologies and research methodologies.

2.4 Feminist methodology and research

Qualitative research processes, analysis and evaluations are dependent on the research paradigm (Coyle & Tickoo, 2007). Thus, defining the feminist methodology in feminist research is crucial for framing and contextualising the findings. In feminist theory, there has been much debate about the nature of sex, gender, reproduction, identity, and power (Mikkola, 2022). These factors are not independent but interrelated and socially and politically constructed. Gender can be thought of as a social construction, in terms of what people are, what they do, what relationships and inequalities there are between people, and what meanings we ascribe to these factors (Ramazanoglu & Holland, 2002). Gender can be analysed from different perspectives, but for the purposes of this thesis, it is argued that feminist knowledge of gender should include practical investigation of the lives of women, their experiences, relationships with the medical services and inequalities, both perceived and actual (Ramazanoglu & Holland, 2002).

Gender can be viewed as fitting into socially constructed and variable categories. In practice, there are not simply two binary categories as highlighted by recent difficulties in classifying professional athletes (Braumuller et al., 2020); there is intersexuality, transgenderism, those who are nonbinary and many others (Kuehnle, 2020). Despite this, in medical terms, gender and sex are commonly still recorded within binary categories. In Australia, one can only refer to newborn babies as female or male; any infant with ambiguous genitalia is assigned a gender to be recorded on their birth certificate (Parliament of Australia, 2021). Understanding power relations is at the core of feminist research, and therefore, arguably investigation of gendered lives by feminists may also include the study of men and masculinity. Similarly, men’s studies are also informed by feminist theory and politics.

Feminist methodology always entails some theory of power because power is not equally open to all. Feminists question who has the power to produce knowledge or acquire knowledge and whose knowledge is legitimate (Anderson, 2020). Feminist methodology is distinguished as such by the extent that it is shaped by feminist theory, politics and ethics and grounded in the experience of women. Feminist scholars place women at the centre of research as both the subjects of inquiry and the researchers with the aim of illuminating women's experiences, uncover sexist biases and androcentric epistemologies, and pave the way to a gendered understanding (Stacey & Thorn, 1985).

Feminist research methodologies are comprised of many subcategories and theories (Dankoski, 2008). Reinharz (1992) defines feminist research as the 'methods used by self-identified feminists, those seen in feminist journal articles and/or books, or those used in research that has been recognized by organizations honouring feminist research'. Waller (2005) highlights some of the common characteristics of feminist research methodologies:

1. attention given to marginalised people in social contexts;
2. consideration of the ethics of all people engaged in the research process;
3. understanding of the lack and unattainability of true objectivity in research;
4. individual experience and history are fundamental to understanding social interaction; and
5. motivation and desire to change societal institutions, cultures and structures.

Gender research is grounded in multiple theoretical frameworks and perspectives, and the use of just one theory is insufficient (Hammarstrom, 1999). Consequently, the research presented in this thesis is underpinned by the three main feminist epistemologies: feminist empiricism, feminist standpoint theory and social constructivism.

2.4 The concept of 'womanness'

'Womanness' in itself is a contested ideology, indeed as feminist philosopher Simone de Beauvoir (1949/2015) states, "one is not born, but rather becomes a woman", implying there is more to womanhood than female biology. Indeed, in modern society, many question what it means to be a woman and what defines a woman (Stryker 2020). For feminist theory, we must be able to separate out parts or units that concretely define womanness. Some have criticised the category of woman as it implies an homogeneous group (Gunnarsson, 2011) and does not allow for intersectionality. However, there are those who question whether acknowledgement of individuality of women and groups of women should warrant obliteration of an entire term. Indeed, when considering the inclusion of women as a category in medicine, we must also consider the gender norms expected in society, which may underpin the perceptions of women by healthcare professionals. Samulowitz et al. (2018) conducted a theory-guided literature review on gender bias in healthcare and gendered norms towards patients with chronic pain, determining that descriptions of female and male patients were distinct, and that men were more likely to be perceived as stoic or brave and women as emotional, complaining and malingering. Similarly, gender bias, as measured using the Implicit Association Test, in cardiologists was noted to affect the perception, investigation and treatment of female patients (Daugherty et al., 2017). Consequently, we must acknowledge that despite flaws in the ideology of womanness and of using woman categorically, these perceptions are ubiquitous in society (Gunnarsson, 2011) and affect medical research, education, and patient care.

2.5 Reflexivity

At the centre of this research is the practice of reflexivity, which is a complex reflective process that requires the researcher to acknowledge her own social position, how that position affects the research produced, and the position of the academy and its code of silence for those studying minority groups (Acosta, 2020). Feminist research should centralise the interplay between the researcher and the researched. It is important to acknowledge that full representation of women is not possible (Letherby, 2003); however, I have endeavoured to ensure a diverse representation of women in my work by inviting a broad sample of women to participate. Within the practice of reflexivity, the researcher must locate herself within the research and acknowledge that all accounts are representations of reality and therefore open to critique (Letherby, 2003). Researchers are arguably in a position of power, and therefore, we must ask how we can study power imbalances and, identify solutions and mitigating strategies through claims of knowledge (Ackerly & True, 2008).

As a disabled woman in academia, amplifying the voices of other chronically ill and disabled women is important to me. As both a clinician and a patient, I have witnessed firsthand many of the issues in women's health outlined in my research. These factors influenced my research both in how I conducted studies and in how I interpreted the results. Reflexive thematic analysis was conducted according to Braun and Clarke (2021), and guided reflection on my role as researcher (Letherby, 2002) and how my experiences affected and influenced the research. I analysed the words of others during the qualitative aspects of my work, from my own social, economic, political, and cultural perspectives, and this was reflected on during the data collection and analysis processes and acknowledged during presentation of my findings. I kept detailed notes regarding my thoughts and feelings throughout the interviews I conducted for the qualitative aspects of my research. These notes largely consisted of the impact the content of the interviews had on my own sense of trauma that I had suffered as a patient. I used these notes to ensure that when I was analysing the data, I did not allow these feelings to impact and guide my interpretation, but rather focus on the words and experiences of the participating women. I also kept notes on how I collected the data, the process of the interviews themselves, how the data were analysed and how the data were reported. I utilised these notes consistently throughout the data analysis process.

Further, research is political, and as researchers, we often do not have control over how other people will perceive our work. Working with oppressed groups carries risk of misinterpretation and cultural reduction, classifying all individuals within the group as similar or the same (Acosta, 2020). It is important that all research is framed and contextualised as the perspective and interpretation of the researchers and that further disadvantage or harm is not brought upon marginalised groups.

2.6 Ethical issues surrounding this research

Much of the research presented in this thesis is low risk and utilised publicly available data, such as published literature, online course outlines and clinical textbooks. However, this thesis also presents work that was assessed by a Human Research Ethics Committee (HREC) as in accordance with the principles outlined in *The National Statement of Ethical Conduct in Human Research* (National Health and Medical Research Council et al., 2018b) and *The Australian Code for Responsible Research* (National Health and Medical Research Council et al., 2018a) for two studies: 'Self-Reported Time to Diagnosis and Proportions of Re-diagnosis in Female Patients With Chronic Disease in Australia' and '"I Just Want to Feel Safe Going to a Doctor": Experiences of Female Patients With Chronic Conditions in Australia'. The greatest risk was that of psychological harm from discussing or answering questions about medically sensitive and potentially traumatising topics. To mitigate this risk, participants of both the survey and the interview studies were informed prior to commencing that the topics discussed are sensitive and may cause some distress. Interview participants were required to give informed consent verbally on audio-recording, and all participants (both survey and interview) were informed they could withdraw at any time without prejudice. On occasions during the interviews that the interviewer noticed distress, the participant was given the option to pause or terminate the interview. Numbers for support agencies such as the Samaritans were provided to all participants. As this research involved discussion of medical conditions and other sensitive subjects, there was a risk to confidentiality from data collection. To mitigate this risk, all data were either de-identified (interview) or anonymous (survey). Interviews were conducted by one primary researcher. For reduced risk of psychological harm, participants were informed of the nature of the research, the use of data and confidentiality considerations prior to consenting to participate.

2.7 Concluding comments

Research paradigms are comprised of ontology, epistemology, methodology and methods, and are based on the underlying assumptions of the researcher. Consequently, the researcher’s methodology guides the research methods selected. Reflexivity is therefore an important component of research, ensuring the researcher positions herself, her experiences, and her assumptions in relation to the research conducted and the impact this may have on the interpretation of results. Feminist methodologies and reflexivity underpin the feminist research presented in this thesis. Chapter 3 discusses how feminist theory has been utilised in the design of the research throughout this doctoral work.

Chapter 3: Enhancing Evidence-Based Medicine: A Feminist Critique

I Felt a Funeral in My Brain

I felt a Funeral, in my Brain,
And Mourners to and fro
Kept treading - treading - till it seemed
That Sense was breaking through -

And when they all were seated,
A Service, like a Drum -
Kept beating - beating - till I thought
My mind was going numb -

And then I heard them lift a Box
And creak across my Soul
With those same Boots of Lead, again,
Then Space - began to toll,

As all the Heavens were a Bell,
And Being, but an Ear,
And I, and Silence, some strange Race,
Wrecked, solitary, here -

And then a Plank in Reason, broke,
And I dropped down, and down -
And hit a World, at every plunge,
And Finished knowing - then –

(Dickinson, 1861)

3.1 Introduction

This chapter discusses the three main feminist epistemologies—feminist empiricism, standpoint theory and social constructivism—with an explanation of each theory and how this was utilised in the research presented in this thesis. The research within this thesis is centred on medical research and medicine, which is grounded in androcentrism as discussed in Chapter 1. This chapter also provides a feminist critique of evidence-based medicine (EBM) and suggestions for conducting future medical research in an equitable manner.

3.2 Empiricism

Feminist research is often seen as diametrically opposed to the reductive, quantitative positivist paradigm. Positivism is the scientific study of the social world, an intellectual movement that aimed to progress from the Enlightenment project following the French

Revolution of 1789 and the later First World War (Fuller, 2001). Philosophically, positivism is the view that only factual knowledge obtained through measurement and observation is reliable (Collins, 2010). However, not all feminist researchers subscribe to the stereotype of positivist opposition. Feminist empiricism argues that androcentrism may be corrected by strict adherence to the existing methodological norms of positivist science (Tolman & Brydon-Miller, 2001).

Feminist empiricism argues for realism—that there is a truth to be discovered that researchers can objectively observe and study. Androcentrism may be mitigated with the application of rigorous positivist scientific methods. This empiricist epistemology allows feminists to advocate for improved scientific methods by working within current scientific paradigms (Wigginton & Lafrance, 2019). Feminist empiricists therefore conduct positivist science with the assumption that there is an objective reality to discover (Wigginton & Lafrance, 2019).

As argued by feminist author Virginia Woolf, however, science is not without sex — 'she is a man, a father, and infected too' (Tolman & Brydon-Miller, 2001). Feminist empiricist researchers utilise standard positivist methodology with an underlying awareness of the sex and gender biases that underpin research (Tolman & Brydon-Miller, 2001). The research in this doctoral thesis utilises feminist empiricism within the quantitative studies, such as the cross-sectional study 'Mind the Gap: Reporting and Analysis of Sex and Gender in Health Research in Australia', presented in Chapter 4. Similarly, the empiricist epistemology also underpins the 'Representation of Women and Women's Health in Australian Medical School Course Outlines, Curriculum Requirements and Selected Core Clinical Textbooks' study, presented in Chapter 5, and 'Self-Reported Time to Diagnosis and Proportions of Re-diagnosis in Female Patients with Chronic Conditions in Australia: A Cross-Sectional Survey', presented in Chapter 6. As per feminist empiricism, feminist values underpin both research projects, each evaluating the inclusion of women in research and educational materials. This evaluation amounts to quantitative 'facts'—an objective analysis of numbers of research studies or educational materials that adequately include women. The adequate inclusion of women in both research and educational materials is determined by the objective prevalence of the specific disease by sex and gender.

3.3 Standpoint theory

Standpoint theorists posit that positivist scientific approaches to science do not acknowledge the influence of social context and experience on the researcher's processes (Wigginton & Lafrance, 2019). Women's experiences have not been represented effectively in research because they are framed in patriarchal concepts, language, and perspectives (Wigginton & Lafrance, 2019). Smith (1987) developed standpoint theory with the aim of examining women's stories to understand how their social relations and societal structures affect and inform their experiences and values (Wigginton & Lafrance, 2019). Standpoint theory is the belief that while feminism is political, it must also be centrally anchored with method, epistemology, and truth. Women and men create their own realities through their different experiences, meaning there are multiple truths and experiences (Hekman, 1997).

Standpoint feminists argue that the scientific method itself is responsible for scientific accounts that echo the patriarchal influences (Dugdale, 1990) and hypothesise that scientific method serves the desires of the men who conduct it and therefore lacks objectivity (Helman et al., 2020). Standpoint feminists reason that there is a need for new scientific method that does not reject attributes considered to be 'feminine', such as feelings and empathy (Dugdale, 1990). Standpoint feminist Fox Keller (1995) believed that science needed to be de-gendered and involve acknowledgement of feelings and intuitions (Dugdale, 1990). Standpoint theory argues that science does not operate separately from social order but is a necessary part of it. Standpoint theory argues that all 'knowers' are socially situated, and therefore, all knowledge is also socially situated. Recent iterations of standpoint theory incorporate intersectionality (Wigginton & Lafrance, 2019).

Feminist standpoint theory centres on Marxist theories that women can frame their own experiences of oppression (Millen, 1997). Standpoint is a position of engaged interest and acknowledges that from some societal perspectives, the relations between humans are not visible (Hartstock, 1986). The work presented in this thesis, particularly in Chapter 6, "I Just Want to Feel Safe Going to a Doctor": Experiences of Female Patients with Chronic Conditions in the Australian Healthcare System', is underpinned, in part, by standpoint theory, meeting the five claims or criteria of standpoint as outlined by Hartstock (Hartstock, 1986; Winant, 1987):

1. Material and economic life conditions and limits our perception and understanding; the bourgeoisie and the proletariat understand the world differently (Marx & Engels, 1884). Hartstock additionally argues our reproductive life also forms our understanding, meaning women and men have different understanding of the world.

The women interviewed as part of this thesis have different perceptions to men and the androcentrism presented historically in medicine and medical research. In a patriarchal society, with medicine as a central patriarchal structure and the medical sphere as a powerful authoritarian body (Foucault, 1973), women may have a different standpoint to men.

2. The understanding available to the two different societal groups is not only different but opposed. In systems where there is domination, the vision available to the prevailing group will be 'partial and perverse'. Hartstock argues that in a patriarchal society, androcentrism— or a masculinist society— eroticism is misdirected.

Medicine has historically discounted the perceptions of women and women's health problems, attributing them to 'weakness' and mental disorders (Tasca et al., 2012). The prevailing group's (men's) vision of women in medicine has been 'partial and perverse'. This research centres on the perspectives and experiences of women.

3. The understanding available to the dominant group cannot be dismissed as false or irrelevant. In capitalist societies, all members must conform to the dominant way of life; as everyone must participate in buying and selling, capitalism cannot be dismissed. Similarly, masculinity cannot be determined irrelevant to women because men have the power to structure social relations that women must also participate in.

The patriarchal systems underpinning modern medicine are not irrelevant; women must still seek healthcare within existing systems and participate in the power structure relations and structures, simultaneously utilising them and maintaining them. This research seeks to promote equity for female patients through highlighting gaps in research, education, and clinical care.

4. One must fight for the vision of the oppressed group. Standpoints must be won through theoretical analysis and political struggle. Construction of the proletarian standpoint must be mediated by the struggle against the ruling class. Similarly, feminist standpoint must be mediated by the struggle against patriarchy.

Participating in this research may, in some respects, represent the struggle against the medical patriarchy, ensuring that women's stories and voices are heard.

5. Standpoint can be the starting point for a struggle for liberation, and adoption of standpoint exposes the real relations between human beings. Within a patriarchy, human relations are inhumane and once revealed will not be tolerated.

The research presented in this thesis reveals unequal human relations that form the foundation for further research and advocacy for female patients.

Standpoints are emancipatory perspectives; having a standpoint is by default engaging in social criticism (Winant, 1987) and may lead to advocacy against societal structures such as a patriarchal healthcare system. Early standpoint work faced criticism for focusing on the experiences of Western, white, middle-class women, and as a result, intersectionality became an important aspect of standpoint theory (Wigginton & Lafrance, 2019). Other criticisms of standpoint feminism include that, like positivism, it does not break with traditional boundaries of science and leaves uncontested the dichotomies that structure sexual difference: culture/nature, masculine/feminine, objective/subjective, reason/intention and active/passive (Dugdale, 1990). Finally, as feminist theorist Sandra Harding (1986) argues, standpoint theories assume all women are unified by a common feminine identity (Dugdale, 1990; Harding, 1986). Standpoint theorists may suggest existence of a feminine conception of knowledge that is grounded in traditionally feminine attributes such as intuition, emotion and care (Millen, 1997); however, in reality femininity cannot be defined as a set of fixed character traits that define all women (Windsor, 2015), and to attempt to do so may be considered inherently un-feminist. Further, standpoint theory assumes that oppression is uniform and that women identify as an oppressed group because of their gender and not for any other factor such as ethnicity or social class, thus marginalising other oppressive struggles (Millen, 1997). The counter argument, however, lies within the androcentric invalidation of the female experience in society. It is important to remember that ultimately, women are never ‘just women’ and concurrently exist with class, ethnicity, and sexuality, all of which affect views and experiences (Millen, 1997).

3.4 Social constructivism

Social constructivists argue that science is a creator, rather than a reflection, of reality; therefore, researchers are an important component of knowledge construction (Anderson, 2020). Social constructivism is heavily influenced by Foucault’s *History of Sexuality* (1976), highlighting the notion of sexuality as an entity outside of mainstream biomedical frameworks (Morrow, 1995). Foucault asserts that the history of sexuality is a form of power-knowledge; power-relations cannot exist without knowledge and knowledge is created by power-relations.

Similarly, French philosopher Simone de Beauvoir (1949/2015) also analysed gender, challenging the concept that what we previous thought of as natural with the idea that gender is in fact socially constructed. These analyses opened gender up to the challenges of feminism. Social constructivist feminists believe that it is not possible to seek an objective truth; rather, truths are relative and dependent on the social context of the researcher and the subjects. Social constructivists favour the idea of multiple truths and realities located in time, place and person (pluralism) (Wigginton & Lafrance, 2019). In contrast to feminist standpoint theory, social constructivists suggest there are many conflicting social discourses, and none should be privileged; a power-neutral knowledge does not exist (Millen, 1997).

Social constructivism emphasises the individual's experience of the world, rejecting empiricism's ideals of objectivity. Discourse, or the way language shapes experience, is a fundamental part of social constructivism (Parker, 1992). Language creates reality (Schuler, 2019; Wigginton & Lafrance, 2019). Social constructivists reject the category of 'woman' because it is socially constructed and exclusionary to those who transcend other oppressed groups outside of the white, cis-heterosexual, middle-class woman (Millen, 1997). Similarly, unlike standpoint theorists, social constructivists do not recognise masculinity in scientific methods. Scientific methods from the social constructivist perspective can include story-telling, non-linguistic elements (for example meaningful configurations of techniques or routines) and strategies of recording field data (Dugdale, 1990).

The idea that gender is a social construct underpins many feminist theories; however, there is no real consensus on how these social constructs came into being (Gunnarsson, 2011), as discussed in Chapter 1. Thus, social constructivism has been open to criticisms, largely owing to the practical difficulties of constructing research projects utilising the paradigm (Millen, 1997). Intersectionality may be accommodated alongside research from a social constructivist epistemology by ensuring analysis of subgroups is also conducted (Anderson, 2020). Social constructivism informs the thematic analysis (Braun & Clarke, 2006, 2021), utilised in Chapter 6, '"I Just Want to Feel Safe Going to a Doctor": Experiences of Female Patients with Chronic Conditions in Australia'.

3.5 Evidence-based medicine: Feminist criticisms and implications for women's health

"To question the foundations of a discipline or practice is not necessarily to deny its value, but rather to stimulate a judicious and balanced appraisal of its merits" (Ashcroft & ter Meulen, 2004, p119). EBM started out as a new paradigm for practising medicine, replacing theoretical reasoning and anecdote with evidence from high-quality studies (Greenhalgh et al., 2014). From the outset, critics have expressed concerns that methods for gathering evidence are flawed and questioned the external validity of studies gathering information from groups of people and applying them to the individual (Howick, 2011). Here, I will review the conceptual background of EBM, discuss some of the general criticisms of EBM and finally critique EBM from a feminist perspective.

3.5.1 Evidence-based medicine: Setting the scene

The philosophical origins of EBM date back to 19th century Paris, and became mainstream in the medical communities in the 1980s and 1990s (Sackett et al., 1996). By the mid 1990s both undergraduate and postgraduate medical programs had incorporated EBM into their curricula. EBM is defined as the explicit use of the current best evidence in deciding the clinical care of the individual patient (Sackett et al., 1996). Traditionally, practising EBM requires combining clinical acumen and expertise with external evidence based on high-quality clinical research (Sackett et al., 1996; Straus & McAlister, 2000). Clinical acumen is important, particularly when considering the differing social and economic circumstances of individual patients. The best available evidence is defined as clinically relevant human research surrounding diagnostic tests and the efficacy of treatments (Worrell, 2002). Neither clinical acumen nor best evidence alone is enough for safe patient care, and the practice of effective, safe clinical medicine is underpinned by both (Sackett et al., 1996). External evidence should strongly inform, but never replace, clinical acumen. Clinical expertise should be utilised to determine if the best available evidence applies to the individual circumstances of the patient and how it should be integrated into individual patient care (Haynes et al., 2002).

EBM developed in response to poorly designed observational research that rendered the clinician dependent upon personal professional expertise (Horwitz et al., 2017). Alongside it came refreshed enthusiasm for positivist-style science —the application of the scientific method that operationalises, measures and analyses characteristics to detect patterns in covariation (Coyne & Wright, 2015; Goldenberg, 2005) —and the EBM movement attempts to remove more intuitive aspects from clinical medicine and replace them with more vigorous scientific approaches (Goldenberg, 2005). The EBM movement is centred on five interlinked ideas (Goldenberg, 2005):

1. Clinical decisions must be based upon the best available evidence.
2. The clinical problem should determine the type of evidence sought.
3. Identifying best evidence should be through epidemiological and statistical thinking.
4. Evidence-based conclusions are only useful if put into practice.
5. Performance should be consistently evaluated.

The centrepiece of EBM is the hierarchy of evidence (Figure 3.1) (Alper & Haynes, 2016), which places systematic review and meta-analysis at the top of the pyramid, as the strongest level of evidence, followed by randomised controlled trials (RCTs), with opinion pieces at the base of the pyramid.

Figure 1

The hierarchy of evidence (Alper & Haynes, 2016)

3.5.2 Criticisms of evidence-based medicine

Despite the clear logic underpinning EBM, there have been numerous criticisms from a variety of researchers both within and outside of the medical sphere. Goldenberg (2005) argues that EBM is problematic in that it maintains archaic views of evidence as facts. Positivism has been undermined by post-positivist philosophies of science (Goldenberg, 2005) as flawed in that the only positions it acknowledges as meaningful are those that are measurable and therefore scientifically verifiable.

Philosopher Thomas Kuhn (1996) claimed that our observations are in fact underpinned by our background beliefs and assumptions, be they consciously or unconsciously, and therefore can never truly be objective. Additionally, Hume et al., (2000) argued that our observations are always the product of interpretation (Goldenberg, 2005). The Duhem–Quine thesis states that it is impossible to test one single scientific theory in isolation because empirical testing will always require one or more background assumptions that several other hypotheses or measurements are correct (Quine, 1951). Quine described this further as underdetermination, whereby every scientific theory will have at least one opposing theory that is supported by the scientific evidence (Lauden, 1990).

Underdetermination tells us that the evidence available to us at any given time may be insufficient to determine what conclusions we should draw in response to it (Quine, 1951). Chin-Yee (2014) argues that EBM exacerbates underdetermination because there are several auxiliary hypotheses in clinical trial settings. These auxiliary hypotheses are propagated by confounders found in real-life settings, such as social and environmental factors, that cannot be controlled, (compared with laboratory settings where control enables fewer alternative explanations for a given result) (Chin-Yee, 2014). EBM is based on evidential hierarchies that ultimately underdetermine the core beliefs of medical practice, resulting, according to Chin-Yee (2014), in an “epistemic attitude that is sceptical of disease pathology” (p925), limiting medical research by neglecting theoretical frameworks that may better integrate knowledge. Chin-Yee argues that the emphasis EBM places on the RCT devalues other valid epistemologies and underdetermines clinical medicine and the knowledge base used for clinical practice. Feminist social epistemologists have characterised underdetermination as a ‘gap’ between theory and observation. Facts only provide evidential support for a theory in conjunction with an auxiliary hypothesis. Two researchers with differing background assumptions may legitimately interpret evidence in different ways (Goldenberg, 2013).

Guidelines and protocols are derived from EBM resources (Franco et al., 2020). In terms of clinical practice, critics of EBM describe concerns of the impact of guidelines and protocols on the clinical acumen of the doctor. Degradation of clinical expertise and reliance on medical tests and technology (Goodman, 2010; Lu, 2016) can create confusion when presented with the ‘atypical’ patient who does not fit the standard diagnostic criteria

(Kostopoulou et al., 2008) nor responds to treatment as expected. Mant (1999) states that ‘a clinical trial is the best way to assess whether an intervention works but it is arguably the worst way to assess who will benefit from it’ (Mant, 1999; Schattner & Fletcher, 2003). Population differences (genetic, cultural, health systems) are different from individual patient differences (such as co-morbidity, age, and previous treatments), making translation from large RCT data to the individual all the more challenging, a concept known as ecological fallacy (Schattner & Fletcher, 2003).

RCTs often do not recruit any patient who is outside of the ‘average’ for that disease (Feinstein & Horowitz, 1997), and inclusion criteria are strict (Schattner & Fletcher, 2003). Additionally, the conditions generated in RCTs, with high-tech laboratories, meticulous follow-up, and strict inclusion criteria, are often quite far removed from the conditions encountered in real-life clinical practice (Schattner & Fletcher, 2003). Also, average patients are often defined from clinical studies, which have historically excluded women, and thus, women may not be included in the typical patient picture (Merone, 2021a). Recent cross-sectional analysis of published clinical trials in Australia has demonstrated that in certain specialties, this sex and gender gap in research lingers and may continue to obscure the clinical picture for females and people of other genders (Merone, Tsey, Russell, & Nagle, in press).

Evidence-based medicine is often used to create clinical patient care protocols, defined as a diagnosis-specific written statement of standard procedures for clinical care against which clinicians can be assessed and their practice standardised (Heymann, 1994). Protocol-driven medicine has many criticisms, including giving clinicians a ceiling of knowledge and care, limiting expertise and clinical acumen (Siner & Connors, 2015). Limited expertise can have adverse effects when presented with the ‘atypical’ patient. Further, EBM has been criticised as increasing reliance on technology, erasing the human aspect and reducing patients to ‘technological objects’ (Frankford, 1994; Mykhalovsky & Weir, 2004). Medical humanists express concern that EBM does not take adequately into account patient preference or choice.

One challenge of practising EBM is the time required for clinicians to keep pace with the latest evidence (Sackett et al., 1996). Additionally, there is a noted 17-year lag between publication of evidence and translation of findings into clinical practice, resulting in clinicians’ reliance on data that are potentially out of date (Morris et al., 2011). Combined with the only relatively recent calls to require the inclusion of women in clinical research (Carcel, 2019; Mastroianni et al., 1994), this could significantly adversely affect the health of female patients, particularly considering implementation of including women in clinical research has been slow.

3.5.3 Androcentricity and evidence-based medicine

Historically, medical research has been conducted on the male body, and the results broadly generalised to women (Holdcroft, 2007) and the health of those who identify as intersex, transgender, or other genders (Harper, 2007). As a construct of the man-made world, medicine is androcentric (Merone, 2021), not only assuming male bodies to be the norm, but also regarding male-dominated knowledge as the most valid (Cleghorn, 2021). Since ancient philosopher Aristotle determined women’s biology to be that of a ‘mutilated male’ (Horowitz, 1976), women’s bodies have been deemed too biologically erratic to be useful or valuable in scientific study (Cleghorn, 2021). Androcentrism assumes that all people are valued according to male standards. The androcentrism of medical research can perpetuate stereotypes of women as ‘difficult’ when they do not respond to treatments as expected, (as per the male norm). Historically, women’s health problems have been attributed to either their reproductive organs or their mental health (Cleghorn, 2021), and these myths are observed in modern medicine; women are more likely than men to be discharged during serious medical events (Chen et al., 2008) and to have their physical symptoms attributed to mental illnesses (Carnlof et al., 2017; Kesserwani, 2020).

In addition to the inherent flaws of EBM, it is stipulated as part of the process that continuous methodological evaluation is required for a true EBM process to occur. However, there is little evidence that this is occurring, particularly with regard to women's health, with many trials failing to recruit adequate numbers of female participants and, where women are recruited, results often not analysed by sex or gender (Merone, Tsey, Russell, & Nagle, in press). This means that an EBM approach fails women's health on many levels.

There is evidence that incorporating EBM into undergraduate courses enhances medical student critical thinking (Wang et al., 2017); however, there is also evidence that EBM degrades the ability of the clinician to think critically. Factors that contribute to this inhibition include continuing medical education courses, pharmaceutical industry updates, physician experience, role models, and published reviews of healthcare practices (Scott, 1997). One of the largest contributors, however, is the development of clinical practice guidelines. There is emerging evidence that clinicians who choose to think rather than follow guidelines have a greater chance of experiencing litigation (Scott, 1997), thereby discouraging use of clinical acumen. EBM encourages practice based upon the 'average' or 'typical' patient; however, individuals, as noted, rarely present in standard manners in real-life settings. It is therefore arguable that EBM inhibits critical thinking when presented with the 'atypical' patient, which may contribute to the gender gap and misdiagnoses observed for female patients.

3.5.4 Evidence-based medicine and feminist epistemologies

Consequently, from the feminist perspective, EBM is problematic. We can examine this from three feminist epistemologies: feminist empiricism, feminist standpoint and social constructivism.

Feminist empiricism aligns with the foundation of EBM in that it argues for realism; there is a truth and reality to be discovered that researchers can objectively observe and study. Sexism and androcentrism may be managed and removed with the application of rigorous scientific methods. This epistemology allows feminists to work within current scientific paradigms by advocating for ‘better’ science (Wigginton & Lafrance, 2019). Feminist empiricists conduct positivist science, assuming there is an objective reality to discover (Wigginton & Lafrance, 2019). In this way, feminist empiricists could bridge the gap between EBM advocates and critics, contextualising empirical evidence on the grounds that no theory develops in isolation (Goldenberg, 2013; Hankinson Nelson, 1993). Empiricist feminists argue that strict methodological controls as seen in EBM and the RCT cannot, and must not, filter out the social background of all involved in the research. They advocate for more authentic accounts of the interconnections between knowledge and socioeconomic and political relations (Goldenberg, 2013). These researchers utilise standard positivist methodology with an underlying awareness of the sex and gender biases that underpin research (Tolman & Brydon-Miller, 2001). Feminist empiricists typically utilise one of two themes: that production of knowledge is a social process or that communities (as opposed to individuals) are the agents of knowledge (Goldenberg, 2013).

Feminist standpoint theorists argue that positivist approaches to science do not fully acknowledge the influence of social context and prior experience on the researcher and their processes for developing, conducting, and analysing research (Wigginton & Lafrance, 2019). Indeed, for EBM, there is a notable lack of acknowledgement of the social background of patients and the impact of the experiences of the researchers on their results and interpretation. The perspective of feminist standpoint theorists is that women’s experiences have not been represented effectively in research because they are framed in patriarchal concepts, language, and perspectives (Wigginton & Lafrance, 2019). Standpoint feminists postulate that the scientific method itself is responsible for scientific accounts that echo patriarchal social relations and influences (Dugdale, 1990). They hypothesise that scientific method is lacking true objectivity and mostly serves the desires of the men (Helman et al., 2020) who conduct it.

Consequently, their argument is that there is need for a new scientific method that does not reject attributes considered to be ‘feminine’, such as emotions and perceptions (Dugdale, 1990). Standpoint feminist Evelyn Fox Keller believed that science needed to be de-gendered and involve acknowledgement of feelings and intuitions (Dugdale, 1990).

Social constructivists (Anderson, 2020), argue that science creates reality rather than reflects it; therefore, researchers are an inherent component of knowledge construction. Social constructivist theory posits that seeking an objective truth is not possible; truths are relative and dependent on the social context of the researcher and the subjects. This allows for the idea of multiple truths and realities located in time, place, and person (known as pluralism) (Wigginton & Lafrance, 2019). In contrast to feminist standpoint theory, feminist social constructivists suggest there are many conflicting social discourses and none should be privileged; however, they acknowledge that under current paradigms, a power-neutral knowledge does not exist (Millen, 1997). Social constructivism emphasises the individual’s experience of the world, rejecting empiricism’s ideals of objectivity.

The way language shapes experience is a fundamental part of social constructivism, known as discourse, ‘a series of statements which construct an object’ (Parker, 1992). Discourse refers to meanings, metaphors, representations, and stories that cohere to produce particular versions of events. Language creates reality (Schuler, 2019; Wigginton & Lafrance, 2019). Social constructivists focus on multiple discourses and reject the idea of ‘woman’ as a category because it is socially constructed and exclusionary to those who transcend other oppressed groups outside of the white, cis-heterosexual, middle-class women: women of colour, women of different socioeconomic groups, transgender women, those assigned female at birth and who identify as nonbinary or another gender, and those with different sexual orientations (Millen, 1997). This is challenging in the EBM sphere, which frequently groups people enrolled in clinical trials by categories such as sex and gender. Despite this categorisation, results are often not analysed by sex nor gender (Merone, 2021), rendering this sub-categorisation moot.

3.5.5 Evidence-based medicine: Moving to an inclusive future

From a feminist epistemology, there are many gaps observable in EBM, and these may contribute to some of the discrepancies between the care of women and men observed in clinical practice and outcomes. For EBM to move forward and assist in narrowing the sex and gender gap in clinical medicine, trials need to address their systemic failings and acknowledge underdetermination. Incorporating the feminist epistemologies and stronger understanding of societal influences into future scientific study and clinical practice can only support and enhance EBM for the benefit of both the patient and the clinician.

Feminist empiricism, standpoint and social constructivism all advocate for use of multiple sources of knowledge, and from the feminist perspective, the RCT alone is insufficient to provide evidence for clinical practice. Utilising the results from other study designs, such as observational studies, alongside the RCT may reduce underdetermination by incorporating evidence that is gathered in more natural settings. Allowing an expansion on the definition of EBM to include well-conducted observational studies higher up the hierarchy of evidence and alongside the RCT may enhance the evidence base for women's health.

Finally, the clinical acumen must not be degraded more, but rather supported by EBM and utilised alongside the current best evidence (Lewiecki & Binkley, 2009). Critical thinking should be reinforced within the medical school curricula to enable doctors to assess the evidence while holding their experience in esteem, particularly when considering that no patient is *typical*.

3.6 Concluding comments

This chapter has situated the research presented in this thesis within the supporting feminist epistemologies: empiricism, standpoint and social constructivism. Feminist criticisms of EBM have also highlighted significant gaps in medical research for women’s health and equity. Chapter 4 proceeds to further describe these gaps in the contemporary medical literature.

Part Two: Investigating Sex and Gender Gaps in Australian Health Research and Medical Education

Chapter 4: Assessing the Sex and Gender Gap in Medical Research

The Pain Reliever

Silence is the sound the knife makes
slitting the skin.

Can you identify my weakness,
a pricking sensation
and numbness in one limb?

Can you hold this tongue?
Tell me, what is the function
of meticulous courage.

You are the most yourself
when you are in the motion.

One can be quick and too quick.
I have a stomach too.
It gets hungry.

If I be of necessity
opportunity,
if there be the slightest chance of success,
why have a mind, if?

Does that scream in the night across the alley
beg an answer? Are we crowning
into the sludge of an injury and its repair?

An elephant is larger and stronger than a horse;
but it is not preferred as a beast of burden.

Strength is a wee umbrella
in the storm.
This the friction sound heard
in inspiration, expiration, or both.

For convenience of description,
blood is bright red and frothy.

Have you earned the privilege
of making mistakes?

There really is no sex in science.

The nomenclature lifts
delicate subjects up from the plane
in which language places them.

Man has more strength,
woman, more endurance.

The hands and the instruments
are the chief sources of danger.

This fever.

> There is no subject on which so much has been written
> and so little known.
>
> (Adams, 2018)

4.1 Introduction

This chapter presents, via two research papers, the sex and gender gaps in the contemporary research. The first paper, ‘Sex Inequalities in Medical Research: A Systematic Scoping Review of the Literature’, investigates the extent of research into the sex and gender gap in contemporary research. This systematic review identified several studies that demonstrate ongoing misogyny in medical research. The second research paper assesses the extent of the sex and gender gap in contemporary Australian health research, utilising a representative cross-sectional sample of studies published in the year 2019. This cross-sectional analysis examines the proportion of female and male participant recruitment to Australian health research and assesses whether results are analysed by sex and/or gender.

4.2 Sex inequalities in medical research: A systematic scoping review of the literature

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Sex Inequalities in Medical Research: A Systematic Scoping Review of the Literature

Lea Merone,[1,*] Komla Tsey,[1] Darren Russell,[1,2] and Cate Nagle[1]

Abstract

Background: Historically, medical studies have excluded female participants and research data have been collected from males and generalized to females. The gender gap in medical research, alongside overarching misogyny, results in real-life disadvantages for female patients. This systematic scoping review of the literature aims to determine the extent of research into the medical research sex and gender gap and to assess the extent of misogyny, if any, in modern medical research.

Methods: Initial literature searches were conducted using PubMed, Science Direct, PsychINFO and Google Scholar. Articles published between January 01, 2009, and December 31, 2019, were included. An article was deemed to display misogyny if it discussed the female aesthetic in terms of health, but did not measure health or could not be utilized to improve clinical practice.

Results: Of the 17 included articles, 12 examined the gender gap in medical research and 5 demonstrated misogyny, assessing female attractiveness for alleged medical reasons. Females remain broadly under-represented in the medical literature, sex and gender are poorly reported and inadequately analyzed in research, and misogynistic perceptions continue to permeate the narrative.

Conclusion: The gender gap and misogynistic studies remain present in the contemporary medical literature. Reasons and implications for practice are discussed.

Keywords: feminism; gender; health disparities; gender gaps; medicine

Background

Amid calls for Australian research policy to align with those in Europe and United States and increase equality in sex and gender recruitment in medical research,[1] the sex and gender gap in medical practice is drawing increasing media attention.[2,3] Females account for >50% of the global population and, therefore, a significant proportion of the patient population,[4] yet women wait longer than men for both a diagnosis[5] and pain relief, and[6,7] are more likely to be misdiagnosed or discharged during serious medical events.[5]

Historically, medical studies have excluded female participants and research data have been collected from males and subsequently generalized to females[8] and

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[1] School of Health Sciences, James Cook University, Townsville, Queensland, Australia.
[2] Cairns Sexual Health Service, Cairns North, Queensland, Australia.

*Address correspondence to: Lea Merone, MBChB(Hons) FAFPHM, School of Health Sciences, School of Health Sciences, James Cook University, 383 Flinders Street, Townsville 4810, Queensland, Australia, E-mail: lea@doctors.org.uk

those who are intersex and do not have the reproductive anatomy characteristic of female or male.[9] There are several postulated reasons for preferring males in research, including concerns for decreasing fertility or harming pregnancy,[10] researcher bias from predominantly male researchers,[11] and perception of the male as representative of the human species and, therefore, the norm.[12]

The gender gap in medical research, alongside overarching misogyny, results in real-life implications for female patients.[13] The "Yentl syndrome," named after the central protagonist in the 19th century story by Isaac Beshevis Singer, is the phrase coined by Dr. Bernadette Healy that describes how, for a woman's illness to be taken seriously, she must prove herself to be as unwell as a male counterpart.[14] Yentl syndrome as a cause of delayed care for female patients is well documented in the medical literature.[13] Lack of research evidence from female patients may result in delay in treatment; applying inappropriate, ineffective, or harmful treatments; or the withholding of effective treatments.

The resulting detriment to women's health is evidenced in the contemporary literature; recent studies have demonstrated that women with acute myocardial infarction (MI) present with different symptoms to men and are less likely to be identified during angiography than men, simply because they are often underinvestigated and subsequently less likely to be managed appropriately.[15] Six-months after admission for MI, female patients, especially younger women, were more likely to suffer major adverse events and overall mortality.[15,16]

Androcentricity in medical research has historically disadvantaged and damaged female patients, from inaccurate diagnoses of "hysteria" and related barbaric treatments such as clitoridectomies and extended periods of enforced bedrest, to the more modern discrepancies observed in diagnoses and management of female patients.[17] The hysterical discourse is often used colloquially, with terms such as "mad" and "crazy" used to describe "difficult" women who do not respond to treatment or diagnosis as expected.[18]

Young et al. examined the discourse surrounding patients with endometriosis, determining that the pain and experiences of these patients were often dismissed as psychological.[18] In keeping with this, a recent study in the United States determined an average time to diagnosis of endometriosis from first consultation was 4.4 years and this was shorter in women who were aged <18 years and 40–49 years and those referred to and investigated by gynecologists.[19]

The concept of females being "difficult" is embedded in societally and culturally ingrained misogyny.[17] Historically, the perception of beauty has been used to oppress women, whereby maintenance of fertility and aesthetics was of paramount importance. The use of beauty as a tool of oppression has become known as the "beauty myth" and was analyzed by feminist writer Naomi Wolf in her book "The Beauty Myth: how images of beauty are used against women."[20] This myth is evident in the medical literature today, highlighted by recent mainstream media controversies over doctors rating the aesthetic attractiveness of their endometriosis patients.[2,21] Wolf asserts that the "beauty myth" is a tool of oppression and a political weapon against women.[20]

The "hidden curriculum" may be an important contributor to the outcomes of the androcentricity of medical research on the experiences of female patients. The hidden curriculum pertains to the aspects of medicine that are not formally taught to medical students: the attitudes and values collected from their experiences with senior clinicians on the wards and in general practice. Perceptions from androcentric medical research, whereby female patients do not fit the male mould and, therefore, are "difficult" or "mad," may be passed down through the hidden curriculum to junior staff members, thereby continuing the cycle.[22] In addition, medical students arguably become acculturated to the historically masculine medical environment that demands conformity.[18]

As more is learnt about the gender gap and misogyny in medical research, and the impact this has upon female patients, it is important to determine whether misogyny continues to permeate the narrative in modern medicine. It is also important, while examining misogyny in medical research, to realize that sex and gender are distinct, yet the terms are often used interchangeably. Sex refers to the biological and physiological characteristics that define humans as male, female, or intersex.

Gender, rather, is a societal construct that refers to roles, activities, and behaviors, and encompasses a wide range of identities beyond male, female, and intersex.[23] In this systematic scoping review, we aim to explore the extent of study into sex and gender gaps in the published literature and assess whether misogynistic characterization is prevalent in contemporary medical research.

Methods

Search strategies and study selection

A three-phase approach to searching the literature was employed. Initial literature searches were conducted by one author (L.M.) using PubMed, Science Direct (Elsevier) PsychINFO, and Google Scholar, in line with current recommendations (9). Key words were used for each database and combined with Boolean operators AND and OR. A second search of each database was performed using different terms. All search terms are outlined in Table 1. Finally, a citation search was performed to identify studies that may not have been captured in the search terms.

Inclusion criteria

Selected articles included all peer-reviewed journal publications published between January 01, 2009, and January 01, 2019. Studies were restricted to English language articles, and those where full text was not available were excluded. Opinion pieces, editorials, and nonpeer-reviewed publications were also excluded. An article was deemed to display misogyny if it discussed/assessed the female aesthetic in terms of health, but either did not measure health, or if the research could not be deemed useful or beneficial for clinical practice.

A total of 30 full texts were assessed by two authors using stringent inclusion and exclusion criteria (Table 2); a further 13 were excluded, of these 6 were editorials or reports rather than research, 2 were based on the gender gap in scientists rather than patients, and the remaining 5 examined clinical care and interventions rather than the presence of a gender gap in the literature. A total of 17 articles were included in the qualitative analysis.

Table 1. Search Terms

Search number	PubMed (MeSH)	Science Direct	PsychINFO	Google Scholar
1	Sex	Sex	Sex	Sex
	Translational medical research	Gender	Gender	Gender
	Biomedical research	Sexism	Sexism	Sexism
	Gender gap	Research Gender gap Medical research	Research Gender gap Medical research	Research Gender gap Medical research
2	Women	Women	Women	Women
	Aesthetic	Sexism	Sexism	Sexism
	Disease	Attractive	Attractive	Attractive
	Research	Aesthetic	Aesthetic	Aesthetic
	Attractive	Research	Research	Research

Table 2. Inclusion and Exclusion Criteria

Inclusion criteria	Exclusion criteria
Research article	Opinion piece, editorial, etc.
English and available	Non-English or unavailable
Examines the gender gap in medical research or focuses on female aesthetics in medicine	Examines the impact of gender on clinical care
2009–2019	Before 2009

Data extraction

The results were merged and duplicates removed using Endnote X9.3. Data were collected from the 17 included articles using a data extraction tool (Table 2) to collect the study name, lead author and year, methods, aims and objectives, and results. Aims and objectives were taken as direct quotes from the articles where possible, to avoid any interpretation bias. Analysis was conducted according to the 2009 Ppreferred Rreporting Iitems for Ssystematic Rreviews and Mmeta-Aanalysis (PRISMA) checklist.[24]

As demonstrated in the PRISMA flow chart (Fig. 1), 2176 articles were identified by the study search, 2146 were excluded due to lack of relevance. Thirty full texts were assessed for eligibility, with 13 excluded as they did not meet the inclusion criteria. Seventeen articles were included in the analysis.

Results

Of the 17 included articles, 12 examined the gender gap in medical research and 5 demonstrated misogyny, assessing female attractiveness for alleged medical reasons. Three studies were reviews of the published literature[25–27] defined as collation of all empirical evidence that fits prespecified eligibility criteria,[28] nine were cross-sectional analyses[29–38] (observational studies of the published literature over a defined time period[39]), and the five remaining studies were within-subject experimental design.[40–43] Of the 12 studies examining gender gaps (Table 3), 11 were conducted in the United States[25,26,29–33,35–38] and 1 in Canada.[34]

The five experimental design studies were the same five studies that demonstrate misogyny (Table 4). These five studies were conducted in the United Kingdom ($n=2$),[40,41] Poland ($n=2$),[42,43] and Italy ($n=1$).[21] Results are presented in Tables 3 and 4.

Three themes were identified: females remain underrepresented in biomedical research, sex and gender are poorly analyzed and reported in research, and several contemporary research articles display ideas that can be construed as misogynistic.

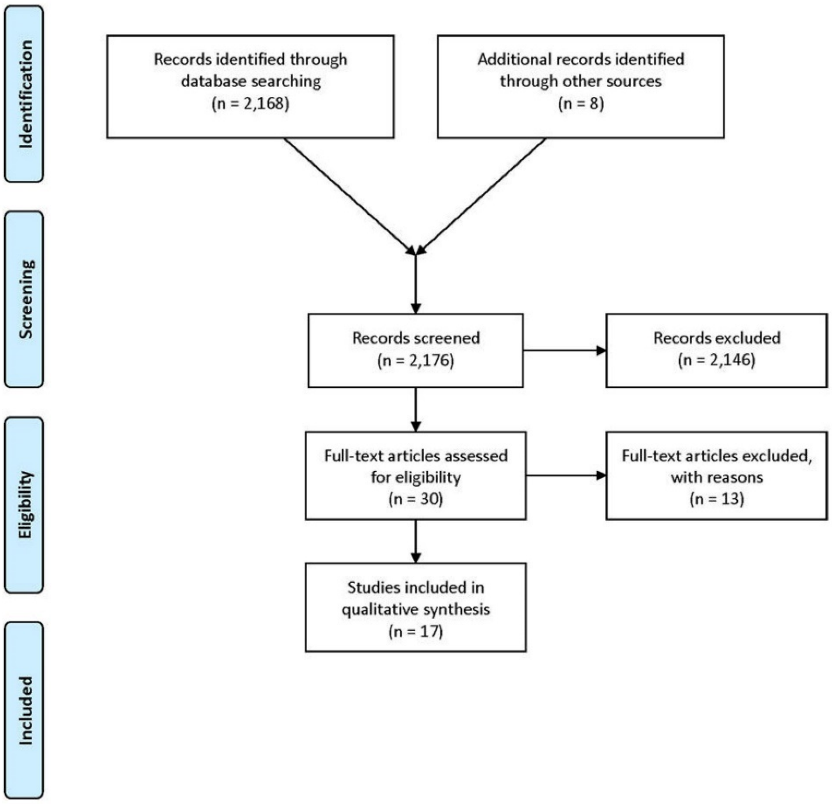

FIG. 1. PRISMA flow chart of the search strategy. PRISMA, Ppreferred Rreporting Iitems for Ssystematic Rreviews and Mmeta-Aanalysis.

Proportion of females versus males in clinical trials

A total of seven published articles analyzed the proportion of females–males participating in research trials.[25,30–32,34–36] Under-representation of women was noted, largely because of discrepancies between specialities, with some specialist fields recruiting more female participants than male participants, and others recruiting fewer females than males. Kong et al. observed that in cell biology, 60% of studies gave no information on the sex of the cells studied.[33] Two studies noted that specifically cardiovascular research appeared to under-represent women.[25,32]

Reporting and analysis by sex and gender in clinical trials

Six published articles examined the analysis and reporting of results by sex or gender.[26,29,31,33,34,38] These articles found that analysis by sex or gender was somewhere in the range of 6%–38%. Sugimoto et al. noted that articles with authors' with female names were more likely to report results by sex or gender.[38]

Examples of misogyny in medical research

Five articles displayed ideas that could be perceived as misogynistic[21,40–43] with three of these five studies

Table 3. Results: Representation of Female Participants in the Contemporary Medical Literature

Study name, authors, year	Methods/description	Specialty	Study aims/objectives	Results
"Representation of women in randomised controlled trials of cardiovascular disease prevention" Melloni et al. (2010)[25]	Reviewed the literature for female representation. Examined 156 clinical trials of CVD prevention	Cardiology	"To determine female representation over time and by clinical representation"	135 (86.5%) of the trials examined recruited both male and female participants, 20 recruited just males, and 1 recruited just females. Proportion of women in the trials increased from 9% in 1970 to 41% in 2006. Enrollment of women in RCTs for CVD has increased but remains low relative to population disease prevalence. Female representation was high for trials for the diseases: hypertension, diabetes, and stroke, and lowest for heart failure, coronary disease, and lipidemias, Females were represented in 30% of trials used to produce heart disease prevention guidelines.
"Inclusion, analysis and reporting of sex and race/ethnicity in clinical trials: have we made progress?" Geller et al. (2011)[29]	Cross-sectional analysis of the published literature. Identified RCTs in 9 journals through 2009, 86 were eligible for analysis.	Nil specific	"To determine the current level of compliance with these guidelines for the inclusion, analysis, and reporting of sex and race/ethnicity in federally funded randomized controlled trials and to compare the current level of compliance with that from 2004"	In total, 30/86 were sex specific. Of those that were not, the median enrollment of women was 37%. Seventy-five percent did not report outcomes by sex. Nine studies had fewer than 20% female participants. Only three studies noted their lack of diversity as a limitation.
"Participation of women and sex analyses in late-phase clinical trials of new molecular entity drugs and biologics approved by the FDA in 2007–2009." Poon et al. (2013)[30]	Cross-sectional analysis of clinical trials. Evaluated LPCTs and BLAs for women's participation, 2007–2009.	Nil specific	To provide "an update on the current status of the participation of women in late-phase clinical trials (LPCTs) submitted to support the approval of new drugs and biologics by the FDA"	Female participation in LPCTs was 43% (decrease from 52% in 2001) and 57% (increase from 45% 1995–1999) for BLAs.
"Sex bias exists in basic science and translational surgical research" Yoon et al. (2014)[26]	Authors reviewed 2347 articles for sex reporting	General surgery	To determine "that sex bias exists in surgical research"	Sex reporting was poor; for animal studies 22% did not specify sex, and where sex was specified, 84% used male animals only. For cell research, 76% did not report sex, again where sex was reported, 71% were male. For female-prevalent diseases, 44% did not specify sex studied and those that did, only 12% used female animals.
"Determining if sex bias exists in human clinical research" Mansukhani et al. (2016)[31]	Cross-sectional analysis of published literature. Extracted data from 1303 research articles across five clinical journals	Nil specific	"To determine if sex bias exists in human surgical clinical research"	In total, 38.1% of studies reported data by sex, 33.2% analyzed results by sex, and 22.9% discussed implications of sex in the results. Few studies included men and women equally. Inclusion and matching of the sexes varied greatly.
"Mind the gap: sex bias in basic skin research" Kong et al. (2016)[33]	Evaluated skin research publications between 2012 and 2014 to determine whether the sex was disclosed	Dermatology	To "explore how often discovery in cutaneous biology stems from the study of one sex"	No sex information was provided in 60% of the studies of cells from humans and animals. Where sex was declared, 70% were male.
"Reporting of sex and gender in randomised controlled trials in Canada: a cross-sectional methods study" Welch et al. (2017)[34]	Cross-sectional examination of gender reporting and proportions in the random cross section of 100 articles published in the Canadian medical literature	Nil specific	"Provide preliminary assessment of the extent and nature of reporting about sex and/or gender, including whether sex/gender analysis was carried out"	No study analyzed the effect of sex/gender on their results, and when they were considered, it was focused on the biomedical differences alone, despite the fact >50% of studies examined nonpharmacological interventions. Only 6% performed gender/sex subgroup analysis. No article defined sex/gender. No RCT mentioned gender-diverse populations.

(*continued*)

Table 3. (Continued)

Study name, authors, year	Methods/description	Specialty	Study aims/objectives	Results
"Participation of women in clinical trials supporting FDA approval of cardiovascular drugs" Scott et al. (2018)[32]	Cross-sectional analysis of published literature. Assessed enrollment of women in 36 drug trials from 2005 to 2015.	Cardiology	"To examine women's participation and the reported safety and efficacy by gender for pivotal cardiovascular disease (CVD) trials submitted to the U.S. Food and Drug Administration (FDA) supporting marketing applications"	Proportion of women enrolled ranged 22–81% with a mean of 46%. Women were well represented in studies examining hypertension and atrial fibrillation, over-represented for studies exploring pulmonary hypertension and under-represented in heart failure and coronary artery disease studies.
"Sex bias in hand surgery research" Kalliainen et al. (2018)[35]	Cross-sectional evaluation of the recent literature for inclusion of both sexes in research and the use of sex as a dependent variable in hand surgery. In total, 386 studies published in 4 journals for 2 years.	Hand surgery	"To provide a jumping-off point for the conversation in the hand-surgery community about sex-based outcomes"	An equal number of males and females were included in clinical studies; however, many individual studies did not include equal numbers of each gender. The female–male ratio depended on the pathology and surgery required.
"The more things change, the more they stay the same: a Study to evaluate compliance with inclusion and assessment of women and minorities in randomised controlled trials" Geller et al. (2018)[36]	Cross-sectional analysis of the published literature. Examined 782 RCTs across 14 journals in 2015	Nil specific	"To investigate current levels of compliance with guidelines for inclusion, analysis and reporting in NIH-funded RCTs and compare the results with those from 2009 and 2004"	In total, 35 studies enrolled just one sex, median enrollment of women in the remaining studies was 46%, however, 15% of the studies enrolled fewer than 30% women. Only 26% reported the effect of sex as a covariate. The NIH guidelines from the NIH revitalization act 1993 have not resulted in significant increases in reporting results by sex.
"Count me in: using a patient portal to minimise implicit bias in clinical research recruitment" Kannan et al. (2019)[37]	Cross-sectional study offering patients who utilize an online patient portal the opportunity to volunteer for the research recruitment registry (U.S.).	Nil specific	"Determine differences in volunteering to join a research recruitment registry between men and women"	Women volunteered for the research recruitment registry at a slightly greater proportion than that of all portal users. Supports theories that bias against women in clinical recruitment is due to bias rather than women's unwillingness to be involved.
"Factors affecting sex-reporting in medical research; a cross-sectional bibliometric analysis" Sugimoto et al. (2019)[38]	Bibliometric cross-sectional analyses of >1.5 million articles published during 1980–2016 were examined for sex reporting.	Nil specific	To determine the "degree of sex-reporting across health sciences and the role of gender in sex-related reporting."	Sex-related reporting increased over the years. Articles with female lead authors had greater chance of reporting sex (OR 1.26). In biomedical research, sex remains under-reported (31%). Scarcity of women in science may be related to inadequate reporting of sex in research.

BLA, biological license application; CVD, cardiovascular disease; LPCT, late phase clinical trial; RCT, randomized controlled trial.

Table 4. Results: Evidence of Misogyny in the Contemporary Medical Literature

Study name, authors, year	Methods/description	Specialty	Study aims/objectives	Results
"Judging the health and attractiveness of female faces: is the most attractive level of facial adiposity also considered the healthiest?" Coetzee et al. (2011).[40]	Males and females from a university cohort were asked to transform the adiposity in photographs of female's faces to optimize attractiveness and then optimize health.	Nil specific	"To test if people differentiate between the level of facial adiposity they find attractive and healthy in female faces"	Females determined there is a significant difference between a healthy level of adiposity and an attractive level of adiposity. For males the difference was far smaller.
"Attractiveness of women with rectovaginal endometriosis: a case-control study" Vercellini et al. (2013)	Four physicians (two male, two female) were asked to evaluate the attractiveness of women undergoing surgery for endometriosis on a likert scale. Physical examination of the women included measurement of the breast–underbreast ratio.	Gynecology	"To evaluate the physical attractiveness of women with and without endometriosis"	Women with rectovaginal endometriosis were deemed by researchers to be more attractive than those with endometriosis of other locations. These women were also leaner, had larger breasts, and earlier coitarche.
"Female facial appearance and health" Gray et al. (2012)	In total, 105 female participants were photographed and then undertook a self-reported health questionnaire regarding bouts of rhinovirus or influenza. Observers rated the photographs for femininity, attractiveness, health, makeup and mood.	Nil specific	To determine whether femininity, health, and attractiveness would "correlate negatively with bouts of illness"	There was a general trend for facial femininity and attractiveness to correlate negatively with bouts of upper respiratory tract illness, but not with gastrointestinal illness. Concluded that facial attractiveness and femininity may indicate a woman's health history.
"Costs of reproduction are reflected in women's faces: post-menopausal women with fewer children are perceived as more attractive, healthier and younger than women with more children" Marcinkowska et al. (2018)	In total, 571 male and female participants evaluated photographs of the faces of 30 women of varying parity and asked to choose the faces they found most attractive, younger, and healthier.	Nil specific	To determine whether the "high costs of reproduction" are "perceived by others when they evaluate facial attractiveness"	Women who had given birth to fewer children were judged as more attractive, younger, and healthier by both male and female participants. Examination of historic photos determined that more attractive younger women had higher reproductive success.
"Analysis of the visual perception of female breast aesthetics and symmetry: an eye tracking study." Pietruski et al. (2019)[43]	Eye-tracking technology was utilized for 100 participants (50 male, 50 female) observing images of different female breasts. Attractiveness was determined by duration and location of gaze fixation.	Breast surgery	To "objectively analyse the visual processes taking place during the assessment of female breast aesthetics and symmetry" for "more reliable surgical outcomes"	Key characteristics of gave patterns for males and females were the same. Most fixations were on the nipple/areola area, suggesting it is a key area for symmetry. More attention was paid to lower breast shape than upper breast/chest/clavicle areas. Authors state it is unknown how visual patterns translate to assessment of attractiveness.

stating that they assess female attractiveness as a marker of health.[21,40,42] Pietruski et al. conducted an analysis of visual tracking of the aesthetic of breasts, however, also stated their method is potentially flawed in that there is limited evidence as to how visual patterns translate to assessment of attractiveness.[43]

Discussion

This review highlights several issues regarding sex and gender in the medical literature. Females remain broadly under-represented in the medical literature, sex and gender are poorly reported and inadequately analyzed in research, and misogynistic articles continue to permeate the narrative.

Females are largely under-represented in biomedical research

Several studies determined that women are largely under-represented in medical research. Geller et al. analyzed 86 randomized controlled trials (RCTs) across 9 journals and found female representation to be just 37%, with only 3 studies noting the limitations of lack of diversity.[29]

Perception of the disease, rather than actual sex prevalence, appears to drive the representation of females in medical research.[44] For diseases that are perceived to affect men more than women, androcentricity dominates the research picture. Melloni et al. examined the representation of women in cardiovascular disease prevention RCTs. Although most studies in Melloni's analysis recruited both sexes and the proportion of women participants was noted to be increasing, there were still 20 studies noted to have recruited only male participants, versus just 1 study with only female participants recruited. Importantly, female representation was higher in diseases perceived to affect women more, such as hypertension and stroke.[25]

Similarly, Scott et al. also examined the participation of women in cardiovascular drug trials, and determined that in diseases believed to affect women in greater numbers than men, such as hypertension, atrial fibrillation, and pulmonary hypertension, women were either adequately represented or over-represented. In diseases perceived to affect greater number of men than women, such as coronary disease and heart failure, females were under-represented.[32] Kalliainen et al. noted that the female–male recruitment ratio in hand surgery research was dependent on the pathology, but the ratios recruited were roughly in keeping with sex prevalence of the disease,[35] noting a need to increase members of the less-represented sex to enhance statistical power.

The *1993 National Institutes of Health Revitalisation Act* recommends that women and men be included in clinical trials based on the sex prevalence of the disease and to provide data on the efficacy of treatment in each sex,[45] which may help account for the under- and over-representation of females depending on disease. However, the perceptions of sex-related prevalence appear frequently to be outdated; for example, coronary artery disease is the commonest cause of death in both men and women[46] and women experience greater functional disability and symptoms burden and a higher prevalence of nonobstructive coronary artery disease than men.[47]

Similarly, women make up 30% of the gout disease population; however, they make up just 5.3% of gout clinical drug trial participants.[30] Geller et al. conducted a cross-sectional study of RCTs across 14 journals published in 2015 and determined that the guidelines from the *1993 National Institutes of Health Revitalisation Act* have not resulted in significant increases in reporting results by sex.[36] Indeed, Poon et al. noted in a similar study that female participation in clinical trials has decreased since the 1990s.[30]

Not only is it important to acknowledge outdated gender-based beliefs, the representation and participation of women in medical research are important because medical research informs the development of clinical guidelines. Clinical guidelines directly impact the lives of patients, therefore, if there are sex and gender differences in presentation, management, and clinical response to management, it is vital these are described. Melloni et al. conducted an analysis of published RCTs and determined that in clinical trials used to inform guidelines for cardiovascular disease prevention in women, female participation was just 30%.[25]

Kannan et al. explored recruitment bias using a cross-sectional study of patients volunteering for research through an online portal and concluded that under-representation of women in clinical trials is not due to the unwillingness of women to volunteer, but rather owing to bias within trial design and recruitment.[37]

Sex and gender are poorly reported and analyzed in contemporary biomedical research

Lack of female representation in research was noted consistently throughout review of the literature, however, another related issue was the lack of sex reporting or inclusion in analysis of many medical and biomedical studies. Kong et al. evaluated sex bias in published dermatological research, much of which is on nonhumans such as cell lines or animals; 60% of the cellular studies from both humans and animals provided no information regarding sex. Where sex was declared, 70% of the cell lines studied were from males.[33]

Welch et al. supported this observation in a cross-sectional study of RCTs in Canada, finding that no studies considered the influence of sex and only 6% of studies performed a subgroup analysis for sex.[34] Similar findings are noted consistently in other studies, and sex reporting appears particularly poor in animal and cellular studies.[26,31,38] Analyses of results by sex are seemingly poor across all study types.[26,31,34]

Some of the gender discrepancy has been explained by Hankivsky et al.; examination of statements surrounding sex and gender inclusion from 45 health-research funding agencies and 10 sex/gender health journals determined there is little consistency in whether sex and gender are mentioned in funding and publication guidelines. There is also significant variation in the conceptualization of sex and gender and how researchers address this in research. The criteria set by agencies fail to address the complex relationship between sex and gender and health.[27]

Misogyny is evident in the medical research. A total of five studies exhibited misogyny. Vercellini et al. utilized a likert scale for clinicians to subjectively assess the attractiveness of women undergoing surgery for endometriosis.[21] Although this publication caused outrage in the global media and across social platforms such as Facebook and Twitter,[2] it is far from unique. Three studies proposed to assess the attractiveness of the female face as a measure of health, however, none of them utilized objective measures of health.[40–42]

Marcinkowska et al. determined that women with higher parity are perceived as less attractive and healthy, but the study did not provide information regarding objective measures of health from which this conclusion was generated.[42] A further study by Pietruski et al. applied eye-tracking technology to ascertain the attractiveness of female breasts in the context of reconstructive surgery; however, authors acknowledged that the link between lingering gaze and attractiveness is unknown,[43] raising the question of why this study was conducted.

Studies displaying misogyny are problematic for clinical medicine and patient care for several reasons. First, they continue to perpetuate the concept of the "beauty myth" and the utilization of the female aesthetic as a tool of oppression and prejudice. In highlighting female beauty, the authors of the articles inadvertently suggest that patient care should be altered based on the aesthetic of the patient. Despite the findings of Vercellini et al. that attractive women are more likely to have severe endometriosis,[21] it is unlikely that this will be incorporated into clinical practice given the subjective nature of the assessment.

Consequentially, studies that focus on the female aesthetic add little to the care of women and may be deemed unethical. Furthermore, the beauty myth has been debunked, evidenced by the evolving nature of society's preference of female aesthetics, from the voluptuous women of the 1940s and 1950s to the emaciated females of the 1970s to 1990s, and finally to the contemporary fashion of fitness and athleticism as beautiful.

As Wolf writes, "there is no legitimate justification for the beauty myth," but rather the emphasis on beauty is about power and patriarchy, where the aging woman is most feared as advancing age is associated with increased knowledge, power, and respect.[20] Possibly as a result of the beauty myth, women's identities may be entrenched in their physical attractiveness, which ensures their vulnerability to external approval.[20]

Failure to achieve the gold standards to beauty impacts on self-esteem and possibly subsequent success.[2,48,49] Studies focusing on female attractiveness may serve to reinforce false beliefs surrounding beauty and increase hostility toward women.[50] Hostile sexism may lead to perpetuation of the hysterical discourse[51] and increase time to diagnosis and occurrence of misdiagnoses.

Although sexism remains present in the medical sphere, patient care is compromised. The research gap and the publication of misogynistic research may adversely affect female care and contribute to the negative perceptions of female hysteria and the gap in time to diagnosis experienced by many women. The androcentric history of medical research led to assumptions about women's health and response to treatments based solely on studies from male bodies.[10,17] A rapidly growing body of evidence from clinical research demonstrates that females and males can differ greatly in their susceptibility and presentation of disease and their response to treatment and profile of adverse effects.[23]

A more immediate issue with studies that display misogyny is the trust patients place in the medical profession. Women reportedly feel a sense of distrust in the medical profession, with many professing acute awareness that doctors have the power to label them as "anxious" or "depressed" rather than address their physical pain or symptoms.[17]

Physicians assessing physical attractiveness as part of a clinical assessment is arguably entering dangerous territory when it comes to the doctor–patient relationship.[2] Doctors are bound by the Hippocratic Oath and a set of laws from registering boards, under which the boundary of relations with patients is clear and absolute.[52] Rating patient attractiveness is, therefore, both inappropriate and extremely subjective, consequentially it must not be allowed to blur the clinical picture.

Other countries have developed research policies to address the sex and gender imbalance in research and to stipulate that sex must be reported; Australia has somewhat lagged on this.[1,23] Until we address the gender gap and misogyny in medical research, we run the risk of the health care of female patients remaining substandard to the care of male patients.[53] The consequences of neglecting sex and gender differences are wide reaching—including inaccuracies in science, adverse health outcomes, and experiences and cost ineffectiveness.[23,54]

Limitations

This review has a few limitations, first in that sex and gender are largely considered in binary terms and there is no discussion of intersexuality, nonbinary, transgender, or any others on the gender spectrum because there is very limited literature on gender gaps in these population groups, and the authors highlight a need for further research in this area. Second, only articles from the recent decade were included, this was to allow the review to examine only the most contemporary literature, however, it is likely that more historical review would yield more evidence of misogyny and gaps in gender analysis.

Finally, the definition of misogyny in research was determined by the authors, because there was no literature previously examining this topic in the medical literature, there is no gold-standard way to measure the misogyny of a research article. In much the same way as the Bechdel test for positive female representation within media,[55] the authors propose it may be of use to develop a tool to assess misogyny in medical research and to provide guidelines to avoid future publication of misogynistic research.

Conclusions

The gender gap and misogynistic studies, which serve little to improve women's health, remain present in the contemporary medical literature. There may be several drivers for the gender gaps and misogyny revealed by this scoping review, including outdated perceptions of sex prevalence of diseases, unhelpful discourse surrounding female patients and illness, and the ongoing perpetuation of the beauty myth. The hidden curriculum in medical education may be an important and seemingly unexplored contributor to the outcomes of the androcentricity of medical research on the experiences of female patients.

Author Disclosure Statement

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Abbreviations Used

BLA = biological license application
CVD = cardiovascular disease
FDA = Food and Drug Administration
LPCT = late phase clinical trial
MI = myocardial infarction
PRISMA = preferred reporting items for systematic reviews and meta-analysis
RCT = randomized controlled trial

4.3 Mind the gap: Reporting and analysis of sex and gender in clinical trials in Australia, a cross-sectional study

4.3.1 Abstract

4.3.1.1 Introduction

Historically, medical studies have under-represented female participants, and most research data have been collected from males and generalised to other genders. This paper aims to determine if there is a sex and/or gender gap in recent Australian health research.

4.3.1.2 Methods

This descriptive cross-sectional study of the published literature examines recent Australian-based clinical trials for inclusion of sex and gender. Medians and interquartile ranges were calculated for study sample sizes and female:male representation. Proportion of sex and/or gender was analysed by the clinical specialty of the trials. The *t*-test was used to ascertain significance of any differences in recruitment of females and males.

4.3.1.3 Results

A total of 88 papers were included in the analysis. Most studies (n = 63) were randomised clinical controlled trials. Overall, women constituted 55% (IQR 30% of all participants). Of the 71 mixed-sex studies, only 8.9% (n = 7) analysed the data by sex. Women were significantly under-represented in cardiology and nephrology studies and over-represented in psychiatry, care of the elderly and orthopaedic studies.

4.3.1.4 Conclusion

When analysed by specialty, women are over-represented in specialties considered to be female-patient dominated, such as psychiatry and pain medicine, and under-represented in specialities such as cardiology and oncology. The over-representation of women in some specialties can reinforce gender stereotypes, potentially harming women. Additionally, exclusion of males from these areas of research may be of disservice to men’s health.

4.3.2 Introduction

Historically, medical studies have shown bias against equitable female inclusion because of concerns that research may harm the female reproductive system or that the variability of menstruation may affect the reliability of the results (Bruinvels et al., 2017; Liu & Mager, 2016). This exclusion of women was further enhanced by perceptions of the male body as the norm (Dresser, 1992). Consequently, most research data have been collected from cis-gendered males and generalised to females and those who are intersex, transgender or elsewhere on the gender spectrum (Dresser, 1992; Sex and Gender Sensitive Research Call to Action Group et al., 2020) (respectfully referred to herein as gender nonbinary). Cis-gendered people are those who identify as the phenotypic gender they were assigned at birth. There is a call for Australian research policy to align with those in Europe and the US and increase equitability in sex and gender reporting in medical research (Sex and Gender Sensitive Research Call to Action Group et al., 2020).

It is recommended that percentages of each sex and gender recruited into clinical research be proportional to the disease-specific sex and gender prevalence (Holdcroft, 2007). Sex refers to the biological and physiological characteristics that define humans as female, male or intersex, while gender is a societal construct that refers to roles, activities and behaviours, and encompasses a wide range of identities, including woman and man (Sex and Gender Sensitive Research Call to Action Group et al., 2020). Individuals with varying sexes and genders experience diseases and respond to treatments differently and consequently clinical research should analyse results by sex and gender (Morselli et al., 2016).

There are significant discrepancies between the medical care of female and male patients that are likely associated with the deficiency in knowledge of disease manifestation, investigation and management in females (Steinberg et al., 2021). Females tend to wait longer than males for a diagnosis or pain relief (Chen et al., 2008) and are more likely to be misdiagnosed or discharged during serious medical events (Nabel, 2000; Robertson, 2014). A recent systematic scoping review of evidence underpinning a sex and gender gap in the Australian and international medical literature highlighted several issues; females remain broadly under-represented in the medical literature, and when females are included adequately, sex and gender are poorly reported and insufficiently analysed (Merone et al., 2021b). The 2007 *National Statement on Ethical Conduct in Human Research* (updated in 2018) (National Health and Medical Research Council, 2018) requires fair participant inclusion in Australian clinical trials. However, these guidelines do not specifically recommend sex and/or gender proportions or stipulate performing analysis of data by sex.

The aim of this paper is to determine if there remains a sex and/or gender gap in contemporary Australian health research. The objectives of this study were to determine the representation of females in a sample of recently published clinical studies (both RCTs and observational studies) conducted in Australia to determine if results are analysed by sex and if there is a difference in sex representation between specialties.

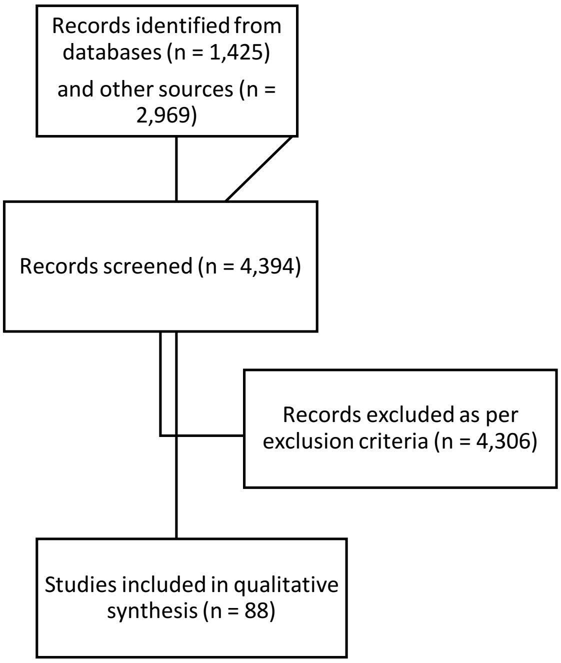
4.3.3 Methods

This descriptive, cross-sectional study of the published peer-reviewed literature examined a sample of the recent (2019) Australian-based clinical studies. The published papers were evaluated for inclusion of sex and the gender spectrum, both in the trial and in the analysis of the data.

Australian studies were defined as those conducted in Australia, utilising Australian-resident participants. Multi-centre trials were included provided they were conducted in Australia. Age restriction was applied; inclusion of trials was limited to participants aged 18 years or more. The inclusion and exclusion criteria are provided in Table 4.1. We excluded clinical trial protocols as there were no results to determine whether data had been analysed by sex and/or gender. Any texts that were not subject to peer review were also excluded (Figure 4.1).

Figure 4.1

Flowchart of the search strategy and paper selection criteria



Owing to the large heterogeneity of studies included, we categorised trials by medical specialty, rather than by specific disease. For this reason, it was not possible to determine under-representation of females by disease-specific prevalence. We therefore determined that across a specialty, representation of women and men should be 50:50. Medical specialties were determined in one of two ways: if it was stated in the paper, it was categorised accordingly; when the specialty was not stated, the ICD-10 was used (World Health Organization, 2016).

A search for the terms ‘Clinical Trial’ AND ‘Australia’ AND ‘adult’ was conducted using commonly used databases to obtain a broad sample of papers: PubMed, Medline (hosted by OVID), PsychINFO and Science Direct (Elsevier). Where a trial was listed as completed on the ANZCTR, the paper was searched for on the databases listed above. All searches were limited to completed Australian studies published in 2019 as we are exclusively seeking to determine if there is a sex and/or gender gap in contemporary Australian research.

The study was guided by Arksey and O'Malley's (2005) framework with modifications by Levac et al. (2010). The lead author (LM) collated studies, removed duplicates and conducted the initial screen of articles by title and abstract. Full texts of included studies were reviewed independently by two authors (LM and KT). A data extraction form was developed to tabulate variables of interest: medical specialty, study design, sample size, proportion of females to males, and analysis by sex and/or gender. Where studies gave percentage of females and males by trial arm, an average was calculated. We calculated the median and interquartile range for study sample sizes and female:male representation. Proportional sex and/or gender representation were then established by clinical specialty of the trial. Finally, using statistical package Stata14 (Stata, 2022), we performed paired *t*-tests where possible for representation of females and males across the mixed-sex studies that provided information on sex proportions.

Table 4.1

Selection criteria

Inclusion criteria	Exclusion criteria
- Published 1 Jan to 31 December 2019 - Randomised controlled trials (RCTs) or non-randomised clinical trials, cohort studies, case control studies, clinical registered trials - Hospital or community patient population - Conducted in Australia - Adults ≥18 years	- Clinical trial protocol without completed data - Non-peer-reviewed papers - Duplicate paper - Full text not available

4.3.4 Results

4.3.4.1 Search results

The database search yielded a total of 1,425 records, and the search of the Australian Clinical Trials Registries (Australian Government, 2021) produced 2,696 published studies.

Following screening of titles and abstracts for selection criteria, a total of 88 papers were included in the analysis.

4.3.4.2 Description of sample

Most studies (n = 63) were RCTs. Other designs included observational studies (n = 19, of which 5 were cohort studies), and feasibility/safety or effectiveness trials (n = 6).

The 88 studies were divided into mixed-sex (n = 71) and single-sex (n = 8 female only, n = 1 male only) categories. There were eight studies that did not provide information on sex or gender proportions.

The 71 studies with mixed-sex participants included the following specialties: psychiatry (n = 22), oncology (n = 8), neurology (n = 6), gerontology (n = 6), pain management (pain) (n = 5), cardiology (n = 4), respiratory (n = 4), orthopaedics (n = 4), endocrinology (n = 2), gastroenterology (n = 2), ophthalmology (n = 2), nephrology (n = 2), general practice (n = 1), microbiology (n = 1), dermatology (n = 1) and complementary medicine (n = 1). Of the nine single-sex studies, specialties included were oncology (n = 3), obstetrics and gynaecology (n = 2), sexual health (n = 1), gerontology (n = 1), rehabilitation (n = 1), and psychiatry (n = 1).

4.3.4.3 Sex and gender representation

There were no studies that explicitly included intersex people or gender nonbinary people. There were eight studies with only female participants, three of which related to gynaecological and obstetric health and one relating to each of endocrinology, psychiatry, sexual health, endometrial cancer, and breast cancer. All eight of these studies were specific to female biology except for the breast cancer study. A single study examining prostate cancer recruited only male participants.

For both the mixed-sex and single-sex studies, the median overall sample size was 107.5 (IQR 291.25) and the range of participants across the studies was 7 to 250,648. The median female sample size across all studies was 55% (IQR 30%), and the median male sample across all studies was 45% (IQR 30%). Of the 79 mixed-sex studies, only 8.9% (n = 7) analysed data by sex.

Representation of sex varied widely between specialties (Figure 4.2 and Table 4.2). Specialties that significantly under-represented females in Australian research were cardiology (female:male ratio 30:70, *p* = 0.01) and nephrology (female:male ratio 38:62, *p* = 0.02). Specialities that significantly over-represented females were psychiatry (female:male ratio 67:33, *p* = 0.02), orthopaedics (female:male ratio 68:32, *p* = 0.001) and care of the elderly (female:male ratio 65:35, *p* = 0.02).

Figure 4.2

Percentage of females:males included in 2019 Australian studies by specialty (n = 71)

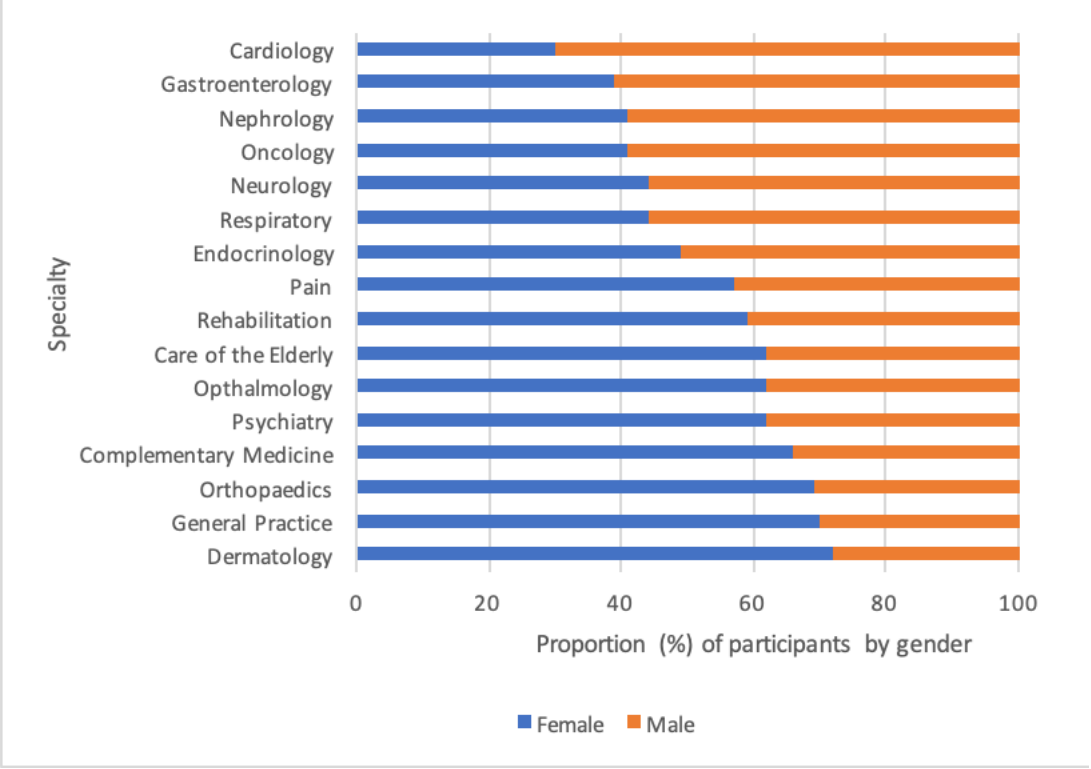


Table 4.2

Paired t-test analysis of sex representation in mixed-sex studies by specialty

Medical specialty	Number of studies included	Mean (SD) percentage inclusion of females	Females 95% CI	Mean (SD) percentage inclusion of males	Males 95% CI	*t*-test score	*p*-value
Respiratory	4	44.39 (17.88)	15.94, 72.83	55.61 (17.88)	27.16, 84.06	–0.63	0.57
Cardiology	4	29.68 (6.88)	18.73, 40.61	70.32 (6.88)	59.38, 81.27	–5.91	**0.01**
Psychiatry	22	57.43 (23.04)	47.46, 67.39	37.79 (21.08)	28.67, 46.90	2.42	**0.02**
Pain	4	57.1 (8.40)	43.73, 70.47	42.9 (8.40)	29.53, 56.27	1.69	0.19
Orthopaedics	4	68.90 (3.64)	63.11, 74.69	31.08 (3.62)	25.31, 36.83	10.42	**0.00**
Oncology	8	32.91 (21.65)	17.42, 48.39	57.09 (27.15)	37.67, 76.51	–2.04	0.07
Ophthalmology	2	61.75 (16.62)	–87.55, 211.05	38.25 (16.62)	–111.05, 187.55	1.00	0.5
Neurology	4	46.88 (7.55)	34.85, 58.90	45.13 (7.55)	41.10, 65.15	–0.82	0.47
Gastroenterology	2	39 (7.07)	–24.53, 102.53	61 (7.07)	–2.53, 124.531	–2.20	0.27
Endocrinology	2	49.35 (34.43)	–260.04, 358.75	50.65 (34.43)	–258.74, 360.05	–0.03	0.98
Care of the elderly	5	65.1 (8.92)	54.03, 76.17	34.9 (8.92)	23.83, 45.97	3.7	**0.02**
Nephrology	2	41.10 (4.10)	4.25, 77.95	63.90 (2.97)	37.21, 90.58	–28.50	**0.02**
Overall	63	48.07 (23.36)	42.83, 53.30	51.68 (33.64)	36.76, 46.59	1.69	0.09

Of the single-sex studies, three of the eight women-only studies (Callaway et al., 2019; Carolan-Olah & Sayakhot, 2019; O'Reilly et al., 2019) concerned conditions from which biological males do not suffer, such as gestational diabetes and endometrial cancer. One single-sex female study, however, was related to and breast cancer (Singleton et al., 2019), which affects both females and males. The single male-only study concerned prostate cancer (Sachs et al., 2020).

There was no clear consensus in the literature on the use of the terms ‘sex’ and ‘gender’. No study recruited participants outside of the binary sexes, female and male, while five studies used the term gender to refer to biological sex.

4.3.5 Discussion

Our analysis highlights several issues with the diversity of study populations in Australian clinical research. Several studies (n = 5) used the term gender to refer to biological sex. Other studies have found that clinical researchers often use the terms sex and gender synonymously, and conflating the terms may lead to confusion about the contributions of sex and gender to health and incomplete analysis of health research data (Johnson et al., 2009). Krieger (2003) argues that greater precision is needed when considering whether to analyse sex and/or gender (or neither) in clinical research, requiring critical thinking and an understanding of how sex and gender interact to determine which is warranted (Krieger, 2003).

4.3.5.1 Sex and gender representation in health research

Our study demonstrated that in 2019, females represented approximately half of all participants in Australian health research. This finding is echoed in a large-data study in the US, which also showed a 50:50 female:male representation across all clinical trials but significant discrepancies between clinical specialties (Steinberg et al., 2021). Adequate overall female representation across all health research is possibly indicative of the successful and relatively recent efforts to include females in clinical trials, and the development of sex-based therapeutics (Ramsay, 2019).

We found that intersex people and gender nonbinary people, however, are severely under-represented in Australian clinical research, almost to the point of non-existence outside of the study of sex and gender. Intersex variations include genetic, hormonal and phenotypic variance; therefore, intersex people, similar to females, may differ in their presentation of disease and response to treatment when compared with the male body. Despite this, other research has shown that there is a significant gap in clinical research outside of the focus on the sexual characteristics of intersex people (Jones, 2018). Research suggests that 1.7–4% of humans have some kind of intersex variation (Intersex Human Rights Australia, 2013); however, many of these are not apparent without testing; thus, these estimates may be conservative (Jones, 2018). The 2016 Australian census determined there were 1,260 sex and/or gender diverse people in Australia, and this figure is believed to be an under-estimation (Australian Bureau of Statistics, 2016). In keeping with our findings, a recent review of the literature (2016) determined far fewer clinical studies of transgender people explored their health outside of their transition and mental health, and where there were studies surrounding general health, they were exclusively about transgender people rather than inclusion in clinical trials with cis-gendered people (Marshall et al., 2019). It has been noted previously that transgender people are 'invisible' in clinical research (Chan, 2019). Our study demonstrated a total absence in the explicit participation of gender nonbinary people in Australian health research. The exclusion of intersex and gender nonbinary people from clinical research may serve to further disadvantage these population subgroups in much the same way as women, leaving uncertainty around clinical diagnosis and response to treatment. Additionally, once gender nonbinary people are included in health research, sub-analysis by sex and gender should be performed (Welch et al., 2017).

4.3.5.2 Analysis by sex and gender in health research

Analysing by sex allows researchers to identify differences between females and males that may be important for clinical diagnosis and management (Krieger, 2003). Our findings indicate that in 2019, few studies in the Australian clinical literature analysed their results by sex and none by gender. These findings are in keeping with other studies. DeBruin (1999) noted that when women are included in adequate numbers in clinical studies, rarely is sex-specific analysis performed to determine the effects of sex on the results. When sex analysis is performed, it is often done without regard for advancing women's health, such as how the disease specifically affects women or differences in treatment that may be required (DeBruin, 1999). Analysis of results by sex appears to be poor across all study designs (Mansukhani et al., 2016; Welch et al., 2017; Yoon et al., 2014) and, as demonstrated by our analysis and other studies, is not improving. According to Vidaver et al. (2000), inclusion of women as study subjects did not improve over a 5-year period of analysis following publication of guidelines on the inclusion of female subjects in clinical trials (Vidaver et al., 2000). More recently, Geller et al. (2018) determined that National Institutes of Health (NIH) policies have not resulted in significant increases in reporting by sex (or race and ethnicity) (Geller et al., 2018).

Analysis of results by sex is important because women's and men's anatomy and physiology are different (Barajas-Martínez et al., 2021; Marrocco, 2016; Merone, Tsey, Russel, & Nagle., 2022; Ortona et al., 2019), and females and males may be more prone to different diseases and respond differently to treatments and interventions (Merone et al., 2022; Morselli et al., 2016). The sex and gender research gap may translate into real-life impacts for female patients. For example, organ transplants in female patients are less successful than in male patients (Puoti et al., 2016); post-menopausal women respond differently to anti-depressant treatment than males (Sramek et al., 2016), and females are diagnosed later than males with peanut allergy despite outnumbering male allergy sufferers (Institute of Medicine (US) Board on Population and Public Health Practice, 2012). While subgroup analyses can increase Type 1 errors in research (Tanniou et al., 2016), females have been significantly under-represented in previous medical research and we maintain it is important to power studies to perform sex-based analysis to aid in closing the research and medical gap between females and males.

4.3.5.3 Sex and gender representation in health research by specialty

The results presented in this cross-sectional analysis suggest that women are adequately included in clinical research overall; however, when results were analysed by clinical specialty, females were shown to be under-represented in the research of some medical specialties and over-represented in others. This has been observed in a large-data study in the US, with similar discrepancies noted in cardiology and nephrology research (Steinberg et al., 2021). This 2021 analysis of sex inclusion in US trials demonstrated that in adult medicine, cardiology clinical trials had the most significant association with lower recruitment of females (Steinberg et al., 2021). In keeping with this study, our results show that it is possibly the researchers' perceptions of sex prevalence (Eaton et al., 2011; Moller-Leimkuhler, 2007), that drive recruitment percentages of females into clinical trials, rather than sex-prevalence statistics, as recommended by Mastroianni et al. (1994) in the *NIH Revitalization Act* (1993). It is possible that perceptions of disease prevalence are driven by what is observed in clinical practice; however, under- or over-representation of women in health research may alter diagnosis patterns and enhance existing perceptions that may be unfounded.

Studies have reported that the perception of disease and sex biases may be primary drivers for under-representing females in medical research, rather than proportion of females and males affected by the disease (Feldman et al., 2019; Merone et al., 2021b). Many perceptions of sex-related prevalence appear to be outdated; for example, ischaemic heart disease is the leading cause of death in high-income countries in both females and males (Yahagi et al., 2015) and females experience greater functional disability, symptom burden, and higher prevalence of non-obstructive coronary artery disease than men (Kothawade & Bairey Merz, 2011). Melloni et al. (2010), examined the representation of females in cardiovascular disease RCTs. Twenty studies recruited only male participants compared with a single study that recruited only female participants. Importantly, female representation was higher in cardiovascular diseases that are perceived to affect females more, such as hypertension and stroke, but lower in diseases perceived to affect fewer females, such as coronary disease (Melloni et al., 2010). Welch et al. (2017) performed a cross-sectional analysis of Canadian clinical research to ascertain the inclusion of female participants and the extent of sex-based analyses, determining that while the gap in terms of female inclusion is not large, females are under-represented in clinical research for some specialties and sex-based analysis is significantly under-utilised (Welch et al., 2017).

Cardiovascular disease has historically been perceived to be a disease affecting men rather than women (Merz, 2011; Vogel et al., 2021; M. Woodward, 2019). However, evidence shows that in more recent times this is not the case. In the general adult Australian population in 2018, the absolute risk for lifetime prevalence of heart disease was very similar between women and men with approximately a 1% difference—4.2% and 5.4%, respectively (Australian Bureau of Statistics, 2018). Further, recent statistics from 2019 show that heart disease is increasing in younger women (Arora et al., 2019; Vaccarino et al., 1999) and that outcomes are poorer for women than for men (Khan et al., 2018). This may be partially due to the observed research gap. Females with acute myocardial infarction present with different symptoms than men, are less likely to have their infarction identified during diagnostic angiography than men (Daly et al., 2006; Gudnadottir et al., 2017), and are often under-investigated and consequently less likely to be managed correctly (Khan et al., 2018). The rising incidence of cardiovascular disease in young females aged less than 40 years (Regitz-Zagrosek, 2012) does not appear to correspond to an increase in representation in the recent research literature. The *Australian Longitudinal Study on Women's Health* (Women's Health Australia, 2021) is helping to decrease the research gaps; however, as our analysis highlights, in general cardiology research studies, females remain under-represented.

In high-income countries, the prevalence of chronic kidney disease (CKD) is higher in women than in men (Carrero et al., 2017), yet this is not reflected in the proportion of females recruited to nephrology research. Renal physiology is also different in females and males; females have 12% fewer glomeruli than males (Maimonides, 2011) and female sex hormones increase the synthesis of angiotensinogen but decrease synthesis of angiotensin-converting enzyme, both of which increase the risk of hypertension (Cobo et al., 2016). Further, in the general adult population, the lower muscle mass of females compared with males means that reference ranges for estimates of glomerular filtration rate in blood tests may be inappropriate (Cobo et al., 2016). Despite these important differences, sex differences are neglected in nephrology research (‘Women’s Health and Kidney Disease’, 2018). In keeping with our findings, analysis of female participation in research by burden of disease in the US demonstrated that, alongside oncology, neurology and immunology, nephrology had the lowest female enrollment relative to disability-adjusted life years (Steinberg et al., 2021).

Our study suggests that research in the care of the elderly appears to be biased towards females; however, this may be owing to the longer lifespan of women; there are more elderly women than men, and consequently, they are more likely to present to services and be recruited into trials. Despite their longer lifespan, women of all ages are more likely than men to report poor health and see their doctor; therefore, in this age group, where women often outnumber men (Luy & Mingawa, 2014), it is possible that there may be some selection bias when recruiting to clinical trials. Research conducted in Canada also suggests that women report poorer health because of their longer lives and therefore greater likelihood of developing health problems (Luy & Mingawa, 2014). It is possible that this factor is also at play when considering the results for orthopaedic studies, which included predominantly elderly patients aged over 60 years; osteoporosis is related to falling oestrogen levels and more common in elderly females (Curtis & Safford, 2012).

The findings from this study suggest that research in psychiatry appears to also be significantly dominated by female participants, even though high numbers of both women and men are affected by psychiatric ailments. Of note, men are more likely than women to die by suicide, whereas women remain more likely to be diagnosed with an anxiety or personality disorder (Department of Health, 2009). The dominance of female participants in psychiatry is possibly rooted in historical perceptions of women as ‘hysterical’ (Jackson, 2019). Hysteria was the first mental health disorder that was considered a ‘female disease’, driven historically by perceptions of women as ‘weak’ and ‘guilty’ of sins or supernatural influence (Tasca et al., 2012). As a diagnosis, hysteria diminished in the 1970s and was deleted from the *Diagnostic and Statistical Manual of Mental Disorders III* (DSM III) in 1980 (Tasca et al., 2012), although it has been argued that other terms such as anxiety, borderline personality disorder and bipolar mood disorder have come to replace this label for female patients, and these conditions have consequently become stigmatised and potentially over-diagnosed (Swartz, 2013). If this is the case, this may assist in the explanation of the sex and gender gap swung in the favour of the female participant in psychiatric research. We postulate that this may then become a self-fulfilling prophecy and enhance perceptions of women as anxious or hysterical, to the detriment of women’s health. Mental ill-health in women is frequently misunderstood, potentially leading to bias and prejudice.

4.3.6 Limitations

Many of the included studies used the terms sex and gender interchangeably. This lack of definition and clarity is a limitation of this study, and to mitigate this we explored sex and/or gender representation in the published health research literature. The data collected were study results published during a single year and therefore may not be truly representative of clinical trials across Australia. The data collected were also limited to those that were published, and it is possible that some of the studies analysed results by sex and found no differences and therefore did not include these results in their publication. Heterogeneity across studies made analysis by disease unfeasible, therefore we analysed data more broadly by specialty, and assumed that the required representation of female and male participants be 50:50. This assumption was used as the basis for determining over and under representation. Finally, on specialty sub analysis, some sample sizes were small and therefore may not be an accurate representation of female inclusion.

Restricting studies to those conducted in Australia, and utilising Australian-resident participants, limited the inclusion of studies in our analysis, but by focusing on research in Australia, our findings can inform Australian public health.

4.3.7 Conclusion and implications for public health

Overall, the inclusion of women in clinical research conducted in Australia appears balanced; however, when analysed by specialty, women are over-represented in specialties perceived to be female-patient dominated, such as psychiatry, and significantly under-represented in specialities such as cardiology and nephrology. Despite increasing numbers of female participants in medical research, there is observable over- and under-recruitment in some medical specialties. Over-representation of women in some specialties can reinforce gender stereotypes, potentially harming women. Additionally, exclusion of males from these areas of research may be of disservice to men's health. Where women are adequately represented, there is rarely gender-based analysis. Intersex and gender nonbinary people also remain under-represented in the general medical research.

4.4 Concluding comments

This chapter has highlighted the ongoing sex and gender gaps in health research, both globally and in Australia. Misogynistic views of women are also noted to appear in the published scientific literature, potentially further marginalising and perpetuating stereotypes of female patients. Chapter 5 seeks to investigate if the same sex and gender gaps are present in medical education resources such as curriculum standards, course outlines and core clinical textbooks, possibly indicating the translational impacts of sex and gender gaps in health research.

Chapter 5: Representation of Women and Women's Health in Australian Undergraduate Medical Education

Hospital Parking Lot, April

Once there was a woman who laughed for years uncontrollably after a stroke.

Once there was a child who woke after surgery to find his parents were impostors.

These seagulls above the parking lot today, made of hurricane and ether, they

have flown directly out of the brain wearing little blue-gray masks, like strangers' faces, full

of wingéd mania, like television in waiting rooms. Entertainment. Pain. The rage

of fruit trees in April, and your car, which I parked in a shadow before you died, decorated now with feathers,

and unrecognizable
with the windows unrolled
and the headlights on
and the engine still running
in the Parking Space of the Sun.

(Kasischke, 2008)

5.1 Introduction

Health research provides the evidence base not only for clinical practice but also for clinical education. Consequently, the ongoing sex and gender gap in health may translate into sex and gender gaps in medical school curricula and clinical textbooks. This chapter presents an analysis of Australian medical school course outlines, the *Australian Medical Council Standards for Assessment and Accreditation of Primary Medical Programs* (Australian Medical Council, 2012), and clinical textbooks for inclusion of women's health, including consideration of the different social and economic circumstances of women and inclusion of women's health outside of their reproductive health.

5.2 Representation of women and women’s health in Australian medical school course outlines, curriculum requirements and selected core clinical textbooks

5.2.1 Abstract

5.2.1.1 Background

Historically, medical research has, outside of reproductive health, neglected the health needs of women. Medical studies have previously excluded female participants, meaning research data have been collected from males and generalised to females. Knowledge gained from research is translated to clinical education and patient care, and female exclusion may result in gaps in the medical school curricula and textbooks.

5.2.1.2 Methods

This study involved a desktop review of the *Australian Medical Council Standards for Assessment and Accreditation of Primary Medical Programs*, the online publicly available Australian medical school course outlines, and a textbook analysis of the recommended textbooks.

5.2.1.3 Results

There are no fixed or explicit requirements to include women’s health in Australian medical school curricula. Medical school course outlines do not adequately include women’s health; similarly, clinical medicine textbooks do not account for sex and gender differences.

5.2.1.4 Conclusion

Important sex and gender differences in medicine are not reflected adequately in the medical school course outlines, curricula or clinical textbooks. This may have significant consequences on women’s health.

5.2.2 Background

Historically, medical research has, outside of reproductive health, neglected the health needs of women (Mehta et al., 2016). Medicine, acknowledged as both science and art, is as much social and cultural as it is scientific (Cleghorn, 2021). Gender is a social construct (Winter, 2015), and as medicine developed throughout history, it has in many ways enforced the constructed gender divisions, from Aristotle, who defined women as anatomically 'mutilated' men (Mercer, 2018), to Freud and Breuer (1895/1955), who utilised female case studies to develop the psychoanalytic concept of hysteria. Even in the relatively modern era, myths surrounding the female body and health have persisted (Cleghorn, 2021). Such sex and gender myths today may manifest as a sex and gender gap between female and male healthcare; women wait longer than men for diagnosis (Nabel, 2000) and pain relief. Further, women are more likely than men to be misdiagnosed or discharged during serious medical events (Chen et al., 2008; Merone et al., 2021b; Nabel, 2000). Previously, medical studies have excluded female participants, meaning research data have been collected from males and generalised to females (Holdcroft, 2007) and intersex people (Harper, 2007).

Research has demonstrated that biological differences and disparities in the social environments of females and males contribute to the variation in health and disease between women and men (Hamberg, 2008). Medicine as an institution has been accused of being 'gender blind' and considering the sex and/or gender of the patient to be largely irrelevant to clinical care. Additionally, the ideology and preconceptions of clinicians regarding gender roles and gender expression may negatively influence treatment and outcomes (Verdonk et al., 2009).

There are many advocates for incorporating gender medicine, defined as 'a study of the differences in men's and women's normal function and in their experiences of the same disease', into medical education (Hocklietner et al., 2013). Despite efforts to implement gender medicine into medical school curricula across Europe and the US, overall appetite for this has been poor (Hocklietner et al., 2013). Yet, in spite of this, there is increasing recognition that sex as a biological variable needs to be considered when educating clinicians and future clinicians on evidence-based diagnoses and treatments (Regensteiner et al., 2020).

Knowledge gained from research is translated to clinical education and patient care (Clayton, 2016); therefore, gaps in clinical research will inevitably be translated into gaps in the medical school curricula and textbooks. This may adversely affect women's health. Additionally, lack of inclusion of women and people of colour enhances implicit biases among clinicians, positioning the white 70 kilogram male as 'normal' and implying anything other is 'abnormal' (Benoit et al., 2020). Given the importance of the research evidence base to both clinical practice and education, it is imperative that information is up to date and accurate and accounts for differences in sex and gender (Alexanderson et al., 1998). Sex and gender gaps may be prominent in medical school course outlines and curricula, influencing students' implicit gender views (R. Parker et al., 2018) and potentially affecting patient care, particularly that of women.

The sex and gender gap in medical education may also be observable in medical textbooks. Clinical guidelines and textbooks are guided by the literature, and there is a known lag of 17 years between publication and translation to patient management (Morris et al., 2011). Although efforts are being made to reduce this gap (Elliott et al., 2014), it is important to note as even as female participation in clinical trials increases, there will be a significant delay before the results of these are reflected in the medical school curricula, textbooks and patient care.

There are currently 20 medical schools across Australia, each with a course outline and learning outcomes available online. The aim of this two-phase quantitative study is to explore the representation of women and women's health in medical school course outlines, the

Standards for Assessment and Accreditation of Primary Medical Programs by the Australian Medical Council (2012), and recommended clinical medicine textbooks, with attention to gender and sex differences in the social circumstances, presentation, diagnosis and medical care of female patients.

5.2.3 Methods

This study involved a desktop review of the *Australian Medical Council Standards for Assessment and Accreditation of Primary Medical Programs*, online publicly available medical school course outlines, and a textbook analysis of the recommended textbooks.

5.2.3.1 Phase 1: Review of the Australian Medical Council Standards for Assessment and Accreditation of Primary Medical Programs and online course outlines

5.2.3.1.1 Data collection

The *Standards for Assessment and Accreditation of Primary Medical Programs* by the Australian Medical Council (2012), the criteria against which medical education programs are evaluated, were reviewed and data were collected on:

- whether a unit on women's health is stipulated in the guidelines as a requirement for the medical course;
- if requirements of any women's health components include non-reproductive elements; and
- if requirements of any women's health components include acknowledgement of the differing socioeconomic circumstances of women and men.

A review was also undertaken collating publicly available course outline information from Australian universities providing entry to practice programs for medicine. The data collection tool was developed using the Queensland Government Gender Analysis toolkit (The Office for Women, 2018). This data collection tool gathered information on the presence or absence of female inclusion in course outlines and whether that inclusion extended beyond sexual or reproductive health for women.

Data were collected on the number and proportion of medical schools that:

- provide an online course outline;
- designate women's health courses or learning outcomes that are centred on the reproductive system;
- designate women's health courses or learning outcomes that are not centred on the reproductive system;
- designate women's health courses or learning outcomes that highlight medical differences between females and males; and
- designate women's health courses or learning outcomes that highlight social and cultural differences between females and males.

5.2.3.1.2 Data analysis

Descriptive statistical analysis of these data summarised the extent to which women's health is included in the *Standards for Assessment and Accreditation of Primary Medical Programs* by the Australian Medical Council and the Australian medical schools' course outlines. This included:

- requirements for women's health components within medical school curricula;
- number and proportion of medical schools that had a designated women's health course; and
- number and proportion that included women's health outside of sexual or reproductive health (such as obstetrics and gynaecology rotations).

5.2.3.2 Phase 2: Textbook analysis

A clinical medicine textbook is one that is focused on the diagnosis, investigation and management of disease. Use of clinical medicine textbooks is common in medical schools across Australia.

Analysis of medical school-recommended textbooks was guided by a data collection form modified from that developed by Alexanderson (1999). The table of contents and indices of each book were hand searched for 'gender', 'sex', 'male', 'female', 'men' and 'women' to determine if there is specific inclusion of women's health outside of reproductive medicine.

Informed by a previous cross-sectional analysis (Merone, Tsey, Russell, & Nagle, in press), the specialties with the least female representation in research were selected for analysis: cardiology, gastroenterology and nephrology. Two diseases were selected from each specialty: coronary heart disease (CHD) and heart failure; irritable bowel syndrome (IBS) and peptic ulcer disease; chronic kidney disease (CKD) and renal calculi. These were selected as per similar work by Dijkstra et al. (2008) as they are:

- common within the selected specialty (e.g. coronary or atherosclerotic heart disease for cardiology);
- represent a major public health issue (e.g. have significant population prevalence across all sexes and genders); and
- involve potentially relevant biomedical, psychosocial, and cultural-, sex- and gender-related issues.

5.2.3.2.1 Data collection

Alexanderson (1999) developed a framework specifically for gender analysis in medical textbooks. A version of this framework was adapted for this study, eliminating sections that were irrelevant, for example, sections that pertained to public health medicine and questions about references to author and scientist gender. Additionally, in part, the methods of

Parker et al. (2017) were employed to examine gender representation in images used in medical textbooks. Parker et al. (2017) examined the ratio of females to males represented in images and case studies and, where relevant, examined the narrative of the image to determine if females are more frequently shown to be in domestic-type roles and males more frequently shown to be in professional roles. Data were collected on:

- number of words in the index referring to female sex and/or gender, male sex and/or gender, and sex and/or gender more generally;
- presentation of (in terms of sex and/or gender):
  - disease epidemiology
  - disease aetiology
  - risk factors for the disease
  - treatment for the disease and response to treatment
  - specific mention of women's symptoms;
- representation of sex and/or gender in textbook images:
  - number of images depicting females and males
  - images positioning people in stereotyped roles (e.g. females in domestic roles and males in professional roles).

5.2.3.2.2 Data analysis: Textbook content analysis

Descriptive statistics were conducted to determine if there is a difference between male and female representation both within and between recommended textbooks. This included information on whether gender differences in disease aetiology, risk factors, presentation, investigation and management were included, and additionally whether consideration was given to the different socioeconomic circumstances of women and the impacts this may have on their health.

5.2.3.2.3 Data analysis: Textbook image analysis

The data were used to determine the relative frequencies of men and women represented in images and whether gendered representations were stereotyped. This included examination of representation of female bodies and presence of stereotyped images, such as men in professional roles and women in domestic roles.

5.2.4 Results

5.2.4.1 Phase 1: Review of the Australian Medical Council Standards for Assessment and Accreditation of Primary Medical Programs and online course outlines

The *Australian Medical Council Standards for Assessment and Accreditation of Primary Medical Programs* (Australian Medical Council, 2012) was reviewed utilising a modified version of the curriculum analysis data collection tool. There is no explicit mention or direction regarding a requirement for specific course content on women's health in the assessment guide or procedure provided. Women's health was listed as a potential clinical placement; however, no requirement for this is clear in the document. There was no recommended course content for women's health, nor acknowledgement of the different social circumstances specifically for women.

Of the 20 Australian medical schools, one medical school provided insufficient online course outline information for analysis and was thus excluded. Nineteen medical schools were included; 84% (n = 16) stated they had a course pertaining to women's health. Of these 16, fourteen of the courses were listed as clinical rotations in women's health or obstetrics and gynaecology between years 3 and 5 of medical school. There was one course that stated there was a women's health workshop, but no further details were provided, and one course that provided two elective subjects in women's health in years 1 and 5, again with no further details provided. Of the 16 courses, only two medical schools provided sufficient information regarding learning outcomes for full assessment of the inclusion of women's health. None of the course information or outlines provided appeared to focus on women’s health or social circumstances outside of reproductive medicine or obstetrics and gynaecology.

5.2.4.2 Phase 2: Textbook analysis

Of the 20 medical schools in Australia, 10 provided their recommended clinical textbook list online. Table 5.1 outlines the list of books provided and the frequency of recommendation.

Table 5.1

Clinical medicine textbooks recommended by 10 Australian medical schools and the frequency at which the textbook was recommended

Textbook title and edition (year of publication)	Frequency of recommendation
Kumar and Clarke Clinical Medicine 8th edition (2012)	5
Harrison’s Principles of Internal Medicine 18th edition (2011)	4
Oxford Handbook of Clinical Medicine 9th edition (2014)	4
Davidson’s Principle and Practice of Medicine 22nd edition (2014)	2
Stewart Core Clinical Medicine (2010)	1
Gibson’s Essential Clinical Medicine (2009)	1
Toronto Notes Essential Medicine Notes 2020	1

Six textbooks out of the recommended seven were included in the analysis; one textbook was deemed unsuitable for the analysis owing to its unusual structure and format—diseases were not discussed as separate entities and it was not possible to conduct the analysis.

5.2.4.2.1 Textbook content analysis: Number of words in index

No clinical textbook included in this study had a dedicated chapter or section on women’s health. The median number of words referring to women, men, and gender in the index across all the textbooks included is presented in Table 5.2.

Table 5.2

Median number of words referring to women, men and gender across the indexes of all included textbooks

Words referring to sex and/or gender	Median number of words (interquartile range, IQR)
Referring to women/female sex and gender	2 (IQR 22.5)
Referring to men/male sex and gender	1 (IQR 13)
Referring to gender	1 (IQR 5)

5.2.4.2.2 Textbook content analysis: Presentation of disease in clinical textbooks

A total of 36 sections—one for each of the six diseases—were examined within six textbooks. All six textbooks assumed women and men to have the same symptoms for all diseases, although one textbook did state, in the case of CHD, that women are more likely to have atypical chest pain, but recommended the same treatments and predicted the same consequences and natural history of disease for women and men. No textbook acknowledged the differing social circumstances for women and men as contributing factors to disease and response to treatment, and no textbook stated whether their recommendations were based on research from women and men or men alone.

Across the six diseases, most textbooks presented disease aetiology, risk factors and symptoms as the same for women and men and did not consider disease pathology or presentation to differ between the sexes (Table 5.3).

The following aspects with regard to disease presentation were considered:

- Epidemiology: Epidemiology was more likely to be presented by sex than any other information provided by the textbooks (n = 8 out of 36 sections). One textbook, when describing IBS, gave the total epidemiology (males and females combined) and the epidemiology for females only. One textbook listed IBS as a functional disease.

- Aetiology and course of disease: Disease aetiology was consistently presented across all textbooks as one entity (n = 35 out of 36 sections, with one section that did not present this information), with no differences specified between females and males. One textbook noted that females and males have different patterns of CHD: females are more likely to have small-vessel disease, compared with males, who are more likely to have large-vessel disease. Another textbook noted differences in 24-hour urinary calcium excretion between females and males in the aetiology of renal calculi.
- Disease risk factors: Risk factors for disease were often not presented (n = 17 out of 36). When presented, risk factors were not differentiated by sex or gender (n = 19 out of 36). Four textbooks presented male sex as a risk factor for certain CHD, and one textbook listed male sex as a risk factor for heart failure, but one acknowledged this higher risk in men was comparative only to premenopausal women. Another textbook listed male sex as an ‘alarm’ symptom in IBS and suggested searching for an organic cause of disease.
- Treatment and response to treatment: Treatment and response to treatment were most frequently provided as universal across females and males (n = 35 out of 36 sections); however, one textbook stated that at angiography for females with diagnosed CHD, the coronary arteries are more likely to appear normal without clear mechanism or understanding of why this may be, rendering this treatment unhelpful.
- Women’s symptoms: One textbook mentioned that women’s symptoms and experiences may differ from men’s, in terms of CHD and atypical chest pain. Otherwise, across all textbooks, there was no specific mention of women’s symptoms and how they may differ from those of a man.

Table 5.3

Descriptive statistics representing the presentation of sex data across all the six specified sections of the examined medical textbooks

Area	Presented by:	Number of sections (out of a total of 36 across 6 textbooks)
Epidemiology/Prevalence	Sex (females and males separately)	8
	Total prevalence (males and females combined)	17
	Female prevalence only	1
	Male prevalence only	1
	Not presented	10
Aetiology	Sex (females and males separately)	0
	Presented females and males as the same	35
	Not presented	1
Disease risk factors	Sex (females and males separately)	0
	Presented females and males as the same	19
	Not presented	17
Response to treatment	Sex (females and males separately)	1
	Presented females and males as the same	35
	Not presented	1
Specific mention of women's symptoms	Yes	1
	No	35

One textbook did not include a chapter or section on renal calculi and this was thus categorised as “not presented” across all categories.

5.2.4.2.3 Textbook Image analysis

Across the six specialties in six textbooks, there were 10 relevant chapters with no images at all and 22 that contained images without people (e.g. graphs, flowcharts, radiology images, ECGs). There was one photo of a patient undergoing a scan; their sex was not able to be determined. One image demonstrated an illustration of a male body as the norm, and another image was a gender-neutral illustration. There were no images portraying gender stereotyping

5.2.5 Discussion

Medical studies are underpinned by assumptions about sex and gender that are in keeping with social norms (S. Morgan et al., 2013). According to the *Australian Medical Council Standards for Assessment and Accreditation of Primary Medical Programs* (Australian Medical Council, 2012), there are no apparent requirements stated for women's health inclusion in medical school curricula, nor is there mention of including aspects of women's health within medical and surgical specialty teaching. Within the online content reviewed, this lack of emphasis on women's health is clear; most medical schools provide a clinical rotation in obstetrics and gynaecology, with no other mention of women's health or social situations, particularly outside of reproductive medicine. This has been observed historically throughout medicine, with women's health problems being attributed to their different genitalia and reproductive organs (Cleghorn, 2021). This is in keeping with other curricula analyses conducted in the US (Martin et al., 2016; Miller et al., 2013) and represents a significant gap in women's health (S. Morgan et al., 2013).

5.2.5.1 Medical school course outlines do not appear to adequately include women's health

In keeping with our findings, a 2013 survey of American medical schools ascertained that 70% did not have a formal sex- and gender-integrated curriculum (Miller et al., 2013). This was supported by analysis of the curriculum at one such medical school, where it was determined that images and curricula did not represent the US population by sex/gender or ethnicity (Martin et al., 2016).

Our findings suggest that Australian medical schools may lag behind other high-income countries in terms of incorporating women's health and gender equity into their course content. Yut-Lin (2009) conducted a systematic review of the literature and demonstrated that medical schools in the US and Canada have gender-sensitive medical school curricula, with set criteria and guidelines to address sex and gender stereotyping. This includes content, language and processes that create gender sensitivity rather than perpetuate stereotypes. Content, it was ascertained, should be inclusive, and not consider the white male to be the ‘norm’; language should not contain words that promote stereotypes, and processes should address the hidden curriculum, such as presenting women’s health and case reports after men’s and perpetuating the idea of men as the ‘norm’ and women as ‘other’ (Yut-Lin, 2009). One university in the US developed an integrated longitudinal women’s health curriculum emphasising the social and biological differences between women and men and disease processes that are unique to women (Yut-Lin, 2009). Similarly, a medical school in Europe successfully integrated sex- and gender-based medicine into all course content from basic science to clinical assessments, including the differences in disease between females and males (Ludwig et al., 2015). Classes in gender medicine have been included in one Dutch medical school’s curricula since 2008, and this spurred a nationwide project to implement gender-based curricula in all medical schools (S. Morgan et al., 2013). The importance of gender medicine has also been acknowledged by governments in Sweden, Pakistan, the Philippines, Canada and Australia (S. Morgan et al., 2013); however, in Australia this acknowledgement does not appear to have filtered down into medical school curricula and course outlines.

Despite the findings of Yut-Lin (2009), assessment of medical students’ sex and gender knowledge at one US university indicated significant gaps in their sex- and gender-based curricula and expressed a need for gender-based medicine to be further embedded and expanded into the curriculum (Miller et al., 2012).

5.2.5.2 Clinical medicine textbooks do not appear to adequately account for sex and gender differences

For each included disease in our study, most textbooks described epidemiology as total numbers of males and females; however, in diseases with strong perceptions of a sex-based predominance, such as CHD, epidemiology was more likely to be sex-segregated. One textbook provided total prevalence and female-only prevalence, which allows for inference of male prevalence; however, this may also lead to a sex-specific diagnosis presumption and enhance sex- and gender-based preconceptions and ideologies. Otherwise, all other aspects of presentation, tests, treatment, and disease consequences were largely presented assuming females and males to be the same. This assumption is a fundamental flaw with medical textbooks, alongside other notable issues such as containing out-of-date information (Jeffrey et al., 2012).

Previous analysis of recommended medical textbooks also highlighted that a significant number of textbook conclusions are out of date or missing information from recently published studies (Jeffrey et al., 2012). Another study noted that medical textbooks omit evidence regarding the clinical frequency of disease manifestations (Richardson & Wilson, 2002). A previous review (1998) of select medical textbooks in Sweden determined that the male patient is presented as the norm and that gender stereotypes are perpetuated throughout the text and case examples (Alexanderson et al., 1998). Parker et al. (2017) conducted a sex/gender review of anatomy textbooks used by Australian medical schools, determining that imagery remains predominantly male-centred, and stereotyped roles such as the man in professional roles and the woman in domestic roles were reinforced. This study, however, did not find evidence of stereotyped images, perhaps reflecting progression of societal views on women, or perhaps a result of increased use of important test parameters such as ECGs and radiographs within clinical textbooks.

Studies have long demonstrated the use of the male body in medical and anatomy textbooks, with potential consequences of medical students viewing the male body as the ‘norm’ and additionally being less aware of female anatomy and less confident with female examinations (Giacomini et al., 1986; Mendelsohn et al., 1994). S. Morgan et al. (2013) examined 10 contemporary anatomy textbooks to determine if they are sex and gender neutral.

Most anatomy textbooks used male illustrations and images as the standard for both surface and internal anatomy, and images of female anatomy were mostly limited to the breasts and reproductive organs. Some of the images depicting female anatomy were old-fashioned and lacking detail in a slightly older edition of the textbook. One textbook that contained clinical cases favoured male examples as both doctor and patient; where female cases were provided, they were for conditions that are perceived to be associated with women, such as varicose veins and osteoporosis. Survey of medical student perceptions and attitudes to sexism demonstrated that a minority of students display overt sexism in the form of sexist remarks, or have witnessed overt sexism from senior clinicians, particularly related to anatomical sources (Morgan et al., 2013, 2017). However, while many students claimed to be sensitive to sex and gender, they simultaneously failed to associate sexism with the negative aspects of sexism within anatomy teaching materials (Morgan et al., 2013).

Dijkstra et al. (2008) examined sex- and gender-specific content of 11 recommended medical textbooks in Dutch medical schools, investigating the content of cardiology/internal medicine, psychiatry and pharmacology. In keeping with our findings, sex- and gender-specific information was lacking and there were few indications of sex and gender in the indices. Cardiology textbooks neglected specific mentions of women's health outside of single-line mentions. Psychiatry textbooks referred to the influence of hormonal fluctuations on depression, but otherwise sex- and gender-related information was also absent. Safe levels of alcohol consumption for men and women were mentioned by one textbook, and two textbooks briefly considered the higher vulnerability of women to alcohol. Pharmacology textbooks gave no sex- and gender-specific information but did discuss interactions between oral contraceptives and other medications. Pharmacology textbooks, in keeping with clinical medicine textbooks, do not make it clear that the evidence base is derived from research that has historically excluded women (Dijkstra et al., 2008).

Analysis of gender representation in psychiatry textbooks found that women were more likely to represent diseases that have higher female prevalence and men represent diseases with higher male prevalence. However, in diseases with equal or unknown prevalence, males were used in vignettes over females (Leo & Cartagena, 1999). Murciano-Goroff (2015) examined illustrations in general medical and general surgical textbooks, determining sex and gender subjectively on the basis of appearance of the faces, chests and genitals and concluding that medical and surgical textbooks may continue to under-represent females and advocating for more student exposure to female bodies.

5.2.5.3 Importance of sex and gender representation in medical textbooks

Epidemiological studies have emphasised the differences in disease incidence and prevalence between women and men, and patient advocacy groups have campaigned for acknowledgement of sex and gender differences in disease (Miller, 2014). Failure to acknowledge and educate future clinicians on sex and gender differences in medicine and inadequate representation of women and women's health can perpetuate sexist stereotypes and maintain ideology of the male as the 'norm' and the female as abnormal, or 'other'.

Neglecting sex- and gender-specific medicine in medical textbooks can have adverse effects on the knowledge base of medical students and subsequent adverse effects on women's health. There are numerous examples within the six diseases examined in this paper of differences between women and men in the epidemiology, presentation, management and outcomes of disease (Legato, 2009). Women have relatively higher morbidity, mortality and poorer prognosis following ischaemic cardiac events than men (Fairbairn et al., 2020). Studies have demonstrated that women present with different, 'atypical' symptoms of CHD, such as sharp pain, fatigue, shortness of breath and indigestion (Mehta et al., 2016). Descriptions in the textbooks of women's symptoms as 'atypical' compared with men's is exemplary of the androcentricity in medicine and medical research.

Heart failure with preserved ejection fraction (HFwPEF) is almost doubly common in women than men, and risk factors for this type of heart failure (hypertension and obesity) are more prevalent in women (Westerman & Wenger, 2016). HFwPEF is less responsive to standard heart failure medications than heart failure with reduced ejection fraction (HFwREF). Data demonstrate that women and men respond differently to angiotensin-converting enzyme inhibitors (ACE-inhibitors), a frequently used heart failure medication, with women less likely to experience benefit from the drug unless they are appreciably symptomatic (Westerman & Wenger, 2016). Additionally, women treated with digoxin for HFwREF had a higher death rate than women who took placebo; this was not observed in males in the trial (Westerman & Wenger, 2016; Yancy et al., 2013), nor is it mentioned in any of the clinical textbooks analysed in this study.

While IBS is twice as prevalent in women for those who seek healthcare, in the general population the difference is less marked, suggesting women are more likely to seek help for their IBS than men, rather than necessarily being more likely to suffer IBS in the first instance (Adeyemo et al., 2010; Lovell & Ford, 2012). The effect of the menstrual cycle on IBS was absent from the clinical textbooks that were analysed. Women report an increase in gastrointestinal symptoms around the time of menses compared with other stages of their cycle, commonly including loose stools, bloating and pain (Adeyemo et al., 2010). Female sex hormones are known to modulate gut motility and visceral pain (Meleine & Matricon, 2014). Studies have also demonstrated that IBS symptoms are inversely related to testosterone (Houghton et al., 2000), meaning that hormonal and sex-based differences may be important in IBS pathogenesis and treatment.

Female sex is of significant influence on post-operative morbidity and mortality following peptic ulcer perforation, with one study demonstrating women patients requiring more post-operative ventilator support and experiencing more renal failure than men (Sivaram

& Sreekumar, 2018). While symptoms, risk factors and management appear to be the same for females and males, the textbooks do not state the increased risk of female sex, particularly for older women, for both peptic ulcer disease and the life-threatening complication of perforation.

Chronic kidney disease is more common in women than men in high-income countries, regardless of age (Carrero et al., 2017), yet women are under-represented in CKD clinics (Carrero et al., 2017). Renal physiology differs between women and men. Female sex hormones affect the kidneys of women, increasing the synthesis of angiotensinogen but decreasing renin and angiotensin-converting enzyme synthesis, influencing blood pressure regulation (Cobo et al., 2016). Glomerular filtration rate (GFR) reference ranges may not be appropriate for women, yet all clinical textbooks assumed women and men to require the same tests and treatment for CKD. Estimated GFR (eGFR) calculations are based on serum creatinine measurements, which are influenced by muscle mass. In the general adult population, women tend to have lower muscle mass, leading to lower creatinine measurements. This could lead to inaccurate eGFR recordings and thus inappropriate treatment for women (Cobo et al., 2016).

Women who are obese are at greater risk of developing renal calculi than women with a healthy body mass index, and the risk is higher for younger women (Alshoabi et al., 2020). It is possible that different compositions of renal calculi are more prevalent by gender; for example, a recent study demonstrated that males are more likely to suffer uric acid stones, while females are more likely to suffer calcium and magnesium calculi (Shamsuddeen et al., 2013). These stones have different risk factors, which were not apparent in the textbooks.

5.2.6 Limitations

A limitation of this study is that the online content analysis constituted a desktop review of course outlines only and was restricted to information publicly available. We would recommend an in-depth analysis of medical school curricula from across Australia to further assess whether women’s health is omitted from medical school curricula outside of reproductive medicine. A second limitation is that six common diseases were selected as a representative sample to assess the presentation of women’s health. This sample was guided by previous cross-sectional analysis and deliberately focused on medical specialties with lower recruitment rates of women into clinical trials. However, the result of sampling might have biased the results, and it is possible that examination of other diseases would reveal more emphasis on women’s health simply because of better inclusion in clinical trials.

5.2.7 Conclusion

The important sex and gender differences in medicine are becoming increasingly known by researchers and clinicians, yet these are not reflected adequately in the medical school course outlines, curricula or clinical textbooks. This may have profound consequences on women’s health in terms of diagnosis, time to diagnosis, rates of misdiagnosis, and response to tests and treatment, thus widening the sex and gender gap in clinical medicine. No textbooks discussed the significant socioeconomic differences in women and the impacts this can have on women’s health. Clinical textbooks are a central recourse for medical students in Australia, and omission of important sex and gender differences is a stark oversight. We recommend further in-depth analysis of medical school curricula in Australia and an urgent review of translation of research into clinical textbooks and guidelines to ensure sex and gender equity in clinical care. Further, there is a need for *Australian Medical Council Standards for Assessment and Accreditation of Primary Medical Programs* to require that medical schools provide a course on women’s health outside of reproductive medicine. Enhancing awareness of sex and gender differences in medicine will enable physicians to treat males and females according to their differing medical presentations and needs rather than assumptions and perceptions.

5.3 Concluding comments

This chapter has ascertained that there appears to be a sex and gender gap in the standards of medical school curricula, course outlines and recommended core clinical textbooks in Australia. It is possible that this sex and gender gap is related to the observed sex and gender gaps in health research as research is used to provide the evidence base for both medical education and clinical practice. Chapter 6 seeks to explore the experiences of female patients in Australia, given the observed sex and gender gaps in health research and education.

Part Three: Exploring the Experiences of Australian Women with Chronic Conditions

Chapter 6: Experiences of Australian Women with Chronic Conditions

When I Am Dead, My Dearest

When I am dead, my dearest,
Sing no sad songs for me;
Plant thou no roses at my head,
Nor shady cypress tree:
Be the green grass above me
With showers and dewdrops wet;
And if thou wilt, remember,
And if thou wilt, forget.

I shall not see the shadows,
I shall not feel the rain;
I shall not hear the nightingale
Sing on, as if in pain:
And dreaming through the twilight
That doth not rise nor set,
Haply I may remember,
And haply may forget.

(Rossetti, 1848)

6.1 Introduction

Chronic conditions that are often termed ‘functional’, ‘medically unexplained’ or ‘psychogenic’ are difficult to diagnose and considered diagnoses of exclusion (Boulton, 2019; Institute of Medicine, 2015; Spiegal et al., 2010). These conditions typically are complex and have longer times to diagnosis as time must be taken to rule out other ‘organic’ conditions. Considering a condition to be a diagnosis of exclusion can, in itself, lengthen time to diagnosis and increase risk of misdiagnosis (Institute of Medicine, 2015). These long waiting times are perhaps multifactorial—a symptom of under-research in women’s health resulting in a lack of knowledge from health professionals regarding female disease presentation, or a symptom of systemic bias and misogyny, meaning women are more likely to be dismissed or told their symptoms are ‘in their head’ before a diagnosis is made (Johansson et al., 1996). The pathologising of ‘difficult’ women and femininity has a long history, particularly in psychiatry, dating back to Ancient Greece and popularised with Freudian accounts of hysteria in the 18th and 19th centuries (Freud & Breuer, 1895/1955; Ussher, 2013). The concept of female patients as ‘difficult’ has been termed a modern manifestation of the hysterical discourse (Merone et al., 2021).

This chapter presents two manuscripts exploring the experiences of females with chronic conditions in Australia. A survey was conducted to ascertain average time to diagnosis and proportions of re-diagnosis for women with chronic conditions. This was followed by a series of 20 semi-structured interviews, which gave Australian women with chronic conditions an opportunity to tell the stories of their experiences in the Australian healthcare system. While it is difficult to ascertain whether the experiences outlined in this chapter are related to the observed sex and gender gaps in medical research and education, this work does highlight that there are gaps in the healthcare of female patients in Australia that require considerable work to address.

6.2 Self-reported time to diagnosis and proportions of re-diagnosis in female patients with chronic conditions in Australia

6.2.1 Abstract

6.2.1.1 Background

The diagnosis of chronic conditions in women is complicated by the historical androcentricity in medical research. Sex and gender gaps in health research may translate to unequal healthcare for women. This cross-sectional survey study aims to ascertain the median time to diagnosis, proportions of re-diagnosis, and time to re-diagnosis for Australian women with chronic conditions.

6.2.1.2 Methods

This online survey collected anonymous data from voluntary participants. Data were analysed using Stata14. Cox proportional hazards models were used to analyse time to diagnosis and re-diagnosis. A logistic regression analysis was used to assess significance of re-diagnosis rates by diagnosis, age at diagnosis, income, employment, state of residence, disability status and Indigenous status.

6.2.1.3 Results

The median time from first appointment to initial diagnosis was 6 months (range 1 day – 50 years, IQR 3.74 years). The median time to re-diagnosis was 4 years (range 1 day – 43 years, IQR 9 years). Almost half of the women (n = 161/343, 47%) reported their primary condition being re-diagnosed. From the complete responses, 40% were re-diagnosed from one organic condition to another organic condition; however, 32% of women originally diagnosed with psychological, MUS or chronic pain were later re-diagnosed with organic conditions.

6.2.1.4 Conclusion

Median wait times for a diagnosis for women in Australia, when factoring in high proportions of re-diagnosis and time to re-diagnosis, are 4 years. It is important that clinicians

are aware of high re-diagnosis rates in female patients and understand the potential impact of systemic biases on the diagnostic process for women under their care.

6.2.2 Background

Diagnosis of disease in women is complicated by the androcentric history of medical research (Merone et al., 2021), and systemic and societal gender biases (Katz et al., 2010; Ussher, 2013). Previously, women's health has been under-researched, and results obtained from studies of male bodies have been assumed to apply to females (Dresser, 1992; Sex and Gender Sensitive Research Call to Action Group et al., 2020). Assuming females and males to be the same is flawed, and studies have demonstrated physiological (Barajas-Martínez et al., 2021), hormonal (Marrocco, 2016; Ortona et al., 2019), microbiotal (Vemuri et al., 2018) and socioeconomic differences (Backholer et al., 2017) that affect women's health, symptoms (Gijsbers van Wijk & Kolk, 1997), test results and responses to treatment (Merone, Tsey, Russell, & Nagle, 2022b). Despite this, many studies continue not recruiting enough women (Merone, Tsey, Russell, & Nagle, in press) and many more studies do not analyse their results by sex and/or gender (Merone et al., 2021b).

A recent cross-sectional analysis demonstrated that while across all clinical research in Australia, female participation was 55%, when analysed by medical specialty, certain specialty areas over- and under-represented women (Merone, Tsey, Russell, & Nagle, in press). Perception of disease, rather than actual sex prevalence, may drive representation of women in medical research (Feldman et al., 2019). If this is the case, it could become a self-fulfilling prophecy, whereby under-diagnosis of some conditions in women enhances the perception of those conditions as male dominated, leading to lower recruitment of women into clinical trials pertaining to that condition.

Conditions with female predominance such as fibromyalgia (Arout et al., 2018); myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) (Faro et al., 2016);

autoimmune conditions, for example, systemic and cutaneous lupus erythematosus (collectively referred to from herein as lupus) and rheumatoid arthritis (RA) (Sohn, 2021); postural orthostatic tachycardia syndrome (POTS) (Shaw et al., 2019); vulvodynia; and endometriosis receive less research funding than diseases such as heart disease, cancers, dementia and—more recently—coronaviruses (NIH, 2021). Lack of funding has ongoing impacts on clinical knowledge regarding pathophysiology, presentation, treatment options and responses to treatments, which may significantly affect women's health (Institute of Medicine (US) Committee on Health Research and the Privacy of Health Information, 2009). Additionally, several of these female-dominated conditions are considered diagnoses of exclusion when all radiology and laboratory results are normal or non-specific (Fred, 2013). These conditions may be termed as 'psychogenic', 'medically unexplained symptoms' (MUS), or 'functional' (Tack, 2019). The reality of these conditions may well be that owing to limited research funding, we simply do not yet know the pathogenesis, rather than the conditions being largely or entirely psychological in origin. Gender biases may also enhance the appearance of some conditions as being female-dominated; Katz et al. (2010) surveyed American rheumatologists and uncovered a gender bias in the diagnosis of fibromyalgia, with physicians being more likely to seek a more accepted organic disease in male patients (Katz et al., 2010).

Studies have shown that sex and gender differences are also largely excluded from medical education materials such as clinical and anatomical textbooks and medical school course outlines and curricula (Dijkstra et al., 2008; Martin et al., 2016; Merone, Tsey, Russell, & Nagle, 2022b; Miller et al., 2013; Parker et al., 2017). A previous review of sex/gender representation in anatomy textbooks determined that imagery remains male-centred (Parker et al., 2017). Consequently, students may come to view the male body as the norm, and the female body as 'abnormal'. Additionally, students may become less confident with female anatomy and examinations (Giacomini et al., 1986; Mendelsohn et al., 1994). Descriptions of women's symptoms as ‘atypical’ compared with those of men exemplifies androcentricity in medicine and research (Merone et al., 2022).

The sex and gender gaps in research and education may translate into real-life impacts and unequal healthcare for women. There are notable sex and gender differences in acute care; women wait longer in the emergency department for a diagnosis (Robertson, 2014) and for adequate analgesia (Chen et al., 2008). A large study outside of Australia noted that women wait longer than men for a diagnosis (Westergaard et al., 2019). Internationally, women are noted to frequently be misdiagnosed and then later re-diagnosed (Krassen Covan, 2022). The average time to diagnosis and rates of re-diagnosis are not yet documented for Australia, and most studies pertain to individual specific conditions rather than general chronic conditions. This study aimed to ascertain the median time from presentation to initial diagnosis, the proportion of women who were re-diagnosed, the median time to re-diagnosis, and the impact of socioeconomic factors on time to diagnosis and re-diagnosis.

6.2.3 Methods

A cross-sectional survey of Australian women was conducted online, hosted on the survey software *Qualtrics*. The survey was devised using guidelines from Kelly and Gurr (2020), Valerie and Ritter (2012), and Letherby (2003). All data collected were anonymous. Adults aged 18 years and older who were born and reside in Australia were included. Participants unable to understand and respond to written English were not included. Inclusion and exclusion criteria are outlined in Table 6.1. The following data were collected: initial diagnosis, age at initial diagnosis, re-diagnosis, time to re-diagnosis, income, employment, state/territory of residence, Indigenous status, disability status, current age, and secondary diagnoses. A summary of the data collection tool is provided in Box 1.

Box 1: Summarised data collection tool

Age (years)

Indigenous status

State/Territory of current residence

Name of closest town/city

Employment status

Household Income bracket (AUD) per week (after tax)

Disability status/identity

First diagnosis (the one that was diagnosed chronologically first)

Specialist who cares for first diagnosis (e.g cardiologist).

Number of other diagnoses

List of other diagnoses

Age at first diagnosis

Time from first presentation with symptoms to first diagnosis

Has the first condition been re-diagnosed?

Number of times the diagnosis changed

Time from first diagnosis to re-diagnosis

Name of re-diagnosed condition

Initial or primary diagnosis was defined as the first diagnosis that an individual received, and re-diagnosis was defined as the ultimate diagnosis a condition was given, noting that some individuals had their condition re-diagnosed multiple times before an ultimate diagnosis (at the time of survey) was received. Secondary diagnoses were defined as any separate diagnoses received after and alongside the initial diagnosis.

Table 6.1

Inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
- Adults aged 18 years and older	- Participants unable to understand written English
- Australian citizen (born and residing in Australia)	
- Initial diagnosis received aged 18 years or older	

6.2.3.1 Data collection

Participants were recruited by convenience sampling via social media (Twitter and Facebook). The study was advertised using relevant hashtags and notices in relevant Australian support groups of chronic conditions, including but not limited to chronic pain, endometriosis, lupus, mast cell activation syndrome, epilepsy, asthma, cancer, ME/CFS, fibromyalgia, depression, anxiety, Ehlers–Danlos syndrome (EDS), POTS, and disability. Prior to completing the survey, participants were informed via the information leaflet that the topics discussed were sensitive and may cause some distress, and subsequently that they may withdraw at any point until their survey is submitted. Ethics approval was obtained, and all participants provided consent.

6.2.3.2 Data analysis

The primary outcomes were the self-reported diagnosis, and time to primary diagnosis and re-diagnosis, and proportions thereof, in participants with one or more chronic conditions. The secondary outcomes were the associations of the primary outcomes with diagnosis, age at diagnosis, income, employment, disability status and Indigenous status.

Data were analysed using Microsoft Excel and the statistical software package Stata14. Descriptive statistics were used to summarise the data. To analyse time to event (diagnosis and re-diagnosis) and association of any variables (diagnosis, age, income, employment, state/territory of residence, Indigenous status and disability status), the Cox proportional hazards model (Cox & Oakes, 1984) was used. Logistic regression analysis was used to assess significance of re-diagnosis rates by diagnosis, age at diagnosis, income, employment, state of residence, disability status and Indigenous status. Diagnoses were analysed specifically if more than five people received the same label; if fewer than five people were diagnosed with a condition, these were grouped by medical specialty.

Conditions that were very rare or unable to be categorised (e.g. a symptom rather than a diagnosis given) were grouped together as ‘unclear’ or ‘rare’. As the diagnosis with the most definitive tests of all the common chronic conditions diagnosed in this sample, type 2 diabetes mellitus (T2DM) was selected as the reference group. Diagnoses were then grouped by the researchers into two categories: medical conditions that are traditionally considered to be ‘organic’, such as heart disease, diabetes and autoimmune disease, and medical conditions that are traditionally considered to be psychological/psychosomatic, MUS or idiopathic chronic pain, such as ME/CFS, fibromyalgia, chronic regional pain syndrome and mental illnesses. Researchers then assessed the proportion of ‘organic’ diagnoses that were re-diagnosed to MUS diagnoses and vice versa.

Regarding the question of re-diagnosis, the survey contained three response options: ‘yes the condition was re-diagnosed’, ‘no the condition was not re-diagnosed’ and ‘unsure’. Those unsure about their re-diagnosis status were categorised as ‘no’ for the purpose of this analysis, with the rationale that there was no definitive re-diagnosis timeline, and if an individual’s condition had been fully re-diagnosed, it was assumed the individual would be aware.

6.2.4 Results

There was a total of 467 responses. The demographic details of participants are summarised in Table 6.2.

Table 6.2

Participants' demographic characteristics

Demographic characteristics	Number of participants (%)
Indigenous Status	
Aboriginal	15 (3%)
Torres Strait Islander	2 (0.4%)
Aboriginal and Torres Strait Islander	2 (0.4%)
Non-Indigenous	435 (93%)
Not stated	13 (2%)
State/Territory of residence	
Australian Capital Territory	20 (4%)
New South Wales	120 (26%)
South Australia	37 (8%)
Queensland	96 (21%)
Northern Territory	9 (2%)
Tasmania	19 (4%)
West Australia	25 (5%)
Victoria	139 (30%)
Not stated	2 (0.4%)
Employment status	
Disability support or pension	82 (18%)
Full-time employed	196 (42%)
Part-time employed	2 (0.4%)
Self-employed	41 (9%)
Unemployed	31 (7%)
Temporary employment	10 (2%)
Retired	27 (6%)
Full-time carer	7 (1%)
Student	16 (3%)
Other	50 (11%)
Not stated	5 (1%)
Current age range (years)	
18–25	13 (3%)
26–35	104 (22%)
36–45	121 (26%)
46–55	129 (28%)
56–65	72 (15%)
66–75	18 (4%)
76+	3 (0.6%)
Not stated	7 (1%)
Household weekly income after tax (AUD)	
0–743	145 (31%)
744–1431	121 (26%)
1432–2433	104 (22%)
2434+	87 (19%)
Not stated	10 (2%)
Disability status	
Disabled	182 (39%)

Demographic characteristics	Number of participants (%)
Not disabled	186 (40%)
Unsure	97 (21%)
Not stated	2 (0.4%)
Age range at initial diagnosis (years)	
18–25	142 (30%)
26–35	97 (21%)
36–45	62 (13%)
46–55	36 (8%)
56–65	8 (2%)
66–75	1 (0.2%)
76+	0 (0%)
Not stated	121 (26%)

6.2.4.1 Diagnoses

Initial diagnoses were extremely varied and included common conditions, such as asthma, T2DM, cardiac conditions, arthritis and mental illnesses, and some very rare conditions, such as VACTERL syndrome (vertebral defects, anal atresia, cardiac defects, tracheo-esophageal fistula, renal anomalies and limb abnormalities), narcolepsy, Scheuermann's disease and hidradenitis suppurativa. Eleven diagnoses were unclear or listed as symptoms, rather than a diagnosis. The most common 12 conditions reported as an initial diagnosis are presented in Table 6.3. These 12 diagnoses made up 168 (52%) of 325 responses to this question. The remaining conditions were grouped by specialty, using classifications in the ICD-10 (World Health Organization, 2016), for analysis (Table 6.4).

Table 6.3

Most common initial diagnoses

Initial diagnosis	Number of participants reporting (% of total, n = 325)
Endometriosis/Adenomyosis	29 (9%)
Fibromyalgia	27 (8%)
Myalgic encephalomyelitis/Chronic fatigue syndrome (ME/CFS)	24 (7%)
Systemic lupus (SLE)/Cutaneous lupus/Mixed connective tissue disease (MCTD)	18 (5%)
Autoimmune arthritis including rheumatoid arthritis (RA) and psoriatic arthritis	12 (4%)
Depression	11 (4%)
Postural orthostatic tachycardia syndrome (POTS)	10 (3%)
Chronic pain	9 (3%)
Anxiety	9 (3%)
Irritable bowel syndrome (IBS)	9 (3%)
Chronic tonsillitis	5 (2%)
Type 2 diabetes mellitus	5 (2%)

Table 6.4

Grouped conditions

Diagnosis (grouped by specialty)	Number of participants reporting (% of total, n = 325)
Musculoskeletal (MSK) conditions	29 (9%)
Neurological conditions	18 (5%)
Cardiac conditions	14 (4%)
Unclear	12 (3%)
Psychiatric conditions	11 (3%)
Gastrological conditions	10 (3%)
Thyroid conditions	9 (3%)
Gynaecological conditions	9 (3%)
Haematological conditions	8 (2%)
Respiratory conditions	8 (2%)
Dermatological conditions	8 (2%)
Infective/viral conditions	5 (2%)
Endocrine conditions	4 (1%)
Cancers	4 (1%)
Renal conditions	4 (1%)
Rare conditions	4 (1%)

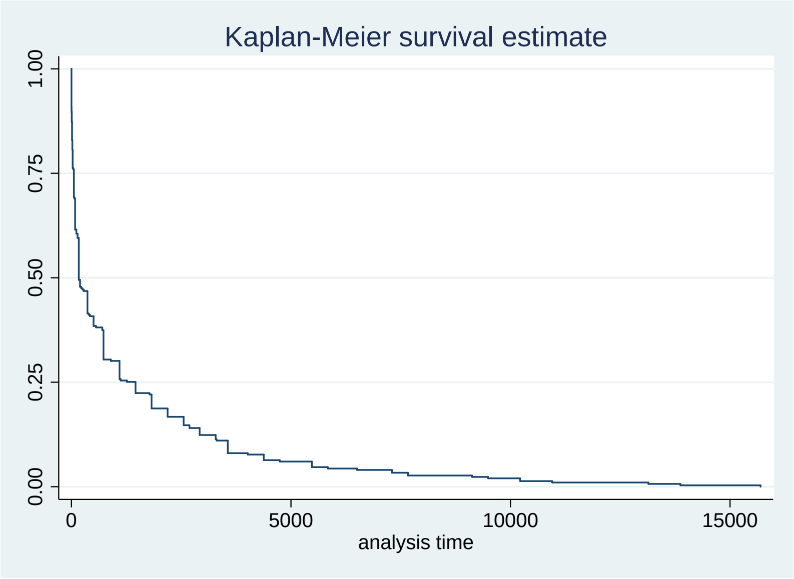
The median number of secondary diagnoses (in addition to the initial diagnosis) was three (IQR 3, range 0–20). Secondary diagnoses were wide-ranging and included EDS, lupus, mental illness, mast cell activation syndrome, fibromyalgia, ME/CFS, endometriosis, osteopenia, IBS, inflammatory bowel disease and cancers.

6.2.4.2 Time to initial diagnosis

The median and modal for time from first appointment to initial diagnosis was 6 months (range 1 day – 50 years, IQR 3.74 years). Kaplan-Meier survival analysis demonstrated 25% of participants received an initial diagnosis within 56 days (2 months), 50% by 168 days (6 months) and 75% by 1,460 days (4 years) (Figure 6.1).

Figure 6.1

Kaplan–Meier survival estimate for event: Time from presentation to a doctor with symptoms to initial diagnosis of the condition



Initial diagnoses that significantly delayed time to diagnosis were anxiety, IBS, autoimmune arthritis, ME/CFS, migraine, endometriosis, fibromyalgia, chronic pain syndromes, lupus/MCTD, POTS, mental illness (category), cancers, neurological conditions, gastrological conditions, musculoskeletal conditions, thyroid conditions, gynaecological conditions and cardiovascular conditions (Table 6.5). No initial diagnoses significantly shortened time to diagnosis. The only demographics to significantly affect the time to initial diagnosis were age bracket 36–45 years, which lengthened this time (coef. −0.4228682, *p* = 0.05), and being on disability support pension or equivalent, which shortened the time (coef. 0.4835686, *p* = 0.05). These results are summarised in the supplementary material.

Table 6.5

Diagnoses that significantly delayed time to diagnosis

Diagnosis	Coefficient	Std. Err.	z	*p*>z	95% CI
Anxiety	–1.340	0.614	–2.18	**0.029**	–2.544, –0.137
IBS	–2.711	0.625	–4.33	**0.000**	–3.937, –1.485
Autoimmune arthritis	–1.949	0.559	–3.49	**0.000**	–3.045, –0.854
ME/CFS	–2.797	0.526	–5.32	**0.000**	–3.828, –1.766
Migraine	–2.039	0.589	–3.46	**0.001**	–3.192, –0.885
Endometriosis	–3.126	0.536	–5.83	**0.000**	–4.177, –2.076
Fibromyalgia	–2.720	0.520	–5.23	**0.000**	–3.739, –1.701
Chronic pain	–2.444	0.629	–3.88	**0.000**	–3.677, –1.211
Lupus/MCTD	–2.273	0.535	–4.25	**0.000**	–3.321, –1.225
POTS	–2.619	0.640	–4.09	**0.000**	–3.874, –1.363
Mental illness	–2.402	0.726	–3.31	**0.001**	–3.825, –0.978
Cancers	–3.192	0.287	–2.48	**0.013**	–5.714, –0.669
Neurological	–2.370	0.564	–4.20	**0.000**	–3.476, –1.265
Gastrological	–2.354	0.613	–3.84	**0.000**	–3.555, –1.153
MSK	–2.311	0.553	–4.18	**0.000**	–3.394, –1.228
Thyroid	–2.036	0.630	–3.23	**0.001**	–3.271, –0.801
Gynaecological	–2.449	0.587	–4.17	**0.000**	–3.600, –1.297
Miscellaneous	–2.021	0.567	–3.57	**0.000**	–3.132, –0.910
Infective/Viral	–1.664	0.663	–2.51	**0.012**	–2.964, –0.364
Cardiology	–2.041	0.668	–3.06	**0.002**	–3.351, –0.732

6.2.4.3 Re-diagnosis rate

Almost half of the women (n = 161/343, 47%) reported their primary condition being re-diagnosed (Table 6.6); a further 36 women were unsure if their condition had been re-diagnosed or not (10%). Of those 161 women who had their primary condition re-diagnosed, 58 (36%) women stated this had happened three or more times. Re-diagnosis rates are presented in the supplementary material.

Table 6.6

Re-diagnosis rates of participants with chronic conditions

Variable	Proportion	Standard error	95% CI
Re-diagnosed	0.47	0.269	0.417, 0.5226
Not re-diagnosed	0.42	0.267	0.374, 0.479
Unsure	0.11	0.166	0.076, 0.142

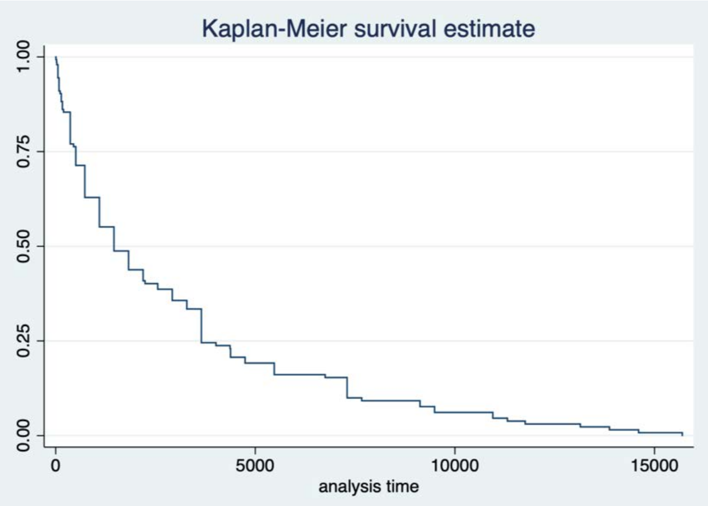
Diagnosis, age at diagnosis, income, employment, state/territory of residence, disability status and Indigenous status had no effect on rates of re-diagnosis; however, residing in Tasmania was approaching significance (coef. −1.67147, p = 0.06) (see the supplementary material).

6.2.4.4 Time to re-diagnosis

The median time to re-diagnosis was 4 years (IQR 9), with a modal value of 1 year (range 1 day – 43 years). Survival analysis demonstrated 25% of participants received a re-diagnosis within 504 days (18 months), 50% within 1,460 days (4 years) and 75% by 3,650 days (10 years) (Figure 6.2).

Figure 6.2

Kaplan–Meier survival estimate for event: Time to re-diagnosis



Of the 128 respondents who gave complete responses including their original diagnosis and their re-diagnosis, 40% (n = 51) were re-diagnosed from one organic condition to another organic condition; however, 32% of women originally diagnosed with psychological, MUS or chronic pain were later re-diagnosed with organic conditions (Table 6.7). Diagnosis, age at diagnosis, income, employment, state/territory of residence and disability status had no significant effect on time to re-diagnosis; however, identifying as Torres Strait Islander was significantly associated with shorter time to re-diagnosis (supplementary material), although this is based on a sample of two participants.

Table 6.7

Re-diagnoses in women with chronic conditions in Australia

Primary diagnosis group	Re-diagnosis group	Number (%) n = 128
Psychological, MUS or chronic pain condition	Organic condition	41 (32)
Organic condition	Psychological, MUS or chronic pain condition	17 (13)
Psychological, MUS or chronic pain condition	Another psychological, MUS or chronic pain condition	19 (15)
Organic condition	Another organic condition	51 (40)

6.2.5 Discussion

Participants typically obtained an initial diagnosis within 6 months; however, 47% of women reported re-diagnosis and a median period of 4 years between initial diagnosis and re-diagnosis, indicating women are potentially waiting a long time for adequate treatment and risk progression of their condition. Additionally, there are potential risks associated with receiving treatment for an incorrect initial diagnosis.

6.2.5.1 Australian women with chronic disease participating in an online survey receive an initial diagnosis within 6 months

Our study determined a median diagnostic time of 6 months for women with chronic conditions in Australia; however, this ranged between 1 day and 50 years, and was accompanied by a high rate of re-diagnoses, suggesting misdiagnosis of the initial condition. It is unclear why the 35–46-year age group at diagnosis was significantly associated with shorter time to diagnosis. It is difficult to assess if 6 months is a lengthy duration to diagnosis as there are no comparative data on male times to diagnosis. A UK study defined a delay in cervical cancer diagnosis as a duration longer than 3 months from first presentation with symptoms to diagnosis (Lim et al., 2014). Lim et al. (2014) observed a delayed diagnosis in 60% of symptomatic women. Another study noted delays in diagnoses for female patients with cystic fibrosis; compared with males, females experienced a 4-month delay in diagnosis in a large study of 11,275 cystic fibrosis patients (Lai et al., 2002). Conversely, cross-sectional analysis of 7,101 individuals with diabetes in Canada determined that proportionally more males are diagnosed late than females (Roche & Peizhong, 2014).

6.2.5.2 Almost half of Australian women with chronic disease participating in an online survey have their initial condition re-diagnosed at least once

This study ascertained that almost half of female patients with chronic disease are re-diagnosed for at least one occasion. This is in keeping with findings from other studies. Focus groups with fibromyalgia patients report a long and stressful journey to diagnosis with high misdiagnosis rates (Arnold et al., 2008). The 2012 National Health Interview Survey estimated, using surrogate markers, that fibromyalgia is misdiagnosed in about three-quarters of respondents (Walitt et al., 2016). According to the Lupus Foundation of America, a lupus (encompassing four different types of lupus: systemic, cutaneous, drug-induced and neonatal) diagnosis takes on average almost 6 years from first developing symptoms, with a high misdiagnosis or re-diagnosis rate and an average of four different healthcare providers (Lupus Foundation of America, 2016). This was supported by a 2018 UK survey of lupus patients, demonstrating an average time to diagnosis of 6.4 years, with 47% initially being misdiagnosed.

Our findings of high re-diagnosis rates are in keeping with Geraghty & Blease (2019), who found that 40% of referrals to one ME/CFS clinic were eventually diagnosed with another chronic or psychiatric illness. This narrative review of the literature also determined that patients with ME/CFS report frequent misdiagnosis of their condition, possibly related to guidelines that recommend against over-investigation of ME/CFS patients as a drain on resources, leading to under-diagnosis (Geraghty & Blease, 2019). Review of 418 referrals to a specialist ME/CFS clinic revealed a 37% rejection rate owing to inappropriate referral, and of those, 61% had a likely alternative diagnosis (Geraghty & Blease, 2019).

6.2.5.3 Australian women participating in an online survey experience on average a 4-year wait for re-diagnosis of their chronic condition

The median time to re-diagnosis was 4 years. These findings are in keeping with the current literature. A large 2019 population study at the University of Copenhagen demonstrated that men are diagnosed with chronic conditions at comparatively younger ages than women, and that women on average waited 2–5 years longer than men to obtain a diagnosis (Westergaard et al., 2019). Rare or chronic conditions take on average 7.6 years to diagnose across both women and men in the US, and 5.6 years in the UK, with patients visiting an average of eight physicians and receiving two to three misdiagnoses (Shire, 2013). There are however some areas that appear to have improved in this regard. A 2015 Danish study of autoimmune arthritis demonstrated a significant but decreasing time from presentation to diagnosis from 29–66 months in the year 2000 to 3–4 months by 2011 (Sorensen & Hetland, 2015). The discrepancy in diagnostic waiting times extends across all medical specialties, even to oncology, where even with higher cancer screening rates (Okten et al., 2018), women have longer diagnostic intervals for several cancers, including, but not limited to, bladder, colorectal, gastric, head and neck, lung, and lymphoma (Din et al., 2015; Lyratzopoulos et al., 2013; Sarasqueta et al., 2020).

Our findings of a lengthy time to a final diagnosis in women are possibly a sign of a sex and gender gap in medical care. Studies exploring specific chronic conditions have demonstrated that there is potentially a sex and gender difference in the time from presentation to a doctor with symptoms to receiving diagnosis. Hudson et al. (2009) assessed the wait time in Canada between onset of Reynaud’s phenomenon and the diagnosis of systemic sclerosis and diffuse cutaneous systemic sclerosis in female and male patients, determining that women’s wait was significantly longer than that of men; however, following other manifestations of illness, this wait time decreased to insignificance (Hudson et al., 2009). This suggests support for the Yentl syndrome; a woman must prove herself at least as sick, if not more sick, than a male counterpart to receive diagnosis and treatment (Merz, 2011).

The findings of this study suggest that women with female or female-dominated conditions experience a lengthy time to final diagnosis. In keeping with this, a 1996 study from the US and UK demonstrated a diagnostic delay from presentation with symptoms to diagnosis of endometriosis to be an average of 11.73 and 7.96 years, respectively (Hadfield et al., 1996). Recent reports state that although this time is decreasing, the average wait time for diagnosis of this painful gynaecological condition is still between 4 and 11 years (Agrawal et al., 2019; Soliman et al., 2017). Similarly, despite lupus being a condition that predominantly affects females, a UK survey study reported a longer time to diagnosis in women than men (6.9 years versus 4.5 years, respectively) (C. Morgan et al., 2018). Women’s protracted diagnostic journey for lupus also frequently included doctors diagnosing their symptoms as medically unexplained or psychosomatic (C. Morgan et al., 2018).

It is unclear why there is a lengthy duration between presentation, diagnosis and subsequent re-diagnosis in this study. Other studies have suggested that diagnostic delays may be, in part, due to patient anxiety and avoidance of medical appointments. A 2010 survey demonstrated that 38% of patients were afraid of their doctor not taking their symptoms seriously, thus delaying diagnosis (Choy et al., 2010). Despite observation of diagnostic delays in female-predominant conditions, surprisingly little work has been done to quantify this delay against male diagnostic times. This should be an area of further research to better understand the sex and gender gaps in medicine and improve women's health.

6.2.5.4 Re-diagnosis of chronic conditions in Australian women participating in an online survey most commonly follows the patterns of organic-organic and psychogenic-organic

This study found that a third of women who were re-diagnosed were originally given a psychological or MUS diagnosis that was later re-diagnosed as an organic illness. These findings perhaps signal a propensity to first diagnose women with psychological conditions before seeking the organic cause and have been observed in other studies. Utilising a sample of 23 women recruited from online patient forums, Mendelson (2009) determined most women had experienced dismissal of their symptoms and refusal to refer them for further investigation, leading to misdiagnoses of lupus as medically unexplained, psychological or fibromyalgia. Assessment of 50 patients with an MS diagnoses noted a misdiagnosis rate of 58%, with women particularly likely to have their symptoms initially misattributed to psychiatric conditions or MUS and men more likely to be offered referral for orthopaedic assessment (Levin et al., 2003). A retrospective survey of 107 patients with paroxysmal supraventricular tachycardia demonstrated that symptoms are unrecognised after initial medical examination in 55% of patients and that women were more likely than men to have their symptoms attributed to psychological causes such as panic and anxiety disorders (65% versus 32%, respectively) (Lessmeier et al., 1997). POTS is another chronic condition more prevalent in women than men, often associated with other disorders with orthostatic intolerance such as dysautonomia or EDS. POTS is especially common in younger women, and it is frequently undiagnosed or misdiagnosed as anxiety for several years before correct diagnosis (Kesserwani, 2020).

6.2.6 Limitations

Surveys have several limitations, including participant interpretation of the questions, inflexibility in answering questions and recall bias. Further, this survey focused on obtaining median times to diagnosis, rates of re-diagnosis and time to re-diagnosis, meaning there is potentially a lack of depth surrounding the process in-between initial and final diagnosis. Also, surveys potentially contain skewed data; the cohort of women who volunteered for this study may be those who have had the most positive or the most adverse experiences within the medical system. Consequently, the participants may not be representative of the population of women with chronic conditions in Australia. Additionally, although the sample size exceeded statistical power calculations, it is still small, and this must be recognised when considering the results presented. Whilst this study contains results useful for women's health, we would recommend further study to ascertain if times to diagnosis and rates of re-diagnosis are similar in men.

6.2.7 Conclusion

Median wait times for a diagnosis for women in Australia, when factoring in high rates of re-diagnosis and time to re-diagnosis, are 4 years. The literature suggests women wait longer for a diagnosis compared with men, even for female-predominant conditions. Almost half of the women in this survey reported their condition being re-diagnosed, and 32% of these women were first diagnosed with an MUS condition before being re-diagnosed with an organic condition. In Australia, there has been no comparative work with male participants; therefore, it is difficult to confirm a sex-based discrepancy and further research is required. It is important that clinicians are aware of high re-diagnosis rates in female patients and understand the potential impact of systemic biases on the diagnostic process for women under their care.

6.2.8 Supplementary data

Supplementary Table 6.1

Cox proportional hazards model: Time to diagnosis by initial diagnosis, age, income, employment status, state/territory, Indigenous status and disability status

Diagnosis	Coefficient	Std. Err.	z	*p*>z	95% CI
Type 1 diabetes	1	1	1	1	1
Anxiety	–1.340147	0.6140401	–2.18	**0.029**	–2.543643, –0.1366505
IBS	–2.710938	0.6254887	–4.33	**0.000**	–3.936874, –1.485003
Tonsillitis	–1.237265	0.8739107	–1.42	0.157	–2.950098, 0.4755688
Autoimmune arthritis	–1.949613	0.5591079	–3.49	**0.000**	–3.045444, –0.8537811
ME/CFS	–2.797071	0.5261669	–5.32	**0.000**	–3.828339, –1.765803
Migraine	–2.038876	0.5885391	–3.46	**0.001**	–3.192392, –0.885361
Endometriosis	–3.126426	0.5360605	–5.83	**0.000**	–4.177085, –2.075766
Fibromyalgia	–2.719947	0.5200291	–5.23	**0.000**	–3.739185, –1.700708
Depression	–0.4099745	0.5815703	–0.70	0.481	–1.549831, 0.7298823
Chronic pain	–2.444011	0.6291124	–3.88	**0.000**	–3.677049, –1.210973
Lupus/MCTD	–2.273381	0.5347509	–4.25	**0.000**	–3.321474, –1.225289
POTS	–2.618538	0.6403519	–4.09	**0.000**	–3.873604, –1.363471
Mental illness	–2.401615	0.7263045	–3.31	**0.001**	–3.825146, –0.9780843
Cancers	–3.19151	0.287232	–2.48	**0.013**	–5.714428, –0.668572
Neurological	–2.370281	0.5639784	–4.20	**0.000**	–3.475658, –1.264903
Gastrological	–2.353943	0.6127873	–3.84	**0.000**	–3.554984, –1.152901
Endocrine	–1.122071	0.6321984	–1.77	0.076	–2.361157, 0.1170155
MSK	–2.311001	0.5525364	–4.18	**0.000**	–3.393952, –1.22805
Thyroid	–2.035923	0.630024	–3.23	**0.001**	–3.270747, –0.8010983
Gynaecological	–2.448559	0.5873454	–4.17	**0.000**	–3.599735, –1.297383
Renal	–1.100082	0.9301448	–1.18	0.237	–2.923132, 0.7229683
Haematological	0.1378137	0.7231473	0.19	0.849	–1.279529, 1.555156
Miscellaneous	–2.020981	0.5668083	–3.57	**0.000**	–3.131905, –0.9100569
Infective/viral	–1.66402	0.6631686	–2.51	**0.012**	–2.963807, –0.3642332
Respiratory	–0.9536113	0.6503845	–1.47	0.143	–2.228342, 0.321119
Cardiology	–2.041281	0.6679847	–3.06	**0.002**	–3.350507, –0.7320549
Age (years) at diagnosis					
18–25	1	1	1	1	1
26–35	–0.1142207	0.1788798	–0.64	0.523	–0.4648187, 0.2363772
36–45	–0.4228682	0.219011	–1.93	0.054	–0.852122, 0.0063855
46–55	0.3728048	0.2982437	1.25	0.211	–0.2117421, 0.9573518
56–65	–0.3196987	0.4991788	–0.64	0.522	–1.298071, 0.6586738

Diagnosis	Coefficient	Std. Err.	z	*p*>z	95% CI
Weekly household income (AUD)					
0–743	1	1	1	1	1
744–1431	0.0109972	0.2036187	0.05	0.957	–0.388088, 0.4100825
1432–2433	0.1497865	0.214515	0.70	0.485	–0.2706551, 0.5702281
2434+	0.0250699	0.2293314	0.11	0.913	–0.4244113, 0.4745511
Employment					
Employed	1	1	1	1	1
Disability	0.4835686	0.2441818	1.98	**0.048**	0.0049809, 0.9621562
Temporary	0.4095042	0.525388	0.78	0.436	–0.6202373, 1.439246
Self	–0.353397	0.2675661	–1.32	0.187	–0.8778169, 0.171023
Other	0.3041039	0.1817845	1.67	0.094	–0.0521873, 0.660395
State/Territory of residence					
NSW	1	1	1	1	1
Victoria	0.0102873	0.2005402	0.05	0.959	–0.3827643, 0.4033388
Queensland	–0.1195511	0.2196371	–0.54	0.586	–0.5500319, 0.3109297
NT	–0.1059509	0.5227762	–0.20	0.839	–1.130573, 0.9186716
South Australia	0.057449	0.2895484	0.20	0.843	–0.5100555, 0.6249534
West Australia	–0.4017	0.3604845	–1.11	0.265	–1.108327, 0.3047467
ACT	0.2183389	0.3891928	0.56	0.575	–0.5444649, 0.9811428
Tasmania	–0.2702374	0.3914314	–0.69	0.490	–1.037429, 0.4969541
Indigenous status					
Non-Indigenous	1	1	1	1	1
Aboriginal	–0.1313299	0.4380412	–0.30	0.764	–0.9898749, 0.7272151
Aboriginal & Torres Strait Islander	–0.8139712	1.206539	–0.67	0.500	–3.178745, 1.550803
Torres Strait Islander	–1.113063	0.8051271	–1.38	0.167	–2.691083, 0.4649574
Disability status					
Disabled	1	1	1	1	1
Unsure	0.2723727	0.1981068	1.37	0.169	–0.1159096, 0.660655
Not disabled	0.1559574	0.2168983	0.72	0.472	–0.2691555, 0.5810703

Note. NSW = New South Wales; NT = Northern Territory; ACT = Australian Capital Territory.

Supplementary Table 6.2

Logistic regression: Re-diagnosis rates by initial diagnosis, age, income, employment, state/territory of residence, Indigenous status and disability status

Diagnosis	Coefficient	Std. Err.	z	*p*>z	95% CI
Type 1 diabetes	1	1	1	1	1
Anxiety	–0.1340442	1.252375	–0.11	0.915	–2.588655, 2.320566
IBS	0.3510873	1.257043	0.28	0.780	–2.112672, 2.814847

Diagnosis	Coefficient	Std. Err.	z	*p*>z	95% CI
Autoimmune arthritis	–0.0765181	1.197868	–0.06	0.949	–2.424297, 2.27126
ME/CFS	0.0476521	1.118327	0.04	0.966	–2.144228, 2.239532
Migraine	1.637125	1.318946	1.24	0.215	–0.9479622, 4.222213
Endometriosis	0.2491382	1.110753	0.22	0.823	–1.927897, 2.426174
Fibromyalgia	–0.5431109	1.121382	–0.48	0.628	–2.740979, 1.654758
Depression	0.231708	1.204774	0.19	0.847	–2.129605, 2.593021
Chronic pain	1.917214	1.355919	1.41	0.157	–0.7403392, 4.574767
Lupus/MCTD	–0.2443922	1.14936	–0.21	0.832	–2.497096, 2.008312
POTS	2.469421	1.507637	1.64	0.101	–0.485493, 5.424334
Mental illness	0.6168758	1.302256	0.47	0.636	–1.935499, 3.169251
Cancers	1.535003	2.03915	0.75	0.452	–2.461657, 5.531663
Neurological	–0.3345257	1.178022	–0.28	0.776	–2.643406, 1.974354
Gastrological	0.5796472	1.23762	0.47	0.640	–1.846044, 3.005338
Endocrine	–0.0194029	1.290155	–0.02	0.988	–2.54806, 2.509254
MSK	1.128414	1.160604	0.97	0.331	–1.146328, 3.403155
Thyroid	–0.0112384	1.205483	–0.01	0.993	–2.373941, 2.351464
Dermatological	0.1554792	1.407561	0.11	0.912	–2.603289, 2.914247
Gynaecological	0.5234007	1.221781	0.43	0.668	–1.871245, 2.918047
Renal	0.605251	1.834362	0.33	0.741	–2.990033, 4.200535
Haematological	0.1754191	1.507105	0.12	0.907	–2.778452, 3.129291
Miscellaneous	–0.1559142	1.179532	–0.13	0.895	–2.467755, 2.155927
Infective/viral	1.368149	1.428901	0.96	0.338	–1.432446, 4.168743
Respiratory	0.3682056	1.34277	0.27	0.784	–2.263575, 2.999987
Age (years) at diagnosis					
18–25	1	1	1	1	1
26–35	–0.1099316	0.3313735	–0.33	0.740	–0.759412, 0.5395485
36–45	0.2871332	0.3884154	0.74	0.460	–0.474147, 1.048413
46–55	–0.5714871	0.5343717	–1.07	0.285	–1.618836, 0.4758623
56–65	–0.3838744	0.9080378	–0.42	0.672	–2.163596, 1.395847
Weekly household income (AUD)					
0–743	1	1	1	1	1
744–1431	–0.4941456	0.3797174	–1.30	0.193	–1.238378, 0.2500869
1432–2433	–0.3688002	0.3979254	–0.93	0.354	–1.14872, 0.4111192
2434+	–0.5947789	0.4212824	–1.41	0.158	–1.420477, 0.2309193
Employment					
Employed	1	1	1	1	1
Disability	–0.2086164	0.4600489	–0.45	0.650	–1.110296, 0.693063
Temporary	–1.806551	1.335181	–1.35	0.176	–4.423458, 0.8103562
Self	0.0094125	0.5175128	0.02	0.985	–1.004894, 1.023719
Other	0.2431778	0.3471336	0.70	0.484	–0.4371917, 0.923547
State/Territory of residence					
NSW	1	1	1	1	1
Victoria	–0.1367792	0.3580846	–0.38	0.702	–0.8386121, 0.565054
Queensland	–0.2896088	0.4032254	–0.72	0.473	–1.079916, 0.5006984

Diagnosis	Coefficient	Std. Err.	z	*p*>z	95% CI
NT	–0.4500622	1.004319	–0.45	0.654	–2.418491, 1.518367
South Australia	–0.4510594	0.5500861	–0.82	0.412	–1.529208, 0.6270896
West Australia	–0.6256979	0.6275863	–1.00	0.319	–1.855744, 0.6043487
ACT	–0.3189275	0.7074629	–0.45	0.652	–1.705529, 1.067674
Tasmania	– 1.67147	0.8875957	–1.88	0.060	–3.411126, 0.0681854
Indigenous status					
Non-Indigenous	1	1	1	1	1
Aboriginal	0.04373	0.785759	0.06	0.956	–1.496329, 1.583789
Torres Strait Islander	0.6708925	1.583725	0.42	0.672	–2.433151, 3.774936
Disability status					
Disabled	1	1	1	1	1
Unsure	–0.587072	0.3599083	–1.63	0.103	–1.292479, 0.1183354
Not disabled	–0.6455135	0.3994115	–1.62	0.106	–1.428346, 0.1373186

Note. NSW = New South Wales; NT = Northern Territory; ACT = Australian Capital Territory.

Supplementary Table 6.3

Cox proportional hazards model: Time to re-diagnosis by initial diagnosis, age, income, employment status, state/territory, Indigenous status and disability status

Diagnosis	Coefficient	Std. Err.	z	*p*>z	95% CI
Type 1 diabetes	1	1	1	1	1
Anxiety	–1.548715	1.709498	–0.91	0.365	–4.899269, 1.801839
IBS	–2.10012	1.818582	–1.15	0.248	–5.664475, 1.464236
Autoimmune arthritis	–1.302561	1.721978	–0.76	0.449	–4.677576, 2.072455
ME/CFS	–1.496968	1.766967	–0.85	0.397	–4.96016, 1.966223
Migraine	–0.2792046	1.780403	–0.16	0.875	–3.768729, 3.21032
Endometriosis	–1.250097	1.726791	–0.72	0.469	–4.634546, 2.134352
Fibromyalgia	–1.110412	1.759113	–0.63	0.528	–4.558211, 2.337386
Depression	–1.658441	1.733496	–0.96	0.339	–5.05603, 1.739149
Chronic pain	–0.149883	1.688589	–0.09	0.929	–3.459456, 3.15969
Lupus/MCTD	–1.762891	1.723587	–1.02	0.306	–5.141059, 1.615278
POTS	–0.8936385	1.739835	–0.51	0.608	–4.303652, 2.516375
Mental illness	–0.8949151	1.395106	–0.64	0.521	–3.629272, 1.839442
Cancers	1.841628	3.651833	0.50	0.614	–5.315834, 8.99909
Neurological	–1.127938	1.759427	–0.64	0.521	–4.576352, 2.320475
Gastrological	0.2255261	1.692092	–0.13	0.894	–3.090914, 3.541966
Endocrine	–0.5231696	1.907756	–0.27	0.784	–4.262303, 3.215964
MSK	–0.7928909	1.671181	–0.47	0.635	–4.068345, 2.482564
Thyroid	–0.1748463	1.811428	–0.10	0.923	–3.72518, 3.375487
Dermatological	0.9803836	1.98008	0.50	0.621	–2.900502, 4.861269
Gynaecological	–1.21193	1.797077	–0.67	0.500	–4.734137, 2.310277
Renal	2.615947	2.330163	1.12	0.262	–1.951089, 7.182983
Haematological	3.222211	1.90542	1.69	0.091	–0.5123438, 6.956766
Miscellaneous	–1.639301	1.772931	–0.92	0.355	–5.114182, 1.835581
Infective/viral	–1.099417	1.811232	–0.61	0.544	–4.649367, 2.450532

Diagnosis	Coefficient	Std. Err.	z	*p*>z	95% CI
Respiratory	–0.215362	0.078948	–0.10	0.917	–4.290023, 3.859303
Cardiology	–2.364074	2.150113	–1.10	0.272	–6.578219, 1.85007
Age (years) at diagnosis					
18–25	1	1	1	1	1
26–35	–0.034429	0.3270116	–0.11	0.916	–0.67536, 0.6065021
36–45	–0.4696796	0.3870512	–1.21	0.225	–1.228286, 0.2889268
46–55	–0.4473623	0.5659464	–0.79	0.429	–1.556597, 0.6618722
56–65	–0.9999764	1.248079	–0.80	0.423	–3.446166, 1.446213
Weekly household income (AUD)					
0–743	1	1	1	1	1
744–1431	–0.1588396	0. 4559175	–0.35	0.728	–1.052421, 0.7347423
1432–2433	–0.2303388	0.3880934	–0.59	0.553	–0.9909879, 0.530310
2434+	–0.4657359	0.4415365	–1.05	0.292	–1.331131, 0.3996597
Employment					
Employed	1	1	1	1	1
Disability	–0.2248043	0.4218441	–0.53	0.594	–1.051604, 0.6019951
Temporary	–3.569777	3.080342	–1.16	0.247	–9.607137, 2.467584
Self	–0.6035291	0.5119879	–1.18	0.238	–1.607007, 0.3999488
Other	0.018774	0.4937403	0.04	0.970	–0.9489391, 0.986487
State/Territory of residence					
NSW	1	1	1	1	1
Victoria	–0.0055228	0.3604077	–0.02	0.988	–0.7119089, 0.700863
NT	–0.587751	1.12702	–0.52	0.602	–2.79667, 1.621168
South Australia	–0.5497808	0.5480669	–1.00	0.316	–1.623972, 0.5244106
West Australia	–0.7129653	0.6415619	–1.11	0.266	–1.970403, 0.5444729
ACT	–0.4066569	0.6731827	–0.60	0.546	–1.726071, 0.9127569
Tasmania	–1.219491	0.9092168	–1.34	0.180	–3.001523, 0.5625415
Indigenous status					
Non-Indigenous	1	1	1	1	1
Aboriginal	–0.0793209	0.7021657	–0.11	0.910	–1.45554, 1.296899
Aboriginal & Torres Strait Islander	–0.405854	1.264886	–0.32	0.748	–2.884985, 2.073277
Torres Strait Islander	4.204948	1.527405	2.75	**0.006**	1.21129, 7.198606
Disability status					
Disabled	1	1	1	1	1
Not disabled	0.630847	0.345632	1.83	0.068	–0.0465792, 1.308273

Note. NSW = New South Wales; NT = Northern Territory; ACT = Australian Capital Territory.

6.3 "I just want to feel safe going to a doctor": Experiences of female patients with complex chronic conditions in Australia

6.3.1 Abstract

6.3.1.1 Background

The androcentric history of medicine and medical research has led to an ongoing sex and gender gap in health research and education. Sex and gender gaps in research and education may translate into real-life health inequities for women. This study aimed to explore the experiences of female patients with chronic health conditions in the Australian health system, considering existing sex and gender gaps in medicine.

6.3.1.2 Method

This qualitative study used semi-structured in-depth interviews with a sample of adult women with chronic conditions in Australia. Thematic analysis was undertaken, guided by Braun and Clarke (2006). Software NVivoX64 assisted in the management of the data. Coding was performed prior to grouping into subthemes and central themes. To allow for potential researcher biases, the principal researcher engaged in the practice of reflexivity, including the writing of detailed notes during analysis.

6.3.1.3 Results

Twenty adult Australian women with chronic conditions were interviewed. Diagnoses were varied and included EDS, chronic fatigue syndrome, functional neurological disorder and inflammatory bowel disease. Four central themes emerged: diagnostic difficulties, spectrum of healthcare experiences, understanding medical complexity, and coping with symptoms.

6.3.1.4 Conclusion

Women with chronic conditions in Australia report pain, fatigue and suffering that significantly affects their daily lives. There was a shared experience of feeling that the pain and suffering of women was dismissed or not taken seriously. Many women expressed trauma

because of their experiences in healthcare, and often this led to a fear of accessing health services. The participants highlighted a need for more knowledge, understanding and empathy from healthcare practitioners.

6.3.2 Background

Medical research has historically been androcentric (Liu & Mager, 2016; Merone, Tsey, Russell, & Nagle, 2021a); most research has been performed on the bodies of the average male and generalised to females (Holdcroft, 2007; Dresser, 1992; Sex and Gender Sensitive Research Call to Action Group et al., 2020). There is evidence to suggest that globally this sex and gender gap in health research is ongoing (Welch et al., 2017), and a recent cross-sectional analysis highlighted a specialty-based sex and gender gap in Australian health research (Merone, Tsey, Russell, & Nagle, in press). This research gap is thought to possibly translate into a gap in medical education whereby medical schools and clinical textbooks frequently omit women's health sections outside of reproductive and sexual health (Merone, Tsey, Russell, & Nagle, 2022b).

It is possible that sex and gender gaps in research and education translate into real-life health inequities for women. The paucity of research of females may result in the greater prevalence of MUS observed in women (Nimnuan et al., 2001), possibly as a result of a lack of knowledge surrounding the female presentation of disease and response to treatment. Research has demonstrated a gender bias in the diagnosis of MUS and somatic symptom disorder, with female patients significantly more likely to be diagnosed with these syndromes than male patients (Clareus & Renstrom, 2019). The specialty with the highest prevalence of MUS, determined in a UK epidemiological study, was gynaecology (Nimnuan et al., 2001). Women wait longer for a diagnosis than men. In the emergency department, women also wait longer for analgesia and have their pain inadequately managed compared with men (Chen et al., 2008). Gender discrepancies in time to diagnosis are observed in cancers; in the diagnosis of bladder cancer, women with haematuria experience longer waiting times for urology assessment than men (Garg et al., 2014), and similar delays have also been observed in the diagnosis of colorectal, gastric, head and neck, lung, and lymphoma cancers (Din et al., 2015).

A recent survey of women with chronic conditions in Australia demonstrated women wait an average of 4 years for a definitive diagnosis and almost half of these women are re-diagnosed at least once (Merone, Tsey, Russell, Daltry, & Nagle, 2022). This survey ascertained that of the women who were re-diagnosed, 32% were originally given a diagnosis of a psychological condition or MUS and later re-diagnosed with an organic condition Merone, Tsey, Russell, Daltry, & Nagle, 2022). Women are notably more likely than men to be dismissed or told their symptoms are ‘in their head’ before a diagnosis of organic disease is made (Johansson et al., 1996). Despite noting gaps in women’s research and healthcare, little research has been conducted to capture the experiences of women with chronic conditions in the Australian healthcare system.

This semi-structured in-depth interview study aimed to explore the potential effects of the research gap in medicine on the experiences of female patients with complex chronic health conditions in the Australian health system.

6.3.3 Method

6.3.3.1 Research team

The design, analysis and writing team consisted of four members: three professors and one PhD candidate; two identify as women and two as men. The principal researcher, who also coded the data, identifies as a white, disabled woman. This study was guided by feminist social constructivism, using an inductive approach to analysis.

6.3.3.2 Participants

Adult women with at least one chronic condition and residing in Australia since birth or early childhood were eligible to participate. Regrettably, women unable to speak or understand spoken English were excluded as this study was unfunded. We recruited and interviewed women until thematic saturation (Guest et al., 2020) was reached and then continue interviews for two further participants. Women were recruited via social media, specifically Facebook and Twitter. As per a recent survey analysis (Merone, Tsey, Russell, Daltry, and Nagle, 2022), the study was advertised using relevant hashtags and notices in appropriate Australian chronic conditions support groups, including but not limited to chronic pain, endometriosis, lupus, fibromyalgia, general chronic disease, IBS, autoimmune disease, heart disease, depression, anxiety, EDS, cancer, asthma, diabetes, POTS and many more. Interested participants were required to voluntarily contact the principal researcher and, following provision of the information material and informed consent, were recruited to the study.

6.3.3.3 Procedures

The interviews were conducted using a mixture of videoconference and telephone formats. The data collection tool was devised using guidelines from *Learning From Strangers, the Art and Method of Qualitative Interview Studies* (Weiss, 1996), *Feminist Research in Theory and Practice*, *Feminist Research in Practice*, and *Grounded Theory Research: A Design Framework for Novice Researchers* (Chun Tie et al., 2018) and informed by a review of the literature. The principal researcher conducted semi-structured interviews, asking women to tell the story of their condition and experiences in the healthcare system in Australia. If topics were not raised by the participant, the interviewer prompted responses using the questions outlined in Box 1. Demographic characteristics collected were age, state of residence, primary diagnosis, and secondary diagnoses. Primary diagnosis was determined by the participant as either their first diagnosis or the diagnosis that is most prominent in their life.

Box 6.1

Outline of questions used to prompt responses from participants

1. How does your diagnosis/diagnoses affect you on a day-to-day basis?
2. Talk me through the journey of your condition. Perhaps start with your symptoms and diagnosis through to now.
3. Were you previously given another diagnosis for this condition? If so, tell me more about it.
4. How have health professionals responded to your illness?
5. Tell me about any positive experiences you've had in healthcare during your journey.
6. What would you like to see change or improve with treatment regarding your condition?

With informed consent, interviews were audio-recorded on a digital voice recorder, and participants were informed that they could withdraw at any time without explanation up to the point of analysis. Where the interviewer noticed any distress, interviews were paused and participants given the opportunity to cease the interview and either resume another day or withdraw entirely. A professional transcription service was used to transcribe interviews. There was no identifying information provided to the transcription service, and each participant was identified only with a unique identifying code comprised of the interview number and primary diagnosis. This study was approved by the University Human Research Ethics Committee (H8547).

6.3.3.4 Data analysis

Inductive thematic analysis was guided by the framework described by Braun and Clarke (2006): familiarisation with the data, transcription of verbal data, generation of initial codes, searching for themes, reviewing themes, defining themes, and producing a report. The principal researcher read the transcripts several times and conducted the analysis.

To mitigate the risk of potential researcher biases and opinions affecting the results of this study, the principal researcher engaged in the practice of reflexivity according to the model developed by Alvesson and Skoldberg (2009). The principal researcher kept a series of reflective notes following each interview regarding emotional responses and thoughts that occurred at the time. These notes were used when coding and theming the data to reduce the impact of the experiences of the researcher on how the data were interpreted. Trustworthiness and rigour of the study were enhanced by monitoring the research process reflexively. To strengthen credibility, ensure language was free from bias and demonstrate respect to the chronic condition community, this paper was reviewed by two external female consumer stakeholders with chronic conditions.

6.3.4 Results

Twenty adult Australian women with chronic conditions were interviewed throughout January and February 2022 for a median of 39 minutes (IQR 22.25, range 17–91). The age range of participants was 21–67 years (median 42, IQR 19.25). The demographics of the participants are provided in Table 6.8.

Table 6.8

Participant state/territory of residence and primary diagnoses

Demographic	Number of participants
State/Territory of residence	
Victoria	7
Queensland	5
New South Wales	2
South Australia	1
Northern Territory	1
Australian Capital Territory	1
Tasmania	1
Not stated	2
Primary diagnosis	
Ehlers–Danlos syndrome	8
Myalgic encephalomyelitis/Chronic fatigue syndrome	3
Chronic pain syndromes	2
Depression	1
Ulcerative colitis	1
Irritable bowel syndrome	1
Functional neurological disorder	1
Pelvic congestion	1
Long-term sequelae of encephalitis	1

Nineteen out of the 20 women had one or more secondary diagnosis. Secondary diagnoses included POTS, depression, complex post-traumatic stress disorder (PTSD), endometriosis, dysautonomia, supraventricular tachycardia, and fibromyalgia.

Participant responses were analytically coded into four main themes (Table 6.9): diagnostic difficulties, spectrum of healthcare experiences, understanding medical complexity, and coping with symptoms.

Table 6.9

Three levels of themes in this study

Theme	Subthemes	Codes
Diagnostic difficulties	Challenges in obtaining a firm diagnosis	Delayed diagnosis Benefits of a diagnostic label Access to clinicians Seeking another opinion Own responsibility to solve the problem Consumer stakeholders

Theme	Subthemes	Codes
Spectrum of healthcare experiences	Misdiagnosis	Assumptions of doctors Impact of COVID-19 Psychological diagnosis Being too young
	Unclear diagnosis	Lack of objective evidence of disease Multiple diagnoses Normal test results Non-specific test results
	Dismissed	Disbelieved Abandoned by professionals Not being listened to
	Sexism/misogyny	Experiences of female friends/other patients Need for culture change in medicine
	Trauma and safety	Denied help Stigma Sense of blame Rude healthcare staff Bullying and abuse from healthcare staff Accused of faking symptoms Fear of accessing services Weight stigma Vulnerability Shame and humiliation Low expectations for help Gaslighting Insensitivity Frustration with doctors
	Being listened to	Empathy Being listened to Being taken seriously Doctors admitting they do not know
	Advocacy	Self-advocacy Family advocacy Doctors as advocates Doing own research
Understanding medical complexity	Need for more knowledge and understanding	Need for more education for clinicians Need for staff to understand women’s health Consulting consumer stakeholders Problems with research and funding Learning from past errors

Theme	Subthemes	Codes
	Medical complexity	Desire for partnership with healthcare staff Problems commencing in childhood Multiple diagnoses Flexible or adaptive practice
	Altruism to tell their story	Appreciation for this research Importance of telling their story
Coping with chronic conditions and healthcare experiences	Suffering with symptoms	Pain Fatigue Cognitive dysfunction Variability of symptoms Self-management of symptoms Improvement with treatment
	Psychological and social impact of chronic illness	Sense of failure Anxiety and depression Social isolation Loss of identity Support from peers Support from social media Patients as communities Sense of inconvenience to carers Acceptance Strength and persistence Futility Hope
	Poorer quality of life	Help from NDIS Disability Burden

6.3.4.1 Diagnostic difficulties

Participants discussed their journey from initial symptoms to diagnosis, and a significant theme that was expressed by almost all women was the difficulty in obtaining a firm diagnosis. Recurrent misdiagnosis and re-diagnosis were common, and several women consequently had difficulty identifying their primary diagnosis:

> *I think the diagnosis I don't have is my most important diagnosis, but I can't tell you what that is and I can't tell you which of the things going wrong with me is most important today*. (Interviewee 20, diagnosis of EDS with POTS and lupus)
>
> *But finding the diagnosis, no one was interested.* (Interviewee 10, diagnosis of EDS)

Participants frequently attributed their difficulties to challenges convincing doctors and healthcare staff that they felt unwell and had a medical condition:

> *It can be really difficult trying to convince doctors that you are sick.* (Interviewee 10, diagnosis of EDS)
>
> *It's really really hard then to go back on 20 years of medical records saying that there's nothing really wrong with you and you're basically making it up.* (Interviewee 13, diagnosis of EDS)

As part of the diagnostic process, it was common for the women interviewed to have been given a mental health diagnosis prior to being re-diagnosed with a physical condition. A psychological misdiagnosis was associated with even greater difficulties obtaining a diagnosis for physical symptoms:

> *They were like, you're just anxious, it's just anxiety. I'm like, what that explains my liver function?* (Interviewee 13, diagnosis of EDS)
>
> *Everything that happens once you get the psyche label attached to you is they forget everything else, and it is Hell.* (Interviewee 19, diagnosis of FND)

In some cases, the participants expressed that owing to the difficulties they experienced in obtaining a clear diagnosis, they had ultimately stopped seeking answers for their symptoms:

> *I gave up looking for formal diagnoses.* (Interviewee 08, diagnosis of ME/CFS)

Many women emphasised the importance of obtaining a diagnostic label for their mental and physical wellbeing. Diagnostic labels were associated with having a condition that can be treated and is taken seriously by doctors. Additionally, a diagnostic label was noted to be important to be able to communicate their problems to other health professionals:

> *When I received a diagnosis of EDS it changed—a lot of things did change because the doctors were able to recognise that this is actually what's going on and it wasn't this*

> *huge medical mystery where the patient is just making things up in their head.* (Interviewee 02, diagnosis of EDS and POTS)
>
> *I somehow have to convey that I have all the symptoms that would qualify me for a diagnosis of lupus, which is very, very unhelpful for my relationship with every new doctor I have to explain this to. . . . I wish I had said to him, but do you understand the impact it has on my relationship with every other doctor, that I have lupus that we're not calling lupus?* (Interviewee 20, diagnosis of EDS with POTS and lupus)

Many of the women who experienced misdiagnosis or received an unclear diagnosis expressed frustration that doctors often felt them 'too young' to be experiencing their symptoms and believed that this posed a significant barrier to a firm diagnosis and treatment:

> *Saying, because of my age I must be bulimic.* (Interviewee 12, diagnosis of dysautonomia)

In response to unclear diagnosis, misdiagnosis or lack of effective symptom relief, several women reported accessing alternative healthcare services, such as integrative general practitioners, Chinese and herbal medicine practitioners, and homeopathic professionals. Diagnosis and treatment from alternative practitioners was associated with a greater sense of wellbeing, feeling believed and increased patient satisfaction, even if physical symptoms did not always resolve:

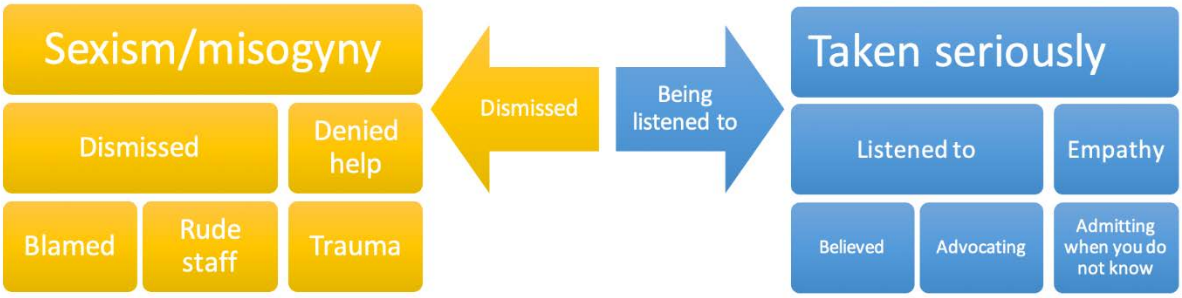
> *She stood me up, sat me down, took my blood pressure and heart rate, stood me up and did it again and went no, no, no, this is not okay, a 19-year-old should not be doing this, you go back to the GP and ask for a cardiologist. So, my homeopath triggered my cardiology referral.* (Interviewee 20, diagnosis of EDS with POTS and lupus)

6.3.4.2 Spectrum of healthcare experiences

There was a wide variety of experiences in the healthcare system that were distributed along a spectrum. At one end of the spectrum, many women felt dismissed by their doctors, with several expressing they felt this was due to sexism. Those who felt dismissed reported being denied help with their illness, and there was a sense of blame for not responding to treatments or for being unwell. Some of the women reported that healthcare staff were rude to them and accused them of faking their illness. At the other end of the spectrum, positive experiences in healthcare were associated with being listened to, being believed and other doctors advocating for their treatment. The spectrum of experiences is highlighted in Figure 6.3.

Figure 6.3

Experiences as a spectrum during encounters with healthcare staff in Australia



All the women interviewed expressed feeling dismissed on at least one occasion. This was associated with adverse emotions, such as feeling frustrated with their doctors or feeling vulnerable:

> *When I saw the pain specialist, he was very dismissive of my pain.* (Interviewee 11, diagnosis of EDS)
>
> *It's also very frustrating because it's taken ten years for someone to notice.* Interviewee 10, diagnosis EDS)
>
> *It's frustrating and I've definitely been brought to tears by it on a number of occasions because you're vulnerable.* (Interviewee 01, diagnosis of chronic pain and CIN3)

Being dismissed was not only frustrating, but also strongly related to a feeling women were not believed, or that the symptoms were entirely psychological:

> *Honestly, I will let something go until I'm near being hospitalised now because of a lifetime of being dismissed or not believed.* (Interviewee 01, diagnosis of chronic pain and CIN3)
>
> *It's the first line of well, we couldn't figure it out easily, so maybe you're just anxious.* (Interviewee 20, diagnosis of EDS with POTS and lupus)
>
> *Lots of people since have said it's in my head, but the ones I listen to say it's not. Off to the psychologist. They did nothing.* (Interviewee 14, diagnosis of diagnosis of chronic pain)

Feeling as though they were not receiving the help they needed for their condition was common. This was accompanied by a sense of abandonment and having to learn to manage symptoms for themselves, with inadequate symptom management and follow-up:

> *I just remember I didn't get any help during that period, I just had to tough it out, basically.* (Interviewee 02, diagnosis of EDS and POTS)
>
> *They sent me home from hospital while I was still paralysed, basically said it's not a stroke, get used to it.* (Interviewee 10, diagnosis of EDS)
>
> *They weren't giving anything for the pain.* (Interviewee 13, diagnosis of EDS)
>
> *I would say he's been supportive in that very general sense, but there's never been a huge amount of follow up or anything.* (Interviewee 04, diagnosis of depression with PTSD)

Alongside frustration at diagnostic difficulties and being dismissed, there was a strong sense of trauma, including stigma, prejudice, shame and blame received from health services, from many of the women who were interviewed:

> *The way in which you're treated in emergency department is like you are just drug seeking. I've certainly felt like I'm also doctor shopping at times.* (Interviewee 07, diagnosis of EDS with endometriosis)

> *I feel deeply ashamed and a great amount of guilt about my medical situation.* (Interviewee 02, diagnosis of EDS and POTS)

Several women attributed their adverse experiences and difficulties in obtaining a diagnosis and adequate treatment to systemic and institutionalised sexism and misogyny:

> *The GP was just pretty shocking. She just kind of told me to suck it up and that I should be a better wife to my husband.* (Interviewee 04, diagnosis of depression with PTSD).

> *I think this is just more of the generalised socialisation of women, that it's all in our heads. . . . there's a lot of misogyny within the way that women's pain is assessed and interpreted.* (Interviewee 11, diagnosis of EDS)

> *I spent a lot of years being dismissed as an anxious woman rather than having my physical symptoms investigated.* (Interviewee 13, diagnosis of EDS)

Additionally, one woman reported receiving an out-of-date and widely accepted misogynistic diagnosis:

> *My discharge summary says hysteria is my diagnosis. Imagine how that feels to read that the health service thinks you have hysteria?* (Interviewee 19, diagnosis of FND)

Further, there was a sense that each doctor was limited to knowledge within their own speciality, and this was a hinderance to diagnosis as doctors would be unable to consider conditions outside of their own expertise. This was accompanied by a desire for healthcare to be more holistic:

> *I've just felt that every doctor is just ticking off their one box and quite dismissive of how it's impacting my whole life.* (Interviewee 11, diagnosis of EDS)

The reported adverse experiences and sense of being disbelieved were linked to use of the words ‘trauma’, ‘gaslighting’, and an associated fear of accessing health services:

> *The gaslighting is implicit, even if somebody’s telling you they believe you that you’re not doing okay, they’re saying, well, everything is ok. Your tests came back okay, so you must be okay.* (Interviewee 06, diagnosis of ME/CFS)
>
> *I believe I have been pushed to a number of psychological crises due to the experiences with [the medical] professionals that I have explained.* (Interviewee 02, diagnosis of EDS and POTS)
>
> *It was enough to turn me off getting anymore treatment from medical providers for these mental health issues for several—I guess five or six—years.* (Interviewee 04, diagnosis of depression with PTSD)

Almost all the participants described traumatic adverse events in their experience of healthcare, including bullying and intimidating behaviour from healthcare staff, and some were overtly accused of faking their illness:

> *I then heard the paramedic next to me telling me to stop it [name omitted] I know you are faking this; I know you have pseudo-seizures.* (Interviewee 02, diagnosis of EDS and POTS)
>
> *They were accusing me of being bulimic, they were accusing me of purposely doing something, purposely taking I think they’re called loop diuretics or something.* (Interviewee 12, diagnosis of dysautonomia)

Adverse experiences were associated with a fear of accessing services and a sense from some women of being unsafe in hospital owing to professionals misunderstanding their complex conditions:

> *There's a ton of fear every time you step into the room, because you're worried about what the reaction to your new issues are or your old issues, which I'm sick of hearing about.* (Interviewee 07, diagnosis of EDS with endometriosis)

> *We have literally stopped calling 000 because I am at more risk of harm in a hospital from people who don't follow basic seizure protocols.* (Interviewee 19, diagnosis of FND)

> *I just want, I don't know, to feel safe going to a doctor. I really am petrified of doctors.* (Interviewee 15, diagnosis of pelvic congestion)

At the other end of the spectrum, positive experiences in healthcare were strongly related to finding a doctor who listened and took their illnesses seriously. Doctors being able to admit when they did not have an answer was also something valued by several participants:

> *She actually said to me, I'm happy to do some reading about this because I don't understand. I nearly fell off my freaking chair!* (Interviewee 07, diagnosis of EDS with endometriosis)

> *I saw a doctor there who was the first doctor who actually listened to me.* (Interviewee 14, diagnosis of chronic pain)

Empathy was a high-rated quality in a healthcare professional and associated with positive feelings towards healthcare:

> *When you're already vulnerable and terrified you lose your voice and you're really reliant on healthcare professionals to use their empathy, foresight and advocate for you and care for you.* (Interviewee 01, diagnosis of chronic pain and CIN3)

Advocacy in all forms was another strong theme surrounding experiences in healthcare, with women often describing the importance of self-advocacy, advocacy from family members and sometimes advocacy from doctors, particularly general practitioners:

> *I'm quite, I think, a confident, vocal advocate for my needs, but ironically that's quite difficult when you have a neurological condition in and of itself.* (Interviewee 18, diagnosis of long-term sequelae post-encephalitis)
>
> *Friends and family know that I've got a very high pain threshold. If anything they're the ones screaming by my side advocating for me if they're there at the time.* (Interviewee 01, diagnosis of chronic pain and CIN3)
>
> *About a year into it my GP said, look, this is ridiculous. I'm just going to write to the haematology department and ask them to treat you.* (Interviewee 20, diagnosis of EDS with POTS and lupus)

6.3.4.3 Understanding medical complexity

Participants almost unanimously identified that there was a need for more knowledge, research and education for clinicians to understand complex chronic conditions that affect primarily women, such as EDS and ME/CFS:

> *I think a lot of education needs to be done from the first point of call for people because you just get blank stares or you get disbelief, so you get gaslit and it's horrible.* (Interviewee 09, diagnosis of ME/CFS)
>
> *Education all round. Treatment research. There's no money going into pain research. It's not even a recognised disease.* (Interviewee 14, diagnosis of chronic pain)
>
> *I think there's just seriously still a dearth of understanding and literacy about mental health issues even amongst some professionals, which is pretty poor I think given a country like Australia especially—I think our health system should be doing much better than that.* (Interviewee 04, diagnosis of depression with PTSD)

The understanding and knowledge of medical complexity and chronic conditions of frontline doctors such as ED physicians and general practitioners was noted to be an area for development:

> *There's a huge problem with the way doctors diagnose. When you go to a GP these days, if you've got your average run-of-the-mill stuff, they can cope with that.* (Interviewee 13, diagnosis of EDS)

> *Especially our frontline needs a lot more training.* (Interviewee 01, diagnosis of chronic pain and CIN3)

There was an expressed need for doctors and other healthcare professionals to be more empathetic and understanding and less dismissive of female patients with complex and chronic conditions. This theme was particularly common among women who reported being actively engaged in patient advocacy:

> *I just want people to be less judgemental, more empathetic and compassionate with every sort of disease.* (Interviewee 07, diagnosis of EDS with endometriosis)

The majority of women identified that their problems began in childhood and were often re-diagnosed later on as adults as their medical complexity increased. Many women expressed that they have very complex medical histories and needs, with multiple diagnoses and adverse reactions to treatments. Additionally, many felt that the medical system was not equipped to manage chronic and complex conditions and that anyone who did not fit the known diagnostic criteria is often dismissed:

> *I've had such rare conditions that people have just kind of gone well, she must be making it up, she can't really have all these random symptoms that make nothing.* (Interviewee 10, diagnosis EDS)

> *The concrete diagnosis that I have at the moment is POTS and EDS, but there are still ongoing things that could be diagnoses as well, like mast cell activation syndrome and gastroparesis but I've had a bit of trouble getting concrete diagnoses for those.* (Interviewee 02, diagnosis of EDS and POTS)

Many of the women found their experiences in the health services extremely distressing to discuss; however’ there was a true sense of altruism to tell their story, with many women expressing appreciation for the opportunity to tell health professionals about their encounters:

> *But it’s important for people to know about this—that what happens to us in hospital, what happens with the ambulance calls and everything else that happens.* (Interviewee 19, diagnosis of FND)
>
> *I want someone to hear this story, because I don’t think—I don’t believe it’s individual doctors.* (Interviewee 20, diagnosis of EDS with POTS and lupus)

6.3.4.4 Coping with complex chronic conditions and healthcare experiences

The most experienced symptom described by the women interviewed was pain, with almost all women reporting significant daily pain, most commonly of the joints or the abdomen. Several women used adjectives such as ‘excruciating’, ‘severe’ and ‘chronic’ to describe their pain. Many women described reliance on analgesia and nerve blocks to manage their pain, yet despite requirements for pain relief, there was a sense of judgement from healthcare providers that affected access to care:

> *This GP was quite judgmental of this chronic pain issue, and I would say, in a sense, coaxed me to have a trial without any medications.* (Interviewee 07, diagnosis EDS with endometriosis)

Following this, many women reported fatigue as a common but poorly understood symptom and a significant daily grievance:

> *The biggest symptom at the moment for me is the fatigue.* (Interviewee 10, diagnosis of EDS)
>
> *Doctors do not understand—and I’m sorry for the generalisation but just do not understand fatigue.* (Interviewee 18, diagnosis of long-term sequelae of encephalitis)

Additionally, there was an overall sense of great suffering that severely affected the daily lives of all the women who were interviewed:

It doesn't give me one second break. It's equivalent to torturing someone. (Interviewee 19, diagnosis FND)

Essentially, it's derailed most of my life. (Interviewee 06, diagnosis ME/CFS)

Owing to their daily symptoms and suffering, the women interviewed described the poorer quality of life they experience. Many of the women reported their capacity to work or perform general activities of daily life were affected:

I don't really feel like I can live day to day like most people. (Interviewee 09, diagnosis of ME/CFS)

If I'm able to make myself food, then I feel like that's a good day. (Interviewee 10, diagnosis of EDS)

I managed to keep working for quite a while, but it was at the expense of a social life. (Interviewee 08, diagnosis of ME/CFS)

A few women reported feeling socially isolated and a loss of identity because of their symptoms and chronic conditions:

I didn't have contact with anyone outside of my mum, so I was very socially isolated. (Interviewee 04, diagnosis of depression with PTSD)

It certainly has really affected my identity, my self-identity. (Interviewee 18, diagnosis of long-term sequelae post-encephalitis)

Conversely, some women noted the importance of the patient-community via support forums and social media:

So, I'm connected in a group, an FND support group, and we meet once a month. (Interviewee 19, diagnosis of FND)

One participant, however, noted that the negative experiences of friends and those on support groups can affect their own perceptions of the health system and increase anxiety around seeking healthcare:

> *Because of these negative experiences that my friends have had with further investigations, I'm almost depleted.* (Interviewee 16, diagnosis of IBS)

Similar to this experience, many women stated also suffering anxiety and depression, not as a cause of their chronic condition, rather because of their ongoing suffering, both physically and because of their own adverse experiences in the healthcare system:

> *The anxiety in the past year has been crazy and it's not about my illness, I've always been ill. . . . But dealing with the professionals—you can't write your own referrals; you can't write your own pathology scripts to go and get a blood test. There are certain things you need a doctor for, and I can't get anyone to listen to me, it's just crazy.* (Interviewee 15, diagnosis of pelvic congestion)

While all the women described physical and emotional suffering, there was also a wide sense of acceptance of their situation, often based in perceptions of doctors being unable or unwilling to offer further help:

> *Just kind of accepted that this is life.* (Interviewee 10, diagnosis of EDS)
>
> *Often, I will get ignored about it anyway if I ask, if I'm having a particularly bad flare-up from time to time, because it does flare up from time to time. It's very hard to convince anyone to investigate it further anyway. So, you just learn to deal with it yourself.* (Interviewee 01, diagnosis of chronic pain and CIN3)

While there was great suffering reported, it must also be acknowledged that there was a strong sense of strength, with several women discussing how they engage in patient advocacy and 'push through' their symptoms.

6.3.5 Discussion

This qualitative interview study revealed that women with complex chronic conditions in Australia experience difficulties in obtaining a diagnosis and subsequently have experienced a spectrum of encounters with healthcare staff, ranging from feeling dismissed to feeling believed and listened to. Many women feel there is a poor understanding of medical complexity and women's health from healthcare staff. Further, women suffer a wide range of symptoms that significantly affect their quality of life and activities of daily living.

The women in this study reported significant challenges and obstacles to obtaining a diagnosis for their conditions. Although there are many studies pertaining to female suffering and experience of chronic conditions (Joachim & Acorn, 2003; Gordon et al., 1998), there is little literature surrounding the experiences of women with complex chronic conditions in obtaining a diagnosis and receiving medical treatment. All the women interviewed in this study described some degree of diagnostic difficulty with at least one of their chronic conditions, and these difficulties were associated with a sense of frustration, feeling dismissed, or suspecting they were not believed or taken seriously. Researchers and clinicians have long noted that diagnostic difficulty and ambiguity lead to frustrations from clinicians (Isaac & Paauw, 2014) and a sense of de-legitimisation or dismissal from patients (Pierret, 2003), which may in turn result in mistrust of healthcare providers (Johnson & Johnson, 2006). Despite this, there is a paucity of literature comparing the diagnostic experiences of females and males and examining diagnostic journeys of female patients.

Many women described being misdiagnosed or re-diagnosed on at least one occasion; this appeared more common where problems began in childhood and original diagnoses were later re-diagnosed as more disease features manifested. This finding was supported by a recent (2022) survey of Australian women with chronic conditions, wherein almost half of the women reported being re-diagnosed on at least one occasion (Merone, Tsey, Russell, Daltry, & Nagle, 2022). Misdiagnosis and re-diagnosis may contribute to longer waiting times for an ultimate diagnosis, delays in treatment and progression of the chronic condition (Merone, Tsey, Russell, Daltry, & Nagle, 2022).

Many of the women interviewed stated their symptoms had at some point been attributed to psychological conditions, most commonly anxiety. Research has demonstrated that women are often diagnosed with a psychological or MUS condition prior to later being re-diagnosed as having an organic condition (Merone, Tsey, Russell, Daltry, & Nagle, 2022). Further, women are noted to be at greater risk than men of having their physical symptoms attributed to psychological causes, often without thorough investigation (Clareus & Renstrom, 2019). Finally, prior research supports this study; women (and men) with chronic conditions often feel their anxiety is related to having a chronic condition, rather than anxiety causing their physical symptoms (DeJean et al., 2013).

Many of the participants reported significant and traumatic adverse experiences in the healthcare system, from being accused of faking their symptoms to being denied care and help. These experiences were associated with a sense of medical trauma and being ‘gaslit’. Medical gaslighting is a term that is becoming increasingly common in the literature and is defined as an experience of invalidation, dismissal and inadequate medical care (Sebring, 2021). Emerging research is demonstrating that medical gaslighting is felt particularly among female patients suffering with medically ambiguous or unexplained syndromes, such as ME/CFS and POTS (Evenson, 2021).

Several of the women in this study described experiencing trauma because of their healthcare experiences, rather than as a direct result of their symptoms. It is long noted that women are more likely to suffer from MUS or ambiguous complex chronic illness than men and that women suffering with these conditions must learn to manage them within the context of a hostile medical and social culture (Johnson & Johnson, 2006). In keeping with our findings, a 2015 focus group study of Australian women with chronic conditions discovered that women have a sense of disempowerment and dismissal through interactions with healthcare systems (DiGiacomo et al., 2015). There was little literature from the patient perspective to support our findings of doctors accusing female patients of faking their illness or medical trauma and gaslighting; however, this may be owing to little recognition of these factors affecting patient care and a research oversight to date. The work of Young et al. (2018), however, supports the idea that clinicians may view women as attention-seeking, exaggerating or ‘mad’ when presenting with complex, painful and poorly understood conditions such as endometriosis. Other research has supported this gender bias in the care of chronic pain and diagnosis of chronic and acute conditions (Chen et al., 2008; Daly et al., 2006; Katz et al., 2010; Lyratzopoulos et al., 2013; Merz, 2011; Naamany et al., 2019).

Some of the women expressed they felt their traumatic experiences were due to systemic sexism. It is possible that adverse experiences in healthcare for women are related to an underlying misogynistic culture in medicine (DiGiacomo et al., 2015; K. Young et al., 2018) and medical research (Merone et al., 2021b), lack of research knowledge (Merone, Tsey, Russell, & Nagle, in press), lack of education about women’s health (Merone, Tsey, Russell, & Nagle, 2022b) and compassion fatigue from clinicians (Sinclair et al., 2017). A 2013 Swedish survey of adverse hospital encounters demonstrated that a feeling of ‘being wronged’ in female and male patients was associated with not being believed, not being listened to and feeling disrespected (Wessel et al., 2013). Within this survey and the findings of an earlier (2007) study, women were noted to be over-represented in terms of negative encounters (Upmark & Alexanderson, 2007; Wessel et al., 2013).

Despite a high number of reported adverse experiences in healthcare, every woman interviewed could describe at least one positive experience. Positive experiences were primarily associated with a feeling of being listened to and taken seriously and were often discussed with a tone of surprise and adverbs such as ‘actually’. This finding was supported by Wessel et al. (2013) in their survey, noting being listened to, being treated with respect, and believing the patient were all consistent with positive encounters. The patient experience is known to affect outcome, health and wellbeing, with positive interactions associated with better outcomes (Stewart, 1995).

Many women believed their adverse events to be related to a lack of knowledge and understanding about complex chronic conditions on the behalf of the healthcare providers. Research has demonstrated that GP knowledge surrounding complex medical issues is lacking, to the point that many GPs do not accept ME/CFS as a condition at all (Pheby et al., 2021). Healthcare is becoming increasingly complex, and treatment is dictated by the evidence, which may be imprecise, conflicting (Plsek & Greenhalgh, 2001) or inappropriate for certain groups in society, such as women (Merone et al., 2021a). In complex systems, unpredictability and acceptance of the unknown is inevitable. There is an urgent need for new conceptual frameworks to replace the traditional ‘reduce and resolve’ approaches to healthcare (Plsek & Greenhalgh, 2001).

Women who were involved in patient advocacy noted a gap in the medical research and a requirement for consumer engagement. Consumer engagement is becoming increasingly acknowledged as an essential part of the health research process (Manafo et al., 2018). Critical stakeholders such as patients and patient advocacy groups can help identify current gaps in health research and aid in consideration of the role of trauma in lived experience (P. Roche et al., 2020).

The women in this study reported poor physical health and quality of life, with significant emotional and social impacts. Women with chronic conditions report poorer physical health than men with chronic conditions (O’Neill & Morrow, 2001). Many women described daily pain, fatigue, and a significant decrease in their quality of life. This is in keeping with the literature on chronic pain, with a recent mixed-methods study of both female and male chronic pain patients showing significantly lower mean quality of life scores compared with the general population and patients with other long-term conditions (Hadi et al., 2018). Respondents in this mixed-methods study described the adverse impacts of pain on their physical functioning, professional lives, social lives, relationships, sleep and mental health (Hadi et al., 2018). Similarly, a 2018 cross-sectional study of chronic pain in female breast cancer survivors demonstrated an association between pain and poorer quality of life, particularly in younger women (Hamood et al., 2018). Another 2018 cross-sectional analysis of Australian women with chronic pain drew an association between women's response to pain, such as catastrophising, and impact of pain on quality of life (Sewell et al., 2018). In contrast to this cross-sectional analysis, several women in our analysis reported feeling anxiety because of their symptoms rather than the cause of them; however, there was no sense of catastrophising, but rather a wide sense of acceptance and strength, alongside frustration at feeling dismissed. This sense of acceptance and illness as a part of life has been observed in an interview study examining the experiences of ageing women with chronic conditions (Giddings et al., 2007).

Many of women interviewed described living with disabling fatigue. Fatigue is a common but poorly understood symptom of many chronic conditions (Flechtner & Bottomley, 2003; Menting et al., 2018), and other studies, in keeping with our findings, have demonstrated that it is strongly associated with decreased participation in social activities (Murphy et al., 2019). Fatigue is frequently ignored in cases where there are no laboratory findings to support a cause, and unexplained fatigue is associated with a poorer quality of life (Yoo et al., 2018). As several women in our interviews were diagnosed with conditions still considered to be medically unexplained despite increasing evidence to the contrary, such as ME/CFS, it is possible that receiving less treatment is associated with increased fatigue and greater impacts on quality of life. Additionally, other research notes the importance of validating the experiences of women who suffer with fatigue (Kralik et al., 2005).

This study presents the experiences of Australian women with complex chronic health conditions in the healthcare system. In some ways, this study builds upon existing knowledge of sex and gender gaps in medical care; however, this study strongly highlights some strikingly similar adverse experiences reported by female patients. There is little prior research on female patients' experiences of medical gaslighting, dismissal and disbelief. The work presented here has important implications for female patient care in an androcentric medical system. It is vital that clinicians understand and listen to their patients to provide the best and safest clinical care.

6.3.6 Limitations

This research has several limitations. First, the principal researcher did not consult with patient advocates in the design of this study; however, this was mitigated to some extent by review of the paper pre-publication by consumer stakeholders. Women who did not speak English were unable to participate owing to lack of funding for translators; therefore, an important population group was excluded and this may affect transferability. Recruitment for this study occurred predominantly through social media and this may have resulted in bias towards women who are more educated, more technologically connected and more likely to be willing to share any adverse experiences. Many of the women in this study had MUS conditions, which is potentially a result of the lack of research highlighted; this raises questions about the transferability of findings to women with chronic conditions that have established diagnostic tests and are easier to diagnose. However, by interviewing 20 women with a range of conditions, we demonstrate that across a spectrum of conditions, there are common themes in the healthcare experiences of Australian women with complex chronic conditions. Finally, as with all qualitative research studies, there is the potential for researcher bias and interpretation. We have sought to mitigate this as far as possible; all data were collected and analysed by the principal researcher, and during both processes, the author engaged in reflexivity as recommended by Braun and Clarke (2021).

6.3.7 Conclusions

Women with complex chronic conditions in Australia report pain, fatigue and suffering that significantly affect their daily lives. Despite their sense of acceptance, many women felt frustration towards medical practitioners and there was a shared feeling that the pain and suffering of women is dismissed or not taken seriously. Many women expressed trauma because of their experiences in healthcare, and this often seemed to lead to a fear of accessing health services, even in potentially life-threatening situations. All the women interviewed highlighted a need for more knowledge, understanding and empathy from healthcare practitioners surrounding the care of women with complex chronic conditions.

6.3.8 Recommendations

We would recommend the following to address the adverse experiences of women in the Australian healthcare system:

- Addressing the research gender gap by journal requirements for researchers to recruit appropriate numbers of women to clinical research and to analyse results by sex and gender
- Inclusion of women’s chronic conditions in medical school curricula
- Educational sessions for clinicians and students on women’s health, medical complexity and management of chronic conditions in women
- Empathy training for clinicians surrounding women’s health, medical complexity and management of medical uncertainty

6.4 Concluding comments

This chapter has explored the experiences of Australian female patients with chronic conditions. It is difficult to ascertain if 6 months to receive an initial diagnosis is a lengthy period of time, as there are no data on male times to diagnosis to compare this with. There appear to be high proportions of re-diagnosis in female patients in Australia, with a prolonged time of 4 years to receiving a firm diagnosis. Additionally, many women appear to be diagnosed with psychological or MUS conditions and later re-diagnosed with an organic condition. Semi-structured interviews support the survey findings. Many women described difficulties in obtaining a diagnosis, being misdiagnosed or re-diagnosed, feeling dismissed by their doctors, and believing that these experiences may, in part, be due to a systemic sexism in medical services. It is not possible to draw a direct link between these experiences and the observed sex and gender gaps in health research and medical education. This research has, however, demonstrated that sex and gender gaps persist and that female patients in Australia believe that there is a lack of understanding and knowledge from healthcare providers surrounding women’s health, chronic conditions and medical complexity.

Chapter 7: Discussion, Conclusions and Recommendations

Still I Rise

You may write me down in history
With your bitter, twisted lies,
You may trod me in the very dirt
But still, like dust, I'll rise.

Does my sassiness upset you?
Why are you beset with gloom?
’Cause I walk like I've got oil wells
Pumping in my living room.

Just like moons and like suns,
With the certainty of tides,
Just like hopes springing high,
Still I'll rise.

Did you want to see me broken?
Bowed head and lowered eyes?
Shoulders falling down like teardrops,
Weakened by my soulful cries?

Does my haughtiness offend you?
Don't you take it awful hard
’Cause I laugh like I've got gold mines
Diggin’ in my own backyard.

You may shoot me with your words,
You may cut me with your eyes,
You may kill me with your hatefulness,
But still, like air, I’ll rise.

Does my sexiness upset you?
Does it come as a surprise
That I dance like I've got diamonds
At the meeting of my thighs?

Out of the huts of history’s shame
I rise
Up from a past that’s rooted in pain
I rise
I'm a black ocean, leaping and wide,
Welling and swelling I bear in the tide.

Leaving behind nights of terror and fear
I rise
Into a daybreak that’s wondrously clear
I rise
Bringing the gifts that my ancestors gave,
I am the dream and the hope of the slave.
I rise
I rise
I rise.

(Angelou, 1978)

7.1 Introduction

In this final chapter, I will first provide an over-arching discussion, to link and highlight the important aspects of my thesis and findings together. I will also discuss the relevance of sex and gender gaps for clinical education and practice, highlighting examples from six health conditions. The major conclusions drawn are discussed in relation to the research aims. The chapter, and thesis, concludes with a series of recommendations for further research and translation of this research into education and clinical practice.

7.2 Discussion and conclusions

These studies have explored and uncovered ongoing androcentricity in medical research and medical education, and the potential impacts these have on medical practice and the subsequent experiences of female patients with chronic conditions in Australia. The first part of the thesis examined the historic origins of patriarchy, explaining how medicine developed as a patriarchal institution and how feminism has developed throughout history. Feminist progression and development of feminist thought have aided in the development of feminist epistemologies. This research is grounded in feminist epistemology and my own lived experience as a woman with chronic disease. Evidence-based medicine is the positivist cornerstone of modern clinical practice (Goldenberg, 2005), yet it is notably flawed when utilised as a sole epistemology. Positivist research omits the value of lived experience, mechanistic learning, and clinical acumen (Howick, 2011). In an environment where research has historically neglected women, it is quite possible that the evidence upon which we lay the foundations of medical practice is not truly applicable to females (Merone et al., 2021a).

Modern medicine, built on the foundation of androcentric research (Merone et al., 2021a), has been accused of having a narrow perspective, and this may be of disservice to female patients. In his work *The Birth of the Clinic*, philosopher Michel Foucault argues that modern medicine encourages a reductive thinking style, termed as the ‘medical gaze’

(Foucault, 1973). The medical gaze perceives the patient less as a person and more as a collection of cells and tissues, while neglecting the patient as an individual and as part of a wider society, all of which affect health and disease (Foucault, 1973). The medical gaze may modify the patient's story to fit in with the biomedical model of care, leading medicine to be doctor-focused rather than patient-focused, thereby creating an abusive power structure (Misselbrook, 2013). The biomedical model of care restricts disease to the narrow definition of the organic—that which can be objectively observed and measured. This creates a medical environment that is concerned largely with the physical aspects of illness and one that is confined by the limitations of current knowledge and research (Farre & Rapley, 2017). It can be said that the medical gaze and EBM have many parallels (Hazelton Walsh, 2010). Given that the research foundations of EBM are androcentric, it is quite possible that the medical gaze is not only doctor-focused, but also male-focused, thereby creating an abusive power structure that particularly adversely affects women. If health research remains androcentric, there will be ongoing and potentially significant negative impacts on women's health.

The second part of this doctoral work addressed research objectives one and two and sought to ascertain if there is evidence of ongoing sex and gender gaps in contemporary health research and medical education. A cross-sectional analysis of Australian health research highlighted several significant areas of ongoing sex and gender gaps in health research. While female representation across all clinical specialties was approximately 50%, when specialty sub-analysis was performed, it was discovered that there is a specialty-based sex and gender gap that may be based in stereotyped perceptions of disease prevalence. For example, females were significantly under-represented in cardiological studies, but over-represented in gerontological studies. Perpetuation of stereotyped recruitment may adversely affect women's health and become a self-fulfilling prophecy of over- and under-detection and treatment of conditions in women. The research evidence base is used to inform both medical education and clinical practice (Clayton, 2016). Continuation of stereotyped perceptions and gaps in healthcare may therefore translate into medical school curriculum guidelines, curricula, and clinical textbooks. It is quite possible that the overall sex and gender balance in health research is due to endeavours in recent years to include more women in health research, and observed specialty-based gaps may simply be due to lack of female interest in certain clinical trials and research. Further research is required to determine the reasons driving the specialty-specific over- and under-recruitment of female participants.

The second aim of this doctoral work was to ascertain if gaps in the health research literature may translate into gaps in medical school curriculum guidelines, medical school course outlines and recommended clinical textbooks in Australia. Analysis of curriculum guidelines, medical school online course outlines and recommended clinical textbooks demonstrated that women’s health is often omitted. It is not a requirement of medical school curricula accreditation to provide a course on women’s health, although a clinical rotation in women’s reproductive medicine such as obstetrics and gynaecology is both recommended and observed across Australian medical schools. Outside of reproductive health, women’s health is not mentioned in online medical school course outlines. A review of commonly recommended clinical textbooks determined that women’s illness is frequently assumed to be the same as that of a man, with the same clinical presentation, recommended treatment and expected response to treatment. This omission is despite a wealth of evidence that women frequently present differently, have different test results, and respond to treatment for many diseases differently to men (Hamberg, 2008). Further, no textbook referred to the impact of the different social and economic circumstances of women and the effect this has on women’s health. This may result in a knowledge gap for health practitioners when treating female patients—approximately half of all patient encounters. Therefore, it is possible that the observed gaps in health research and medical education may translate into clinical practice and subsequently affect the experiences of female patients with chronic conditions.

There is growing evidence that women and men experience disease differently in terms of symptoms, signs, test results and responses to treatment, despite there still being specialty-specific gaps in the recruitment of women to health research. The textbook analysis conducted as part of this doctoral work involved a review of six diseases: CHD, heart failure, IBS, peptic ulcer disease, CKD and nephrolithiasis (kidney stones). These diseases can be examined in depth to highlight the differences between females and males and the importance of including women in medical research and providing women’s health-specific clinical education.

The physiological differences in the hearts of women and men were reflected in neither the textbooks nor curricula; compared with men, women have a lower left ventricular mass that preserves better with ageing, greater left ventricular contractility, smaller coronary arteries, a lower rate of cardiac cell apoptosis and less vasoconstriction (Bozkurt & Khalef, 2017).

Following ischaemic cardiac events, women have relatively higher morbidity, mortality and poorer prognosis than men (Gao et al., 2019). Women with CHD generally present later in life with different symptoms and lower coronary artery disease assessment scores (Fairbairn et al., 2020). This, however, was not reflected in any of the medical textbooks analysed, despite epidemiology often being presented by sex for CHD. While one textbook acknowledged that females are more likely to present with atypical chest pain with myocardial infarction, there was no further information given. However, the differences between female and male CHD are pronounced and important. Studies have clearly demonstrated that women present with different, ‘atypical’ symptoms of CHD than men (Mehta et al., 2016). The description in the literature of women’s symptoms as ‘atypical’ compared with men’s is exemplary of the androcentricity in medicine and medical research.

Pathophysiology of CHD differs between women and men, yet this was also not reflected in the textbooks. This difference is reflected in tests for CHD; several studies have highlighted inadequacies in the reference range of a marker of cardiac cell damage, troponin I, with strong evidence that lower ranges are required to diagnose myocyte damage in female patients (Shah et al., 2015; Trambas et al., 2014; K. K. Lee et al., 2019). While women are less likely than men to undergo angiography, women are more likely than men at angiography to have normal coronary arteries; approximately half the women with symptoms of CHD and abnormal blood tests have normal coronary arteries at angiography but are then found to have significant microvascular dysfunction (Westerman & Wenger, 2016). There is no proven risk factor modification or treatment for microvascular dysfunction, which may be caused by hormonal changes or chronic inflammation (Westerman & Wenger, 2016). Despite strong evidence that women with chest pain, but angiographically normal coronary arteries, are not a low risk group (Westerman & Wenger, 2016), this is not reflected in the content of current clinical textbooks.

Studies have demonstrated that women are treated less aggressively for CHD than men, with fewer invasive procedures, fewer revascularisations and overall poorer clinical outcomes (Guimaraes et al., 2017). Multiple studies have demonstrated women are less likely to be treated with guideline-directed therapies, or undergo cardiac reperfusion therapies or receive timely cardiac rehabilitation (Mehta et al., 2016). A recent large trial in the US has shown improvement in the treatment and outcomes for women, potentially reflecting the healthcare system's progression in women's CHD care (Guimaraes et al., 2017). It would be pertinent for medical textbooks and curricula to highlight the sex discrepancy in CHD care in an endeavour to increase physician knowledge and enhance the care of female patients.

The psychosocial differences between men and women in CHD are notably different but neglected throughout all textbooks to almost total exclusion. Guimaraes et al. (2017)

determined that women with CHD presented with more concurrent comorbidities, stress and depression compared with men and were more likely to be widowed, divorced or single, and unemployed (Guimaraes et al., 2017). Additionally, when women did not report stress and depression, they had better outcomes than men; however, when stress and depression were reported, outcomes between men and women were similar, suggesting that the social differences between men and women may directly affect cardiovascular health and outcomes (Guimaraes et al., 2017). Other studies have demonstrated, in women, the link between psychosocial determinants of health and CHD. Wang et al. (2007) examined a sample of 80 women and determined that family and work stressors may progress atherosclerotic heart disease in women (Wang et al., 2007).

Women with coronary artery disease are at high risk of developing heart failure (Bozkurt & Khalef, 2017). By age 40 years, women and men have an equal lifetime risk of developing heart failure, and as risk increases with advancing age, older women are at greater risk than men (Bozkurt & Khalef, 2017). Most textbooks presented heart failure epidemiology as a total for females and males. The epidemiology of heart failure, in absolute numbers, is roughly the same for men and women, with poor prognosis and high mortality rates for both binary sexes (Westerman & Wenger, 2016). Heart failure with preserved ejection fraction (HFwPEF) is almost doubly common in women than men. Risk factors for HFwPEF, such as hypertension and obesity, are also more prevalent in women than men (Westerman & Wenger, 2016). While over-representation of these risk factors may contribute to the higher prevalence of HFwPEF, it is also postulated that there are differences in the structural re-modelling of the heart between females and males; women are more likely in response to chronic high pressure to develop thickening of the heart muscle, whereas men are more likely to suffer dilatation of the heart (Westerman & Wenger, 2016).

The distinctions between the two types of heart failure in women and men were not reflected in the textbooks but are important; HFwPEF is less responsive to standard heart failure medications than heart failure with reduced ejection fraction (HFwREF). Women with HFwREF are more likely to have a non-ischaemic cause and have been significantly under-represented in clinical trials of standard therapies, comprising fewer than 30% of participants (Westerman & Wenger, 2016). Research data demonstrate that women and men respond differently to heart failure medications. Women are less likely than men to experience a benefit from taking ACE-inhibitors unless they are appreciably symptomatic (Westerman & Wenger, 2016). Women treated with digoxin for HFwREF had a higher death rate than women who took placebo; this discrepancy was not observed in males in the trial (Westerman & Wenger, 2016; Yancy et al., 2013). Research demonstrates a sex difference in heart failure complications and progression, with women more likely to develop atrial fibrillation and associated stroke, particularly in HFwPEF, and are more likely to be treated with digoxin than men despite evidence of adverse outcomes (Madan et al., 2019). These important differences were not reflected in the textbooks or curricula, and treatments for heart failure were considered the same for women and men.

Signs and symptoms of heart failure, although assumed to be the same in the clinical textbooks, can differ between women and men, with women presenting with higher rates of shortness of breath, exercise intolerance and oedema than men. Women also report poorer quality of life and higher impact on activities of daily living than men (Bozkurt & Khalef, 2017). Similarly, although textbooks considered diagnostic tests to be universal for both sexes, this is not the case. Echocardiographic reports should be adjusted to body mass for female patients, and VO_2 (oxygen consumption) is lower in women than in men, while blood markers of heart failure (natriuretic peptide) are naturally higher in women (Bozkurt & Khalef, 2017).

Women are two to three times less likely to be referred for an implantable cardioverter-defibrillator for heart failure than men, and represent just 23% of patients referred for cardiac re-synchronisation therapy despite trials demonstrating that women receiving cardiac re-synchronisation therapy have better outcomes than men in terms of both morbidity and mortality (Westerman & Wenger, 2016). In terms of left ventricular assist devices, women are again under-represented in clinical trials and more likely to be referred when their symptoms are more severe compared with a man's (Cook et al., 2015). Heart transplantation is also skewed towards men, with women representing just 29% of recipients in the US, and long-term survival is comparable between women and men (Westerman & Wenger, 2016). Despite the outlined sex differences, women survive longer with heart failure than men, aside from when the cause is coronary artery disease, in which case survival rates are similar (Bozkurt & Khalef, 2017).

In both types of heart failure, women report poorer health-related quality of life compared with men (Westerman & Wenger, 2016). Despite the differences in treatment response, some researchers argue that owing to the under-representation of women in heart failure research and lack of specific studies dedicated to female heart failure, standard clinical guidelines should be applied (Bozkurt & Khalef, 2017). We, however, argue that the known sex and gender differences should be apparent in the clinical textbooks and curricula to aid in appropriate diagnosis and treatment of women patients.

Studies have demonstrated that there are sex and gender differences in IBS prevalence. While IBS is twice as prevalent in women for those who seek healthcare, in the general population, the difference is less marked, suggesting women are more likely to seek help for their IBS than men, rather than necessarily being more likely to suffer IBS (Adeyemo et al., 2010; Lovell & Ford, 2012). Despite this, men are under-represented in IBS studies (Adeyemo et al., 2010), and it is unclear if this is owing to a struggle to recruit men or perceptions of IBS as a female-dominated condition. The epidemiology of IBS is inaccurately portrayed in clinical textbooks as a female-dominated condition, which may lead to over-diagnosis of IBS and the misdiagnosis of other conditions as IBS.

While symptoms are presented as the same for women and men across all textbooks, a 2010 meta-analysis demonstrated sex differences in the symptoms of IBS. Women are more likely to report pain, abdominal bloating and constipation-dominant IBS than men (Adeyemo et al., 2010). The effect of the menstrual cycle on IBS was absent from the clinical textbooks that were analysed. Women report an increase in gastrointestinal symptoms around the time of menses compared with other stages of their cycle (Adeyemo et al., 2010). Additionally, several studies indicate improvement in IBS symptoms in women post-menopause, and that women using HRT are more likely to suffer IBS than those who are not (Adeyemo et al., 2010). Other studies have noted the improvement in post-menopausal women’s IBS symptoms and suggest that many of the sex differences observed in IBS are related to the menstrual cycle (Kim & Kim, 2018; O. Lee et al., 2001). Evidence suggests women are at higher risk than men for developing post-infective IBS (Kim & Kim, 2018).

Despite mounting evidence to the contrary, IBS was still considered by one textbook to be a functional disease. Research has demonstrated that there is stigma surrounding the IBS diagnosis, with doctors expressing a ‘public’ textbook view of IBS and a ‘private’ view of frustration and absorbed prejudice (Dixon-Woods & Critchley, 2000). The inaccurate perceptions of IBS as both a functional and predominantly women’s disease may have adverse outcomes for women’s health, and stigma is also associated with poorer health outcomes in IBS patients (Whorwell & Dipesh, 2020). A recent publication in *The Lancet* detailed the likelihood of differing pathologies for different symptoms of IBS, and included solid evidence for alterations in the intestinal microbiome leading to inflammatory responses as a potential physical cause for IBS (Holtmann et al., 2016). Changes in cytokine profiles have also been noted in IBS, with women with IBS having higher serum TNF-α levels than men with IBS (Kim & Kim, 2018).

Female sex hormones are known to modulate gut motility and visceral pain (Meleine & Matricon, 2014); however, none of the clinical textbooks discussed this fundamental sex difference. Oestrogen and progesterone both inhibit smooth muscle contraction, and progesterone is implicated in peristalsis. These factors would explain the dominance of constipation IBS in women, aside from during menses when ovarian hormones are low and diarrhoea is often reported (Kim & Kim, 2018). Studies have also demonstrated that IBS symptoms are inversely related to testosterone (Houghton et al., 2000). A 2015 survey of 557 people on sex differences in IBS supported previous findings that women suffer more bloating, constipation and lower quality of life scores than men with IBS; however, there was no notable difference in depression, pain, impact on activities of daily life and extra-colonic symptoms (Bjorkman et al., 2015).

Although women and men were universally assumed to be the same in terms of treatment and response to treatment across textbooks, there are notable sex differences in the response to IBS treatment. Women with IBS have been noted to respond better to 5-HT_3 and 5-HT_4 receptor agonists than men, and in this instance, a lack of male inclusion in clinical trials is noted to affect guidelines for the treatment of male IBS (Kim & Kim, 2018). Owing to the hormonal impact on female IBS, it is important that sex differences in treatments are further explored. Most medications for IBS are metabolised by the P450 (CYP) pathway, which may be affected by oestrogen and progesterone (Kim & Kim, 2018). This may affect the efficacy of IBS drugs for males, given their low levels of oestrogen and progesterone compared to women.

Textbooks typically gave no attention to the different social and economic circumstances of women; however, these are important in the IBS patient experience. Women report higher rates of interruptions to their interpersonal relationships and work than men (Kim

& Kim, 2018). The psychological aspects of IBS are often focused on, with many continuing to consider IBS a psychosomatic disorder affecting predominantly women (Anbardan et al., 2012); however, a 2015 questionnaire study demonstrated that males are more likely to report interpersonal problems than females and were characterised by hostile-dominant personality types (Thakur et al., 2015).

Most textbooks either did not present peptic ulcer epidemiology or presented it as the total for women and men combined. Females, however, account for >50% of cases and tend to be older and have more comorbidities than men (Thorsen et al., 2013). Males tend to suffer from gastric ulcers, whereas females suffer more from duodenal ulcers (Mustafa et al., 2015)—an important distinction that all textbooks failed to make. Importantly, young women, an often-overlooked group, are more and increasingly likely to suffer a perforated peptic ulcer than men. Older women are also at higher risk than men, and this is thought to be related to increasing NSAID use with age (Wysocki et al., 2011).

Female sex is also of significant influence on post-operative morbidity and mortality following peptic ulcer perforation, with one study demonstrating women patients have greater post-operative morbidity than men (Sivaram & Sreekumar, 2018). Symptoms, risk factors and management of peptic ulcer disease appear to be the same for females and males; however, the textbooks do not state the increased risk of female sex, particularly for older women, for both peptic ulcer disease and the life-threatening complication of perforation. This oversight could lead to diagnostic delays and greater risk of complications for female patients.

Despite the important sex differences in CKD in terms of epidemiology, risk factors, symptoms and management (Cobo et al., 2016), most textbooks either did not present the epidemiology, or presented total epidemiology rather than sex-specific. As with the other conditions analysed, the presentation, risks, treatment, and outcomes were universally assumed to be the same for both women and men.

Regardless of age, CKD is more common in women than men in high-income countries (Carrero et al., 2017). Yet, compared with their representative population, studies have shown that women are under-represented in CKD clinics (Carrero et al., 2017). Renal physiology differs between women and men, and female sex hormones oestrogen and progesterone affect the kidneys of females, increasing the synthesis of angiotensinogen but decreasing renin and angiotensin-converting enzyme synthesis, affecting blood pressure regulation (Cobo et al., 2016). These physiological differences in renal function are also why women do not respond to ACE-inhibitors in the same way as men, yet these drugs are prescribed both for heart failure and certain kidney diseases. Progression to end-stage renal disease is believed to be slower in women; however, as with many medical studies, women have been under-represented in clinical studies and results have been reported by sex in just 30% of studies that included women (Cobo et al., 2016).

Glomerular filtration rate (GFR) is used to estimate the functioning of the kidney. Studies have suggested that estimates and reference ranges for GFR may not be appropriate for women. Estimated GFR (eGFR) calculations are based on serum creatinine measurements, which are influenced by muscle mass. In the general adult population, women tend to have lower muscle mass, leading to lower creatinine measurements and potentially resulting in inaccurate eGFR recordings. This may ultimately result in inappropriate treatments being administered to women (Cobo et al., 2016).

Sex hormones also influence renal function. Younger women frequently use oral hormonal contraceptives, which have been shown to increase risk of microalbuminuria, glomerulosclerosis and tubular fibrosis. Oral oestrogen use appears to affect kidney function in a dose-dependent manner. A large observational study demonstrated a protective effect of testosterone on kidney function; males with low testosterone levels and CKD showed increased mortality (Haring et al., 2011).

Dialysis is the mainstay of management for end-stage CKD; however, women are less likely than men to start dialysis. This could be because women are more likely to die before reaching dialysis, and further study is required (Carrero et al., 2017). Women are more likely to die from CKD; however, once they have started dialysis, women and men have equal survival rates (Cobo et al., 2016). Additionally, women generally require lower dialysis doses than men, probably owing to body composition differences (Cobo et al., 2016) and are more likely to suffer from adverse events due to drug overdosing (Carrero et al., 2017). Women are less likely than men to undergo kidney transplantation (Cobo et al., 2016), despite evidence for better outcomes and graft longevity in female patients (Kummer et al., 2012). The reason for this discrepancy in transplantation is currently unclear.

Textbooks assumed the consequences of CKD to be the same for women and men; however, osteoporosis (Khairallah & Nickolas, 2018) and CKD-related bone mineral disorder are more common in women (Cobo et al., 2016). Anaemia is also more common in female CKD patients than male patients, and women undergoing dialysis require 39% more erythropoietin-stimulating agents than men (Cobo et al., 2016) and are more likely to be poor responders to treatment (Carrero et al., 2017)—again, a neglected but important fact among medical textbooks and CKD guidelines (Carrero et al., 2017).

Studies have demonstrated that among the general US population, awareness of kidney disease among those with CKD is low, particularly in female patients (Cobo et al., 2016). Women are more likely to adapt the family environment to accommodating CKD than men, but demonstrate more disease-related depression and anxiety (Cobo et al., 2016). Women on dialysis treatment express lower quality of life satisfaction scores than men. These psychosocial impacts can manifest as poor adherence with care and increased risk of complications (Cobo et al., 2016).

Most textbooks that presented the epidemiology of renal calculi did so by sex, with one presenting the total and male sex epidemiology only. Despite archaic views that males are more affected by nephrolithiasis than females, this is no longer the case, with a large-data study in the US confirming a decrease in the male:female ratio between 1997 and 2002 from 1.7:1 to 1.2:1 (Alshoabi et al., 2020). While four of the textbooks presented risk factors as the same for women and men, evidence shows this is also erroneous and important sex differences are omitted from the educational literature. Research shows that women who also suffer with obesity are at greater risk of developing renal calculi than women with a healthy body mass index, and the risk was higher for younger women (Alshoabi et al., 2020). Different compositions of renal calculi are more prevalent by gender; for example, a recent study demonstrated that females are more likely to suffer calcium and magnesium calculi, whereas males are more likely to suffer uric acid stones (Shamsuddeen et al., 2013). These stones have different risk factors, which were not apparent in the textbooks.

Clinicians remain uneducated regarding the important differences between women and men's health. This deficiency in knowledge is likely rooted in the androcentric history of medical research and is perpetuated by ongoing sex and gender gaps in the contemporary research. There is potential for a cycle of events, whereby women are over- or under-diagnosed with specific conditions, thereby skewing the observed population prevalence and resulting in continued gaps in the research literature. It is imperative therefore that research studies not only recruit more females to studies, but also that results are analysed by sex and gender. It follows then that clinical guidelines and textbooks must be updated more frequently to reflect the current literature, particularly as female participation in research begins to equalise. It is possible that the ongoing sex and gender gaps in medical research and education lead to similar gaps in clinical practice and affect the experiences of female patients.

Part three of this doctoral work sought to address research objective three and explored the experiences of women with chronic conditions in Australia. A survey of women with chronic conditions in Australia was conducted to ascertain the length of time to diagnosis and proportions of re-diagnosis. In keeping with the current literature, an average time of 4 years to final diagnosis was recorded. Approximately half of the women surveyed, however, had experienced at least one re-diagnosis of their condition, indicating previous misdiagnosis. The current literature demonstrates that women wait longer than men for a diagnosis and treatment for both acute and chronic conditions. Women with acute medical complaints are more likely to be discharged during a serious medical event than men. Additionally, female-predominant conditions such as fibromyalgia, autoimmune diseases and gynaecological conditions are more likely than other conditions to be re-diagnosed at least once. Males with female-predominated conditions such as SLE experience shorter wait times to diagnosis and more aggressive treatment. There is no literature on waiting time to diagnosis or rates of re-diagnosis for males; therefore, it is impossible to state that these times represent a sex and gender gap, and further study is required. For a cancer diagnosis, longer than 3 months is considered a diagnostic delay (Lim et al., 2014); however, for other chronic conditions, there is no such definition.

High proportions of re-diagnosis and long waits to final diagnosis may be a clinical, real-life manifestation of the observed sex and gender gap in medical research and education; as less is known about the female body and presentation of disease, it is possible that the underlying pathology of women-dominated conditions is less well understood. Additionally, there is a growing evidence base that women respond differently to many treatments than men, adding further complexity to women's health on the background of an incomplete research picture. These combined factors may make misdiagnosis of women more likely, or indeed, lack of response to treatment may lead clinicians to seek other diagnoses and further increase misdiagnosis and re-diagnosis proportions and time taken to achieve an ultimate diagnosis and effective treatment. Delays in diagnosis and high proportions of re-diagnosis may be detrimental to women’s health, potentially leading to inappropriate treatments with adverse side effects or progression of the underlying disease while an erroneous diagnosis is treated.

Finally, semi-structured interviews with Australian women with chronic conditions revealed a variety of themes, some of which have been scantly documented in the clinical literature. Many women experienced significant challenges in obtaining a diagnosis or diagnoses for their complex, chronic conditions, and several women had sought help via creative or unconventional means, such as travelling to see sub-specialists and seeking advice of alternative practitioners. Difficulty obtaining a diagnosis was associated with a sense of frustration towards healthcare providers. In their health journey, many women experienced adverse experiences with healthcare professionals, including being dismissed, disbelieved, accused of fabricating their illness or being gaslit, and this was accompanied by distress, trauma and an altruistic desire to tell their stories. Positive experiences were described by all women and were associated with being listened to, being believed and clinician empathy. Almost all women noted there was a gap in the knowledge of most clinicians when managing their chronic conditions and that increased empathy was needed when handling complex cases.

It is possible that women with chronic disease notice some knowledge gaps in healthcare professionals that are rooted in gaps in the research literature and medical education system highlighted above. If this is the case, women’s physical and mental health appears to be suffering consequently. Many of the women interviewed described the significant impact their disease has on their daily life and the effect their experiences in the healthcare system have had upon their healthcare-seeking behaviour. It is possible that a lack of knowledge and understanding of women’s health leads to stigma from health professionals, which may in turn adversely affect the patient’s experience. All the participants reported experiencing significant physical suffering, including chronic fatigue and pain, both of which are poorly understood and poorly managed within medicine. Further, a lack of research into the treatment of women's health complaints possibly leads to frustrations from both the patient, who is suffering, and the clinician, who is not observing the expected response to treatment.

This doctoral work establishes that there are ongoing sex and gender gaps in medical research, and this is particularly pronounced in certain specialties such as cardiology. These observed research gaps are likely to drive the similar gaps observed in medical school curriculum standards, course outlines and clinical textbooks. Given that the evidence base drives clinical education, guidelines and practice, neglect of women's health in the literature will likely affect the clinical care of female patients. Women with chronic conditions in Australia wait on average four years for a definitive diagnosis, are frequently re-diagnosed at least once, and express significant dissatisfaction with their medical care. While it is not possible from this work to ascertain if the experiences of women with chronic conditions are directly linked to the observed gaps in health research and medical education, this research has confirmed that sex and gender gaps in medical research, education and medicine are both historic and ongoing.

7.3 Recommendations

Based on the conclusions drawn from the research aims, there are several recommendations that are proposed. These have been divided into recommendations that translate to research, medical education and clinical medical practice.

7.3.1 Recommendations for research

Recommendations for research are:

- larger-scale research to further ascertain the extent of the sex and gender gap in Australian health research;
- detailed assessment of medical school curricula for the inclusion of women's health;

- assessment of male times to diagnosis and proportions of re-diagnosis for comparison; and
- requirements for researchers to perform sex-based sub-analyses to bring women's health research in line with men's.

7.3.2 Recommendations for medical education

Recommendations for medical education are:

- formal requirements for all medical schools to include sex- and gender-based education in their curricula;
- adequate inclusion of women's health and gender differences in medical school curricula, perhaps through gender-based medical units in the pre-clinical years;
- educational sessions and continuing professional development sessions for clinicians on the sex and gender differences in medicine;
- inclusion of women's health sections in clinical textbooks and discussion of women's differing disease presentation and treatment requirements; and
- education for students and clinicians on medical complexity, critical thinking and assessment of evidence, and management of chronic disease in women.

7.3.3 Recommendations for clinical practice

Recommendations for medical clinical practice are:

- patient pathways specific to women's health, with consideration for gender diversity and gender as a spectrum;
- empathy training for clinicians surrounding women's health, medical complexity, and management of medical uncertainty; and
- flexibility in prescribing and symptom management for populations under-represented in research.

7.4 Epilogue

This thesis presents the findings of four years of passionate research and would not have been possible without the participation of the immensely brave and self-less women who sacrificed their time and shared their stories, despite their own ill-health. Profoundly, when people have enquired about the nature of my PhD research, there has not been a single woman who has not then shared a story of her own adverse experiences in healthcare. This only served to increase my motivation to complete this work. I was unfortunately, given my own experiences as both clinician and patient, unsurprised by many of my findings, however the qualitative interviews revealed some tales that made me feel ashamed of the behaviour of some colleagues. I was also moved by the altruism of the interview participants, often sharing their stories with me at great emotional cost to themselves, but with a determination that their voices are heard. I am humbled to have listened to their experiences and shared them with the medical community.

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