AUTOIMMUNITY, IDENTITY, AND MORALISATION: CARING FOR WOMEN WITH AUTOIMMUNE DISEASES IN REGIONAL AUSTRALIA

A Thesis submitted by

Leith Heyman, BSocSc, BA(Hons)

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ABSTRACT

Autoimmune diseases (ADs) affect 1 in 20 Australians and an estimated 324,694 people in regional Australia. Women account for almost 75% of these cases. ADs create a range of challenges for women across their lifetimes, particularly since they are unpredictable, characterised by periods of remission and flare. In addition to the physical realities of ADs, women must also navigate challenges to their identities and the way health, illness, and identities are moralised. Despite recognition that chronic illnesses can be more difficult to manage in regional areas compared to metropolitan areas, little is known about the specific care needs and experiences of women with ADs in regional Australia. Thus, this thesis aims to understand the care needs and experiences of women with ADs in regional Australia through an exploration of the relationships between autoimmunity, identity, and moralisation.

Fieldwork was conducted from June 2017 to June 2018 in regional Queensland. Using a life story approach to ethnography, fifty-five in-depth interviews were conducted with seven women with ADs across this period. All participants came from Anglo-Australian backgrounds, with ages ranging from 26-80. Interviews were analysed thematically, with attention given to privileging women's voices and stories during analysis and interpretation.

Through these analyses, three common illness phases were identified. These include the process of getting a diagnosis, negotiating care after a diagnosis, and making sense of autoimmunity. Women's diagnosis periods were characterised by disconnected care and the denial of care based on the moral judgments of healthcare providers. These prolonged diagnosis and affected women's sense of self and identity. Women were also sometimes complicit in this, avoiding care in order to maintain socially valued identities. Diagnosis periods were characterised by ambiguity and uncertainty, with women coping by engaging in activities that protected or reinforced their identities as productive and active people, even at the expense of their health.

After receiving a diagnosis, women's experiences were characterised by attempts to create new identities and mitigate the impact of chronic illness on existing identities, in addition to accessing effective treatment, peer support, and practical and financial support. While diagnoses are typically considered gateways to these forms of care, this was not always the experience of the women in this study. Many faced barriers to accessing the care they needed. In response, women enacted agency in various ways, absorbing their illness

identities into their existing identities, creating new illness identities, and fighting for access to financial support. In each of these cases, however, the agency women enacted was shaped by a desire to maintain identities that are positively moralised, and thus socially valued, regardless of how this might impact their health.

In the third phase, women attempted to understand and make sense of autoimmunity. This can be difficult since there is continued biomedical uncertainty about the cause of autoimmunity. However, this uncertainty gave women space to develop their own understandings of autoimmunity that made sense in the context of their life stories. In doing so, women often developed multiple, overlapping understandings of autoimmunity to counteract the moralisation they faced and integrate their illnesses into their identities and life stories. These understandings centred around several common explanations for autoimmunity, including stress, environmental causes, and heredity.

Understanding the care experiences of women with ADs in regional Australia through a lens of identity and moralisation has important implications for the care of those with ADs in these areas, as well as those with chronic illnesses more broadly. Care in regional Australia tends to be tightly bound to specific diagnoses. While diagnosis-specific care is important, rethinking the dependency of care on diagnosis would facilitate better access to care for women with diagnosed and undiagnosed ADs. This is particularly important in regional, rural, and remote areas where disease-specific care for ADs is typically unavailable, but also transcends geographic boundaries, with improved access to care also possible for those with poorly understood or rare illnesses. Care should focus on needs in response to illness, rather than diagnosis, which requires a more equitable understanding of what counts as care and who is considered deserving of care.

CERTIFICATION OF THESIS

This Thesis is entirely the work of Leith Heyman except where otherwise acknowledged. The work is original and has not previously been submitted for any other award, except where acknowledged.

Principal Supervisor: Professor Lara Lamb

Associate Supervisor: Associate Professor Celmara Pocock

Associate Supervisor: Dr Jane Palmer

Student and supervisors' signatures of endorsement are held at the University

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LIST OF AUTOIMMUNE DISEASES

Autoimmune disease	Description
Ankylosing spondylitis (AS)	'A condition that mainly affects the spine. The joints of the neck, back and pelvis become inflamed, causing pain and stiffness. The sacroiliac joints are commonly affected in AS . . . Other joints, such as the hips and shoulders, can also be involved. AS can also affect other parts of the body, such as the eyes, skin, bowel and lungs' (Arthritis Australia 2017d).
Crohn's disease	'An inflammatory autoimmune bowel disease characterized by severe and persistent inflammation of the lining or wall of the gastrointestinal tract'(American Autoimmune Related Diseases Association Inc 2018).
Hashimoto's thyroiditis	An 'autoimmune disease that affects the thyroid gland' such that it 'does not make enough thyroid hormone (Office on Women's Health 2018). This often leads to hypothyroidism which 'can cause your metabolism to slow down, which can lead to weight gain, fatigue, and other symptoms' (Office on Women's Health 2018).
Pernicious anaemia	'A rare blood disorder characterized by the inability of the body to properly utilize vitamin B12, which is essential for the development of red blood cells' (National Organization for Rare Disorders 2005).
Polymyalgia rheumatica	'Polymyalgia rheumatica means "pain in many muscles". It is a condition that causes inflammation of the joints and tissues around the joints. This causes muscles to feel painful and stiff, especially in the shoulder, neck and hip areas' (Arthritis Australia 2017a).
Rheumatoid arthritis (RA)	'An autoimmune disease that causes pain and swelling of the joints . . . In RA the immune system targets the lining of the joints, causing inflammation and joint damage. RA usually affects smaller joints, such as the joints in the hands and feet. However, larger joints such as the hips and knees can also be affected' (Arthritis Australia 2017b).

Autoimmune disease	Description
Scleroderma/systemic scleroderma	An 'autoimmune condition of the connective tissue characterized by skin thickening, spontaneous scarring, blood vessel disease, and varying degrees of inflammation' (Shiel 2020). Systemic scleroderma also includes the involvement of internal organs (Shiel 2020).
Sjögren's syndrome	An autoimmune disease that causes an 'abnormal dryness of the mouth, eyes and/or other tissues' (Arthritis Australia 2017c).
Systemic lupus erythematosus (SLE)	A form of lupus that is 'characterised by flare-ups and periods of improvement (remissions), and can affect almost any organ or system of the body. In most people only the skin and joints are affected. However, in some people SLE can also affect the kidneys, lungs, heart, blood vessels and/or brain' (Australasian Society of Clinical Immunology and Allergy 2019a).
Ulcerative colitis	A form of inflammatory bowel disease that causes 'inflammation of the inner lining of the large bowel (colon and rectum)' (Better Health Channel 2014).

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LIST OF ABBREVIATIONS

AD	Autoimmune disease
AS	Ankylosing spondylitis
DSP	Disability support pension
GP	General practitioner
MND	Motor neuron disease
NSAIDs	non-steroidal anti-inflammatory drugs
PBS	Pharmaceutical Benefits Scheme
USA	United States of America
WHO	World Health Organization

PREAMBLE

At 19, I moved from home to my nearest capital city, working full-time and enjoying my independence. About a year later, I started experiencing diarrhoea and stomach pain that did not go away so I dutifully went to the doctor. He ran some stool tests and called me back in for an appointment a few days later to let me know that I had some kind of bacteria in my stomach, I can't remember its name, and to prescribe me some tablets to take for a few weeks. The side effects of those tablets were almost unbearable. I was severely nauseous, barely able to work, and would wake up during the night convulsing. I made another appointment with the doctor to see if there was an alternative medication I could take. He ran the same tests and told me this time that I had salmonella poisoning, that I must be unhygienic, and that if I came back with the same problem again he would send the health department to my house to inspect its cleanliness. I don't remember how I responded, but he insisted I take the same tablets and I complied, starting a three-week course again. Unsurprisingly, I experienced the same side effects and after trying to stick with them for a few days, I gave up, throwing them across the room into the bin.

I couldn't go back to the same doctor again and I didn't want to risk the same outcome with a different doctor so I did nothing. The diarrhoea was easier to deal with than the medication side effects and after a couple of years it became so normal to me that it didn't occur to me to bring it up to a doctor again. The stomach pain was severe at times but I put it down to stress, which made sense to me because my job was stressful. I became severely underweight but, with the exception of my parents, was only ever praised for how I could eat what I wanted and stay thin. My mum thought I had an eating disorder for years and I would joke that it was just that food didn't stay in me for very long. After a couple of years, I started to experience fatigue that steadily got worse. My alarm would go off in the morning and I would sit on the end of the bed and cry, making sure I stopped before I got out of the shower so no one would notice. My work days were long and busy so being tired made sense. I thought that everyone felt this tired and I was just weak and hopeless at dealing with it.

I eventually got so exhausted that, at 24 I quit my job and moved back home to my parents in regional Queensland. I had been studying part-time previously so I enrolled full-time and didn't work again for a year. During that first six months, my symptoms lessened and I put on a little bit of weight, though not much. Then, the diarrhoea started to come back more regularly. I was living with my dad at the time and told him it must be because of all the extra-full-fat dairy he had a penchant for buying; however, when I stopped eating it my symptoms didn't subside. I wasn't too concerned because I still thought of this as something that was normal for me. Then the fatigue started creeping back as well. I could barely stay awake at night and started being late to lectures because the effort it took to get out of bed was exhausting. I went back to my old explanation that everyone felt like this and I was just useless.

I started to suspect something might be wrong when I didn't complete an assignment because I was just too tired, but I didn't think too much of it. I felt like I couldn't go to the doctor because I was tired. It seemed too trivial. I started to get fevers most nights but they would be gone by the morning so again, I brushed them off. By this time, I was also working part-time in retail and one day the whole shop suddenly started spinning and I almost fainted. I crouched in the corner until I felt better and kept working. Then it happened again a couple of weeks later. This time, I thought I better get to the doctor, though only after considerable encouragement from my partner. I explained my symptoms to the doctor and he said that irritable bowel syndrome was the most likely explanation but ran some blood and stool tests. I went back a few days later and he said that based on my inflammation levels, which were very high, it looked like I probably had Crohn's disease. He referred me to a gastroenterologist for a colonoscopy and I received the official diagnosis two weeks after I turned 26.

It was difficult to deal with my diagnosis and its implications initially. The particular form of Crohn's disease I have caused gynaecological complications that have had a significant impact on my life and that I'm still dealing with, seven years after being diagnosed. After being diagnosed, I was prescribed immunosuppressants and my gastroenterologist advised against googling the risks associated with them, so obviously that is one of the first things I did. I was terrified that they would cause

cancer and that I would die, crying in the shower so my family wouldn't see and worry. I had to self-inject one of the medications and this was painful and confronting. I felt sick, depressed, and distressed. My family was incredibly supportive but I felt alone and wanted to meet people who knew what I was going through. There were no Crohn's support groups in my area though, with the closest one about 150 kilometres away. Instead, like thousands of others, I joined and participated in several Facebook support groups. One of those groups had a member with Crohn's disease who posted regularly. She was dying from her disease and in palliative care, often posting photos of herself with tubes coming out of her nose. Coupled with the fear I already had from taking immunosuppressants, this sent me into a complete panic. It turns out, she was a 'catfish' and not sick at all, simply posting for attention. While online support was important for me initially, it wasn't without its issues. It took about a year to feel like the medication was really working and that I wouldn't die. During this time, I also found out what it feels like to not be constantly fatigued and when I look back on my symptoms this is the one that upsets me the most. I spent a lot of time feeling like I was barely existing and putting myself down for something that could have been alleviated had that first doctor shown some more care.

INTRODUCTION

Autoimmunity

There are an estimated 324,694 people in regional Australia suffering from a range of chronic autoimmune diseases (ADs) (Australasian Society of Clinical Immunology and Allergy 2016, p. 1; Australian Bureau of Statistics 2016a; Australian Institute of Health and Welfare 2014, p. 186). ADs are distinguished from other diseases by the role of the immune systems in their aetiology and pathogenesis (Rose & Mackay 2014b, p. 3). As opposed to diseases that may be caused by, for example, a virus or genetics, ADs occur when 'tissue injury is caused by T cell or antibody reactivity to self' (Davidson & Diamond 2014, p. 24). More simply, autoimmunity occurs when the body treats its own tissue as 'other', causing the immune system to damage that tissue. Like ADs, other diseases may also be characterised by 'activation of the innate immune system and an excess of inflammatory mediators (e.g. atherosclerosis, Behçet's disease) (Rose & Mackay 2014a, p. 19); however, it is the specific involvement of self-reactive T cells or antibodies that distinguishes ADs (Rose & Mackay 2014a, p. 6).

There are over eighty recognised ADs with some, such as lupus and rheumatoid arthritis, relatively prevalent and well known, while others, such as Evans syndrome and Rasmussen's encephalitis, are epidemiologically rare and rarely discussed (Hayter & Cook 2012). ADs manifest in a way that often makes them difficult to manage on numerous levels. They are unpredictable, characterised by periods of remission and flare. Their cause is unknown and diagnosis can be lengthy, difficult, and contested. They are often invisible, which can call the legitimacy of the sufferer into question. And while they can be medically managed they cannot be cured, although for some people adequate symptom management is never achieved. Furthermore, the medications commonly used to manage many ADs are not without

risks — cancer, medically induced lupus[1], sensitivity to sunlight, hair loss, weight gain, nausea, and fatigue are just a few regularly reported side effects.

Metaphor and identity

Common metaphors used by sufferers to describe ADs include that the body has turned against itself, is attacking itself, or has waged war on itself (Cohen 2004; Price & Walker 2015, p. 17). Such metaphors reflect how the immune system tends to be described more broadly as 'the body at war' (Martin 1994, p. 96). This filters through to how those with autoimmunity describe themselves, with terms such as 'fighter' and 'warrior' common in online illness communities. Such metaphors can be a source of strength and agency, while simultaneously conferring a moral responsibility onto those with ADs to either continue fighting or surrender (Grue 2016, p. 406). This can create challenges for those with ADs whose illnesses rarely have a clinically defined end point because autoimmunity is not constructed as something that you can 'beat' in the same way that, for example, cancer is. This can have implications for how women then construct and understand their autoimmunity.

Consequently, for many people an AD diagnosis is inevitably tied to their identities and sense of self, challenging perceptions of who they are, who they were, and who they might be. This intersects with the moralisation of health and illness which, in Australia, includes pervasive discourses of personal responsibility that cannot be separated from the illness experience. Those with chronic illness are typically considered responsible for their illness, and at the very least responsible for restoring 'normalcy' in the face of illness (Becker 1998, pp. 45-6). Restoring normalcy is expected to occur through positively moralised and 'productive' activities such as maintaining paid employment and caring for families, despite the impact that ill health has on people's ability to do so. This points to the significance of understanding moralisation and identity and their implications for the management of ADs, the importance of having appropriate structures in place to

[1] Also referred to as 'drug-induced lupus', medically induced lupus occurs when a lupus is caused by a medication. Common triggers include medications used to treat irregular heart rhythms (procainamide), blood pressure and hypertension (hydralazine), and tuberculosis (isoniazid). Medically induced lupus can also be caused by NSAIDs and biologic medications which are used to treat and manage autoimmune diseases.

support the negotiation of challenges to identity, and the need for support to assist in the day-to-day management of ADs in regional settings. Since women overwhelmingly bear the burden of AD diagnoses (they are 2.7 times more likely to contract an AD than men and 78% of individual ADs are more common in women than men) (Hayter & Cook 2012, p. 756) this study focuses specifically on the support needs and experiences of women with ADs.

Chronic illness

Anthropologists have made significant contributions to the study of chronic illness, particularly through 'interpretive efforts'; however it is recognised that 'there remain many questions about how people cope with a particular condition, manage their vicissitude, negotiate the confounding presence of other conditions (i.e. comorbidities), and deal with bodily symptoms that reflect social inequities and injustice' (Manderson & Smith-Morris 2010, p. 12). Despite accounting for 71% of deaths globally (World Health Organization 2021), biomedicine has been unable to develop cures for most chronic illnesses, and in many cases treatment options are inadequate (Stegenga 2018, p. 8). Consequently, it is important that efforts to reduce the prevalence of chronic illnesses occur alongside efforts to improve the everyday management of chronic illnesses for those for whom 'prevention' was never, or is no longer, possible (Warren & Addison 2020, p. 94).

In Australia, chronic illnesses tend to be grouped into four disease categories — cardiovascular diseases, cancers, chronic obstructive pulmonary disease, and diabetes (Australian Institute of Health and Welfare 2014, p. 94). These categories also reflect the categories of 'noncommunicable diseases' targeted by the World Health Organization (WHO 2014). Although several ADs fall into these categories (for example, rheumatoid arthritis and type 1 diabetes) the current chronic disease categories render ADs invisible and obscure the nature of the ADs that do receive attention. This is despite ADs affecting approximately 1 in 20 Australians (Australasian Society of Clinical Immunology and Allergy 2019b, p. 1). For example, both the Australian Institute for Health and Welfare (2014, p. 94) and WHO (World Health Organization 2014, pp. xii-xiv) suggest that tobacco use, physical inactivity, poor nutrition, and harmful use of alcohol represent behavioural

risk factors that are common to all four categories of disease, positioning chronic diseases as lifestyle diseases that are closely related to personal choice and decision-making (Whyte 2012, p. 65). In fact, in the case of ADs, including those examples listed above, the cause of disease is unknown with possible risk factors including genetics and environmental factors such as infectious organisms (Strober & Gottesman 2014, p. 179).

Such classification systems also act to obscure the impact of social, geographic, and economic factors, as well as that of comorbidities, which can have a significant impact on an individual's illness experience and access to appropriate care (e.g. Manderson et al. 2005). Discussion of the chronic illness burden also tends to focus strongly on mortality (e.g. World Health Organization 2014), leaving little space for those who must manage the day-to-day complexities of long-term illnesses that may not necessarily be fatal. This reinforces the focus on prevention (i.e. preventing mortality rather than improving quality of life) through mitigation of lifestyle factors that contribute to common chronic illnesses, limiting access to the day-to-day care people with chronic illnesses actually need. This can be exacerbated for those in regional, rural, and remote Australia where appropriate care can be more difficult to access. Thus, a key aim of this thesis is to highlight the care needs and experiences of those managing long-term AD in regional Australia.

Chronic illness in regional Australia

Despite frameworks being in place to address rural-metropolitan healthcare divides (Australian Government Department of Health 2012), those who live with chronic illnesses in regional Australia (comprising, 'inner regional' and 'outer regional' areas, as defined by the Australian Bureau of Statistics Remoteness Classification (Australian Bureau of Statistics n.d.-b)) continue to face fewer options for healthcare, relative to their metropolitan counterparts. Regional healthcare systems in Australia are characterised by lower numbers of general practitioners, medical specialists, and allied health services (Australian Government Department of Health 2012, p. 12; Australian Institute of Health and Welfare 2010, p. 248). For those with chronic illnesses in regional areas, this translates into restrictions in terms of choice of practitioner and practitioner expertise and can necessitate regular travel

to access appropriate services. These barriers to accessing care compound the financial, physical, temporal, and emotional costs associated with chronic illness management. Regionality also exacerbates the effects of health risks associated with age, sex, education, ethnicity, and socioeconomic status (Smith et al. 2008). Due to the difficulties associated with managing chronic illnesses in regional areas, it is essential that appropriate, effective, and accessible care is available. This is particularly important since the availability or absence of care can influence the course of an illness, the illness experience, and the risk of developing further chronic conditions (Manderson & Warren 2016).

Research aims

This thesis aims to understand and highlight the often overlooked care needs and experiences of women with ADs in regional Australia through an exploration of the relationships between autoimmunity, identity, and moralisation. Using a life-story approach to ethnography, I explore how moralisation and identity intersect with care experiences as women shift through different phases of autoimmunity. These include symptom onset and diagnosis, while also considering how women make sense of autoimmunity and what this means for how they negotiate care over their lifetimes with autoimmunity.

Thesis outline

In light of these research aims, Chapter 2 provides a discussion of the literature that informed this research project and the development of the above research aims and includes literature related to chronic illness support, care, identity, and morality. I consider how the intersection of theories of biographical disruption and moral breakdown can provide a lens through which women's care needs and experiences can be better understood across their lifetimes. This is followed by an explanation of the methodical approach to the study and the data collection and analysis procedures that were adopted (Chapter 3). I describe the life-story ethnography approach and the interviews conducted with seven women in regional Queensland over the course of twelve months. These aim to capture the personal, emotional, and lived experiences of women in regional Australia with ADs.

The substantive chapters of the thesis (Chapters 4-6) follow a narrative structure broadly aligned with key phases in the experience of autoimmunity. These include finding a diagnosis (Chapter 4), negotiating care following diagnosis (Chapter 5), and making sense of autoimmunity (Chapter 6). In Chapter 4, I explore women's experiences of diagnosis through a framework of care. I focus on women's experiences of disconnected care, the avoidance of care, and the denial of care and consider how identity and moralisation are implicated in these experiences. I then examine the intersection of these with the ambiguity many women experience during protracted diagnosis periods.

This is followed by an exploration of common care needs after diagnosis, which include access to effective healthcare, peer support, and practical and financial support (Chapter 5). Here, I argue that access to care can be both facilitated and constrained by diagnosis and explore how women negotiate their access to care accordingly. This includes consideration of how identity, moralisation, and hierarchies of disease may affect access. I then examine how women come to understand autoimmunity in the broader context of their lives and the day-to-day complexities of managing autoimmunity, with attention to how the experiences that shape their lives and identities are implicated in how they make sense of autoimmunity.

In Chapter 6, I consider understandings of autoimmunity as an attack on the self, as well as a systemic bodily issue where autoreactive cells are interpreted as matter-out-of place. I go on to explore how women interpret the cause of their own autoimmunity, which included stress, environmental causes, and hereditary, to identify how these may influence their care needs.

The final chapter draws together these findings, considering how a framework of agency and more flexible approaches to care, decoupled from diagnosis, may improve access to care for women with ADs in regional Australia.

CHAPTER 2: LITERATURE REVIEW

There has been little examination of the challenges associated with autoimmunity and the care needs and experiences of those with ADs. Challenges to identity are widely recognised as significant for those with chronic illnesses, as are those associated with the moralisation of health and illness. Identity and moralisation have also been overlooked as lenses through which care needs and experiences can be explored. Consequently, questions remain regarding how those with ADs navigate chronic illness alongside associated disruptions to their identities and the moralisation of those who are ill. To provide a framework for exploring these issues I examine how chronic illness can impact identity and the self, disrupting a person's narrative sense of who they are and who they might become. These disruptions can intersect with the moralisation of health and illness, where tensions between what 'should' be done in the face of illness and what 'can' be done despite illness are illuminated through Zigon's (2007) concept of the 'moral breakdown.' These issues associated with identities and moralisation, in addition to the physical realities of autoimmunity, mean that access to support is particularly important for women with ADs. However, current conceptualisations of support cannot adequately account for the complexity of living with poorly understood illnesses. Instead, I draw on a framework of care to understand how women navigate life with autoimmunity.

Identity, self and chronic illness

It has long been recognised that a chronic illness diagnosis can lead to challenges to, and shifts in, identities and the self (Charmaz 1983; Mendelson 2006, p. 990). While some focus on the loss of self and identity that may be experienced with chronic illness (Charmaz 1983), others emphasise the agency of the chronically ill and the identity transformations and reconstructions that are often experienced (Miles 2009; Tewksbury & McGaughey 1998). Many of these shifts in identity are related to the realities of living with chronic illness, such as modifying socially valued roles (e.g. partner, parent, productive worker), managing medication side effects, coming to terms with potentially shrinking social networks and a reduced

ability to participate in leisure activities, and facing a suddenly uncertain future (McQuoid 2017, pp. 88-9; Mendelson 2006, p. 990; Nihof 2018, p. 12). Thus, those with chronic illness can often no longer 'engage the world as [they] once could' (Leder 1990, p. 81).

Also implicated in identity challenges are shifts in people's relationships with their bodies when they become chronically ill. Chronic illness can disrupt a person's sense of having a normally functioning body (Charmaz 1995, p. 657) as well as their unconscious awareness of their body and its functions (Leder 1990, p. 76; Manderson 2011, p. 24). This is particularly the case since bodies and bodily functions tend to be given little thought until they are disrupted, whether through felt experiences such as pain or nausea, or the clinical observation of abnormalities such as cancer cells (Leder 1990, p. 71; Manderson 2011, p. 26). Of course, many sensations temporarily break through this unconscious awareness (Leder 1990, p. 76). Chronic illness, however, can create ongoing disruption (Leder 1990, p. 76). These changes can be invisible, visible, or a combination of both. Visible changes, such as curled hands from rheumatoid arthritis or a bent back from ankylosing spondylitis can engender stigma, shame, and discrimination, further increasing the social and moral suffering of the chronically ill (Masana 2011, p. 131; Yang et al. 2007). Conversely, invisible changes to the body – that is, those that cannot typically be seen with the naked eye – may somewhat protect those who are ill from these social and moral consequences of chronic illness (Masana 2011, p. 131). They can, however, come at the expense of access to social support and appropriate healthcare (Masana 2011, pp. 132-3). Regardless of whether they are visible or invisible, these bodily disruptions typically necessitate close attention to bodily functioning, appearance, and sensation which can become crucial for illness management. Where once a person may have given little thought to their bodily functioning, in light of chronic illness they may find their day suddenly highly structured around this, further challenging their identity as someone with a 'properly' functioning body.

Underlying these accounts of the relationship between chronic illness and identity are particular understandings of identity and the self. These include that identities are multiple, multidimensional, fluid, 'linked to the circulation of cultural meanings in a society', and constantly being negotiated between the self and others

(Goffman 1990 [1959]; Taylor & Spencer 2004, p. 4). Thus, identities are not static but reflect a process of identification, or of 'being' or 'becoming' (Jenkins 2008, p. 17). Consequently, identities emerge out of a dynamic process of identification or performance, which involves 'synthesising relationships of similarity and difference' (Goffman 1990 [1959]; Jenkins 2008, p. 18). A range of factors can influence identities including, but not limited to the body, culture, gender, age, ethnicity, education, sexuality, class, relationships, and life experience.

These understandings of identity have been criticised as analytically ambiguous and vague, and implying sameness over time (Brubaker & Cooper 2000; Malešević 2003, pp. 270-1); however, more recent conceptualisation of identity take these into consideration. While there have been calls to replace the category 'identity' with 'identification', which refers to the process of identifying both oneself and others (Brubaker & Cooper 2000, pp. 14, 7), current understandings of identity explicitly recognise that identities are not static or the same over time but represent a process of 'being' or 'becoming' (e.g. Jenkins 2008). Part of the process of identification is 'differentiation from others' (Sokefeld 2001, p. 535), such that 'similarity' and 'difference' are interconnected and cannot be separated in the context of identity (Jenkins 2008, p. 21). As Jenkins (2008, p. 21) argues:

> Neither makes sense without the other, and identification requires both, since to identify with a particular category or group requires an understanding that one shares similarities with that category or group, but also an understanding that one is different from other categories and groups.

Of course, the process of identification is not this clear cut since both similarity and difference can be intersecting and contradictory; however, the point is that neither can exist without the other.

Implicitly linked to these understandings of identity are Western conceptualisations of the relationship between identity and the self (Malešević 2003, p. 273; Moore 1994, pp. 136-7; Sokefeld 1999, pp. 417-8). The self can be conceptualised as a 'reflexive sense' of one's own identities, mediated through understandings of similarity and difference that allow an individual 'to distinguish self-consciously between himself or herself and everything else' (Jenkins 2008, p.

49; Sokefeld 1999, p. 424). Without a sense of self, an individual would find it difficult to act (Jenkins 2008, p. 49). The self can be considered 'superordinate to (though not detached from) the plurality of identities' since it provides the overarching continuity for the multiple identities a person inhabits (Sokefeld 1999, p. 424). The self is not static nor passive, rather 'it is continuously in motion and subject to change' (Sokefeld 1999, p. 424). The agency inherent in the self is demonstrated by the ability of individuals to 'manage identities', including the management of conflicting identities (Sokefeld 1999, p. 424). Thus, the self can be conceptualised as the reflexive sense 'that manages . . . plural identities, lending coherence and continuity to the person's experiences' (Smith 2012, p. 52).

Although many definitions of the self refer to a stable core that manages multiple identities in continually changing contexts, it can be argued that the self is no less stable than an individual's shifting identities (Ewing 1990, p. 258; Smith 2012, p. 56). As identities shift, so does the self. For example, Ewing (1990, pp. 258-9), reflecting on a conversation with a Pakistani woman who, within a short space of time, presented herself as an 'obedient daughter', a 'clever politician' and a 'good wife', among other identities; states:

> When we consider the temporal flow of experience, we can observe that individuals are continuously reconstituting themselves into new selves in response to internal and external stimuli. They construct these new selves from their available set of self-representations, which are based on cultural constructs. The particular development histories of these self-representations are shaped by the psychological processes of the individual. As a result of the process of self-reconstitution, an external observer may see shifts in self-presentation of which the participants in an interaction are unaware.

From this perspective, the self simultaneously provides continuity to experience while also shifting in response to changing circumstances. This reflects, to a certain extent, a psychological perspective of the self as a site of both continuity and change. In this view, the self 'can not only be clarified, elucidated and articulated, but also enhanced, refocused and strengthened . . . [it is] a continuous work-in-progress that develops through concerted effort — but also through simple life-experience itself' (Smith 2012, p. 56). Finally, Ferrara (2002, p. 76, emphasis in original) argues that

‘an identity is a *representation* of the self as perceived by the person.’ From this perspective, identity, or multiple identities, constitute components of the self. While it can be analytically useful to separate the two (e.g. Sokefeld 1999), in practice each is inextricably linked to the other. Thus, both identity and self can be conceptualised as a continuous process of ‘becoming’ (Jenkins 2008, p. 17; Smith 2012, p. 56; Taylor 1989, p. 47).

When identity is positioned in relation to the self in this way, that is, that a ‘core’ self, constituted through narrative, ‘manages’ an individual’s multiple and fluid identities, the argument that ‘identity’ equates to sameness becomes less relevant (Sokefeld 2001, p. 527). In the context of chronic illness, which often involves the experience of change and contradiction, definitions of identity that highlight its multidimensional and dynamic nature are particularly appropriate for providing a framework with which to understand the similarly multidimensional and dynamic experience of autoimmunity. The category ‘identity’ also encapsulates internal and external aspects of identity, both of which are relevant in the context of care since how one perceives oneself, and how others perceive them, impact the illness experience and thus care. What the above criticisms do highlight is the importance of adopting nuanced approaches to identity to ensure its analytical usefulness is not distilled. Thus, for the purposes of this study, identity will be considered a representation, or set of representations of the self that individuals harness as a means of understanding themselves and connecting with and presenting themselves to others. Although conceptualising identity as representations of the self may appear to shift its meaning towards that of ‘outcome’ (Brubaker & Cooper 2000, p. 16), it is also considered to be a reflexive and continuous process of becoming, influenced by culture, experience, and the dynamic interplay of similarity and difference, such that representations and the process of creating, developing, refining, and discarding those representations are inextricably intertwined.

These processes of becoming are facilitated by a consistent, reflexive, narrative self that orders and integrates events to create a sense of our present, past, and future (Giddens 1991, pp. 47-8; Ochs & Capps 1996, pp. 20-1; Taylor 1989, pp. 47-8). In this sense, ‘narrative and self are inseparable’ (Ochs & Capps 1996, pp. 20-1), with the self understood as ‘a story we tell our self about our self, while at the

same time being a story that we tell others about our self', shifting the narrative self from one that is conceptualised as acting internally, to acting both internally and in relation to others (Smith 2012, p. 57). These views of the self as a consistent narrative are borne from the Western normative view that 'each body houses . . . one self' (Flanagan 1998, p. 65). This view occurs alongside the almost contradictory idea that identities are multiple, fluid, and the subject of continuous 'personal and moral development (Flanagan 1998, p. 65). Flanagan (1998, pp. 65-6) argues that the introduction of the idea of a narrative self provides the consistency required to conform to the 'one body, one self' norm by integrating multiple, changing identities into a biographically coherent self. Multiple 'transformed' identities are 'narratively connected' to create a continuous self (Flanagan 1998, p. 66). Individuals who do not conform to the normative 'one body, one self' ideal tend to be pathologised, as in the case of multiple personality disorder where a single individual expresses multiple narrative selves (Flanagan 1998, p. 66). Thus, consistent with the conceptualisations of the relationship between the self and narrative, this study conceptualises the self as a narrative, 'reflexive sense' of one's own identities, mediated through understandings of similarity and difference and allowing an individual 'to distinguish self-consciously between himself or herself (sic) and everything else' (Jenkins 2008; Sokefeld 1999, p. 49).

In the case of chronic illness, the concept of a consistent 'narrative self' is particularly important. When faced with a chronic illness, its symptoms, and the impact of these on daily life, people often engage in meaning-making processes to reconfigure their sense of 'who they have been, and who they can be' (Barker 2002, p. 282). Estroff (1993, p. 260) views this process as occurring along a continuum, positing that:

> Each person locates their illness in relation to self along a continuum of subjectness; that is, how closely linked to one's self or separated as distinct from one's self the illness is considered.

Various factors may influence the degree to which a person incorporates or separates their illness from their sense of self, for example, the location(s) of the illness in the body and whether or not it is perceived as a constant or intermittent presence (Estroff 1993, p. 260). A range of 'sources of suffering' that represent a challenge to, or loss

of, one's self when faced with a chronic illness have also been identified (Charmaz 1983). These include social isolation; loss of independence; and loss of control, both due to restrictions related to illness or loss of control of bodily functions (Charmaz 1983, pp. 172-90; Frank 2013, p. 57). Other sources of suffering include interactions with others that challenge particular identities or sense of self, particularly for those whose illness is visible and pressure from family members to maintain previous levels of daily functioning, for example, in relation to sexual activity, employment, or household tasks (Charmaz 1983, pp. 172-90). The discrediting of an individual's illness experience, such as questioning whether an individual is 'actually' in as much pain as they express; and feeling like a burden to others, were also identified as contributing to challenges to, or a loss of, one's self (Charmaz 1983, pp. 172-90). Of course, this is not a definitive 'list' of the consequences or experiences of chronic illness; however, it does illustrate the potential significance of a chronic illness diagnosis for everyday life.

Much of the suffering associated with chronic illness is closely linked to identity. For example, 'loss of independence' can be experienced as a practical loss, but also as a loss, or fracturing of, one's 'identity as an independent person' (Lempp et al. 2006, p. 112). A range of identities can be affected, such as those related to being 'healthy', or a 'friend', 'employee', 'partner', or 'parent' (Lempp et al. 2006, pp. 112-3). In fact, Karasz et al. (1995) found that among women with lupus an inability to perform socially valued roles was more likely to create psychological distress than the physical symptoms of lupus. Charmaz (1983, p. 191) also describes the reality for some with a chronic illness diagnosis who become, temporarily at least, more dependent on the 'reflections of self by others' at the same time that their relationships with others weaken or become strained. It is at the intersection of these conflicting phenomena that care may become increasingly important, particularly where it involves 'experientially similar others' (Gage 2013).

Biographical disruption

Within the social sciences, the relationship between identity and chronic illness has been broadly conceptualised within the framework of chronic illness as 'biographic disruption' (Bury 1982, p. 42; Pound et al. 1998, p. 490; Williams 2000),

which provides a useful framework for exploring the above issues. Bury (1982, pp. 169-70) conceives of biographical disruption in an illness context as involving three factors: (1) a disruption to a person's 'taken-for-granted assumptions and behaviours', including assumptions about a person's body; (2) a disruption to a person's understanding of their life-story or biography that requires a renegotiation of, or transformation in, how they see themselves in the past, present, and future; and (3) a 'mobilisation of resources', such as support networks, to respond to disruption. Thus, illness is interpreted as a significant life event that triggers a range of responses, including negotiating challenges to existing identities. A key assumption of the biographical disruption model is that 'self-identity relies on the maintenance of a continuous narrative of the self', reflecting current conceptualisations of identity and the self (Reeve et al. 2010, p. 179).

The concept of biographical disruption has been criticised on a number of levels. First, it has been recognized that a focus on illness as an identifiable disruptive event neglects the experiences of those who are born with life-long illnesses, rendering biographical disruption 'adult-centric' (Williams 2000, p. 50). It has also been argued that the assumption that all illness events can be interpreted as biographical disruption fails to consider factors such as age and class. For example, illness in older age may be considered inevitable or expected, such that it is 'biographically *anticipated*', as opposed to disruptive (Pound et al. 1998, pp. 502-3; Williams 2000, p. 51, emphasis in original). Similarly, biographical disruption may reflect the privilege inherent in assuming that good health can be maintained. This contradicts the experiences of those for whom resources, and therefore access to healthcare, are limited, making illness more likely to be normalised (Williams 2000). Carricaburu and Pierret (1995) suggest that a focus on biographical disruption has overshadowed other illness experiences. For example, in their study amongst men with haemophilia who were later diagnosed with HIV, they found that those men who had 'organised their biographies' around haemophilia, experienced 'biographical continuity' when diagnosed with HIV (Carricaburu & Pierret 1995, p. 81). Rather than representing biographical disruption, HIV diagnosis '[reinforced] . . . their identities as haemophilic persons . . . [it] led them to reinforce measures of the sort already taken; there was no disruption' (Carricaburu & Pierret 1995, p. 81). In contrast, for some, and notably for those suffering from chronic pain, continual

disruptions are experienced, as opposed to a single defining illness disruption (Honkasalo 2001).

Williams (2000, p. 52) further observes that the potential for biographical disruption to precede illness has been underexplored. Although she does not discuss biographical disruption, Charmaz's (2002a) analysis of 'Cynthia's' experience of Parkinson's disease reflects this point. Cynthia does not refer to her Parkinson's diagnosis as the most significant disruptive event in her life, but instead the car accident that preceded it, as well as being the sole carer of her daughter who was diagnosed with diabetes as an infant (Charmaz 2002b, p. 33). In fact, she interprets her own illness as a consequence of these two factors, rather than as an isolated, disruptive incident. This is not to suggest that the effects of Parkinson's disease did not have a significant effect on her life, rather it illustrates that the onset of illness is not necessarily considered the 'key' disruptive event in the context of illness. Honkasalo (2001) makes a similar point in her study of the Finnish experience of chronic pain. She argues that rather than the onset of chronic pain representing a single defining biographical disruption, in the context of Finland's recent history, characterised by 'wars and . . . social upheavals', it represented a 'continuation of disruptions — one among many' (Honkasalo 2001, p. 343).

Despite these critiques of biographical disruption, its usefulness as an analytical tool remains. In fact, rather than arguing for the discarding of the concept, Williams (2000, p. 62) asserts that future work on the relationship between illness and biographical disruption requires 'greater attention to the timing, context and circumstances within which illnesses are 'normalised' or 'problematised', and 'the manner in which identities are threatened or affirmed.' I argue that biographical disruption provides a valuable lens through which to explore the care needs and experiences of women with ADs. By focusing on points of disruption (past, present or anticipated) within the wider context of a person's life, insights into the needs, desires, and experiences of women with ADs can be illuminated, particularly since in many cases instances of biographical disruption may coincide with an increased need for care. Exploring the absence of biographical disruption where it would normally be expected to occur, such as when a person is diagnosed with a serious long-term

illness, may be equally telling. Finally, biographical disruption provides a window through which to explore the interplay of identities, chronic illness and care-seeking.

Identity and care

Despite a significant body of literature on the impact of chronic illness on identity (e.g. Asbring 2001; Charmaz 1983; Estroff 1993; Frank 2013; Honkasalo 2001; Mendelson 2006; Wisdom et al. 2008) the implications of the relationships between autoimmunity and identity for care remain underexplored. Understandings of these relationships for chronic illness more broadly, however, are important for informing this. Identity can be implicated in care in various ways throughout different illness phases. For instance, a person's identity as someone who is 'healthy' may affect their perception of disease risk, which in turn can affect help-seeking behaviour (Seppola-Edvardsen & Risør 2017, p. 36). After being diagnosed, new illness identities may again change perceptions of risk and how people access care, with some more readily seeking help for symptoms that may not have previously concerned them (Seppola-Edvardsen & Risør 2017, p. 37). The importance of retaining socially valued identities, such as 'mother' may also be implicated in care and reflect its multidimensional nature. For instance, some women may prioritise the care of their families over attending to their own illnesses, leading to worsening health (Mendenhall 2016, pp. 40-1; Pollak 2018, p. 203). Thus, examining how people access and engage in care in relation to identity can open up new ways to think about caring for people with ADs, as well as the potential ways identity (re)construction could be used as a coping mechanism.

Although identity is not the only factor that influences help-seeking, a dedicated focus on identity and care may offer alternatives to traditional approaches which often focus on assessing barriers (e.g. financial, cultural, geographical) to help-seeking. This focus may also illuminate how identity itself may be used as a health-management behaviour — that is, constructing or reconstructing identities to incorporate what may otherwise be considered a health issue, rather than pathologising or medicalising it. Although it could be speculated that this is less likely to occur when symptoms are physical, such as unintended weight loss or fatigue, it is quite possible that in certain contexts individuals could incorporate such symptoms into their existing identities, or create new identities, rather than seeking

medical help. An extreme example of this has been observed in online 'pro-anorexia' or 'pro-ana' communities where participants reject a medicalised view of anorexia and encourage behaviours that would otherwise usually be pathologised (Warin 2010, p. 82). Instead, they adopt and foster both collective and individual identities based on 'thinness', control and 'purity' in opposition to medicalised models of anorexia where the focus is on illness and recovery (Fox & Ward 2006, pp. 471, 473)

There are further implications of identity for care among those who have been diagnosed with a chronic illness, particularly since chronic illnesses also tend to co-occur with mental health issues such as anxiety or depression. The way one incorporates (or does not incorporate) physical and psychological symptoms into their existing identities, or the way they construct new identities, could have implications for the care they seek, their expectations of experiences of care, and the appropriateness of different forms of care. Where identity can be identified as influencing help-seeking, healthcare providers should 'develop alternative ways in which people can access [care] without having to jeopardize their identity' (Verouden et al. 2010, p. 319). What remains underexplored are the implications of identity reconstruction and transformation for care and the development of particular forms of care in the context of autoimmunity. How do shifts in, or attempts to maintain existing identities or self-concepts influence experiences of care? Conversely, how does care influence shifts in, or attempts to maintain existing identities or self-concepts? How do shifts in, or attempts to maintain existing identities or self-concepts influence care-seeking? What does this mean for the health and wellbeing of women with ADs?

Morality

Morality is another key lens through which the experience of care can be explored. While it is not the intention here to examine debates regarding the nature of morality and ethics, it is important to differentiate between the two. Broadly, morality can be considered what one 'must' or 'should' do based on the expectations of sources of moral authority, while ethics reflects what one can or should do within the constraints of one's own 'degree of power . . . capabilities and capacities' (Brown 2009, ch. 1, np, emphasis in original; Smith 2011, p. 125; Zigon 2007, p.

137). While both terms include expectations of what should be done (Black 2018, pp. 80-1), the distinction between what should be done and the capacity to act is important when discussing the moralising of health since the degree to which a person can engage in health-related behaviours is inevitably constrained by a range of factors such as socioeconomic status, access to resources, access to social and cultural capital, physical capabilities, and time. How people engage in health-related behaviours, including care-seeking, is also shaped by moral authorities.

Sources of moral authority include the institutions, groups or structures that produce and/or reproduce the 'moral order' across the different domains of life. Durkheim (2002 [1961], p. 29) argues that individuals acquiesce to sources of moral authority, not because to do so is 'attractive' but 'because there is some compelling influence in the authority dictating it.' Sources of moral authority are not culturally universal, with different forms of authority differentially weighted depending on the cultural context. For instance, in Western societies biomedicine represents a significant source of moral authority on health, while in non-Western societies local cosmologies involving phenomena such as witchcraft and spirit possession may reflect the dominant moral authority on health (Argenti-Pillen 2000, pp. 90-1). Within cultures, individuals and groups may also place a higher or lower value on particular forms of moral authority. Mathews (2000) illustrates this in her discussion of women's breast cancer support groups in the United States of America (USA), where women's dissatisfaction with biomedically-focused groups was in part influenced by a preference for, or stronger deference to, the moral authority of the Protestant Church as opposed to biomedicine. In this study, key sources of moral authority on health and illness in a Western context include biomedical systems and institutions such as the state and popular media. It is also possible that support groups themselves may represent a source of moral authority that either challenge or reflect the moralisation of health and illness by the biomedical system, the state, and media.

Morality in anthropology

Durkheim's theories of morality have been particularly influential in the social sciences. He broadly defines morality as 'a system of rules of action that predetermine conduct', which 'state how one must act in given situations'

(Durkheim 2002 [1961], p. 24). He stresses that morality does not lie within the individual, nor is there an overarching morality (Durkheim 2002 [1961], p. 26). Rather, morality exists as 'an infinity of special rules' that are context-dependent and permeate all domains of life, such as families, relationships, gender, the workplace, and health and illness (Durkheim 2002 [1961], pp. 25-6). Durkheim (2002 [1961], p. 27) describes an inextricable link between morality and social customs, stating:

> So close is the connection between custom and moral behaviour that all social customs almost inevitably have a moral character. When a mode of behaviour has become customary to a group, whatever deviates from it elicits a wave of disapproval very like that evoked by moral transgression . . . If all social customs are not moral, all moral behaviour is customary behaviour. Consequently, whoever resists the customary runs the risk of defying morality.

Thus, according to Durkheim, morality is closely associated, if not 'congruent with society (or culture)' (Zigon 2007, p. 132). This conflation of morality with society or culture has left morality ill-defined, leading to a ''Durkheimian collapse' (Cassaniti & Hickman 2014, pp. 252, 6; Laidlaw 2002, pp. 312-3; Robbins 2007, pp. 293-4; Zigon 2008, p. 1). There are disagreements and contradictions regarding how to conceptualise and differentiate between morality and ethics, whether to differentiate between them at all, and how morality is discussed in anthropology and examined ethnographically (Cassaniti & Hickman 2014, p. 252; Mattingly & Throop 2018, pp. 476-8). Zigon (2008, pp. 1-2, 23) argues that anthropologists have at times lacked awareness of their own moral assumptions, based on Western philosophical thought, and unwittingly imposed their 'personal moral views onto the lives of the people they study'. Consequently, many studies of morality are not explicitly grounded in morality at the outset; however, a conscious focus on morality at the beginning of a research project may help to mitigate this problem (Zigon 2008, p. 2). In light of these criticisms and the significance of morality in health and illness, this project has a specific focus on morality from the outset. It recognises that while morality may not necessarily be congruent with culture, it is inevitably shaped by culture.

Alternative approaches to the anthropological study of morality are particularly useful for this study. For example, Zigon (2007) argues for an anthropology of morality that is founded on the notion of the 'moral breakdown.' He

observes that ‘most people consider others and themselves moral most of the time’, making morality an ‘unreflective’ and ‘non-intentional’ state of being (Zigon 2007, pp. 133, 135). Conscious moral decision-making occurs when there is a moral breakdown —that is, when a person is forced out of their typical unreflective state to respond to ‘ethical dilemmas, troubles, or problems’ (Zigon 2007, p. 140). A moral breakdown can occur for any number of reasons, from the relatively mundane, such as when a person has the opportunity to board a train without buying a ticket, to societal-wide moral breakdowns, such as those that may occur during times of significant social and political change. At the point of a moral breakdown is an ‘ethical moment . . . the moment in which ethics must be performed’ (Zigon 2007, p. 137). Zigon (2007, p. 139) defines ethics as ‘a tactic performed in response to the… moral breakdown to return to the unreflective moral dispositions of everydayness’. In doing so, he draws on Badiou’s (2001, cited in Zigon 2007, p. 139) maxim ‘Keep Going!’, where, regardless of the characteristics of an ethical dilemma or problem ‘one must persevere and ‘Keep Going!’ to ‘get out of the [moral] breakdown’. Zigon (2007, pp. 139-40) concludes that:

> …what is important in the moment of moral breakdown is not ‘to be good’ or ‘to be a good–’, but to get back to the unreflective moral dispositions of everyday life. It is having accomplished this return that is considered good, not the act itself.

Thus, in Zigon’s conceptualisation, particular acts are not considered inherently good or bad, rather, value is placed on whether those acts address the moral breakdown by facilitating a return to normality.

Conversely, and specifically in response to the ‘Durkheimian collapse’, Cassaniti and Hickman (2014, p. 256) advocate for ‘delineating the moral domain’, that is, identifying the ‘multiple domains of social life that are differentially given moral weight.’ Cassaniti and Hickman (2014, p. 256) position their approach as similar to but contrasting with other approaches that focus on a single aspect of social life, such as the moral breakdown (Zigon 2007), suffering (Good 1994), goodness (Robbins 2013), or evil (Csordas 2013). Instead, Cassaniti (2014) specifically calls for an anthropology of morality and emotion. Drawing on fieldwork in Northern Thailand, she observes that emotions surrounding illness and death are differentially moralised amongst Karen Christians and Northern Thai

Buddhists. Amongst Buddhists, emotions such as 'calmness', 'acceptance', and 'letting go' were morally valued responses to the death of 'Sen', a friend and family member; while stress and having a 'hot heart' (akin to feeling agitated) were considered inappropriate (Cassaniti 2014, pp. 284-7). Conversely, among Karen Christians appropriate and morally valued responses to Sen's death and preceding illness included anger, sadness and feeling 'hot-hearted' (Cassaniti 2014, p. 287). Cassaniti (2014, p. 287) suggests that this comparison of contradictory moralised emotions allows for an understanding of emotions as 'locally constructed moral practices.' In this case study, the valuing of calmness, acceptance and letting go was strongly linked to the moral authority of Buddhism, and theories of karma, impermanence, and detachment (Cassaniti 2014, pp. 288-9). Cassaniti (2014, p. 290) speculates that examining emotion as a 'site for moral practice' illuminated 'what was happening morally' during Sen's illness and death, something that would have been overlooked otherwise. Cassaniti (2014, p. 283) draws on Zigon's (2007) theory of the moral breakdown, conceptualising Sen's illness and then death as a point of moral breakdown and ambiguity where his 'friends and family grappled with how to feel, and how to feel better.' In doing so, she illustrates the usefulness of the concept of the moral breakdown, as well as the value of focusing on a particular moralised aspect of social life.

Moralising health and illness

Cassaniti's (2014, p. 283) case study centres on moral responses to health and illness, which is unsurprising since health and illness are highly moralised. In Western contexts, this can manifest in many ways including, for example, through discourses of personal responsibility, positivity, transformation, and moral expectations surrounding productivity. Although these are not the only aspects of morality that influence illness experiences, they represent some of the key avenues through which the relationship between morality and illness can be illuminated in a Western context. Rosenberg (1997, p. 44), reflecting on current and historical notions of health and morality, argues that:

> The ideal-typical trajectories built into twentieth-century concepts of specific disease imply individual dramas of right and wrong, impulse and denial. Inevitably, such physiologically informed perceptions of self fit easily and consistently into the more general cultural value of control and the achievement of

> moral stature through the denial of material satisfaction. Eschewing fried foods is resonant with moral as well as biochemical meaning. Exercise brings a sense of worth as well as improved cardiovascular status. And monogamy imparts to believers moral stature as well as risk reduction.

Thus, morality is inextricably linked to illness and disease, suggesting that 'deeply held, if often unstated, sensibilities about right and wrong, good and bad, responsibility and danger' are 'embedded' into both contemporary and historical understandings of disease (Brandt & Rozin 1997, p. 1). Consequently, 'moral beliefs and conventions typically have a *material* impact on patterns of disease, clinical care, and the experience of illness' (Brandt & Rozin 1997, p. 5, emphasis in original).

It has also been observed that 'moral judgements and their accompanying cultural meanings are often viewed as the source of additional stigma and despair for patients', while particular behaviours 'associated with health and disease resistance, such as cleanliness, often have moral significance' (Rosenberg 1997, p. 2). Although a conscious effort has been made to position biomedicine as existing outside of morality (i.e. as unbiased and scientifically objective as opposed to 'subjective, relative and indeterminate'); such a view itself represents 'a particular moral position' (Brandt & Rozin 1997, p. 2). In combination, these factors so intertwine morality with health and illness that it is difficult to separate them from these domains. Its reach extends from influencing the behaviours and experiences of individuals to shaping social institutions such as biomedicine.

Healthism

'Healthism' or 'health as a moral obligation' has been identified as a lens through which 'people's experiences of health and illness have come to be understood within contemporary neo-liberal, Western society' (Clarke et al. 2003, p. 171; Crawford 1980; Gibson et al. 2015, p. 132). Healthism is grounded in the notion of self-management and self-care with individuals positioned as morally responsible for their own health and bodies (Clarke et al. 2003, pp. 171-2; Gibson et al. 2015, p. 133; Petersen 2002, p. 197). Clarke et al. (2003, pp. 171-2) observe that:

> Increasingly what is being articulated is the individual moral responsibility to be and remain healthy or to properly manage one's chronic illness(es), rather than

> merely attempt to recover from illness or disease when they "strike" (Clarke et al. 2003, pp. 171-2).

Thus, regardless of whether or not a person is considered responsible for causing their illness, they are 'seen as responsible for restoring normalcy' (Becker 1998, pp. 45-6). It is also recognised that as healthism discourses both produce and reproduce the idea that individuals have a moral obligation to maintain their health, they simultaneously '[buttress] the increasing withdrawal of government support and intervention from health and welfare' and act to avert attention away from the political ecology of illness and disease (Gibson et al. 2015, pp. 133, 46). Conversely, by positioning individuals as responsible for their own health through health-promoting and risk-management behaviours (e.g. diet, exercise, complementary and alternative medicine, and regular preventative screenings), space is created for people to take control of their health and challenge the traditional patriarchal power structures of biomedicine (Gibson et al. 2015, p. 133). Although there are benefits to this, ultimately the impetus for personal responsibility, and the particular form that related behaviours take, may still come from the social and moral expectation to be healthy.

Within discourses of healthism 'individual behaviour, attitudes, and emotions' are perceived as the primary 'symptoms needing attention', despite the aetiology of disease being recognised (Crawford 1980, p. 368). Furthermore, healthy people are positioned as 'model' people, placing social value on health itself, as well as behaviours considered beneficial to health (Crawford 1980, p. 380). This in turn attaches a negative value to illness and behaviours constructed as 'unhealthy'. Crawford (1980, p. 382) argues that healthism increasingly positions poor health as deviant, making it important for people to adopt personal identities 'which [match] dominant social expectations' and stand 'in opposition to the identity of deviant.' Consequently, to be considered healthy (i.e. moral) one must adopt, or at least perform, identities that reflect this such as 'gym junkie' or 'dieter.' For those who are chronically ill, performing such identities can become increasingly difficult when trying to manage the day-to-day realities of illness. Thus, people with chronic illnesses may be less valued because they are ill, and less valued again if they cannot perform identities associated with being 'successfully ill.' This may include, for

instance, following medical advice, maintaining employment, exercising regularly, or following a particular diet, illustrating the strong ties between the domains of identity and morality.

Although the expectations and values underpinning healthism often lead to a focus on self-blame, 'locating illness on a moral plane' can simultaneously give meaning to illness and suffering, something I explore in more depth in Chapter 6 (Hunt 1998, p. 311). Drawing on her study of cancer care in southern Mexico, Hunt (1998, p. 299) argues that causal explanations for illness that attempt to answer questions such as 'why me?' typically evoked moral themes. For instance, she found that 'improper sexual or reproductive behaviour' on the part of oneself or one's partner was considered a common cause of female cancer (Hunt 1998). This included themes of both excess (for example, having too many children or sexual partners) and absence (for example, having no children). She further found that women's explanations for cancer 'often focused on the conflicts they experienced in their role obligations as dutiful wives and devoted mothers' (Hunt 1998, p. 304). Thus, one participant explained that her cancer was due to having too many pregnancies (14) and specifically because she had delivered each child on her own, without support (Hunt 1998, p. 308). Significantly, however, Hunt (1998, p. 308) identified that conceptualising her cancer in this way 'emphasized and gave voice to her frustration' that she could not rely on others for help in her day-to-day life. Thus, while the moralisation of illness can lead to self-blame, exploring this process can also give voice to the broader concerns of participants. More generally, Hunt (1998, p. 301) found that causal explanations were 'based on specific experiences and events, seeking to connect the illness to the details of their [patient's] personal histories', illustrating how identity construction, the self as narrative, morality, and illness can converge as people attempt to make sense of their illnesses. In line with discourses on healthism, such models of illness causation ultimately imply that 'responsible behaviour can avert crisis, and that remedy lies within the self' (Hunt 1998, p. 310). What is considered 'responsible behaviour' in a health context, however, will necessarily differ between cultural, historical, political, economic, and geographical contexts.

Positivity and transformation

Connected to healthism is a moral imperative for those with long-term illnesses to remain positive or experience a positive personal transformation in response to illness. Miles (2013, p. 143) argues that in North American culture people with a chronic illness are expected to experience a ‘personal transformation’, observing that ‘the standard trope is that personal transformation can be achieved when those stricken with illness adopt a positive attitude, embrace the lessons to be learned from suffering, and openly and actively seek self-betterment.’ Speaking outside this trope can lead to rebuke, even by those within a support group who may otherwise share similar illness experiences (Miles 2013, p. 146). The phenomenon of remaining positive in the face of illness has also been observed among the family and friends of cancer patients in Australia (Ussher et al. 2006, p. 2570) and in North American society more broadly (Jain 2010).

Like discourses of healthism, positive transformation also focuses on the individual, reinforcing their 'responsibility for illness, acceptance, and transformation' and often silencing 'alternative discourses that give other meanings to the illness experience' (Miles 2009, p. 9). These issues are pertinent in debates around ADs and have been observed in online support communities. For example, Miles (2009, p. 9) notes in her study of publicly accessible online lupus communities that the focus of discussion is often individuals, including why an individual may be to blame for their illness or flare (e.g. by failing to manage stress), or what an individual can do to improve their symptoms (e.g. reduce stress or alter diet). She observes that structural issues such as the high cost of health insurance in the USA are framed as an individual concern, while other issues such as environmental contamination and its links to lupus are rarely discussed and ‘quickly dismissed as “rumours” and distractions’ (Miles 2009, p. 9). Consequently, while the internet provides an important space for people to discuss the ‘emotional, social and bodily transformations' associated with chronic illnesses, there may be little space to ‘explore more politically charged structural aspects of the illness’ (Miles 2009, p. 10). Barker (2002, p. 296) voices a similar concern, asking ‘in what ways do illness identities run the risk of depoliticizing the forces that create ill health or other distress by locating the origins of our problems within our individual, rather than our social body?’ Furthermore, online communities themselves have their own 'cultural constraints' that members should (or must) adhere to (Armstrong et al. 2012, pp.

348-9) and which are reflected in Miles' accounts of online lupus communities. Thus, while the internet may provide space for women with chronic illnesses to 'try on social identities, negotiate problems, and enact transformations' (Miles 2009, p. 8), this does not occur in an environment free of cultural norms, rules and expectations. In fact, in many cases online environments may simply replicate the social expectations and norms of the offline world.

In some cases, dissatisfaction with discourses of positivity and transformation can lead to the development of new care networks. For example, Mathews (2000, p. 394) describes the formation of a 'shared model of breast cancer experience' within a newly formed breast cancer support group in the USA. The group formed in response to dissatisfaction with other locally available support groups which the participants felt privileged the experiences of white women, relied on male-centred sports and military metaphors, and overlooked the importance of 'religion and spirituality in the healing process' (Mathews 2000, pp. 397-8, 403). Of particular relevance here are the participants' frustrations with other support groups that expected them to remain 'upbeat and positive' regardless of what they were going through (Mathews 2000, p. 397). Rather than avoiding support groups altogether, the participants in Matthews' study formed their own support group with a stronger emphasis on the role of religion in healing and an understanding that it is acceptable to deviate from discourses of positivity. This case also raises questions about the meaning of positivity for different groups and individuals. For instance, it may be the case that the women in Matthews' study did not reject positivity per se, but enacted, embodied, and found value in different forms of positivity, such as spirituality, than those displayed in other support groups.

Despite the difficulties some people experience with discourses of positivity, enacting positivity in the face of illness can allow people to maintain or construct socially valued identities. Gibson et al. (2015) observed that breast cancer sufferers in their study tended to accept responsibility for their illness, either in the context of causation or risk management. Although Gibson et al. (2015, p. 145) acknowledge that there is a social expectation for women to take responsibility for their health, they suggest that 'taking responsibility can also be a strategy of empowerment in response to a frightening illness.' They state:

> This strategy enabled participants to position themselves positively as active and empowered in relation to their health, and as informed health consumers who can participate in decision-making . . . It enabled women with cancer to adopt positive, socially valued identity positions – as active health consumers, empowered, and in control of their health, and as individuals who through their own efforts and will had survived cancer (Gibson et al. 2015, pp. 145-6).

'The identity position of "survivor" is central to current understandings of cancer', which is associated with being terminal, and adopting it allowed women to fulfil their moral responsibilities to remain positive and 'take control' of their health (Gibson et al. 2015, p. 146). Moral expectations relating to positivity and transformation may differentially affect those with chronic ADs, depending on individual illness experiences and personal circumstances. For those with the means (financial, psychological, physical, etc.) and desire to harness positivity discourses for 'empowerment', such discourses may provide an avenue for coping or resilience in the face of illness. For others, a moral responsibility to remain positive in the face of illness may represent yet another hurdle to face in the day-to-day management of chronic illness.

Productivity

Alongside moral expectations to remain healthy, productivity holds high moral value in Western contexts. Hay (2010, p. 260) provides a useful conceptualisation of the relationships between agency, productivity, and chronic illness. Productivity is highly valued in a neoliberal era (discussed below) and consequently the guilt associated with '"wasting time" or failing to "use time wisely"' leads to a 'widespread moral compulsion to be productive.' In the context of chronic illness, this means that those who manage to remain productive despite being ill become 'cultural heroes, models for how illness should be faced.' Hay (2010, p. 260) argues:

> If their illness is visible to the casual onlooker, their activities reinforce and foster a moral ideal of productivity that is applauded by family members, friends, physicians, and mass media. Even if illness is invisible, patients can assert moral worth by not letting their condition "stop them," and their efforts are socially acknowledged and applauded.

Hay (2010, p. 262) coins the term ‘John Wayne Model’ to describe a:

> [w]idespread cultural model for meeting the expectations of meritocratic cultural expectations . . . that . . . involves dealing with illness in such a way that the link between productivity and moral worth is strengthened rather than undermined.

She further argues that there is no culturally acceptable model in opposition to the John Wayne Model — that is, there is no model ‘available for suffering without doing something, because inactivity goes against the deeply buried equation of agency with value as a person’ (Hay 2010, p. 262). Similarly, the valuing of ‘sustained productivity throughout life’ means that those who are unable to fulfil this cultural ideal are often ‘viewed by others, and by themselves, as useless’ (Becker 1998, p. 53). Consequently, Hay (2010, p. 262) argues that individuals exhibit a ‘Suffering Response in which people seek some legitimation of their inactivity as a justifiable and, thus, at least pitiable if not heroic response to an ontological assault that makes getting through each day a constant challenge.’

Reflecting on the John Wayne Model, Masana (2011, p. 132) suggests that striving to be productive in the face of illness may allow some to hide their illnesses and ‘avoid stigma, rejection, disbelief, delegitimation, guilt [and] shame.’ However, in doing so individuals may also limit their options for social support, since those who might otherwise provide support may not know they are unwell (Masana 2011, p. 134). Colvin (2011, p. 4) supports this view, arguing that there is a related cultural expectation that chronic illnesses are kept ‘invisible and manageable’ which can render invisible the everyday realities of living with chronic illnesses. Thus, while the John Wayne Model may represent a strategy of normalisation for those who can remain productive, for others a failure to adhere to the moral imperative to be productive may further delegitimise their suffering. The moral value of productivity may also have implications for care, in addition to rendering care needs invisible. For instance, the idea of actively seeking care may challenge identities rooted in valuing productivity, preventing people from actually accessing care. Others may require specific types of care in order to remain productive. Alternatively, for those who cannot engage in activities considered productive, being dependent on ongoing care may create further challenges to already ruptured identities.

Neoliberal biocitizenship

Healthism, productivity, and discourses of positivity and transformation are shaped by neoliberal discourses. While scholars emphasise different aspects of neoliberalism (Ganti 2014, pp. 91,4; Tronto 2017, pp. 28-9), of most relevance here are its ideological framings. These are underpinned by notions of 'the calculating, self-interested actor, encapsulated in the figure of *Homo economicus*; and the idea of governmentality…the range of knowledge and techniques directed at managing the self through the regulation of everyday conduct' (Ganti 2014, p. 95, emphasis in original). Central to neoliberal ideology as it relates to healthcare is a focus on personal responsibility, positioning care as a 'market problem', and framing families as having the primary responsibility for care (Tronto 2017, p. 30). Part of this responsibility is engaging in everyday risk assessment and mitigation to reduce health risks, improve health, and as a consequence remain productive (Bell 2019, p. 46; Lee 2017, p. 39)

Closely related to neoliberal ideology is the concept of biocitizenship. Charles (2013, p. 772), drawing on the work of Petryna (2002) and Rose and Novas (2005), has described biocitizenship as encompassing 'the host of new politics and biotechnologies which shape and affect an individual's subjectivity, beliefs about genetics, and biological presuppositions to disease, as well as claims to citizenship and participation in national policy.' Of particular relevance here are claims to citizenship, where people have certain rights and responsibilities in relation to the state (Charles 2013, pp. 771-2; Petryna 2004, p. 261; Wehling 2011, p. 226). These responsibilities incorporate particular obligations which reflect the way that health and illness are moralised. These include being a 'good' citizen who makes responsible health choices (Lee 2017, pp. 41-2). As discussed above, those who fail to fulfil these responsibilities, such as engaging in positively valued health behaviours, may be stigmatised, or painted as lazy, irresponsible, selfish or careless.

Taking these framings into account, in this thesis, I use the term 'moralisation' to refer to the process of applying moral judgements and related actions to those who are chronically ill. In doing so, I focus particularly on moralisation that is based on neoliberal ideals of what makes a person valuable. Moralisation can occur externally, such as when a person who is ill is moralised by

another person, group, or system. Moralisation can also be internalised, such as when a person who is chronically ill forces themselves to keep engaging in activities that make their illness worse in order to maintain morally valued identities. In this conceptualisation, some behaviours may be negatively moralised at the outset (e.g. smoking during pregnancy) while others are negatively moralised by virtue of being the inverse of positively valued behaviours, such as being unproductive. This type of moralising is inextricably linked to identity, as people typically strive to enact the ideals of neoliberalism. Where these ideals are not, or cannot be, met the process of moralisation further challenges identities as people are positioned as unworthy, unproductive, or simply not 'good enough.'

Chronic illness support

These issues associated with identities and moralisation create an additional burden for those with ADs, creating complex care needs that mean access to care is particularly important. However, the needs of those with chronic illness have traditionally been conceptualised more narrowly in terms of support, rather than care. There is no standard definition for 'support' in an illness context, with most support literature using 'support' and 'social support' interchangeably. Conceptualisations of social support have been contested as being either ill-defined or too narrow in scope (Callaghan & Morrissey 1993, pp. 203-4; Frohlich 2014, pp. 219-21). In response, Shumaker and Brownell's (1984, p. 13) definition of social support as 'an exchange of resources between at least two individuals perceived by the provider or the recipient to be intended to enhance the well-being of the recipient' is commonly cited. Rather than focusing on defining the term, others have attempted to identify specific dimensions of social support such as providing information, emotional support, practical support, inclusion, and positive interactions (see Frohlich 2014, pp. 219-21). While identifying these dimensions is useful, particularly for research focusing on a specific aspect of support, current conceptualisations of support are inadequate for exploring the needs of those with chronic illnesses (Frohlich 2014). Rather than attempting to identify key aspects of support, Frohlich (2014, p. 223) has begun to develop a 'social support model for people with chronic health conditions,' based on prior work with people with chronic illnesses, and his own experiences of inflammatory bowel disease.

Briefly, Frohlich's (2014, pp. 224-9) model is comprised of a person's health situation (for example, symptoms, social and emotional impacts, treatments, and any other factors related to the management of their condition), their support environment, their needs, their social support behaviours, outcomes resulting from support, unsolicited social support, changes to the support environment, and leaving the support environment. Frohlich (2014, pp. 224-5) makes a number of important points regarding his model that are also relevant for this study: (i) having a chronic illness does not necessarily mean that a person desires or requires an increased level of support; (ii) the person with a chronic illness is ultimately the one who should determine the seriousness of the impact illness has on their life, and the level and type of support required, as opposed to researchers or healthcare providers; (iii) the nature of treatments themselves — for example, relatively simple and effective treatments, versus difficult or uncertain treatments — may affect a person's support needs; and (iv) support needs may fluctuate over time, particularly for conditions such as ADs where people tend to experience periods of remission and flare. Jacobson (1986, p. 252) earlier made a similar point, arguing for recognition that since 'stressful situations . . . may unfold over time', support itself must necessarily have a temporal dimension, making the timing of support, or support as a process, an important area of investigation.

In addition, and perhaps most importantly, a focus on specific forms of support is inadequate for exploring the needs and experiences of those with chronic illnesses (Frohlich 2014). Although the existing literature on chronic illness support is relatively extensive, studies tend to have a strong focus on evaluating particular forms of support for specific illnesses (e.g. Barak et al. 2008; Carmack Taylor et al. 2007; Morris et al. 2015; Uccelli et al. 2004). For instance, Ussher et al. (2006, p. 2565) examine the perceived benefits of cancer support groups, while Brennan and Creaven (2015) explore the social support experiences of people with lupus, specifically focussing on support from healthcare providers and formal support groups. While such studies provide valuable information on the advantages and disadvantages of specific support types for specific illnesses, they tend to only scratch the surface of some of the deeper challenges of being diagnosed with, and living with, a chronic illness. Nor do they facilitate a holistic understanding of the

support experiences of those with chronic illnesses and all that they may encompass. In response to this characteristic of support research, Frohlich (2014, p. 226) argues for a shift in focus to the 'support environment', which is conceptualised as a subset of a person's social networks and defined as 'everybody who the person talks to about the health condition.' Importantly, Frohlich (2014, p. 227) acknowledges that the benefits of support do not necessarily occur only when a person engages frequently and actively with others, as is the case with members of online support groups who may spend more time observing than actively participating.

Care

While Frohlich's expanded understanding of support environments is an important step forward in understanding experiences of chronic illness support, it does not consider forms of support that may not occur through interactions with others, such as self-care, reading blogs, self-help literature, or medical literature; or lurking on online forums or support groups without necessarily (or ever) interacting with others. Reconceptualising support needs and experiences as care needs and experiences can better account for both solitary and interactional forms of support, while also allowing for attention to be drawn to broader factors that impact who does and does not have access to care. The care literature can also better account for the complexities of living with chronic illness, and how these impact different phases of illness. For instance, compared to more narrow understandings of chronic illness support as interactions that benefit the ill person, understandings of care can incorporate rituals of care that can make long-term care possible (Aulino 2016, pp. 96,9) and the moral responsibilities inherent in some forms of care, such as parenting (Mattingly 2014, p. 23). This is particularly important since it is recognised that caregiving can influence experiences of morality, moralisation, and subjectivity (Buch 2013, p. 638; Kleinman 2009, p. 293; Mattingly 2014, p. 23). While the practice of caregiving, such as providing day-to-day personal care, are undoubtedly important to those with chronic illnesses who require such care, this was not foregrounded by the women in my study. As such, I focus here on a broader understanding of care that speaks to different phases of illness.

There are multiple definitions of care, depending on the context in which it occurs. For example, care has been defined as all the things humans do to ‘maintain, continue and repair’ their worlds (Tronto & Fisher, cited in Tronto 1993, p. 103), as ‘persistent tinkering’ in a complex world (Mol et al. 2010, p. 13), as a ‘social and moral practice’ (Sand Andersen et al. 2020, p. 569), and as broad and undefinable (Han 2012, p. 27). In this thesis, I define care in a chronic illness context as an open-ended, continual process of engaging in practices, both alone and in connection with others, to manage and cope with illness (Mol 2008, p. 20; Thelen 2015, p. 509). Care in this definition is underpinned by constructions of need, worthiness, and responsibility and does not always involve positive outcomes (Garcia 2010, pp. 121-8; Stevenson 2014, p. 3; Thelen 2015, pp. 504-5, 8; Wang 2013, pp. 556-7). Thus, care may not necessarily be made available to everyone, be made available to everyone in the same ways, or lead to improvements in health or wellbeing.

In conceptualising care in this way, I draw on understandings of care that can capture the uncertainty, messiness, ebbs and flows, and inequities characteristic of the experiences of women with ADs. This particularly includes conceptualisations of care developed by Mol (2008), Stevenson (2014), and Thelen (2015). Mol (2008, p. 20) introduced the concept of a ‘logic of care’ that represents 'an interactive, open-ended process’ that can be continually reconfigured. Care here is interactional, ongoing, practical and ‘concerned with actively improving life’ (Mol 2008, pp. 20, 90). For healthcare providers, a logic of care involves ‘tinkering with [people], bodies, technologies, and knowledge’ (Mol 2008, p. 12). The strength in Mol's notion of a logic of care, particularly in the context of chronic illnesses such as ADs which can be unpredictable, is the positioning of care as an open-ended process. As people’s needs and identities change over time, as they inevitably tend to with autoimmunity, the process of care continues with adjustments and course-corrections made along the way. Autoimmunity has no end, and neither does care.

In contrast, Stevenson (2014, p. 3) emphasises the interpersonal aspects of care, arguing that it is 'the way someone comes to matter and the corresponding ethics of attending to the other who matters'. Stevenson (2014, p. 3) also emphasises the messiness of care, arguing that:

> Shifting our understanding of care away from its frequent associations with either good intentions, positive outcomes, or sentimental responses to suffering allows us to nuance the discourse on care so that both the ambivalence of our desires and the messiness of our attempts to care can come into view.

In Stevenson's (2014, pp. 3-4) account of what she terms a logic of 'biopolitical care', government responses to tuberculosis and suicide epidemics among Canadian Inuit focused on populations, rather than individuals, and placed ultimate value on 'maintain[ing] the physical life of Inuit.' Although government responses were 'couched by the state in terms of benevolence and concern', they were 'sometimes perceived by Inuit as uncaring, even at times murderous' (Stevenson 2014, pp. 3-4). Thus, while care has traditionally been seen as a compassionate and empathetic process, it is now recognised that care does not always create or maintain 'stable relations' and does not necessarily lead to positive outcomes or emotions for those involved in the process of caring (Garcia 2010, pp. 121-8; Stevenson 2014, p. 3; Thelen 2015, pp. 504, 5, 8; Wang 2013, pp. 556-7). In the case of ADs, this may be particularly relevant for forms of care such as medication that can create additional suffering at the same time as treating illness. This understanding of care can also illuminate tensions between what may be well-intentioned advice, such as that related to diet and exercise, and how the moralising that underpins this can create added burdens on those with ADs.

Like Mol, Thelen (2015, p. 509) recognises the open-ended nature of care, conceptualising it as 'an open-ended process which, as a dimension of social security, connects a giving and receiving side in practices aimed to satisfy socially recognized needs.' Of particular relevance for this study is a focus on socially recognized needs, since care is often rationed with access determined based on particular understandings of whose suffering is legitimate and who deserves care (Thelen 2015, p. 505), which has implications for access to care for women with ADs. While Mol's notion of a logic of care allows for a consideration of care as a collaborative, open-ended process, Stevenson and Thelen's understandings add space for considerations of how need, deservedness, and responsibility are constructed in relation to care.

Reconceptualising support as care allows for the incorporation of the broad range of support mechanisms for which Frohlich advocates, while also creating an opportunity to discover what care means for those with ADs. This understanding of care draws attention to forms of care that may be individual rather than interpersonal and can facilitate the potential discovery of previously undocumented or under-reported forms of care. Exploring individuals' needs through a lens of care also better aligns with calls for chronic illness management to adopt a 'whole person' approach, as opposed to fragmented and illness-specific approaches, particularly among those with multiple chronic conditions (Allen et al. 2015, p. 53). Examining how care intersects with identity and moralisation facilitates this approach, particularly when it is recognised that care is continual and open-ended.

Conclusion

Given the additional difficulties those with ADs can face in relation to identity and moralisation, this thesis explores how women negotiate their identities in the context of ADs which can disrupt their life narratives not just once, but continuously. This is exacerbated by the moralisation of those who are ill, as women may attempt to maintain socially valued identities at the expense of their health. This can make support complex and more difficult to understand in light of diagnoses that may be rare or poorly understood and experienced in regional areas where access to support can be limited. Care is therefore taken as the central concept, rather than support, because it can better account for these complexities and the tensions they create. The ongoing renegotiation of identity, illness, and care for those with ADs reflect not a single biographical disruption, but many. Therefore, understanding how autoimmunity plays out over whole lives filled with disruption is critical to understanding women's experiences and care needs. The next chapter outlines the methods I adopted to examine autoimmunity in this light, with a focus on a life story approach to ethnography.

CHAPTER 3: METHODS

Ethnography and life stories

To understand the ongoing and shifting relationships between autoimmunity, identity, moralisation, and care across women's lifetimes and different illness phases, this study adopted a life story approach to ethnography. There is no single definition of ethnography, with each ethnography influenced by different disciplines, theoretical perspectives, and 'methods of research, analysis and representation' (Atkinson et al. 2007, p. 2; Hammersley & Atkinson 2007, p. 2; Savage 2006, pp. 384-5). Despite this, Atkinson et al. (2007, pp. 4-5) identify the defining characteristic of ethnography as the:

> [Grounding] in a commitment to the first-hand experience and exploration of a particular social or cultural setting on the basis of (though not exclusively by) participant observation . . . It is this sense of social exploration and protracted investigation that gives ethnography its abiding and continuing character.

Similarly, though with less emphasis on the centrality of participant observation, Savage (2006, p. 385, emphasis in original) argues that:

> The way in which ethnography makes links between the micro and macro, between everyday action or interaction and wider cultural formations through its emphasis on *context*, [is what] most clearly distinguishes ethnography from other approaches (and makes it particularly valuable for researching healthcare issues).

Ethnography is increasingly employed in health research since it 'provides in-depth understanding about people's behaviours, and this in turn offers greater opportunity to find . . . solutions to improve their health and well-being' (Liamputtong 2013, p. 162). Because ethnography is grounded in the daily lives of participants (Liamputtong 2013, p. 160), it is a particularly appropriate method for exploring the support needs of women with ADs since the full spectrum of disease management (from medication to accessing informal modes of support) and its consequences are inevitably played out in women's daily lives.

Life story approaches are a common and valued feature of ethnographies (Agar 1980; Atkinson 2012a, p. 116). As the name suggests, life story approaches and other closely related approaches, such as oral history and narrative analysis, focus particularly on the 'recording and interpretation' of people's life experiences' (Bornat 2004, p. 35). What separates a life story approach is the way it 'takes the individual life and its told history with a view to understanding social processes determined [for example], by class, culture, and gender' (Bornat 2004, p. 35). This contrasts to other approaches, such as narrative analysis, that 'tend to be characterised by analyses that place great emphasis on the deployment of psychoanalytical theorizing during and after the interview at the stage of data analysis' (Bornat 2004, p. 35). Liamputtong (2013, p. 122) argues that 'life history interviews function as ideal vehicles for understanding how people perceive their lived experiences, and how they connect with others in society', making them particularly relevant for understanding the care needs of women with ADs. In further support of life story methods, Atkinson (2012a, p. 125) states:

> Life stories serve as an excellent means for understanding how people see their own lives and their interactions with others. They allow us to learn more than almost any other methodology about individual lives and society from one person's perspective. Life stories make connections, shed light on the possible paths through life, and lead us to our deepest feelings, the values we live by, and the commonalities of life.

Life story approaches to ethnography require spending considerable time with participants in order to gather in-depth and comprehensive life stories (Liamputtong 2013, p. 123). Like more traditional ethnographic methods, a life story approach to ethnography can elicit:

> How the participants feel about things, what they consider important in their lives, and how they see the relationship between different life experiences, their difficult times, and the meanings they have constructed as members of society (Liamputtong 2013, p. 123).

Attention to these factors can illuminate the multiple identities of participants and how they have been challenged, maintained, or reconstructed over time and in response to particular events or disruptions, both positive and negative. Life story

approaches are also ‘an effective means of gaining an understanding of how the self evolves over time’ (Atkinson 2012a, p. 117).

A life story approach to ethnography was adopted to gain a deep understanding of women’s experiences of autoimmunity and care and in response to some of the criticisms of the use of biographical disruption theory to explore identity and illness experiences (Chapter 2). In particular, this approach can mitigate against the assumption that a chronic illness diagnosis is a defining, disruptive event in one’s life, which may lead to false assumptions about the impact and significance of illness diagnoses in relation to other life events. Exploring the life stories of participants, rather than focusing exclusively on illness and support narratives, also places women’s narratives in the context of lives that have been full of a range of disruptions. As Estroff (2001, p. 412) articulates, ‘whose biography, after all, is uninterrupted?’ Exploring biographical disruptions in the context of life stories can also better ensure that other identities that may impact care (as opposed to only illness identities) can be identified. This allows distinctions to be made between those who were born with an AD and those who were diagnosed later in life, social factors such as age can be considered, the experiences of those with multiple illnesses can be incorporated, and the multiple disruptions that are negotiated in women’s lives both before, during, and after the onset of illness can be explored. Adopting a life story approach to ethnography also better enables the teasing out of different forms of care (for example, those things that a person may actively engage in, without necessarily consciously recognising them as providing care) which may be lost in interviews focused only on illness.

A life story approach to ethnography is also valuable for exploring the impacts of the moralisation of health and illness on women’s illness experiences. This is facilitated by examining the ‘the different choices that people have faced and how they have dealt with them’, since morality is often inherent and observable in life stories (Plummer 2007, pp. 403-4). A life story approach ‘leads us to see lives as moral struggles, embedded in specific contexts, shaped by particular conventions of time and place’ (Plummer 2007, p. 404). These characteristics of life stories — that they provide a holistic understanding of a person’s life and experience, while also providing a window into both identities and the impacts of particular forms of

moralisation — makes a life story approach to ethnography an essential component of this study.

Participants

ADs are particularly prevalent in Western and industrialised societies, with factors such as diets, lifestyles, and lack of access to hygiene infrastructure and vaccines potentially implicated in the onset of disease (Agmon-Levin et al. 2011, pp. 189-90; Lerner et al. 2015, p. 154). In fact, ADs collectively have previously been referred to as 'Western diseases' because they are less common in low- and middle-income countries but 'increase in frequency following adoption of Western customs' (Bickler & DeMaio 2008, p. 252). This makes a case study in Australia particularly timely and appropriate. Australia can be subdivided into five 'classes of remoteness on the basis of a measure of relative access to services' (Australian Bureau of Statistics n.d.-b). These include major cities, inner and outer regional areas, remote areas, and very remote areas (Figure 1). To determine the remoteness classes, the Accessibility and Remoteness Index of Australia (ARIA+) has been employed to measure 'relative remoteness' (Australian Bureau of Statistics 2018). The ARIA+ 'measures remoteness in terms of access along the road network from populated localities to each of five categories of Service Centre based on population size' (Hugo Centre for Population and Migration Studies 2021). The largest Service Centre category covers populations of over 250,000 or more people, while the smallest category covers populations between 200-999 people (Hugo Centre for Population and Migration Studies 2021). Under the ARIA+, localities with over 1,000 people are 'are considered to contain at least some basic level of services (for example, health education, or retail)' (Hugo Centre for Population and Migration Studies 2021). Larger localities are 'assumed to contain a greater level of service provision' (Hugo Centre for Population and Migration Studies 2021).

For this study, participants were initially sought from the Toowoomba and Southern Downs Local Government Areas (LGAs) (Figure 2 & Figure 3), which include both inner regional and outer regional areas based on their remoteness classification. The Toowoomba and Southern Downs regions sit just west of the area commonly referred to as 'South East Queensland', which encompasses major cities

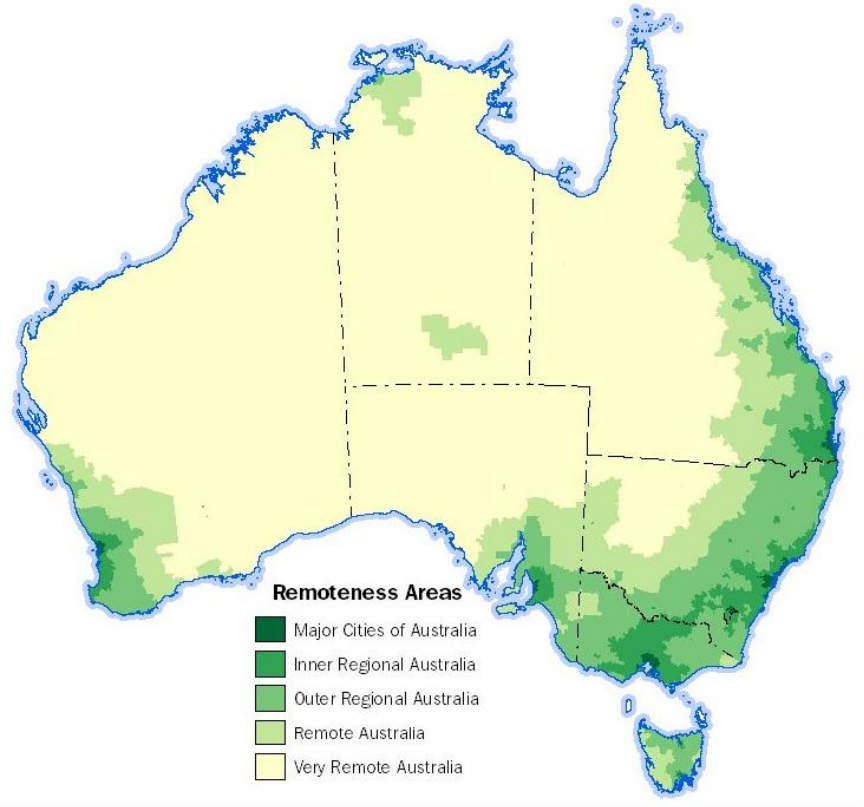
and urban areas such as Brisbane, the Sunshine Coast, and the Gold Coast. The Southern Downs is south of Toowoomba and straddles the Queensland and New South Wales border. The Toowoomba region encompasses the regional centre, the city of Toowoomba, as well as several small regional localities such as Cambooya, Crows Nest, Pittsworth, and Millmerran. The Southern Downs region encompasses the Warwick and Stanthorpe regions, in addition to numerous smaller localities such as Killarney, Allora, Rosenthal Heights, and Ballandean.

These areas were initially chosen as case studies for regional Australia for three reasons: there are known limits to accessing healthcare services in these areas, they encompass different categories of regional areas, and time and financial considerations. First, there tends to be a lack of health services in regional Australia, relative to metropolitan areas (Australian Government Department of Health 2012, p. 9). For example, compared to those in major cities, 2.5 times more people in outer regional areas report not having a GP nearby, while 22% of people in inner regional areas and 30% of people in outer regional areas report not having a specialist nearby (Australian Institute of Health and Welfare 2019). Nationally, there is also a low number of specialists relative to a high volume of patients with ADs (Australasian Society of Clinical Immunology and Allergy Inc 2013, p. 2), exacerbating the difficulties those living with ADs in regional areas face and making the exploration of women's experiences in these areas particularly important. In Toowoomba specifically, despite a growing healthcare sector, a lack of specialist services has been reported by patients, as well as a 'poor perception of quality of health care, both public and private' amongst the local community (Toowoomba Health Community Council 2010, p. 10).

Second, these two regions encompass both inner-regional (e.g. Toowoomba, Warwick) and outer-regional areas (e.g. Stanthorpe, Millmerran), which allows for the inclusion of women in regional areas who may experience differing levels of access to health care and support. For instance, women in the inner regional area of Toowoomba may have ready access to local general practitioners (GPs) and some specialists (e.g. rheumatologists) but may need to travel upwards of 124 kilometres to access other specialists (e.g. immunologists). Conversely, women in the outer regional area of Warwick may have ready access to local GPs but no local access to

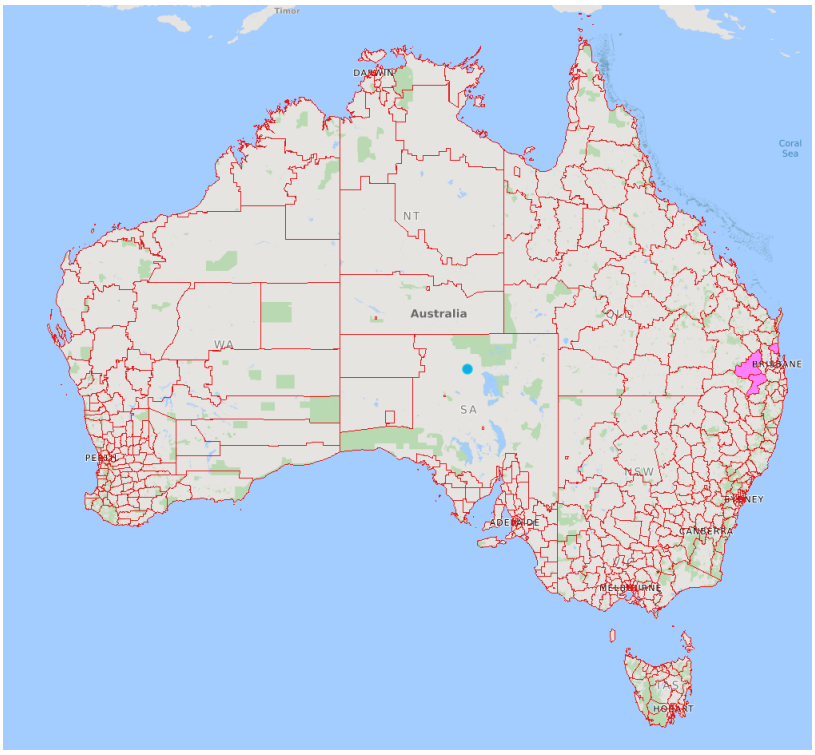
specialists. This may require travel of 84 kilometres to Toowoomba, which has its own limitations on access to specialist services, or 150 kilometres to the nearest capital city. Third, as in-depth interviews and participant observation (see below) formed significant components of the research, it was most practical to conduct this study within an area that is easily accessible from Toowoomba, which is where I reside. It is recognised that women in areas classified as remote or very remote face further barriers to accessing appropriate health care and support; however, due to time and budgetary constraints it was beyond the scope of the study to extend the sample to include these regions.

Figure 1: *Australian Bureau of Statistics Remoteness Classification*



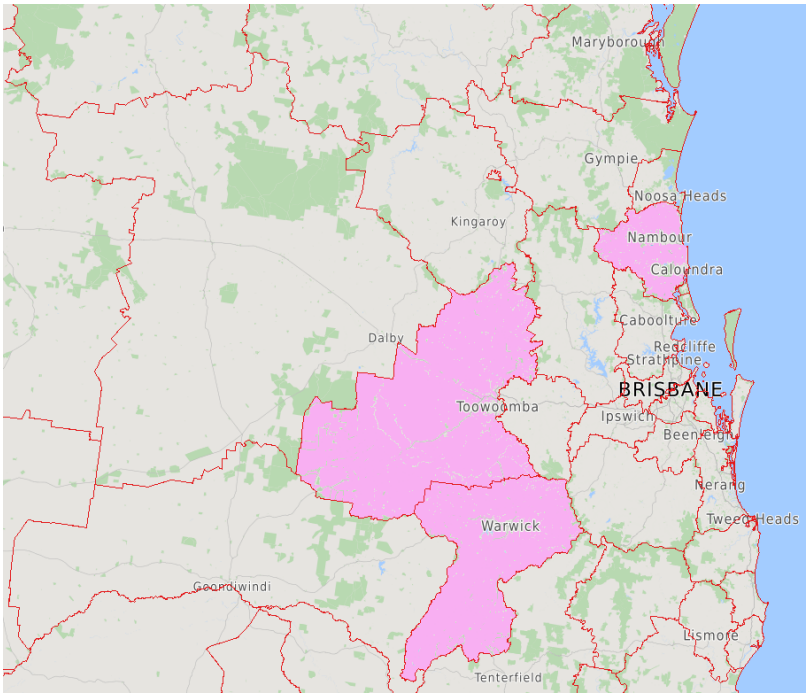
(Australian Bureau of Statistics n.d.-b)

Figure 2: *Australia, with Toowoomba, Southern Downs, and Sunshine Coast local government areas highlighted*



(Australian Bureau of Statistics 2016b)

Figure 3: *Toowoomba, Southern Downs, and Sunshine Coast local government areas*



(Australian Bureau of Statistics 2016b)

The primary participants in this study were women aged 18 years and older with ADs. The study did not extend to women or girls under 18 years of age as there are significant ethical issues involved in conducting health-related research in this age group (National Health and Medical Research Council 2018). It is also recognised that children and young teenagers are likely to have unique care needs and identity issues that could not adequately be addressed in a study that also focuses on adult women. Ethical approval (approval number H17REA068) was obtained from the University of Southern Queensland Human Research Ethics Committee prior to participant recruitment (Appendix 1). Participation was open to women with any AD, and those at any stage of disease, for example, those still going through the diagnosis process, the newly diagnosed, those with long-term experiences of ADs, and those in remission. Women who have an AD that co-occurs with other chronic illnesses were also encouraged to participate since it is increasingly recognised that comorbidity increases the complexity of disease management (e.g. Markle et al. 2015; Porter et al. 2015). Sampling for any type of AD was intentional for three reasons in particular: (1) autoimmunity tends to be underrepresented in qualitative research, as opposed to single ADs such as multiple sclerosis, which contributes to its relative invisibility as a category of illnesses; (2) extending the study to participants with any type of AD can provide more depth and perspective than studies of single illnesses are able; and (3) opening up the study to any AD allows for the inclusion of those with rare diseases, whose experiences may otherwise be overlooked.

Purposive sampling methods, based on region, (Bernard 2011, pp. 145-6) were employed. Because there are over eighty recognised ADs, it was not the aim of this study to produce a sample that is representative of the distribution of each disease in the general population. While I had anticipated that participants may have ended up being representative of only a small number of more common diseases, no two participants in the study ended up sharing a primary diagnosis, despite the sample within the case study area being self-selected. To best ensure the opportunity for people with rarer conditions to participate and give voice to their needs and experiences, participants were recruited through several channels. These include existing local support groups, online forums and support groups for both specific

ADs as well as ADs more generally, illness advocacy groups such as the Lupus Association Queensland, and personal networks.

This process led to a support group on the Sunshine Coast, outside the initial geographic scope of the study, asking to be involved. Since this group was located within driving distance and members expressed similar care access issues as those in the original case study area, ethical approval was granted to widen the geographic scope of the study. Seven participants were recruited in total (see Table 1), with four participants recruited through expressions of interest posted on online support group forums. These were posted with the permission of group administrators. Two participants were recruited through my personal networks and one participant was recruited after approaching me at a research presentation. Two participants were from the Sunshine Coast region, with the remainder in the Toowoomba region. All participants were from Anglo-Australian backgrounds. While it is acknowledged that this is a relatively small sample size, this was intentional and necessary for managing time considerations when conducting ongoing, life story interviews. Smaller sample sizes are also considered appropriate when conducting in-depth interviews in studies that are not intended to produce a representative sample, which is the case here (Crouch & McKenzie 2006, pp. 492-4; Kolar et al. 2015, p. 17).

In addition to managing the practical considerations of conducting life story interviews, spending more time with a small number of participants was fundamental to gaining the level of rapport that allowed participants to open up so generously, as well as to gain the depth of knowledge life history approaches require (Crouch & McKenzie 2006, p. 493). This approach also gave some participants who were not used to speaking about their illness time to become more comfortable disclosing the reality of illness with me. For example, one participant often said they do not suffer too much from their illness and that other people experience worse. It was only after nine hours of interviews over four sessions that she disclosed that her illness was actually quite debilitating. When I arrived for our fifth interview, she had forgotten about the interview as her air conditioner was in the middle of being repaired. While most interviews with participants took place in living or dining rooms, she led me to a sunroom in her house and we had a coffee and informal chat instead of a formal interview. During this, she asked me about my illness experience and we found we

had some common medication experiences, which further helped to build rapport and trust. She also expressed to me that she was struggling with the circumstances of her husband's death, felt lonely, and was having trouble sleeping. These are topics she would typically keep to herself and her willingness to be open about them demonstrates the value of spending more time with a smaller number of participants to build rapport, trust, and a fuller understanding of their experiences (Fontein 2013, p. 77). Had I only conducted one or two interviews, I would have come away with the impression that this participant's illness had a minor impact on her life and that she was not having much difficulty coping.

Spending more time with a small number of participants also better allowed for participant observation, particularly before and after interviews. This included spending time chatting to participants before interviews, having morning tea with them, and having the opportunity to be shown their homes. This was crucial for building rapport and understanding other aspects of participants' day-to-day lives that they may otherwise have felt were not relevant given the project's focus on autoimmunity (Fontein 2013, p. 77). In these moments, participants shared more mundane parts of their life, such as trying to get housework done, but also shared more significant moments, such as family difficulties. One participant turned out to be incredibly creative and after our last interview ended, toured me through her home art studio that I had not seen before and sent me home with one of her paintings. Sometimes during these times I was also able to help participants. For example, one day I arrived for an interview and the participant's family had recently visited. While there, they had tightly closed the condiment jars as they used them. The participant was unable to open them so she had me loosen them for her. Another time I bought along a moisturiser for a participant to try for a skin condition we had in common. Participants also shared with me, with some having a ritual of putting out coffee and homemade cake or biscuits when I arrived, something I found very touching given I knew how unwell they were. Had I only spent a short, predetermined length of time with a larger number of participants, many of these moments would have likely been lost.

***Table 1**: Participant demographic information and illnesses*

Pseudonym	Age	Region	Population of local town	Distance from nearest capital city	Autoimmune diseases	Relationship status and family	Work
Daisy	80	Toowoomba	1,075	146kms	• Rheumatoid arthritis	• Widowed with four adult children (two sons and two daughters)	• Retired
Ellen	65	Toowoomba	348	137kms	• Ulcerative colitis • Polymyalgia rheumatica (contested) • Crohn's disease (suspected)	• Married with three adult children (two sons and two daughters) • Guardian for three young grandchildren	• Unable to work – on disability support pension
Jennifer	64	Sunshine Coast	3,734	95kms	• Sjögren's syndrome with scleroderma overlap • Pernicious anaemia	• Married with two adult daughters	• Fulltime carer to husband with Alzheimer's disease

Pseudonym	Age	Region	Population of local town	Distance from nearest capital city	Autoimmune diseases	Relationship status and family	Work
Kate	53	Toowoomba	100,032	124kms	• Hashimoto's disease	• Married with three adult children (two sons and one daughter)	• Unable to work – on disability support pension
Emily	43	Sunshine Coast	907	112kms	• Systemic scleroderma with heart failure • Lupus • Sjögren's syndrome	• Married with one young daughter and one adult son	• Finance administration
Harriet	36	Toowoomba	100,032	124kms	• Lupus	• Married with two young children (one son and one daughter)	• Works in retail and runs an essential oil business
Lucy	26	Toowoomba	100,032	124kms	• Ankylosing spondylitis	• Engaged, no children	• University administration

The case study areas

As noted above, all participants ended up residing in either the Toowoomba or Sunshine Coast region. Toowoomba is Australia's second-largest inland city, and the surrounding region is largely agricultural. The region's economy and population are strongly connected to this rural way of life, feeling the effects of decades of drought, and with many farmers from neighbouring localities retiring or relocating to Toowoomba city. In 2016, however, the health and social assistance, education and training, retail, and construction sectors accounted for the most employment in the region (.id Consulting 2016a). The Toowoomba region has an estimated population of 170,356, 61.3% of whom are aged between 15 and 64 years (Australian Bureau of Statistics n.d.-a). This compares to a national average of 66.7% (Australian Bureau of Statistics 2021). The median income in Toowoomba is $48,226. For comparison, in Brisbane, the state capital, the median income is $53,602 and the national average is $49,805 (Australian Bureau of Statistics n.d.-a). Of the current population, 32% of people report having private health insurance and it is estimated that 20% of the population has a disability (Australian Bureau of Statistics n.d.-a). Toowoomba has one public hospital, two private hospitals, and access to a range of specialists, although choice of provider can be limited. Public transport is limited to buses that typically run hourly. For specialists not available in Toowoomba, or to access second opinions, the next closest town is Brisbane, which is about 150 kilometres or approximately a 1.5 to 2-hour drive away. For those who do not have access to private transport, Brisbane is only accessible by bus. Those who live outside Toowoomba city, including two of my participants, typically do not have ready access to public transport. To access health services in Toowoomba city, which is approximately 20-30 kilometres or a 30-minute drive away, these women must use private transport.

The Sunshine Coast is approximately 106 kilometres or a 1.5-hour drive north of Brisbane and approximately 228 kilometres or a 3-hour drive from Toowoomba city. It includes both coastal and smaller hinterland localities across several sub-regions, such as Caloundra, Coolum, Nambour and Maroochydore. Health care and social assistance, construction, retail, education and training, and accommodation and food services account for the most employment in the region

(.id Consulting 2016b). The Sunshine Coast has an estimated population of 336,482, 61.3% of whom are aged between 15 and 64 years (Australian Bureau of Statistics n.d.-c). The median income on the Sunshine Coast is $43,226, considerably less than Toowoomba, Brisbane, and the national average (Australian Bureau of Statistics n.d.-c). Of the current population, 29% of people report having private health insurance and is estimated that 20% of the population has a disability (Australian Bureau of Statistics n.d.-c). Like Toowoomba, the Sunshine Coast has access to a range of specialists, but not all specialisations may be available. The Sunshine Coast has three public hospitals, including one small memorial hospital, and four private hospitals. Local public transport is available via bus, train, and ferry services, with train and bus services also available to Brisbane. Bus services are available to those in hinterland locations, though trips can be lengthy. For example, travelling by Maleny to the Sunshine Coast hospital, a distance of approximately 30-40 kilometres, via public transport is a 4-hour round trip. The same trip in a private vehicle , takes just 30-40 minutes each way.

Multi-sited and digital ethnography

By virtue of the sample and particular nature of the study, this project was both bounded and ‘multi-sited’ (Marcus 1995). It was bounded in the sense that it was carried out in a defined regional space, and multi-sited in the sense that it pursued ‘links, relationships and connections’ that ‘follow unpredictable trajectories’ (O'Reilly 2009, p. 145) and extend beyond this geographically identifiable space, including into the virtual world. It was anticipated that for some women, both online and offline care would be important, necessitating the use of digital approaches to ethnography. Broadly speaking, digital ethnography represents the extension of traditional ethnographic methods to the online world (Pink et al. 2016, p. 3). Digital methods may examine, for instance, social media platforms (Kudaibergenova 2019), online gaming (Rea 2018), online forums (Darwin 2017), and digital communication practices (Madianou 2017). Specific methods range from full participant observation in virtual worlds (e.g. Boellstorff 2008); to interacting with, and observing, others in online groups or forums (e.g. Darwin 2017; Hughey 2008); to immersing oneself in material publicly available online, such as blogs and websites (e.g. Keim-Malpass & Steeves 2012). Virtual ethnographic methods are increasingly being employed in

health research, particularly among invisible, stigmatised, or difficult to reach populations (Barratt & Maddox 2016; Darwin 2017, p. 5; Liamputtong 2007, pp. 57-8).

While the examination of online forms of care for chronic illness, such as peer support groups, remains popular, less attention has been paid to the relationships between online and offline forms of care for the chronically ill in the context of people's whole lives. This is despite more recent forms of digital ethnography considering both online and offline worlds, given how tightly they are now entangled (Hine 2017, p. 22). An early exception to this is Orgad (2005a, 2005b) who examined internet use among women with breast cancer. She found that to develop a meaningful understanding of women's internet use, she needed to extend her study to women's offline worlds. Orgad (2005a, p. 53) argues that:

> Patients' use of the internet is deeply embedded in their everyday experience of chronic illness . . . if we are to understand patients' online context, we have to have knowledge of their offline contexts.

Similarly, to better understand women's everyday experiences of autoimmunity as comprehensively as possible, I included engagement with online worlds where this was possible and significant for the women in my study. This supports the development of a 'more complex and rich picture of the relationship between their [women's] lives and the use they make of the internet as both technology and text' (Orgad 2005a, p. 63).

In the end, the use of digital ethnographic methods in this project was limited and represented a secondary method of data gathering, with in-depth life story interviews the primary approach. One participant gave me access to her online support group, hosted on Facebook, and I observed her posts and interactions with others for the duration of data collection, approximately twelve months. This mostly included her welcoming new members to the Facebook group, posting about support group meetings, and providing encouragement and answering questions. The remaining participants either did not use online support groups, did not use online support groups regularly enough to feel it warranted attention, or preferred not to have online interactions observed. Adjusting research methods based on participants'

preferences in this way reflects a 'connective ethnography' approach where 'the field is incrementally defined or bounded' (Dyke 2013, p. 147).

Data gathering methods

A number of data gathering methods were adopted to elicit a holistic understanding of women's experiences of autoimmunity. The primary method of data gathering was in-depth, open-ended interviews, with an initial focus on understanding the life stories of participants. This provided important context for further interviews and participant observation, as well as for the later interpretation of results. The illness narratives of participants were also elicited, as part of their life stories, in order to better understand how participants explain, interpret, and experience their illnesses. The collection of illness narratives is a common approach in qualitative illness research (Becker 1998; Frank 2013; Good 1994; Kleinman 1988) and there is significant 'overlap between narrative and ethnography' (Gubrium & Holstein 1999, p. 561). The collection of narratives in ethnographies that explore illness, identity and morality is particularly useful since:

> Narratives share the *meaning of experience* . . . in recounting events in narratives, tellers also directly or indirectly give their own interpretations and explanations of those events. They also evaluate, in their own terms, the principle people and others featuring in narratives, the meaning of events and wider relevant contexts (Cortazzi 2001, p. 385, emphasis in original).

These interpretations can provide a window through which to view multiple and changing identities. As discussed in Chapter 2, narrative represents one way in which the self is conceptualised and continuity of self is maintained, making narrative methods particularly appropriate for the exploration of identity. Narrative methods can also give voice to previously under-represented groups or invisible groups (Cortazzi 2001, p. 386). Becker (1998, pp. 27, 45) argues that 'narrative is a culture-specific response to disruption' and that all:

> Narratives of disruption . . . have a common plot: a disruption to life is followed by efforts to restore life to normal . . . events are defined not in terms of their singularity but in terms of the contribution they make to the unfolding story or history in question.

However, it is important to recognise that understandings of what it means to act to 'restore life to normal' may differ between individuals. For some, a disruption may become their 'new normal' — the agency involved may reflect the acceptance of the disruption and its effects, rather than an attempt to restore one's life to a previous 'normal' state. In this study, theories of biographical disruption (Bury 1982) and moral breakdown (Zigon 2007) were used primarily as methodological, as opposed to analytical, tools as a way to identify points where identities were challenged or moralisation occurred and how women responded to these.

Where possible and appropriate, participant observation was also employed during interviews with women, particularly during interviews conducted in family homes and during support group meetings. Combining in-depth interviews with participant observation allowed for as complete a picture of women's experiences of autoimmunity as was possible within the scope of the study. Combining these methods also revealed many women's relationship dynamics which were intimately tied to their care needs, something that would not have occurred otherwise. Participant observation was also employed in the online text-based, asynchronous peer support group of the one participant who was actively engaged online.

Data collection and reflexivity

Informed consent was obtained from all participants prior to data collection. All interviews were audio recorded, with permission sought from participants at the beginning of each interview. Interviews were conducted in-person and via phone and video calls (Skype), depending on each woman's location and preference. Due to travel distance, I conducted Skype interviews with one participant and phone interviews with another whose internet data plan was not large enough to accommodate video calls. Travel distance was not the only consideration here though. One participant resides in the same town as me but felt more comfortable having interviews via Skype so that she could do them at home at night, which suggests that these methods should be considered based on participant preferences rather than only practical considerations.

Prior to Skype and phone interviews, I met each of these three women in person and conducted initial informal interviews. I conducted in-person interviews with the remaining four women, all in their homes. While also being a familiar and comfortable space for each woman, this facilitated participant observation and rapport building as I shared in casual conversation with each woman before and after interviews, and often enjoyed coffee and morning tea that they had generously prepared. This became an invaluable part of fieldwork as women opened up their homes and lives. Two participants' husbands were usually at home during their interviews and would contribute now and then, either as they overheard something or after being asked to help remember something by their wives, giving some insight into dynamics of care. Interestingly, video calls did not necessarily create a barrier to these observations, as two additional participants' husbands occasionally joined in on interviews in a similar way. While ethnography historically involved continuous participant observation in a single field site over an extended period of time, this construction of ethnography does not lend itself well to working with a dispersed group of participants (Hockey & Forsey 2020, p. 74). Where participant observation in its traditionally conceived form is not possible or appropriate, ethnographic interviews, such as life story interviews, can facilitate 'culturally appropriate means of conducting socially engaged forms of research, particularly in so-called Western settings' and can be 'the most effective way of producing an ethnography' (Hockey & Forsey 2020, p. 74).

I conducted fifty-five interviews with my participants over the course of twelve months, beginning in June 2017. Each interview lasted for approximately two hours, and I conducted an average of approximately eight interviews with each participant over that time. The frequency, length, and time of interviews were led by the schedules and preferences of participants. For instance, I usually met with one participant fortnightly over six months, while the remaining six participants preferred to schedule interviews as we went along to better take into account their changing commitments. For these participants, the time between interviews typically varied from between two to eight weeks, depending on their preferences at the time. Participants were reminded during each interview that they were not obliged to answer any questions and that they had the right to retract any statements they made.

I used jottings throughout most interviews to provide a basis for the later writing of expanded fieldnotes and to ensure any important observations were not forgotten. Jottings are 'brief written record[s] of events and impressions captured in key words and phrases' which help to 'preserve accuracy and detail' (Emerson et al. 2011, p. 29). Expanded fieldnotes were written immediately after interviews to document context, descriptions, impressions, and reflections, as well as anything that cannot be captured on an audio recording (for example, casual conversations before or after recorded interviews). It is recognised that the process of writing fieldnotes is inevitably one of '[selecting] and [emphasizing] different features and actions while ignoring and marginalizing others' (Emerson et al. 2011, p. 9). Although it is not possible to 'capture everything' (Hammersley & Atkinson 2007, p. 142), in the initial stages of fieldwork, fieldnotes were as broad and extensive as possible to minimise the effects of the process of selection and exclusion, with notes becoming more selective as I further refined my research focus. To maintain confidentiality, pseudonyms were used in all fieldnotes as well as formal written work (Allmark et al. 2009, p. 51), with each participant given the option to choose their own pseudonym. In addition to jottings and fieldnotes, I maintained a reflexive research journal where I recorded personal reflections, emotional responses and 'analytic memos' in which 'progress is assessed, emergent ideas are identified, research strategy is sketched out, and so on' (Hammersley & Atkinson 2007, pp. 150-1). This was particularly important given that I was conducting research 'at home' as both an 'insider' as a woman with an AD and 'outsider' as a researcher (Anderson 2021; Morton 1999; Mughal 2015; Peirano 1998).

My position as both insider and outsider meant that reflexivity was an important process that occurred alongside data collection. The concept of reflexivity recognises that researchers cannot be completely 'objectively distant from their research' (Hammersley & Atkinson 2007, p. 15; Liamputtong 2013, p. 30). Reflexivity involves the researcher recognising and acknowledging the impact that their 'experiences, beliefs, and personal history' have on their research, contributing to the rigour of the data and analysis (Liamputtong 2013, p. 30). Hammersley and Atkinson (2007, p. 151) argue that:

> Such activity should help one avoid lapsing into the "natural attitude" and "thinking as usual" in the field. Rather than coming to take one's understanding on trust, one is forced to question what one knows, how such knowledge has been acquired, the degree of certainty of such knowledge, and what further lines of inquiry are implied.

These processes were important for identifying and course-correcting where my own experiences might have led me to presuppose those of other women. However, I equally recognise that my own experiences have inevitably shaped my research and that as a participant in the social worlds of women with ADs I am also a part of shaping those worlds. This was clear during fieldwork where, at the same time that I was interviewing women about their networks of care, I became part of those networks. For some participants, I became someone who was there to listen and understand, while also being listened to and understood in turn, thus shaping women's illness experiences at the same time as listening to and observing them. These reciprocal relationships can also be a product of an ethnographic approach that involves ongoing encounters with participants, as well as the use of life story interviews which are inherently relational (Atkinson 2012a; Cotterill 1992, p. 596; Sakellariou & Warren 2018, p. 159).

Analysis and interpretation

The data management program *NVivo* was used to store, transcribe, and code audio recordings. Along with repeated readings of audio transcripts, which I transcribed myself, each interview was also listened to at least twice. This facilitated data immersion and helped retain the nuance and context of women's stories which can be lost when interviews are analysed only as written text (Emerson et al. 2011, pp. 13-4). Data immersion is considered a 'crucial practice to enable themes to emerge from unstructured data, for memos to be recorded, for codes to be assigned and for patterns to be noted and explored' (Roberts & Wilson 2002, para. 32). Data analysis and interpretation occurred concurrently throughout the fieldwork period through writing and reviewing fieldnotes, with more structured analysis and interpretation completed once fieldwork had concluded.

A ‘descriptive interpretive’ approach was adopted to privilege ‘women’s voices and their narratives’ during analysis and interpretation (Smythe 2012; Thompson & Blake 2020, p. 25). Interviews and fieldnotes were coded in *NVivo* during the aforementioned process of data immersion to facilitate a thematic analysis. Software such as *NVivo* is valuable for coding, storing, and managing research data, though it is recognised that software cannot interpret or analyse the ‘complex contextual meanings’ of social life (Chowdhury 2015, p. 1140; Roberts & Wilson 2002, para. 21). Since this study adopted a life story approach it was particularly important that portions of women’s stories were analysed in the full context of their life histories, as opposed to analysing aspects of their narratives in isolation from their broader lives. Processes that rely on a ‘fragmented’ coding approach can be ineffective in narrative-based research (Bishop 2012, p. 376). A broader approach, in contrast, can illuminate how participants ‘make sense’ of their experiences, enact agency, and position ‘themselves in relation to broader social structures, institutions, and discourse’ (Bishop 2012, p. 377). Thus, coding was used to ‘name, distinguish, and identify the conceptual import and significance of particular observations’, to develop key themes, and to provide some structure to the analysis of each woman’s experience, rather than as a method to breakup and sort different components of women’s stories (Emerson et al. 2011, p. 175). Codes were used to identify common categories, patterns, and themes in the data (Kim 2016, p. 188). This interpretive process focused on identifying commonalities, contrasts, and disruptions (Bury 1982; Zigon 2007) in the stories women told. It also focused on how they told their stories, how they positioned themselves in relation to others, and what they emphasised as important, to understand the complex relationships between illness, identity, moralisation and support. These analyses identified three common phases in women’s lives with autoimmunity and these structure the proceeding chapters. While women often shared similar experiences, these chapters highlight those that exemplify the common themes that emerged from women’s stories.

Ethical considerations

A number of ethical issues were considered in relation to this project. To support informed consent, participants who expressed an interest in being involved in the study were provided with a participant information sheet (Appendix 4) which

described the purpose, methods, risks, and benefits of participation in more detail. I also had an initial informal discussion with each participant about the project before they provided consent and formal interviews began. Informed consent was obtained verbally and in writing via a consent form (Appendix 3). This included consent to audio record interviews. I also verbally checked with participants periodically before interviews to ensure they remained comfortable having interviews audio recorded.

Because this research involved recording information related to women's health, it was important that the privacy and confidentiality of all participants were strictly maintained. All participants remained anonymous and pseudonyms were used in all fieldnotes as well as formal written work to preserve anonymity (Allmark et al. 2009, p. 51). It was also important to consider that participants may make comments that, on later reflection, they did not want included in the interview record. I regularly reminded participants that they were not obliged to respond to questions that they would prefer not to answer and that I could remove any statements they made at any time. In one case, a participant divulged a significant part of their life story that they felt was important for me to understand, but made it clear that for legal reasons they did not want this included in any formal documentation. In another case, I left some aspects of another participant's family situation out of the project as they were nervous about the outcomes of this situation and preferred that it was not included in any formal documentation.

People with chronic health conditions represent a potentially vulnerable population, particularly the newly diagnosed and those who are currently unwell. It was anticipated that discussing illness and life stories may bring up difficult topics for some participants. Since participation was completely voluntary, the sample self-selected, and participants able to pull out of the study at any time, this risk was considered minimal. Details for referral services were, however, available should a participant have required additional support. It has also been reported that participants often find the process of having someone who listens to, and is interested in, their story therapeutic, cathartic, valuable or empowering, even where some aspects of a person's life may be difficult to reflect on (Atkinson 2012b, p. 120; Liamputtong 2007, p. 29). One participant in particular expressed at the end of the project that they found the process cathartic and that it helped them to work

through some of the issues they experienced as a young person with a chronic illness. The use of an unstructured life story approach also mitigated risks associated with remembering difficult experiences since it allowed people to create their own narratives and as part of this process, they could choose not to disclose particular details about their experiences. Consequently, participants had considerable agency in whether or not experiences that they find upsetting to remember were discussed.

CHAPTER 4: DIAGNOSING AUTOIMMUNITY

This chapter focuses on the relationships between autoimmunity, care, identity, and moralisation during the diagnostic phase of women's illness experiences. While diagnosis can be conceived of as a 'tipping point in the processes of encompassment and exclusion in health care' (Smith-Morris 2016, p. 19), care does not begin only once a diagnosis has been determined. As Mol (2008, p. 47) notes 'life with a disease does not begin once all the facts have been assembled' because the process of investigating symptoms of concern is 'an intervention in a person's life to begin with.' In the context of illness, much of the discussion around care relates to care that occurs, or does not, in relation to a diagnosis. However, tending to the care that people receive during the process of diagnosis is important for shedding light on diverse experiences of both care and autoimmunity. These processes bring into stark relief whose suffering is acknowledged, whose suffering is worthy of investigation, and who is considered deserving of care.

Autoimmunity provides a salient case study here. Even in a sample of seven women, there is considerable diversity in their experiences, ranging from those who received a relatively swift diagnosis, to those who fought for decades for theirs, to those who continue to have their suffering dismissed. For women with autoimmunity, what care looks like in the months, years, or decades leading up to a diagnosis is often unique. Rather than being shaped primarily by the relationship between doctor and patient, women's experiences emerged from specific intersections between identity, moralisation, care, and sometimes neglect that left women in protracted ambiguous states. In exploring women's experiences, I have selected those stories that exemplify three key experiences of care during diagnosis: disconnected care, avoiding care, and the denial of care. I consider how identities, the moral imperative to be productive, and the moralisation of women's bodies are related to women's experiences of diagnosis and care, and how they shape women's responses to their undiagnosed symptoms.

Common to many of the stories that follow is the ambiguity inherent in autoimmune diagnoses, despite diagnosis typically being positioned as something that can provide answers and a way forward (Warren & Manderson 2016, pp. 127,41). Diagnostic categories themselves are 'fluid and permeable', as the boundaries between disease and disease risk become increasingly blurred (Risør & Nissen 2018, p. 22). The associated increasing specificity in diagnosis that facilitates this 'also paradoxically introduces ambiguities and uncertainties' into clinical care as previously unmedicalised bodily states suddenly become medicalised (Risør & Nissen 2018, p. 22; Rohden 2016). In autoimmunity, the typically ongoing, trial-and-error nature of the diagnostic process, as well as the absence of clear biomarkers, further contributes to ambiguity (Risør & Nissen 2018, p. 22; Warren & Manderson 2016, p. 127). A diagnosis itself can also be ambiguous, such as the case of chronic fatigue syndrome (Sachs 2016). In the absence of effective biomedical care, women with ADs must often find their own ways to cope with this ambiguity as they go through the diagnostic process.

Disconnected care

Jennifer: 'Nobody put everything together'

Jennifer was 64 when we started our interviews. She lives in an over 50s village in a small hinterland town in regional Australia where she is a full-time carer for her husband, Mark, who has Alzheimer's disease. Before moving to the village due to Mark's illness, they lived on a five-acre property and enjoyed looking after the gardens and animals they kept. Jennifer has two adult daughters, one who lives about an hour's drive away and another who lives interstate. Neither are particularly involved in Jennifer or Mark's health issues and responsibility for caring for Mark falls on Jennifer's shoulders.

I first met Jennifer face-to-face when she invited me to attend a scleroderma support group meeting to speak about my project and see if anyone else would like to participate. Mark had attended with her and was affectionate, putting his arm around her, rubbing her shoulders and fixing up her shawl. Jennifer would later tell me that he only began to understand and take her illnesses seriously once he started attending the scleroderma support group meetings. Jennifer easily took charge of the

meeting, running through the agenda and making sure everyone kept to their allocated speaking time so the meeting did not run over. Jennifer is bubbly, chatty, and lives up to her reputation of being an ‘energizer bunny’.

Jennifer remembers having unexplained symptoms since childhood, and this is where she begins her story of diagnosis:

> I will just tell you my story because I myself didn't have any remarkable symptoms that came on or anything like that. I have had iron-deficient anaemia all my life. Right from a child, I can remember having iron tablets on and off and being told I was anaemic and this and that. I was always cold as a child and I can remember my older sister telling me, 'get that jumper off, get that jumper off! It's hot!' And we would have a big fight because I would want my jumper on because I was cold. Anyway, so then I had mouth ulcers. From memory, from teenage years on I always had mouth ulcers and had a lot of hay fever from teenage years on as well.
>
> So then when I was . . . 45 and my young brother was 31 he had a terminal brain tumour, so he was having blood transfusions regularly. I decided to try to donate blood to help so I would go to the blood bank and the blood bank would say, 'oh sorry we can't do you.' You know how they do the pre-test before you give blood? So [they would say] 'you're low in iron we can't take blood from you today, come back in so many weeks.' So, I'd trot back . . . 'no sorry, we can't take it, you're still low in iron', and this went on for several months. So, the blood bank then sent a letter to my GP, telling them I had low iron levels, he then sent me to a haematologist who said, 'yes you have iron-deficient anaemia but you also have pernicious anaemia, and there's something else showing up in your blood which I'll need to send you to a rheumatologist for'. So, he then sent me to a rheumatologist and she then finally diagnosed Sjögren's[2] with scleroderma overlap. But that took a couple of years, two or three years to get to that stage, from when the blood bank started first rejecting me. But on and off all through those years I'd been going to the doctor [saying] 'I've got mouth ulcers', [the doctor would say] 'you're not having enough vitamin B, have more vitamin D.' And then I'd go with some other thing, aches or pains or something, [the doctor would say] 'oh you're just worn out' or whatever. Then I'd go with fatigue, [I would say] 'I'm always tired', [the doctor

[2] A list and description of each woman’s autoimmune diseases is found in Appendix 1.

> would say] 'have some more iron and leafy vegetables.' And nobody put everything together, it wasn't until the whole lot was put together that then the diagnosis came about. So then when I had any symptoms I'd just think to myself, 'oh well it's just the Sjögren's or scleroderma', one of them. So, I didn't actually have [all of the] symptoms and go to the doctor going what's wrong with me I have all these symptoms.

Some of the most difficult symptoms Jennifer experiences are gastrointestinal. Speaking about before she was diagnosed, she told me:

> When I did go to the doctor I'd mention different things about my bowels and whatever and they'd say, 'you've got irritable bowel' and they wouldn't tell me what to do about it or anything, it's just irritable bowel. And I used to think, you know, they're just calling it that because they don't know what to call it basically. It would just . . . there was never anything positive or concrete done about it or looked into.

After hearing her story, I suggested to Jennifer that it seemed as though her illnesses were really something she has been dealing with for her whole life, despite only being diagnosed in her forties. She replied, 'yes, but without having a name or knowing that there was anything particularly wrong, I just thought, 'that's life or whatever.' I asked Jennifer what changed for her after receiving a diagnosis and she told me:

> I thought . . . 'ohhh, well that's why I'm always tired, that's why I've got mouth ulcers, that's why I'm always aching here or there'. So now I just think, 'that's scleroderma or that's Sjögren's', or the dry eyes and that sort of thing . . . And not everybody is like this, I understand now.

A protracted diagnosis is a common experience for people with ADs, and the women in my study were no exception. Jennifer faced several barriers that prolonged her diagnosis, with one of the most significant being disconnected care. Disconnected care is closely linked to Mol's (2008) concept of the 'logic of choice' which she juxtaposes with the logic of care. Under a logic of choice, patients are considered customers and healthcare is a 'clearly defined' transaction with 'a beginning and an end' (Mol 2008, p. 20). As its name suggests, the logic of choice is built on the assumption that matters of healthcare are matters of individual choice —

for instance, choosing between different treatment options or healthcare products. The doctors Jennifer visited failed to link her symptoms together, treating each encounter as a discrete transaction and each symptom as distinct and unrelated. This type of fragmentation has been observed in other Western medical systems (Allen et al. 2015) and was likely compounded by the fact that Jennifer tended to visit GPs for a single symptom at a time, herself not considering that they may be linked. In Australia, people are not obligated to visit the same GP or medical practice, so Jennifer also often visited a different GP or different practice when she was not satisfied with the responses to her symptoms, disrupting the continuity required to identify relationships between symptoms over time. Making things more difficult is that standard GP appointments in Australia are usually limited to ten minutes, with anything over this incurring an additional cost. This leaves little time to discuss anything more than a patient's most pressing issue at the time.

Disconnected care, however, is not only the product of time-limited, transactional appointments and visits to different doctors**.** Disconnected care is also related to how the meaning of symptoms in a person's life is addressed. While Jennifer's doctors technically did 'listen' to her complaints about her symptoms — something that is important for care — they tended to ignore the impact that her symptoms were having on her life. This was compounded by the fact that her symptoms were repeatedly explained away as consequences of individual behaviour. For instance, the pain and fatigue Jennifer experienced were brushed off as the result of her 'doing too much' or not eating enough iron-rich foods. In this sense, Jennifer's doctors appeared to 'care about' her symptoms in that they recognised that she had symptoms and that these required a solution (Tronto 1993, p. 106); however, the way they attempted to 'care for' those symptoms through practical action (Buch 2015; Tronto 1993, p. 106) was limited, dismissive, and usually ineffective. These attempts at care, where Jennifer's symptoms, and therefore their resolution, were attributed to her personal choices are underpinned by a logic of choice. The fact that Jennifer was routinely blamed for her symptoms then made it less likely that she would re-visit the same doctor, reinforcing the transactional and disconnected nature of her care. While a logic of choice does not necessarily always lead to disconnected care — many health needs can be adequately addressed through transactional logics — it risks disconnected care when dealing with persistent symptoms that are difficult to

explain. In these cases, disconnected care and discourses of individual responsibility can intersect to create decades-long diagnosis periods.

Avoiding care

Daisy: 'I ignored that of course'

While disconnected care can be, in part, a product of repeated attempts to be diagnosed or have symptoms investigated, care avoidance can emerge where symptoms are ignored, normalised, or misdiagnosed. This was the case for Daisy, who was eighty when we first started our interviews. Her husband had passed away earlier that same year and she was living alone in their home in a small town, about 20 kilometres from the nearest regional centre. Daisy grew up on a farm in a country town with her two sisters, about 60 kilometres from the nearest regional centre and 190 kilometres from the nearest capital city. She married her husband in her early twenties and they initially lived and worked on a property owned by his family in the same area. One of her sisters married her husband's brother so they spent a lot of time together as newlywed couples.

Daisy and her husband have four children, one of whom tragically took his life during the course of my time with Daisy. In the wake of this, Daisy took a break from interviews, calling me some months later when she felt ready to pick back up again. I attended her son's funeral where I met her three other children and grandchildren who she spoke of so often. His death was, of course, incredibly difficult for Daisy, but even more so being so soon after she had lost her husband. Her family are unfortunately no strangers to tragedy, with her son-in-law passing away in an accident on their farm some years previously. Despite the weight of this grief, Daisy persevered like she has her whole life, continuing to be a kind, caring person who loves to laugh.

While Daisy was quite content staying in the home she had shared with her husband, her children were insistent on her moving into Toowoomba, concerned about her being isolated and a little too far away from the nearest hospital for their comfort. We often spoke about what Daisy would like to do about this, which was to buy a nice little house in town with a straight driveway so that she could back out of

it without having to turn her neck, which is stiff and painful from rheumatoid arthritis. After we finished our interviews, Daisy ended up being encouraged to move into a retirement village. I called her one day to see how she was going and she told me it was like living in a doll's house. Although she did not want to move into a retirement village, Daisy often feels she should be agreeable and does not want to cause conflict or worry for others.

Daisy remembers first feeling that she might have a problem in her hands around 1970, when she was in her early thirties. Her youngest son was twelve months old and she was having trouble opening things. She told me:

> That was the first indication that I might be heading for trouble, and I ignored that of course . . . I think I just put up with it thinking that it was something that happened and you've just got to cope the best way you can.

At the same time her younger sister, Anne, was having issues with her knees swelling. Anne's doctor sent her to a rheumatologist who diagnosed her with rheumatoid arthritis and recommended that she have gold injections. Daisy said, 'I don't think she went along with it, she said, 'oh that's ridiculous, I don't need that, I'll be fine.' So, she put up with it.'

Daisy's own symptoms worsened over the two years that followed:

> In 1972 I think it was, I started feeling quite miserable. I had a lot of aches and pains and didn't pay any attention to it and I think that made everything worse because I used to ignore it. I used to get very tired. I was always tired, and people used to say to me, 'you look tired, are you tired?' And I'd say, 'no I'm fine.' But I was tired, I used to get really tired and my hands and legs used to ache a lot. And I used to think, 'oh well it's because I was so busy', because by this time we had four children. Sam [Daisy's youngest son] was born in 1970, so 1972 I would have been pretty busy. And it wasn't until later in the '70s that someone, the GP, had said, 'I think you've got a bit of osteoarthritis, take Panadol [paracetamol] or something.'

Anne's symptoms also worsened around the same time; however, this did not prompt Daisy to seek further investigation of her own symptoms. Daisy told me:

> She [Anne] got decidedly worse. We could tell that she was getting worse because her shoulders used to ache and her hands started to become quite swollen and deformed, and that's when she decided she better do something about it. It must have been 1974, I think, she decided she'd better do something. I think she went to see [the rheumatologist] again and I think she was put on medication, and I just persevered and just thought it was nothing. I used to swallow a lot of Panadol, which probably wasn't a very good idea, it's probably why my kidneys aren't so good now.

By this time Anne had had her first child and was having trouble fastening nappy pins. Anne noticed that Daisy was also having trouble fastening the pins, telling Daisy, 'your hands must be painful because mine definitely are.' Daisy responded, 'no I'm fine, it's only osteo[arthritis], it's no problem.' Daisy's GP had prescribed her an anti-inflammatory medication in addition to paracetamol for osteoarthritis, but it made her feel sick so she stopped taking it. She told me:

> I think I just sort of battled on for a couple more years thinking, 'oh well you're getting old so of course this is going to happen.' Didn't pay any attention really, until about '89 I think.

Daisy's symptoms continued to progress during this time. One of her hands started to curl to the point where she could no longer straighten it and she was experiencing a lot of pain in her hands and neck. She remembers trying to rub some cream into her husband's back one day, laughing as she told me, 'I couldn't get my hand flat, so I had to use this hand. He said, 'use your other hand', and I said, 'I can't, I can't straighten it'. He thought that was funny.' Daisy told me:

> And that sort of just kept getting worse and I ignored it until . . . it was Anne actually, who said to me, 'your hands look worse than mine' and I said, 'no they're not, I'm fine.' She said, 'don't be silly you can't even open your fingers' [laughs] and I said, 'well most people are like that aren't they?' and she said, 'don't be silly.' She said, 'I'll make an appointment with [the rheumatologist]' . . . I just didn't pay much attention to it because I thought 'oh well you know I'm getting older so that happens when you get older, you get all these aches and pains'. Anyway, Anne went ahead and made an appointment for me and that's how it all started. I went to [the rheumatologist] with several blood tests and everything and she told me the sad news that I had rheumatoid. It wasn't osteo, it was rheumatoid.

While Jennifer regularly attempted to seek help from doctors for her symptoms, only to be faced again and again with disconnected care, Daisy put off seeking help for hers. Before eventually seeking help, Daisy continuously dismissed her symptoms by both normalising them and attempting to ignore them. Despite admitting that she was 'feeling quite miserable' with aches, pains, and fatigue Daisy dismissed her symptoms as something that could be expected as a mother of four, at the same time reinforcing her identity as a mother. She also mentioned multiple times that she put her symptoms down to something that happens as you get older. Osteoarthritis is associated with ageing and Daisy used this to dismiss her symptoms, even though they first began when she was in her early thirties.

At the same time that Daisy's symptoms were beginning to manifest, her sister Anne received a diagnosis but, with a similar attitude to Daisy, felt that she could just 'put up with it.' This likely reinforced this attitude with Daisy — or they reinforced this attitude in each other. It would have been difficult for Daisy to voice how she was feeling, given that Anne had a confirmed diagnosis but was choosing to persevere and 'put up with it' rather than begin treatment. Brodwin (1994, p. 93) notes a similar phenomenon among people with chronic pain, arguing that chronic pain can 'represent[s] a performance of cultural and familial idioms', particularly when more than one family member experiences chronic pain. For Daisy, Anne represents a model for how someone with arthritis should behave. Daisy holds her sister's ability to cope in high esteem. When Daisy and I first began interviews, Anne was being treated for breast cancer and, as she has throughout her life with rheumatoid arthritis, has 'pushed through' and not stopped doing the things she values, such as going on trips to visit her children. Throughout our time together Daisy often praised Anne's resilience in the face of illness, telling me that she had 'coped admirably' and that she was 'so proud' of her and how she had coped. In Daisy's case, it was important for her to maintain her identity as a busy mother and wife, and to model her sister's stoic response to pain and illness. Being stoic in response to illness is a morally valued response that reinforced Daisy's moral worth (Hay 2010, p. 262), however, it ultimately delayed care seeking while her illness continued to progress.

Daisy's identity as someone who does not want to cause conflict or bother others was also significant in her decision to delay seeking care. I came to know Daisy as someone who wants to be agreeable and does not want to 'be a bother' and it seems that seeking help for symptoms she felt could be easily explained would have made her feel just that. I share two examples here because this is an important part of Daisy's identity. The first is from her childhood when she was about ten and sent to boarding school in another state. Daisy enjoyed boarding school, telling me through laughter, 'because I lived so far away I was spoilt a bit, and I think I rather enjoyed that.' She then remembers:

> And then for some unknown reason, my mother pulled me out of there, I don't know why . . . And that was really hard, I didn't want to leave at all. But being the nature that I was, I didn't buck the system, I just went along with it. But I was so miserable [at having to leave], I didn't really enjoy being moved. So, she sent me to [another school] for a year and I hated that, so she pulled me out of there and sent me to [a local school]. Oh, it was all these disruptions in my life that really didn't help. I didn't like that at all. But anyway, I had to spend the rest of my schooling at [the local school] which was ok, I guess. But I really would have loved to, if I'd had a more forceful nature I think I would have said please let me stay at [boarding school], which I should have done I suppose. But I just seemed to do what I was told [laughs] which is what I think I was led to believe that I had to do.

Seventy years later, Daisy still avoids what she perceives as inconveniencing other people. Being 'agreeable' is a common gendered identity for women (Weisberg et al. 2011, p. 8), and Daisy points to this herself when she says that this is 'what I think I was led to believe that I had to do.' This particular identity has led to health consequences for Daisy, in addition to her decision to avoid seeking care. A few weeks before we had our first interview, Daisy had been hospitalised and she explained that she needed to be careful not to fall over because she could not get back up on her own. She then told me:

> That's what happened before when I ended up in hospital just a couple of weeks ago. I had a bladder infection and a blood infection and when I got up to go to the toilet on the way back to bed, I fainted and fell. And I couldn't get up, just had no chance of getting up at all. Then I didn't know quite where I was for a minute, [I

> was thinking] ‘what am I doing down here?’ Fortunately, I had my phone, it wasn't far away, so I was able to crawl to the bedside table and ring the ambulance. That was about four o'clock in the morning. Awful time to ring people. I didn’t want to ring any of the family, so I thought, oh I waited until about six [in the morning] until I rang the ambulance.

Shocked, I asked Daisy if she had waited two hours to call the ambulance just to be polite. She smiled and said:

> Well, I didn't like to ring somebody at four o'clock, the poor things. They were probably all . . . actually, they would be up ready to go wouldn't they [laughs]? That was pretty stupid. Anyway, I told them this and they said, ‘oh you crazy lady!’

Being someone who does not make a fuss has been part of Daisy’s identity since she was a child. When coupled with expectations of stoicism that are often prevalent in rural Australia and were performed within Daisy’s family, it is not difficult to understand why she may have chosen to ignore her symptoms rather than seek help from a doctor or admit to others how she was feeling when they asked. Daisy even appears to play down the time she did visit a doctor, only saying, ‘it wasn't until later in the ‘70s that someone, the GP had said, “I think you've got a bit of osteoarthritis, take Panadol or something”’.

Daisy’s story points to the importance of considering diagnoses, identity, and moralisation in accounts of care and how these might contribute to facilitating, or in this case, delaying diagnosis. Receiving a misdiagnosis of osteoarthritis gave Daisy an explanation of her symptoms that made sense to her, particularly since she was getting older and her mother also had osteoarthritis, and reinforced for Daisy that what she was experiencing was normal. This normalising in turn meant Daisy felt a moral imperative to remain stoic and productive despite her suffering. It seems it also made it more difficult for Daisy to seek additional help for her symptoms, despite their progression. For someone who does not want to inconvenience others or ‘buck the system’, going back to the GP and suggesting that they were wrong in their diagnosis of osteoarthritis would have been very difficult for Daisy, particularly considering this diagnosis made sense to her. Visiting a different GP for a second opinion would have been similarly difficult, compounded by the fact that for much

of Daisy's life she only had local access to a single GP at any point in time. While in Jennifer's case this may have facilitated continuity of care, in Daisy's it created a barrier to further investigation. These factors seemed to allow Daisy to ignore how similar her symptoms were to Anne's until Anne herself eventually sent Daisy to see a rheumatologist. Even when Daisy's hands had begun to permanently curl, she dismissed this, saying to Anne, 'well most people are like that aren't they?', again normalising her symptoms. While she did not mention this to me, it is also quite possible that Daisy did not seek further care because she did not want a diagnosis of rheumatoid arthritis. While a diagnosis can provide a sense of relief and understanding, avoiding being diagnosed allows for some hope that there is nothing seriously wrong. Avoiding care meant avoiding a diagnosis and this meant that Daisy could maintain her understanding of her symptoms as normal.

Care denied

Ellen: 'You'd think you're just going crazy'

Ellen was 65 when we started our interviews. She lives with her husband in a small rural town about 25 kilometres from the nearest regional centre. Ellen and her husband, Sam, have three adult children. When I began interviewing Ellen, two of their grandchildren were living with them. Ellen was also in the midst of recovering from chemotherapy and radiation to treat breast cancer. She was often in severe pain, wincing if her youngest granddaughter jumped in her lap, but would try to cover this with laughter, not wanting to upset her. The radiation often left Ellen out of breath and with little energy.

Ellen is softly spoken and a little shy at first. When I started to hear her story and how she had been treated over the course of her life, I was not surprised. I was surprised though to find out that Ellen used to sing in a bush band, something she was keen to get going again. She is also incredibly creative, showing me photos of exquisitely decorated cakes she had made and touring me through her art studio, full of bright paintings. From the time I spent in their home, I could see how close Ellen and her husband, who also has health issues, are. While he never joined our interviews, he popped in and out of the house, with Ellen sometimes calling out to him to help her remember a name or timeline. Other times he would call out,

correcting Ellen when she might have misremembered something. Ellen joked to me that she appreciated how hard he tried to help with the housework but had never seen someone take so long to painstakingly vacuum the house. Ellen has a kind heart, and despite being so unwell always had some morning tea ready when I would arrive at her home, something I found incredibly generous.

Ellen identifies her health issues as starting when she began menstruating at eight years old. Her story is one of multiple diagnoses, some autoimmune, some not. Throughout her life, she has experienced erratic menstruation, abnormal growth as a teenager, fifteen miscarriages, fluid in her breasts, insomnia, unexplained weight gain, ovarian cysts, high oestrogen levels, chronic fissures, perianal and rectal pain, bleeding from the bowel, chronic nausea and vomiting, stomach pain, reflux, severe vaginal pain, severe back pain, trouble passing bowel motions, and allergies to many common medications. These variously led to diagnoses later in Ellen's life. In the early 2000s she was diagnosed with degenerative spinal stenosis, and sometime between 2007 and 2008, she was diagnosed with ulcerative colitis. Her doctors also suspected that she had Crohn's disease but could not confirm this. She was later diagnosed with a prolapsed bowel and had suffered from vaginal prolapse in the past.

Many of the health issues Ellen experienced since childhood were eventually diagnosed almost fifty years later as empty sella syndrome[3], an issue with her pituitary gland. Although this is not an AD, it has significantly shaped Ellen's life and health, and she wonders if it might also be implicated in her autoimmunity. In Ellen's case, empty sella syndrome was caused by a prolactinoma, a benign tumour of the pituitary gland. In about 2000 Ellen had an episode of viral pneumonia, and this seemed to trigger a worsening of her symptoms. She explained:

> After that viral pneumonia then I started getting all these cysts in the ovaries, producing oestrogen way too high feeding all these massive fibroids and cysts in the breasts, there was . . . fibrositis, you name it, all these silly names that

[3] 'Empty sella syndrome is a rare disorder characterised by enlargement or malformation' of the sella turcica, a structure in the skull that houses the pituitary gland (National Organization for Rare Disorders 2017). Empty sella syndrome occurs when the sella turcica either fully or partially fills with cerebrospinal fluid which can lead to a very small pituitary gland, or no visually observable pituitary gland (National Organization for Rare Disorders 2017).

> keep coming up with all these little things but nothing really. They found incontinent veins and all this basic stuff but yeah.

I asked Ellen if at any point her doctors had considered that her symptoms might be linked, and she said:

> Nope. Every one [of the symptoms] was a different one. Every one was to a different little specialist that looked at his little nook and yeah, nothing [individually] was severe enough to make anyone click.

Around 2007, she remembers breaking down in tears in her gastroenterologist's office after decades of unexplained symptoms, telling her:

> Something's wrong. My mum and dad are in their 90s, dad's mum's sister is 105 and still going fine. Something is wrong, it's not in our DNA to be like this [to have health issues].

The gastroenterologist began asking Ellen about all the symptoms she had experienced across her lifetime. She suspected that Ellen may have a pituitary issue (many of the symptoms Ellen described are common indicators of prolactinoma) and this was quickly confirmed by an endocrinologist. By this time, the prolactinoma had choked itself to death and flattened her pituitary gland, meaning treatment was not possible — there was effectively nothing left to treat. It had taken fifty years for a doctor to consider that Ellen's symptoms might be related. While this was far too late to treat the issue, it at least gave Ellen some explanation for decades of being told that she was imagining things or that nothing was wrong. I asked her how she felt when she received the diagnosis and she recalled:

> Well, I felt really relieved because for the first time in my life we had a name for what was going on. Up until then, you'd think you're just going crazy. People think you're mad because you've just got one thing after another, you're a hypochondriac or whatever. It was just lovely to finally know what's been happening, why it's been happening.

While seeking care, Ellen has faced considerable discrimination and dismissal because of her weight. This started when she was a teenager and exhibiting the symptoms that were later diagnosed as a pituitary tumour. Ellen told me about an experience she had when she was 13 and at boarding school:

> So, while I was at boarding school I suddenly grew very quickly. I hit about 16 and a half, nearly 17 stone and 6'1 high. And they sent me to the doctor who put me on a hardboiled egg diet . . . I had one hardboiled egg three times a day — breakfast, dinner, and tea — and on Sundays I had a salad. And yeah, mum and dad paid for boarding fees for that. But anyway, it made absolutely no difference to me growing.

Around 2003 Ellen told me about an experience she had seeking treatment for an issue with the veins in her legs. She told me:

> There was another one where they found that I had incontinent veins. Deep veins in the right leg and shallow veins or incontinent on the left leg. And my GP got all excited that that would be causing such and such pain or whatever and sent me to this vein specialist. And as I walked in the door, my husband was with me, before we even got to sit down he [specialist] looked up at me, he said, 'go and get your stomach banded and when you're skinny-skinny come back and see me.'

During a stay in hospital for an irregular heartbeat, Ellen told me about this encounter with the cardiologist who was overseeing her treatment:

> He [cardiologist] had talked about stomach banding and losing weight and then he just made this snide comment, 'oh well it would be like one lady, she had her stomach banded and I walked in to catch her eating Mars Bars'.

During another hospital admission, Ellen recalls:

> At the hospital another time, I went in with high blood pressure and my husband said to the doctor, 'what's causing the high blood pressure?' And [the doctor said] 'well if she didn't sit on her bum eating junk food all day' [she wouldn't have high blood pressure].

After encounters like this, Ellen told me 'you just feel that deflated, that dejected.' Speaking more generally about these experiences, Ellen said:

> They'd [doctors] just have it in their head that, 'oh you just sit on your bum and eat junk food all day, you eat too much and don't exercise enough.' They don't see, or don't ask, that you've just shovelled 27 tonne of wheat on your own, you know, things like that. You worked as one of the men on the farm. So, these little lily-white doctors just out of their time [at medical school] that have never done a

> day’s work in their life sitting there telling you that if you didn't sit on your bum all day doing nothing [you wouldn't have health issues]. That wears a bit thin after a while.

Ellen’s experiences with diagnostic technologies have also been tempered by her weight. When technologies could neither diagnose nor rule out a particular illness, Ellen has been told that the issue is her weight, rather than the fact that diagnostic technologies are not accessible for diverse bodies. Ellen was diagnosed with ulcerative colitis, an AD and form of inflammatory bowel disease that is confined to the colon, about ten years before our interviews. She began experiencing symptoms in other parts of her gastrointestinal tract and her doctors suspected that she may have Crohn's disease, another form of inflammatory bowel disease which can occur in any part of the gastrointestinal tract (Waugh et al. 2013, p. 152). Ellen told me:

> They did all sorts of tests but they couldn't . . . they said that because I was big it was more difficult than if I was a small person. But they couldn't say it for sure that I had it [Crohn’s disease], but they were virtually treating me for Crohn's.

She reiterated this in a later interview, telling me:

> Because I had an awful lot of ulceration in the top [of the gastrointestinal tract] as well, is why they thought that I was probably Crohn's. But the couple of tests that they sent me to a specialist to try and pinpoint he just said because of my size and that, it was impossible to diagnose as definitely that, but he thought yeah [it was Crohn's disease].

Ellen experienced a similar issue when she was trying to find answers for seven years of chronic pain, nausea, and vomiting that was misdiagnosed as an issue with her gallbladder. She told me:

> Because I'm big, every time they send you for an ultrasound of anything down there nothing shows up. But that's what happened when they were treating me for gall, nothing would show up.

Frustrated with the lack of care for Ellen, her sister eventually took her to see a gynaecologist in the nearest capital city, where Ellen had a different experience:

> When my sister took me down to the gynaecologist, he actually put a dye into me and then did a physical X-ray. And when he looked at the X-ray, he said, 'the dye hasn't dispersed properly', he said, 'no it can't be, it can't be' and then he found the five huge kidney stones. And it was only with this X-ray with the dye that it showed it up. A couple of times I've mentioned it to the doctors and they poo-hooed it. And I wonder if they took an X-ray again with the [dye] that they might actually be able to see something that's going on, whereas with the ultrasound and that they can't seem to get a clear picture of anything.

In this case, there was an alternative to ultrasound available; however, Ellen's previous doctors either chose not to use x-rays or did not know they were an option, instead telling her that nothing was showing up and that it was because she was overweight. This shows an almost complete lack of care on their part and Ellen suffered considerably. She remembers that at one point she experienced 'virtually 12 months of vomiting', notwithstanding the pain known to be associated with kidney stones.

In a third example, Ellen had cysts in her breasts and ovaries that she ended up self-treating with colloidal silver. The treatment appeared to have worked; however, rather than accept that the cysts had gone, Ellen's doctors told her that they were probably no longer showing up on tests because of her weight. Ellen explained:

> I was on the colloidal silver for the one year. And in that year the cysts in the breast, they'd [doctors] drained a couple and they said, 'well once you start getting them you'll get hundreds, they'll just keep growing and you'll have to keep getting them drained' and whatever, cysts in the ovaries. All of a sudden, they couldn't find the cysts in the ovaries — gone. They couldn't find the cysts in the breasts, all gone. Couldn't explain it, [they said] 'oh you're big, maybe we can't see it because you're big.' But they've gone and they've never been there since.

In this case, rather than accept that Ellen's self-treatment may have worked, doctors fell back on the explanation that if nothing is showing up on ultrasounds then it must be because of Ellen’s weight. These encounters exemplify the continual denial of care that Ellen has experienced over her lifetime.

Like Jennifer, Ellen experienced disconnected care. In Ellen's case, however, additional factors played into this fragmentation. As Ellen identified herself, the way that medical specialisations are separated in Australia meant that she had to visit different specialists for each symptom. Because each symptom on its own did not necessarily appear severe, and there was no connection between specialists, Ellen was left suffering for decades. Like Jennifer, a significant gap in care here was the absence of any attention to how those symptoms were affecting Ellen's life. A tipping point for Ellen is when her gastroenterologist stopped to consider her collection of symptoms over her lifetime which allowed her to get a diagnosis of empty sella syndrome. While treatment was not possible, Ellen was incredibly grateful for the care shown by the gastroenterologist and for the legitimisation of her symptoms that followed. This reinforces the importance of understanding the meaning and impact of symptoms on someone's life, rather than focusing only on their clinical presentation, as a means to make sense out of otherwise seemingly disparate symptoms.

Like Jennifer, Ellen had her symptoms dismissed using personal responsibility rhetoric. Ellen's experiences with doctors were, however, also regularly characterised by weight discrimination and related gaslighting, with Ellen made to feel that her symptoms were either all in her head or her fault because of her weight. This in turn led to Ellen's identity as a sane, rational person being threatened. Ellen also experienced gaslighting by doctors, often being told that her health issues were due to laziness or inactivity, when in fact she engaged in hard manual labour on her farm every day. In Ellen's case, weight discrimination appeared to cloud many doctors' willingness and ability to provide appropriate care. Denial of care continues to be a disturbingly common experience for women who are perceived as overweight, with 'obese' bodies constructed as 'morally flawed'(Warin 2014, p. 50). Weight discrimination can be a significant factor in worsened health outcomes due to women's reluctance to seek care and the poor-quality care they receive if they do (Mensinger et al. 2018). This is ironic in an Australian public health environment where we are constantly warned about the health 'dangers' of obesity. By this logic, women who are perceived as overweight are considered more at-risk of health complications, so should have their care prioritised. Instead, the

moral judgements placed on people's weight, and the personal responsibility discourse that goes alongside these, means they are often denied the care they need.

This issue is compounded for women like Ellen by the limitations of diagnostic technologies that are not built to be accessible for all people. The use of an X-ray with dye that Ellen describes was an exception here, and an example of good care for Ellen. As Mol et al. (2010, p. 14) argue:

> Technologies . . . do not work or fail in and of themselves. Rather, they depend on care work. On people willing to adapt their tools to a specific situation while adapting the situation to the tools, on and on, endlessly tinkering.

Had more doctors been willing to adapt and 'tinker' (Mol 2008, p. 12) with the diagnostic tools they had available, Ellen may have been saved from considerable suffering. This also points to the importance of embedding care into the development of medical technologies from the outset. While this specific issue is beyond the scope of this thesis, the fact that there are diagnostic technologies that cannot accommodate people over a certain size is a stark example of how the scientific and medical community moralise certain people, deem people underserving of care (e.g. due to their personal moral failure to maintain thinness), and then police their access to specific forms of care, such as diagnosis.

While Ellen has had an especially difficult experience with the health system over her lifetime, she has still experienced moments of good care, including her experience with the gastroenterologist and gynaecologist mentioned. These encounters in particular aligned with a logic of care (Mol 2008). For instance, many of the symptoms Ellen was experiencing are normally not within the purview of a gastroenterologist, and in the Australian healthcare system specialists tend to stick quite strictly to their specialisation. The fact that the gastroenterologist took the time to listen and ask questions and was then able to facilitate a diagnosis after so many years of suffering was significant to Ellen, particularly when she has had so many negative experiences with healthcare providers. Similarly, the gynaecologist acted on Ellen's concerns, trying a different diagnostic technique to explain her symptoms. Ellen also received good care from her family. Her husband always accompanied her to her appointments and provided emotional support, never feeding into illness

explanations that placed the blame on Ellen's shoulders. He kept searching for answers alongside her. Ellen's sister also provided good care, seeing her suffering, and booking her in and accompanying her to the gynaecologist mentioned above. Unfortunately, outside of her family, positive care experiences were almost absent for most of her life. Ellen's illness experience has overwhelmingly been characterised by the denial of care that borders on neglect.

Emily: 'You almost cost me my life'

Emily was 43 at the time of our interviews. She is married with an 18-year-old son and a three-year-old daughter. I first met Emily when I attended the scleroderma support group meeting that Jennifer had invited me to. Once the formal meeting had ended, Emily sat next to me and gave me a brief rundown of her illness experience and said she was happy to be a 'guinea pig'. Emily is friendly and easy to talk to. We had our interviews over Skype or Facebook messenger, depending on how Emily's internet connection was behaving on the day. Sometimes her husband interjected to make a joke about something she said and other times her young daughter climbed into her lap. Emily works as a finance broker assistant and was initially employed to work about 12 hours a week, something manageable with her illness, but usually ends up happily working closer to 32 hours. Emily often speaks about her illness experiences matter-of-factly, being used to reciting her story. Sometimes though, she is visibly frustrated with how she has been treated. At particularly difficult moments, like discussing how her illness has affected how she interacts with her daughter, or how her suffering has been dismissed, she tries hard to hold back the tears that threaten to come.

Describing what happened when she first started noticing symptoms, Emily told me:

> Before I got sick, I was doing Tough Mudders and running 10k and 21k marathons and stuff like that. And even when I was pregnant, I was training four days a week, morning, and afternoon, and I was really fit. I loved it, I just absolutely loved training. And then I had my daughter and it must have all triggered off during the pregnancy. Because the first sign that I knew maybe something wasn't quite right was all my nail beds flattened right out and I also started, my knuckles and everything started to become really quite pronounced. And I thought, 'oh that's a bit

> odd' . . . Didn't think much of it, told the doctor and he said, 'well let's wait until the end of your six months [post-birth] when all your hormones are back to normal.' Well, it was only six months and two weeks and I was in hospital dying.

About four or five months after Emily gave birth to her daughter, Emily's GP referred her to a rheumatologist. This turned out to be an incredibly distressing encounter with someone who Emily believes 'virtually put me on death's door.' Emily recalled:

> So, he [the GP] sent me to see this doctor [rheumatologist], and we went in, my husband and I — I always take someone with me, I never go to an appointment without someone — and after 10 minutes he virtually said, 'there's nothing wrong with you, leave.' And I said, 'but look at my fingers, there's something definitely going on here.' He had a look at my fingers and . . . I can't remember what he said now, but he had me in tears. He made me feel like an absolute idiot. He was downright rude, absolutely rude. He virtually was telling me it was all in my head. He just completely dismissed me, just completely, like he asked me a couple of questions and looked at me, 'cause at that stage I still had pregnancy weight, like I'd only had my daughter, I think she was about 4 months old or something like that, so I still had excess weight, and he just totally dismissed me and said, 'you're just overweight, that's all it is', and I'm like, 'no there's something going on.'

Emily had no choice but to leave the appointment. On a Saturday in July 2015, only a few weeks after her encounter with the rheumatologist, Emily was raced to hospital with a suspected heart attack. After arriving in the emergency department (ER) and undergoing tests, doctors told Emily that all her results indicated a heart attack, except the tests on her heart itself. Emily remained in the ER while doctors continued to run tests to pinpoint a diagnosis. Eight hours after she was first admitted, the hospital called in its head cardiologist who immediately transferred Emily to the intensive care unit. Emily told me:

> They attached me to every god known wire going. I had things hanging off me everywhere and everyone [in the family] was told to get here as quickly as possible, they didn't know if I was going to survive. So that was pretty hard.

By Monday, Emily had stabilised enough for more testing. She recalls:

> I had MRIs, I had echos [echocardiograms], I had CT scans, angiograms, chest x-rays, lung x-rays, bloods, you name it they did just about everything over the next couple of days.

On Friday, the cardiologist visited Emily along with the hospital's head of immunology. Together, they gave Emily her diagnosis, a moment she remembers clearly. They told her:

> 'Look, this is pretty serious. We're sending you home, you've got systemic scleroderma with heart failure and the only way we know to treat it is to start you on chemotherapy, so we'll see you again on Monday.'

Emily's doctors told her that she had 3-5 years to live. As soon as she was discharged from the hospital, Emily called her parents who insisted that she and her family move into their home. With the help of extended family, they packed up the entire house and moved in with Emily's parents over the weekend. Three days after her diagnosis she began what would end up being eight rounds of chemotherapy over the course of two months. While chemotherapy did not improve the life expectancy Emily's doctors had given her, after eight rounds it had slowed the progression of her disease to a level that her doctors were comfortable with.

Reflecting on her encounter with the rheumatologist in light of her diagnosis, Emily told me:

> I knew there was something going on then, but we didn't realise exactly what was going on . . . I was really tempted, actually my husband was really tempted, both of us were really tempted to walk back into him after I got diagnosed and say, 'you almost cost me my life.' Had he bothered to take the time and look at me and order the tests, he would have seen that the fluid was already collecting on my heart, you know. But he didn't, because he was so blasé about the whole thing and an arrogant pig. I just went about thinking it was all in my head.

I asked Emily if this meant she had taken on what he said, internalising the explanation that her symptoms were 'all in her head.' She answered:

> To a point. And I just sort of put it down to being a new mum again and working and maybe I was just imagining a lot of it, maybe I'm just trying to find a

> reason for being tired. Because, yeah, I was tired and grumpy all the time and couldn't work out why. And everyone is like, 'you've just had a baby you've got to give it time.' So yeah, after a while you do sort of go, 'okay maybe I am just over-imagining things.'

A few months later Emily and I were discussing her specific experiences as a woman with ADs. She came back to her experience with the rheumatologist dismissing her symptoms as 'all in her head', telling me 'I felt that he was totally doing it because I was a woman.'

While the period from symptom onset to diagnosis was relatively short for Emily, compared to the other women in this chapter, it was extremely traumatic and the consequences of even a relatively short delay were life-threatening. For Emily, it was her pregnancy that appeared to both trigger her symptoms and create a barrier to early diagnosis. This may stem at least in part from the historical and continuing essentialising of women as reproducers (Inhorn 2006, p. 350; Manderson 2010, p. 97), with Emily's GP initially explaining her symptoms as pregnancy-related without further investigation. While the timing of her symptoms with her pregnancy made this possible explanation logical, it is telling that there was no further investigation, particularly since Emily told me that her GP was aware of her family's history of ADs. Emily's symptoms only became a matter for further investigation once she was no longer pregnant. Although this contributed to delays in diagnosis, Emily herself recognises that she also initially did not think too much of her symptoms, and her GP's response could also be interpreted as mirroring this. So, while I point out here factors that may have influenced her GP's initial lack of action, Emily herself had no issue with this encounter. In hindsight, she wishes that her symptoms had been investigated at the time but she holds no ill-will toward her GP and continues to see him.

Once Emily's symptoms were referred for further investigation, however, she was denied help because the rheumatologist perceived her as overweight and therefore undeserving of care. This experience was traumatic for Emily and ruptured her embodied knowledge that something was not right with her health. In the face of a specialist who effectively told her that she was not worthy of care because of her

weight, Emily was left to try and explain her symptoms herself. Like Jennifer and Daisy, she did this by linking them to productive and socially valued aspects of her identity, such as being a busy working mother with a new baby. Like Ellen, this encounter also threatened Emily's perception of herself as a sane, rational person who does not 'imagine' symptoms. This made it particularly important that Emily could explain her symptoms, such as fatigue, to prove that they were not imagined. The fact that these identity challenges can be triggered by a single short appointment with an uncaring specialist shows just how damaging this kind of dismissal and denial of care can be for women. As with Ellen, Emily received care from her family, but her experience with the rheumatologist was disrespectful, neglectful, and life-threatening.

Discussion

Chronic ambiguity

Despite having different diagnosis experiences, each woman experienced an uncertain and prolonged diagnosis period. This is not surprising, since ADs are notoriously difficult to diagnose in many cases. For instance, an ankylosing spondylitis diagnosis takes an average of eight years from symptom onset (Reed et al. 2008, p. 323). On average, there is a seven-year delay from symptom onset to diagnosis for people with lupus, and a thirteen-year delay for people with coeliac disease (Lebwohl et al. 2018, p. 72; Price & Walker 2015, p. 54). It does not help that many symptoms that are common across multiple ADs, such as fatigue, fever, inflammation, gastrointestinal issues, and joint or muscular pain, are also common across countless other illnesses. There is currently no single biomedical test to detect the occurrence of an autoimmune response within the body. Although clinical markers can be present in some diseases (e.g. lupus and rheumatoid arthritis) which aids diagnosis these are not present in everyone with these illnesses, and the severity indicated by these clinical markers does not always necessarily reflect symptom severity or suffering. Further implicated in delayed diagnosis is the fact that ADs disproportionately affect women, yet women are 'frequently dismissed from healthcare settings without appropriate tests being conducted', which my study supports (Thompson & Blake 2020, p. 24).

Prolonged diagnosis periods, regardless of the factors that contribute to them, often leave women in ambiguous states, where they must find their own ways of coping with their symptoms in the absence of a diagnosis or adequate care. Chronic illness, particularly when invisible, 'disturbs binary understandings of health and illness' (Harris 2009, p. 48) because chronically ill bodies are ambiguous, unable to be classified as either healthy or sick, and what is ambiguous can seem 'threatening' (Douglas 1966). The chronic ambiguity often experienced by women with ADs in the period before diagnosis can be threatening for both women and healthcare providers alike (Honkasalo 2001, pp. 339-40; Stone 2014, p. 191). For instance, Stone (2014, p. 191) notes that patients with medically unexplained symptoms can 'trigger aversion, fear and even hostility' in their healthcare providers, likely contributing to prolonged diagnosis periods.

While chronically ill bodies can be ambiguous, the presence of a diagnosis can lend them biomedical and social legitimacy, while also providing the possibility of treatment (Warren & Manderson 2016, p. 141). However, in the period between recognising bodily sensations as symptoms requiring care and receiving a biomedical diagnosis, women must find ways to cope with their ambiguous state, neither healthy nor legitimately sick. The ambiguity inherent in undiagnosed chronic illness can be particularly threatening to women's social worlds and sense of self and is often 'met with efforts to re-establish cultural meaning' (Honkasalo 2001, p. 320). This was certainly the case with Daisy, who attempted to avoid this ambiguity by ignoring and normalising her symptoms. Thus, without the legitimacy afforded by a diagnosis, women must 'find their stability in . . . a state of chronic ambiguity' (Honkasalo 2001, p. 340).

Coping with undiagnosed symptoms

Women's responses to this ambiguity reflected internal and external expectations for those who are ill to 'restore normalcy' (Becker 1998, pp. 45-6), where 'normalcy' predominantly meant retaining valued identities and the activities associated with these. Because health and illness are significantly moralised in Western cultures, the onset of women's symptoms and realisation that they are not going to resolve can also be interpreted as a point of moral breakdown (Chapter 2)

where, similarly, there is an imperative to restore a sense of normalcy (Zigon 2007, pp. 139-40). While each woman developed her own coping strategies, what was common among all four was an anchoring of their symptoms to existing identities, particularly those that were underpinned by moral expectations to be productive, such as being a hard worker or busy mother.

This ‘identity management’ (Townsend et al. 2006, pp. 192-3) often occurred at the expense of women’s health. For example, multiple women explained away their symptoms as normal for ‘busy mothers’, carrying on these roles as they tried to remain stoic in the face of their symptoms. One of the key ways Jennifer coped with the ambiguity of undiagnosed and mostly untreated symptoms for so long was by absorbing them into her identity as a ‘productive’ person. More specifically, Jennifer anchored her illness experience to her identity as someone who 'keeps going' despite suffering and adversity. In this way, she was able to maintain both narrative and embodied continuity (Reeve et al. 2010), rather than having her unexplained symptoms disrupt her sense of who she is or the daily flow of her life. Whenever I asked Jennifer how she coped with her undiagnosed symptoms, she would tell me that she just has to force herself to keep going. It is clear that Jennifer’s ‘coping strategies [are] informed by a cultural expectation of productivity’ (Hay 2010, p. 260). Despite the physical consequences of pushing herself to be productive, the personal moral value this gives Jennifer is something that helps her to cope.

Similarly, Ellen also identified as a hard worker who ‘just gets up and gets on with it’, telling me:

> I have always been extremely busy, hands-on, yeah, that's what I find so frustrating with everything. On the farm, I'd work outside with Greg [Ellen’s husband] all day and then I'd work all night. I'd sew for the kids because we didn't have any money, I’d sew their clothes at night and washed, you know everything. I virtually worked around the clock.

While working hard is an important part of Ellen’s identity, at times it also exacerbated the medical gaslighting she experienced. She remembers:

> Even when I had the kidney stones, you know you'd just come home from the doctor and think it must be all in my head, just get on with life. And it didn't stop me doing anything, I worked on the farm as heavy as any man . . . The specialist said one [kidney stone] the size of a grain of sand is excruciating and I had five about 2cm . . . And he said, 'you'd had to have had excruciating pain while they were passing.' And you know, I'd go to the doctor and they'd say nothing is wrong [laughs]. So, you just get on with it.

Maintaining productivity is also built into women's expectations for their future. After Ellen and her husband sold their farm Ellen was working in a mail centre which involved a lot of heavy lifting. She developed severe back pain and her doctor would not give her clearance to return to work. Desperate to keep working, Ellen attempted to get clearance from a government doctor through an advocacy support centre. She told me:

> He said, 'as far as I can see you shouldn't have been working the last seven years'. And that was it, put me off. I was just so shocked. It was the last thing that crossed my mind. I was still trying to get well enough, had the hysterectomy to get rid of the fibroids to try and get back to work but it didn't happen . . . It was really hard for a bit. I felt, yeah, pretty down, or useless or whatever, yeah I just . . . We were, my mum and dad, like dad, worked until he was 80 on the farm. Greg's dad worked until he dropped. You just expected to work you know.

For both Ellen and Jennifer, there is a moral imperative to keep going, maintaining productivity despite illness. When the prolonged diagnosis periods characteristic of ADs intersect with these internalised expectations to be productive, many women are left to 'keep going' for years as their illnesses progress and their health worsens. Despite this, remaining productive can also be a valued coping strategy, particularly when a diagnosis is absent. For Ellen in particular, continuing to engage in productive activities like working on the farm and taking care of her family enabled her to maintain important identities in the face of doctors who were telling her nothing was wrong, threatening her sense of her own reality.

Diagnostic tipping points

While ambiguous and protracted diagnosis periods were common, each woman experienced a different tipping point for diagnosis, pointing to the different forms that care can take. For Jennifer, diagnosis was eventually triggered by

institutionalised care in the form of a letter from the blood bank to her doctor, highlighting concerns with her iron levels. This only happened through Jennifer's own concern for her brother. For Daisy, the tipping point for diagnosis was care from her sister, who booked Daisy an appointment with her rheumatologist and insisted she seek help. For Ellen, a significant diagnosis was only reached when her gastroenterologist acted through a logic of care, thinking about Ellen's symptoms outside her specific specialisation. Finally, the tipping point for Emily's diagnosis was a life-threatening health event that put her in the hospital emergency department where she received her diagnosis. Interestingly, none of these women gained a diagnosis through the typically expected care pathway in Australia, which is presenting to a GP with symptoms, or to a specialist after referral from a GP, and receiving a diagnosis. In most cases, the tipping point for care was the care of someone outside this expected network, pointing to the significance of the agency of others outside the doctor-patient relationship.

In these women's stories, I have framed diagnosis as a process of care, although care did not always occur. I considered women's interactions with healthcare providers as opportunities for care and the consequences for women's health when healthcare providers enacted particular forms of care, and when they did not care at all. I also considered how women care for themselves through these processes. In many cases, these forms of care were important for women's identities to the detriment of their health, aligning with a logic of care, where 'the crucial moral act is not making value judgements, but engaging in practical activities' (Mol 2008, p. 75). This tension mirrors the tension in the concept of care itself, where care does not necessarily lead to positive outcomes. In the absence of a diagnosis, women had to decide whether to care for their identities, and the moral and social value inherent in those, or their physical health. The prioritising of identities over health points to the importance of considering identities as part of the care needs of women with ADs.

In light of the threats that illness can pose to identities, women require care for both their physical health and their identities. Equally important is considering how moralisation contributes to the need to maintain socially valued and 'productive' identities, at the expense of women's health. In the absence of both

diagnoses and forms of care to help address the challenges related to identities and moralisation, women engaged in their own acts of care to cope with their undiagnosed symptoms and retain their identities. Thus, what is considered good care is not necessarily a given but is established through the process of caring. In this process, what is considered care may also change over time, particularly as people's illnesses and lives change along the way (Mol 2008, p. 75). This is not to say that caring practices cannot be identified. In this chapter, healthcare providers listening to people's concerns, taking them seriously, and acting on them emerged as foundational requirements for good care. Perhaps equally important is trusting in people's knowledge of their own bodies. Without this, it may be difficult to take seemingly mundane health concerns as seriously as is often necessary in the context of autoimmunity. In many cases, it is only when the most mundane symptoms are considered together that a diagnosis is reached. The next chapter explores women's experiences after receiving a diagnosis, with a focus on common care needs and how women negotiated access to these.

CHAPTER 5: NEGOTIATING CARE

In Australia, both medical and non-medical care tend to be diagnosis-specific and while this is important, it can create barriers to accessing the care women need. This chapter explores women's experiences of accessing care after receiving autoimmune diagnoses. Women's care needs fell into three broad categories — healthcare, peer support, and practical and financial support — and these frame the stories that follow. I first examine the experiences of Ellen and Lucy who both faced difficulties accessing medical treatment despite receiving a diagnosis. I then explore how women can strategically shift their illness identities and understandings of their illnesses in ways that give them access to local peer support through the stories of Jennifer, Harriet, and Kate. Finally, I consider Emily's experiences which illuminate how a diagnosis can act as both a facilitator and barrier to practical and financial care. Each woman's story demonstrates that a diagnosis cannot guarantee or determine the care someone needs. Instead, it creates the possibility of care within a system where healthcare is rationed and where some diagnoses are privileged over others. This rationing is based on both national and state healthcare budgets and the availability and accessibility of healthcare practitioners and medical technologies,

Healthcare

Ellen: 'Oh, you haven't got that'

All of the women in my study expected effective medical treatment, such as medication, in the wake of their diagnoses. While accessing treatment was straightforward for some, for others, this was not the case. Ellen had access to treatment blocked by her GP who ignored her diagnosis of polymyalgia rheumatica:

> I was getting really bad pain down my arms and I couldn't even hold my paint brush to paint, which was a problem [laughs]. Yeah, so, the doctor sent me to have ultrasounds and x-rays and that, and . . . the doctor that reads it and makes a report of what they're finding, he came out, which you normally don't see, he came out and started asking me all these questions . . . 'where does the pain start from and

> radiate to?' And I said, 'well it starts up here and dulls in there and down my arms and shoulder, through the middle of the back, and then from the waist down it's just really really cruel down both legs.' And he, oh he asked all these different questions, and he said, he wrote it down on a piece of paper, he said, 'I believe you have polymyalgia rheumatica.' I went back in to, it was a little relieving doctor, my doctor was away on long service or something at the time, and she gave me all the printouts and everything on it. And the read outs and everything was pretty well spot on of what I have. And then when my own doctor got back and I told her, she just didn't look at the x-rays or anything and said, 'oh you haven't got that, you don't need that, you really don't need that'. And that was it.

I asked Ellen if she'd been offered treatment at any point and she told me, 'no, just these pain killers', which she had previously told me did not work for her. Her diagnosis was dismissed by her doctor, despite evidence from pathology and a confirmed diagnosis by her relieving (locum) doctor. While dismissal often leads to feelings of delegitimization, in Ellen's case it also left her without access to treatment. While a radiologist may not be the one to typically give someone a diagnosis, the alternative for Ellen was no diagnosis and therefore no explanation or potential treatment for her debilitating symptoms. Ellen's GP appears to first dismiss her diagnosis as inaccurate, without viewing the pathology reports, then dismisses it again on the grounds that 'she doesn't need it'. Of course, Ellen does not need another illness, but this does not suddenly erase her symptoms. This is reminiscent of Fainzang's (2018, p. 46) observation that a diagnosis made by a patient rather than a doctor can lead to the withdrawal of treatment. This can act to reinforce power relations between doctors and patients and, as Ellen's case demonstrates, between doctors and other medical professionals, such as radiologists (Fainzang 2018, p. 46).

In erasing her diagnosis, Ellen's GP also prevented her from accessing the care she needed. More recently, her oncologist also suggested she had polymyalgia rheumatica after inflammation showed up throughout her body during a scan following radiation therapy for breast cancer. The oncologist told her, 'my god look at that, you're like a Christmas tree lit up!' This example demonstrates the power of both diagnosis and those with the authority to diagnose to act as gatekeepers to care. The decision to ignore both the clinical markers and Ellen's suffering meant that the 'cruel' pain Ellen describes above continues today. Thus, even where clinical

markers may hold the key to either diagnosis or access to treatment, they can be dismissed by those who hold diagnostic power.

Lucy: 'I wouldn't have made it to ten years because I was already planning a way out'

While Ellen's clinical markers were ignored by her GP, Lucy's were interpreted as not severe enough to warrant treatment with the most effective medications, leaving her suffering unnecessarily for months. Lucy was 26 at the time of our interviews, living with her fiancé who is about ten years older than her, and about to start a new job in university administration. We first met when Lucy approached me after attending a presentation about my project. At the time, Lucy was getting ready to re-start her English literature PhD after taking a break from it. She met her partner when she first began her PhD, which is when she was diagnosed with ankylosing spondylitis (AS) in 2015. Before becoming unwell Lucy enjoyed being active, going to the gym four times a week to do weights and cardio exercises. She told me that, in hindsight, she is glad that her partner has only known her since she has been unwell because it means he cannot compare her to her previous 'healthy' self. Lucy's AS flares can be debilitating, leaving her in pain, exhausted, and barely able to move as her joints stiffen. She has had to learn new ways of doing everyday things like opening jars, getting off the floor, and drying herself after a shower. Lucy is caring, funny, and loves to swear. We bonded over being young women with ADs and remain friends today.

After being diagnosed with AS, Lucy's rheumatologist 'knew right away' that he wanted to treat her with the medication *adalimumab,* a biologic therapy. Biologic therapies are 'targeted therapies aimed at specific proteins in the immune system that produce inflammation' (Higuera 2020). Unfortunately, biologics are expensive and their use is tightly regulated in Australia. Before Lucy could be approved for a prescription, she had to try three alternative treatments and show that they were ineffective. This process is not without risks though:

> You have to try other treatments for six months and see if your disease responds, which mine did not [laughs]. Mine just kept escalating, which I think is the case for most people . . . The longer you go without biologics the more the AS [ankylosing spondylitis] is just permanently damaging your body and once the

> damage has happened you can't reverse it. The biologics hit the 'pause button' but they can't undo what the disease has already done. It's incredibly frustrating. But I was lucky to get it within a year of symptoms basically because the average diagnosis time for AS is 10 years I think . . . Which is just crazy because the amount of damage that it did to my body in 12 months . . . I wouldn't have made it to 10 years because I was already planning a way out to be honest, if I didn't get that medication. Because I . . . I was like . . . I don't want to do that, I don't want to kill myself, but at the same time I can't walk . . . and when I do walk it is so painful, and I can't use my hands, I can't open jars or containers. And I'd, you know, had the disease explained to me so at that point I knew how much pain I was in and I knew that without this treatment [biologics] it would just continue to get worse so there wasn't a whole lot of hope there at that point.

The alternative treatments, which include non-steroidal anti-inflammatory drugs (NSAIDs), did not work and Lucy experienced continued pain and worsening symptoms. While experiencing debilitating symptoms over those six months, Lucy also had to go through regular testing and maintain a daily diary documenting symptoms such as pain and stiffness levels and any activities she was having difficulties with. After the mandatory six-month period, Lucy was approved for *adalimumab* which is self-injected. She remembers:

> September of 2015 was when I started the injections, and it took about five months to really work. I mean it worked overnight in the sense that the day of my first injection when I woke up the next day I realised that I'd slept through the night without waking up from pain and I just sort of rolled over to get out of bed and I could stand up. I was still a bit limpy but the difference was enough that I was like, 'hang on, I've just gotten out of bed without having to lift myself up with the bedside table.' So that was amazing. But in terms of my overall symptoms and my test results it took five months to really start reducing the inflammation to a significant amount that they could tell it was working, and then the blood tests I had in the sixth month my inflammation levels just completely dropped off.

For many, the physical realities of illness mean their first priority for care is, understandably, effective treatment. In Lucy's case, however, a diagnosis was not enough to access this. Instead, clinical markers acted as a gatekeeper to effective treatment. Despite Lucy's suffering, and her rheumatologist's opinion that biologics were the best course of treatment for her, her clinical markers did not indicate severe

enough disease activity for immediate access to *adalimumab*. At the time of our interviews, *adalimumab* was listed in Australia for $1168 for two injections, which is typically one month's supply. It is subsidised under Australia's Pharmaceutical Benefits Scheme (PBS) which gives Australian residents access to medications at a subsidised rate, if those medications are covered by the PBS and if their diagnosis is approved for the use of that medication under the PBS. Under the PBS, the consumer pays about $40 for two *adalimumab* injections but its use is tightly regulated. Lucy's experience of having to initially try older, less expensive treatments is common across a range of ADs in Australia and internationally (Jutel 2011, p. 141). This system of allocating access to medication almost completely fails to consider the suffering of the sick person while they wait. It also ignores the fact that some of the most significant aspects of suffering cannot be clinically measured (Risør 2018, p. 185).

For Lucy, this suffering was severe — she was considering ending her own life if she could not access the medication she needed. Significant deterioration is not uncommon amongst people with ankylosing spondylitis, with Pelechas et al. (2019, p. 663) emphasising that 'early diagnosis and treatment are imperative' for addressing symptoms and reducing the risk of disease complications. While NSAIDs are a typical first-line treatment for ankylosing spondylitis, 'many patients experience inadequate response, drug intolerance, or even relapse' Pelechas et al. (2019, pp. 665-6). Despite the suffering she experienced over those six months, and the knowledge that immediate use of adalimumab could have prevented much of that, Lucy accepted the regulation of biologics, based on their cost, telling me, 'I get that it's expensive to make and therefore they can't give it to every Tom, Dick, and Harry.' Thus, for Lucy, a diagnosis meant that effective treatment was only a 'possible outcome…not an assured one' (Hardon 2016, p. 27).

In the same six-month period, Lucy also sought psychological care to help her deal with the realities of her diagnosis:

> So, I was in grief counselling for like six months after my diagnosis, getting used to the idea that my body, I really had this feeling that my body wasn't my own anymore. Like I really had this overwhelming depressing idea that my body was doing things that were beyond my control, which is of course always true because

> that's how most of your body operates. But it was doing something against its own interests that I had to deal with and there was nothing I could do about it. I actually had a fantastic counsellor for that, he was hilarious. But he was also a paraplegic, so he was great because he knew what it was like to have your body changed in such a dramatic way, after previously having a perfectly fine, normal functioning body, to suddenly not be able to do things that you used to be able to do and having to get used to all of those changes. So, he was great.

In Lucy's case, psychological support from someone with shared experience was an effective form of care, demonstrating that peer support can, in some cases, be accessed through more formal forms of care. Grief counselling helped Lucy come to terms with her diagnosis, what it meant for her life, and particularly what it meant for her relationship with her body. As Charmaz (1995, p. 657) notes:

> Having a serious chronic illness shakes earlier taken-for-granted assumptions about possessing a smoothly functioning body. It also disturbs a person's previous assumptions about the relation between body and self and disrupts a sense of wholeness of body and self.

For some, 'disruption to bodily knowledge' is navigated through a reimagining of expectations for the future (Becker 1998, p. 44). Lucy, however, could not imagine a future for herself without effective treatment. She was struggling to come to terms with a body that was no longer functioning in the mundane ways we expect, as well as a body that was 'doing something against its own interests', leaving her feeling out of control. Grief counselling with someone who shared Lucy's experience of bodily disruption was significant for her in coming to terms with what her illness meant for her life. This, coupled with eventual access to effective treatment, was a crucial form of care for Lucy in the months after her diagnosis. While accessing grief counselling is not dependent on a specific diagnosis, having a diagnosis opened this up as a care option for Lucy.

Peer support

Jennifer: 'Social interaction is so important'

While Lucy was able to access care from a grief counsellor who had a shared experience of bodily disruption, other women in my study felt a need to connect with others who shared their experiences in a less formal setting. In the previous chapter, I described how Jennifer was diagnosed with Sjögren's syndrome with scleroderma overlap in 2000, after experiencing lifelong symptoms. She has also been diagnosed with Raynaud's phenomenon, pernicious anaemia, and interstitial lung disease. When she was diagnosed with Sjögren's with scleroderma overlap, there was no local support available. Jennifer did not have access to a computer at the time, so she relied on brochures and printed materials from her rheumatologist to find out as much as she could. Her search for information was primarily focused on Sjögren's syndrome. Jennifer also joined a state-based scleroderma association; however, there were no support groups close enough for Jennifer to attend:

> There was no support group and all I got was like, a couple of times a year a little newsletter thing in the mail, there was no interaction . . . there was nothing, it was nothing. Well, they did have the support group [in the State capital] but I couldn't get down to that because I was working and we lived right out the back of [a town about an hour and a half from the State capital] so that was impossible.

About fifteen years later, Jennifer attended a meeting along with a dozen other people to discuss the possibility of developing a local scleroderma support group in her area. She became the point of contact for the group, which now has about 20-25 people attending each monthly meeting and a smaller group who get together for a 'coffee and chat' once a month. The main monthly meetings are quite formal, with an agenda and discussion of items from the Scleroderma Association's state committee. Sometimes guest speakers may be invited, or members may present new information or research on scleroderma. The 'coffee and chat' is more informal, with members getting together for a social catchup. An important factor in Jennifer's involvement in founding the local peer support group was her preference for face-to-face, as opposed to online, support. While online support groups are available for all her diagnoses, she chooses to actively participate only in her local scleroderma support group. Jennifer is a member of an online, asynchronous, text based Sjögren's support group, however, it is based in the USA and she does not feel like she can

relate to the group. She remains a member but does not participate in the group at all. She clearly indicated her preference for face-to-face support, saying:

> I much prefer face-to-face contact, human contact, I much prefer it. Now, why? I don't know. It's so much better. Online it doesn't have the same emotion in it, it doesn't have the same feeling. Online is beneficial if there's nothing else, but you can't beat social interaction with people, like-minded people or, like-minded, that's the best word I can find. Social interaction is so important . . . when you're face-to-face to a person, or even on the phone, you're talking and you'll say something which will trigger something in me and then I'll think of something and then send that back to you, so we'll be sharing back and forth and bouncing things off, whereas by the time you write or type or whatever and then it goes and comes back it's lost a lot of its oomph I think.

While diagnosis-specific peer support is valuable and usually available online for many diagnoses, it is not a good form of care for everyone. For Jennifer, the typical text-based, asynchronous nature of online support groups does not lend itself to connecting with others in a meaningful way. Of course, this is not everyone's experience. For instance, Miles (2009) discusses the importance of online lupus groups for building shared identity and Orgad (2005c, p. 50) describes the importance of online breast cancer support groups for those who are geographically isolated or too unwell to attend a face-to-face group. While Jennifer has a strong preference for face-to-face support over asynchronous online support, her struggle to relate to online groups in the USA also points to the importance to her of place as another anchor for shared experience and understanding. One of the reasons she felt that she could not relate much to the experiences of those in the USA group, despite a shared diagnosis, was due to differences between the USA and Australian health systems. Orgad (2006, pp. 888-9) describes a similar barrier in online breast cancer support groups, emphasizing the importance of shared language and experience around treatment for relating to others online. Thus, while a specific diagnosis can be an important anchor point for accessing peer support, that diagnosis alone may not necessarily be enough to foster a strong sense of relatedness. In these cases, the context in which a diagnosis is experienced is also important for tapping into networks of reciprocal care, such as local peer support.

To access local peer support, Jennifer constructed her illness identity around the condition for which local support was available, and not necessarily the illness that represented her primary diagnosis. This is particularly significant for people who prefer to have an in-person, rather than virtual, care network. For Jennifer, this preference aligns with her self-described identity as someone who 'loves people, loves meeting people, and loves doing things.' Her comorbidities opened up access to this form of care. Without the addition of 'scleroderma overlap' to her primary diagnosis of Sjögren's syndrome, reciprocal care through a local peer support group would remain unavailable to Jennifer. People with multiple diagnoses then, may shift illness identities to access the forms of care they prefer. Since helping to found her local scleroderma support group, Jennifer has continued to embrace her illness identity as someone with scleroderma. In our interviews, she spoke almost exclusively about scleroderma. Although her primary diagnosis is Sjögren's syndrome, and this is the condition she originally focused on when researching her illnesses, she rarely mentioned it. Her discussion of symptoms was usually framed in terms of scleroderma, regardless of whether her other conditions may be contributing. Her Facebook profile picture is a sunflower, the symbol adopted by Scleroderma Australia, and she often signs off emails with sunflower emojis. Scleroderma has become strongly embedded in Jennifer's identity and the support group is key to this.

As further testament to how strongly Jennifer identifies with scleroderma, she is now active in local, state, and national scleroderma associations. Since she became involved with her local scleroderma support group, she has supported others, been supported herself, and helped raise awareness of scleroderma and funds for scleroderma research. She has advocated for individuals in the group, lobbied local members of parliament for funding for scleroderma research, and worked to put together scleroderma support groups in other regional areas. Embedding herself in the scleroderma association in these ways has produced some unexpected forms of care for Jennifer. Being able to care for other people is just as important to her, if not more important, than receiving care herself. She told me that 'keeping busy trying to help other people with scleroderma helps me [to cope].' As well as helping her to cope, 'keeping busy' in the scleroderma association allows Jennifer to retain her identity as a productive person who 'keeps going', a continuation of how she coped

during the decades it took for her to receive a diagnosis (Chapter 4). A local, active peer support group thus gives Jennifer access to reciprocal care, as well as facilitating the maintenance of identities that are important to her. Without access to a local peer group, these identities may have instead been challenged as paid employment was becoming increasingly difficult for Jennifer to manage with her symptoms.

Harriet: 'They know what I'm going through'

While Jennifer's scleroderma diagnosis facilitated access to local peer support, a specific diagnosis is not necessarily required to foster shared experience. Harriet lives in a regional city with her husband and two young children and was diagnosed with systemic lupus erythematosus (lupus) in 2003 when she was 22. At the time, she lived in a small rural town where she had grown up. I first met Harriet at an illness support group that she ran. I had previously reached out to her online about my project and she invited me to come and speak to the group about it. Once we started doing interviews, I would meet Harriet at her home as she usually had her two-year-old son with her. She would make some tea or coffee and we would sit at the kitchen table while her son played in the loungeroom nearby. Occasionally, her husband would pop home during his lunch break, but he was usually quick to come and go.

Harriet works in retail and also runs her own essential oils business, something she is passionate about. During the period of our interviews, she experimented with switching to a plant-based diet (she avoided labelling herself as vegan) to manage her lupus symptoms. She is a very giving person, providing a lot of one-on-one support to members of the support group when they contact her. This would sometimes become emotionally draining for Harriet, who also had her own illness to deal with, as well as the recent death of her mother. Despite working herself, Harriet takes on the majority of the childrearing and household tasks. She firmly believes that she is in control of her lupus, rather than it controlling her, and harnesses this to persevere when her symptoms flare up.

Although she experienced rashes, fatigue, and joint pain, Harriet did not feel that she had many issues with lupus until her first pregnancy in 2011 when she experienced a flare-up and was referred to a rheumatologist for the first time. During a later flare-up, she felt the need for face-to-face support from people who would understand what she was going through. While Harriet acknowledged that her husband was supportive, she felt that she should not complain to him about her illness, telling me:

> He doesn't know the pain that I . . . like I could be in pain some mornings when I wake up that I'm not going to whinge and whine to him about that because it's just what happens, it's just . . . you live with that basically.

Harriet's feelings are typical of the women in my study, with many telling me, matter-of-factly, that they just have to live with their illness and get on with things. This is unsurprising considering most of the women in my study either grew up in rural areas or moved to rural areas as adults, where stoic attitudes towards disruptions in life are common (Cheesmond et al. 2019, pp. 49,55; Rogers-Clark 2002-2003, p. 37). For Harriet, this attitude manifests in feeling like she should not complain to her husband about her pain. Miles (2013, p. 22) observed similar experiences among women with lupus in Ecuador, explaining that the compassion fatigue of family and friends may mean that women 'shy away from talking about how they feel, lest they worry, vex, or irritate their loved ones'. A range of other factors likely influence the decision to avoid complaining about pain, including negative and suspicious attitudes towards those with chronic illness (Honkasalo 2001, p. 328; Jackson 2005, pp. 338-42; Jackson 1994, p. 147) and moral expectations to remain positive in the face of illness (Jain 2010; Miles 2013, p. 143; Ussher et al. 2006, p. 2570).

When women feel like they cannot or should not complain about their illness to friends and family, peer support groups can offer a safe place for them to vent. Harriet is a member of a local essential oils interest group and she coordinates meetings through an online platform. On a whim, she decided to create a lupus support group through the same online platform, telling me that she 'thought it would be great to meet people that know how I feel.' While the group was initially

only for people with lupus, several people with other ADs contacted Harriet to ask if they could also come along to a meet-up. Harriet remembers:

> . . . and then I thought to myself, 'I'm going to change this', because really a lot of our symptoms are the same anyway, the whole chronic fatigue, the chronic pain and everything like that, we're so similar anyway . . . I think it was within the week that I changed it to autoimmune because we are all very similar anyway.

The support group is informal and social, with about 5-10 people attending each catch-up. These are usually at a coffee shop, with decisions about the choice of venue based on accessibility and the different dietary needs of members. The members are predominantly women, though two men did attend at different points over the course of my interviews with Harriet. There is no set schedule, though Harriet tries to organise the catch-ups monthly. Other members also reach out to her from time to time to see if she can organise catch-ups sooner, particularly if they are struggling emotionally. During meetings, members feel safe to complain about their illnesses, medications, and doctors. They also offer and ask for advice on illness management and enjoy non-illness-related conversations about their lives more generally.

Harriet felt more comfortable discussing her illness in this environment with people who shared her experience, reflecting that, 'it's a lot easier and we come from common ground, they know what I'm going through, I know what they're going through . . . and it was just on a whim it was just "oh maybe I should start a group"'. Harriet elaborated on this further:

> I think there is a great need [for care] and it's just, like even within our meet-ups and stuff like that, they're just basically lunch, and we can whine and just have a whinge about it. And you apologise and they're [other members] like, 'don't apologise I know exactly what you're going through.' And it's not that we're whining, we're having someone that can acknowledge, 'yep I have that too and it's okay to feel like that.' And I think too, like the fact that we are open to anyone and yeah, no matter what, like we have that experience so yeah, it doesn't matter who they are it's like, 'yep we feel for you too'.

While Harriet avoids complaining to her husband, she feels like she can express her pain with people who share her illness experience. She does, however, still suffer from the way complaining is moralised, describing how she apologises to the group after 'whinging and whining' about her illness. The safety she feels in the group to do this anyway comes from the acknowledgment of what she is experiencing and that it is okay to complain about it. This represents a form of reciprocal care, with Harriet then acknowledging the same for other members. In this way, peer support groups can provide a safe space where moral expectations about what should and should not be voiced, as well as expectations about remaining positive, are temporarily suspended.

Crucial to accessing peer support was Harriet's ability to reconceptualise her understanding of shared experience. Like Jennifer, Harriet had access to online support groups but she also wanted to connect with people locally. While she initially envisioned connecting with people who share a lupus diagnosis, Harriet quickly expanded her understanding of what constituted a shared illness experience to include those who share similar symptoms and the broader diagnostic category of autoimmunity. The fact that several people who did not have lupus reached out to join her lupus support group demonstrates how people can conceptualise shared illness experience beyond the limits of a specific diagnosis, particularly when it may allow them to access peer support. In these cases, shared experience can shift from a diagnosis to a shared set of symptoms or broader diagnostic category. Similar alignment with the broader category of autoimmunity in addition to more specific diagnoses has also been observed among those with 'shifting' and uncertain diagnoses, where a diagnosis of autoimmunity provides some continuity in an otherwise uncertain diagnostic journey (Joyce & Jeske 2020, p. 4). While initially connected under the category of autoimmunity, Harriet's group has since shifted again, alongside the members' understanding of shared experience. It is now a

support group for 'Spoonies'[4], a term used to describe people with chronic illness. Thus, while a specific diagnosis is often the nucleus for illness support groups, membership criteria can be expanded to include broader shared experience, providing access to care via reciprocal peer support.

Kate: 'At least the autoimmune girls get it'

Kate is one of the members of Harriet's support group and was 53 when we first met. She was diagnosed with Hashimoto's thyroiditis in her late forties after experiencing thirty years of unexplained symptoms. Kate also suffers from degenerative spine disease. I met Kate at the same support group where I met Harriet. Kate is social and will happily lead conversations in the support group and provide advice and opinions. Kate suffers considerably from her illness and she often looks visibly unwell. Sometimes the colour would be drained out of her face, nausea written all over it. Other times her stomach would be visibly bloated while she hobbled gingerly into a support group meeting.

Kate's social circle shrunk significantly after her diagnosis and the support group is one of the only chances she has to get out and socialise so she tries to attend no matter how unwell she is. After meeting at the support group and having an initial chat in a coffee shop, Kate and I held our interviews in her home where she lives with her husband and youngest adult son. Kate has another son as well as a transgender daughter who lives in the USA. All of Kate's children have been diagnosed with Asperger's, and after several interviews, Kate told me that she is also Asperger's. While this created difficulties for her when she was growing up, she said that it has been helpful when dealing with her illness because she can compartmentalise what is going on and look for solutions.

[4] 'Spoon theory' is attributed to Christine Miserandino as a way to explain the careful energy management those with chronic illnesses engage in (Hale 2018, p. 27). Spoons are used as a metaphor for finite units of energy to visualise how those who are ill must budget and ration their energy for tasks that others may do without thinking (Hale 2018, p. 27). For example, a person who is ill may have 10 spoons available on a given day, but showering and making breakfast may take five of their spoons. They must balance the importance of these mundane daily activities with the other tasks they need to complete to ensure they do not worsen their health. 'Spoonies' is a term to describe those who subscribe to spoon theory, but has also become synonymous for a person with a long-term illness.

Kate's family deal with a range of food intolerances, her husband suffers from post-traumatic stress syndrome and chronic pain, and all of her children have been diagnosed with anxiety and a collection of other mental health issues. Both Kate and her husband are on a disability support pension but she tells people they are retired to avoid the stigma associated with this. Because of her family's food intolerances, Kate spends a lot of time cooking. Kate and her husband are very close and she often told me what a wonderful person he is. Her husband was normally at home during our interviews and kept busy working on their home renovations, despite his pain. Kate is straight-down-the-line, confident, self-assured, and proactive about her and her family's health issues. She can be equally as vulnerable though, particularly when reflecting on how illness has plagued her life over the thirty years it took for her to be diagnosed.

Kate experiences a range of symptoms such as difficulty sleeping, chronic pain, nausea, and vertigo. These symptoms impact her body and also seep into her social world. The combination of Hashimoto's and chronic back pain has meant that Kate has had to give up most of the things that she feels define her as a person. Consequently, some of the most difficult side effects of her illness are identity loss and loneliness. Reflecting on when she received her diagnosis, Kate told me:

> So, at first, I was like, 'thank god, finally I know what's wrong and I can research it'. But then it was really like, my whole life is going to change, you know. I still get depressed about it . . . I'm not who I used to be, you know. I can't be that person anymore.

When I asked Kate how she saw herself before her diagnosis and she explained:

> How did I see myself before I found out? Australian dance champion [laughs]. I've got the medals; I've got the trophies. Always thought I'd dance, thought I'd dance 'till I dropped. And all my friends still dance, and they all go away together and dance and I don't get to do that with the most important people in my friendship life. They go and I don't go because I just sit and watch and it's really upsetting . . . And it's the same with singing. Not that I was ever, you know, some incredible singer but I could carry a tune in a bucket [laughs] and we'd go to karaoke and have fun and now I can't do it because my voice, the way it is I sound like a bullfrog, and so it's just upsetting, so I gave that up. And you know it's just all these

> things were the core of ‘that's who I am’. I'm none of that anymore. Well, what do you do? I read [sighs]. I haven't found that magic mix that would give me a social life and . . . I'm not really a drinker, I'll have the occasional drink, but I don't go to the club, I don't gamble, I don't drink, so how do you meet people, how do you socialise?

Kate has struggled significantly in the wake of her diagnosis. While she was severely ill before being diagnosed, often barely able to move, she had hoped that she would find answers and recover. For her though, a chronic diagnosis forced her to re-evaluate the future she once saw for herself and what that means for her identity. The identities that Kate grieves most were those she created with others, and losing those identities threatens those friendships and other relationships (cf Charmaz 1983, pp. 176-80). This is significant since maintaining valued friendships can be important for maintaining a sense of normalcy (Synnes et al. 2020, p. 2) as well as networks of support in the face of chronic illness (de Regt 2019, p. 102; Unantenne et al. 2013, p. 1149). Conversely, disruptions to friendships can lead to emotional isolation which may make the identity challenges associated with chronic illness more difficult to cope with (Winters et al. 2006, p. 279). For Kate, it was not the limitations her symptoms caused that triggered a sense of lost identities, but the naming of her diagnosis. Without a diagnosis, Kate still had hope that things might improve; however, her diagnosis left her feeling that her life as she knew it was gone. This was something that she navigated at the same time as feeling relieved to finally have a diagnosis.

While a diagnosis can sometimes trigger a personal transformation (cf Miles 2009), it left Kate feeling stuck, grieving the future she once saw for herself. After speaking about how her son, who lives with severe anxiety, has grown and moved forward in his life, Kate reflected on her own experience:

> But I don't know how you do that [move forward] when you feel like everything virtually in your life has changed, you’re not yourself anymore, you're not your best self, you're not who you feel you were meant to be, and that's never ever going to change. So how do you . . . how do you work through that and move forward from that and get through the depression of hating your existence? . . . I don't know. I've tried meditation, like hypno-meditation, and talked about, because

> she [hypno-meditation teacher] said that it's like losing someone, only it's you. It's like someone has died, but it's you. And how to go through the stages of grieving and how to move on and how to find other things that you can enjoy about life. But I've really struggled with it, really really struggled with it.

While the physical symptoms of illness are often discussed in biomedical discourse, less attention tends to be paid to the social impacts, outside of adding additional diagnoses such as anxiety and depression which are commonly associated with chronic illness. This is concerning since, for Kate, the physical and social impacts of autoimmunity are equally devastating. Not only was she dealing with physical symptoms, but also the loss of valued identities, the activities most important to her, and the friendships and relationships those fostered, leaving her in a prolonged state of grief and depression. The physical limitations of her illness continue to compound the problem, making it difficult to connect with others and find new ways to create a sense of meaning and purpose in life. Kate's sense of feeling stuck in both her life and her sense of self was also intensified by both internal and external moral expectations, borne of a self-improvement culture, to be her 'best self', despite being seriously ill. These impacts of chronic illness and diagnosis can affect women's lives and health significantly but biomedicine continues to focus predominantly on attempting to treat the physical symptoms of illness.

Kate's struggles with her identity and connecting with others were compounded by an inter-state move before her diagnosis. Her husband was in the police force and suffers from post-traumatic stress syndrome and they moved to help him manage this. However, Kate said, 'I really got depressed and missed all my friends . . . the first three and half years were really hard'. Kate felt the need for local peer support in the wake of her diagnosis but this was difficult to access in a regional city. She told me:

> When I got diagnosed I was searching for anything local, but obviously I kept putting in Hashimoto's [as a search term], and there were groups in [the nearest capital city] and all over the place [online], and so I was online with people and that . . . I talk to people every day in my online groups. For two years I did that, but I just kept going 'jeez it would be nice to meet some people locally that sort of understand and get it.'

While diagnosis-specific online support can be important, it does not necessarily replace local, face-to-face connections. Kate was active in Hashimoto's online support groups for two years, but she still felt a need to connect with others locally who shared her diagnosis. This allowed her to foster a new identity in relation with others through one of the only constants in her life — her illness.

After finding that there were no local Hashimoto's support groups, Kate initially joined a social group through the same online platform that Harriet was using; however, the organised activities were often at night which Kate found difficult to attend with her symptoms. About six months later, she found Harriet's autoimmune group on the same online platform and has been a member ever since. The group has been a lifeline for Kate, who told me:

> Since moving into town and meeting the other girls [from the AD support group] that's helped me. Just to have that social aspect, and talk to other people, and like Sarah and I really get on well. We don't see each other all the time but we spend a bit of extra time together and you know sometimes you've just got to get out of the house. So, I've gone to her place this morning and checked on her and what not. So you have to have something, and not just sit at home and feel miserable all the time . . . When your health is so up and down and you say, 'oh yeah I'll go to that', you get sick that day, and you just go, 'I can't go' and that, and I think your friends get sick of you too. That's hard. Like at least the autoimmune girls get it.

For Kate, local peer support has helped her cope with the social symptoms of her disease, including by creating new identities through shared experience and relational care. While Kate has a strong awareness of the identities she feels she has lost to illness and a sense that she has not yet replaced those identities with something new, she has in fact created a new shared identity as an 'autoimmune girl.' This new identity, as well as the reciprocal care she engages in as part of the autoimmune group, has been facilitated by her broadened understanding of shared experience, beyond a specific diagnosis. Like Jennifer, Kate has also found value in the reciprocal nature of local peer support. Going out and checking in on Sarah gives her something to do, within the limits of her illness, that she finds meaningful.

Although online support was important for Kate, it could not replace her need to connect locally with others who understood her experience. Rather, she uses the two in tandem, with online groups providing her with access to people who share her diagnosis, and her local group providing access to reciprocal care with people who share her experience as someone with an AD. Like Harriet, Kate quickly reconceptualised how she understood shared experience to encompass autoimmunity more broadly. This also led to a new identity for Kate, as someone with an AD. For example, Kate now refers to herself as the 'autoimmune chick' and collectively refers to those in the support group as the 'autoimmune girls.'

Jennifer, Harriet, and Kate's stories all challenge the idea that online support groups can be an effective substitute for local support groups. While all three women still used online support groups — Kate actively, Harriet when she felt the need, and Jennifer begrudgingly — these did not fulfil their need for connecting locally, face-to-face, with others who share their experience. This points to the continued importance of local, face-to-face peer support, despite an abundance of diagnosis-specific online support groups. This is not to suggest that online support groups are not important. They can be crucial for those who have no local options, whose illnesses make it difficult to attend local groups, and who simply prefer online support. Kate recognised the difficulties of accessing support in regional areas and the importance of online options, telling me:

> I don't know what we did before the internet, I really don't. People must have felt so isolated, and if you didn't live in a big city where you could maybe build a support group, if you were just in a smaller area, and you were the only one. Like our support group that we're in, that's open to anyone with an autoimmune disease, imagine if it was just Hashimoto's? I know of two other people in this town that have it, that I know of, but not everyone is interested [in joining a support group].

Harriet and Kate overcame these barriers associated with regionality by reconceptualising how they categorised their diagnoses and understood shared experience. Kate also developed a new illness identity, becoming an 'autoimmune chick.' While this has not resolved the struggles she has experienced with her identities outside her illness, this new identity has been crucial for becoming embedded in new social worlds. These reconceptualisations and new identities have

given Harriet and Kate access to a form of embodied, reciprocal care that online support groups could not provide. In Jennifer's case, the addition of 'scleroderma overlap' to her list of diagnoses was most significant in terms of access to care. It created an opportunity for her to become embedded in a local support group in a way that makes her feel supported and adds value to her life by being able to care for others and retain valued identities. Without that diagnosis, she would have had no access to local support. For Jennifer, this meant using her diagnoses and illness identities strategically, shifting emphasis from their biomedical to social significance. The significance of her scleroderma diagnosis for her rests on how it can facilitate access to reciprocal care, rather than on its biomedical significance in terms of severity and symptoms.

Practical and financial support

Emily: 'Why should my life mean less than someone who has cancer?'

Unlike Jennifer, Harriet and Kate, Emily had ready access to a local face-to-face support group for her primary diagnosis, scleroderma, the same group Jennifer is a member of. When we first began our interviews, Emily was strongly embedded in the support group, taking an organisational role and actively working to raise awareness of, and research funding for, scleroderma. Despite this, Emily's story also illustrates how a diagnosis does not necessarily facilitate the type of care someone needs. Emily particularly felt this while going through aggressive chemotherapy to try and slow the progression of her disease. She struggled with the side effects of chemotherapy, particularly as her scleroderma created additional difficulties. For example, scleroderma hardens the skin, making it difficult to insert cannulas and provide injections. Emily reflected that, because of these difficulties, her 'first session [of chemotherapy] was pretty horrendous, because I had no idea what I was in for.' It took five attempts for the nurse to insert a cannula and Emily remembers that 'by this stage, my mum was a mess, she was crying, she was worse than I was'.

The next morning, Emily experienced a reaction to the treatment, telling me:

> I woke up the next day and didn't feel too bad until I stood up. And then when I stood up, I vomited everywhere. It was really bad. Just yeah, didn't agree with me at all.

That same morning, Emily woke up with shingles over one side of her face and was rushed back to the hospital. She remembers:

> They started treatment on my eye straight away because with the effects of the chemo plus the shingles, I could have gone blind. So, I had to have an ointment put into my eye every two hours for the first fourteen days, as well as being on anti-nausea drugs, and I had to stay away from the family for the first round. I wasn't allowed to be near my baby so that was pretty hard.

Emily went through eight fortnightly rounds of chemotherapy before her specialists were satisfied with how her heart was responding. She explained:

> We didn't have to go past number eight, which was a relief because by that stage my hair had been falling out, I'd lost all my eyelashes and my eyebrows were patchy to the point I was ready to shave them off. And I was over being sick, I was really sick by this stage. So, I'd had enough of being a pin cushion every two weeks. Actually, I was a pin cushion every week because I had to get bloods done every other week. So yeah, that was starting to get a bit much by that stage. I've got some ripper scars on my arms now from all the blood tests and everything like that, trying to get them in.

The constellation of issues Emily was dealing with — a terminal diagnosis, scleroderma symptoms, chemotherapy and its side effects, and additional illnesses like shingles — left her feeling in need of practical support. In Emily's case, it was treatment that triggered a need for additional care, outside what she had access to through the scleroderma support group.

While receiving chemotherapy in the hospital, Emily noticed that cancer patients being treated alongside her had access to care that was not available to her:

> So, I was the only non-cancer patient they were treating at the time. So basically, they [cancer patients] were getting, within the hospital system, they could get pickups and drop-offs from their houses to the hospital. I couldn't get that. They could get overnight stays if they had to. I couldn't get that. They

> could get help at home. I couldn't get that. They could get food cooked for them and delivered to their house. I couldn't get that. I did get to go to a beautiful reinvention thing, I can't remember what they called it now, but you get to go and try on wigs and all that sort of thing and they show you how to put makeup on because your skin complexion changes and all that sort of thing. I did get to go to that, but that's only because my sister-in-law begged and pleaded with them to let me go. That was on the Cancer Council's website, she went through that and got me through onto that. But she rang quite a few people to get me in and had to explain what the situation was. But even in the hospital, I noticed that a lot of the time a lot of the patients would get lunches and food and that sort of thing, and I'd have to ask for mine.

Emily recognised that her scleroderma diagnosis, or more specifically the absence of a cancer diagnosis, acted as a barrier to receiving these types of care:

> The nurses were lovely, but because I wasn't getting the proper [cancer] treatments they didn't seem to come with everything the same, sort of thing. So yeah, it was a bit different . . . Because I didn't actually have an oncology doctor, a lot of mine, I didn't get put through a lot of the registers, so therefore I wasn't able to claim or do things that the normal oncology patients would get. That was the biggest thing. Had I had an actual oncology doctor, I would have been on all the same registers. All my medical aids that I have, all of the other bits and pieces that come with it, you get without any questions. And even private health, as soon as you mention the 'c word' [cancer] they open the doors for everybody.

While her scleroderma diagnosis facilitated access to diagnosis-specific peer support and treatment, it acted as a barrier to receiving the care she needed to cope with chemotherapy. Upsettingly for Emily, she could see others receiving this care right in front of her. The only chemotherapy-specific care Emily ended up being able to access was a type that reinforces the importance of maintaining feminine beauty standards even in the face of terminal illness. While Emily still appreciated being included and was grateful for her sister-in-law's effort, this was not the type of care she really needed. While it is known that diagnosis acts as a gatekeeper to treatment, its influence after this tends to be ignored. Even where diagnosis facilitates access to treatment, it does not guarantee the care patients and their families need to cope with that treatment.

During chemotherapy, Emily also faced barriers to accessing government financial support. In Australia, a Disability Support Pension (DSP) is available to those who meet specific medical and non-medical criteria. Emily's experience trying to access DSP affected her considerably:

> The first time I tried to apply for it was in the August I got diagnosed, so August 2015, and I was in the middle of chemo and they made me see a psychiatrist. And the psychiatrist said, 'you will recover from this,' and I'm like, 'what part of the word "terminal" do you not understand? You know, there's no recovery from a terminal disease.' I had only had chemo, it was really soon, like three or four days prior to going in. So, they make the appointment for you and you can't cancel it, so you have to attend. So, I had literally only just had, I think it was round three of chemo, so I was getting pretty self-conscious by that stage because all my eyebrows had fallen out, most of my eyelashes were starting to come out, my hair was really patchy, I was a funny colour, and the car just made me really sick and I hated travelling anywhere, but I knew I had to go.
>
> Then when we go in there and she asked me all these stupid questions like how long had I been working for prior to getting sick and why did I move out of the house I was living in before I got sick. And I was like . . . 'well I have a baby to look after and I'm doing chemo, we can't function on one wage', it was just really silly questions that I'd already answered in the application. Then she started asking me questions like, 'would you be able to stand up if we found you work?' And I'm like, 'no I'm in the middle of chemotherapy, I can't work, I'm having it every two weeks at the moment', and [she said] 'oh when you're done, you'll be able to go back to work' . . . uhh probably not. I have severe fatigue rah rah rah. And she just wasn't even taking any notice of the letters I brought from the doctors or anything like that. My mum just got really angry and in the end, mum stormed out I think. It ended abruptly anyway, I think mum stormed out and I just said, 'that's enough, I've had enough, I need to go home'. And she declined me. And of course, that just sent panic stations through me then, it's like how are we going to survive? We're never going to be able to do anything or live anywhere other than with mum or dad ever again, and because the more I panicked the more stressed I got, the more my symptoms would flare up. So it was a catch-22, but Centrelink [Australia's government welfare department] didn't seem to care.

Being denied practical care threatened both the financial stability of Emily's family, as she was unable to earn an income while going through chemotherapy, and her identity as an independent adult. Government financial assistance had given Emily the hope that she could remain independent from her parents. That identity had already been challenged by her diagnosis, with Emily and her family moving in with her parents immediately after her diagnosis. The decline of her application for financial support made her feel that her independence would be taken away permanently. Emily felt that the psychiatrist had no knowledge of scleroderma and that this influenced her decision, dismissing Emily's illness experience and ignoring her terminal diagnosis. This then reinforced what Emily experienced during chemotherapy — that she did not have the 'right' diagnosis, or was not 'sick enough', to access the care she needed. As Emily mentioned, the stress this created then worsened her symptoms. In this case, refusing access to care caused physical and emotional suffering, threatened valued identities, and left Emily and her family in a precarious financial position.

Emily decided to apply for the DSP a second time in December of the same year once she had completed her chemotherapy. This time, she requested to be assessed by a nurse or doctor, rather than a psychiatrist. This was something she had to fight for:

> I had to insist and really go off at Centrelink and actually went in there, I can remember crying and saying to them 'this is ridiculous what you're putting me through.'

It paid off. The first nurse she saw had researched scleroderma as part of her assessment of Emily's application and told her that she could not understand why she was not approved the first time, validating Emily's feelings. Emily was then referred to a doctor as part of the application process who had a similar response, telling her, 'I don't know why you're here, they should have approved you straight way.' In January 2016 she was approved for a partial pension. While not the full DSP, it comes with a 'healthcare card' which, in Australia, gives access to subsided medications and subsidised or free medical appointments, which Emily told me was crucial to being able to manage financially. In response to being denied care, Emily engaged in self-advocacy (Thompson & Blake 2020, p. 28) in a final attempt to

access the financial support she needed. This was significant for Emily, given her experience with the psychiatrist in her first assessment. By attempting to access the DSP again, she was putting herself at risk of further distress, illness, and delegitimisation, pointing to how important it was to her to access financial support and retain some independence. While Emily was satisfied with the eventual outcome, she had to fight to access the care she needed while suffering from a terminal illness.

The barriers to accessing practical support that Emily faced due to her diagnosis upset her considerably. During one of our interviews Emily, visibly upset, told me:

> Probably my biggest bugbear about the whole thing about being sick is, I've never wished anyone ill and never do and never will, but it annoys the crap out of me that someone with cancer, their life means more than what mine does. That's how it's made to feel. And that's what upsets me the most. And that's even with my specialists trying to help me . . . they've written some amazing letters for me to try and get different things approved and done and stuff like that and had they not written the letters they did I don't think I would have been successful the second time to get the disability pension. And everything I've had at the hospital they've just been amazing. Like I can't fault them themselves . . . but it's bureaucracy and red tape, because it's a rare autoimmune disease, it doesn't fit into any little round holes that they want to put you into.

When contrasting the responses from the psychiatrist and then nurse and doctor, it appears that the outcome of Emily's initial assessment was based on an ill-informed understanding of Emily's rare form of scleroderma. Potentially implicated in this is 'disease prestige' (Album et al. 2017, p. 50; Stone 2018, p. 60). Disease prestige can be defined as:

> The collective perception of a disease's "worthiness"; the degree to which the sufferer "deserves" care and support. As a social construct, it changes over time and between communities. While health is obviously more desirable than disease, a disease's prestige reflects the community's commitment to care, support and economic investment (Stone 2018, p. 60).

High prestige diseases tend to be 'non-self-inflicted, acute and lethal diseases

with clear diagnostic signs, located in the upper part of the body' (e.g. the brain or heart); associated with 'active, risky and high technology treatment leading to a speedy and effective recovery', or those typically seen in 'young patients, patients who accept the physician's understanding of the disease, and whose treatment results do not involve disfigurement, helplessness, or other heavy burdens' (Album et al. 2017, p. 46). Johannessen (2014, pp. 89-90) has also argued that diseases that reinforce the narrative of a 'hands-on, daring hero [saving] the patient's life' and allow doctors to 'portray themselves as masculine and extraordinary lifesavers, able to act where others fall short' also tend to attract high prestige. Diseases with a higher prestige tend to attract more financial backing, celebrity patronage, opportunities for support, and funding and opportunities for participation in research (Stone 2018, p. 60). Incurable ADs that are often not associated with a specific part of the body tend not to fall into any of these high prestige categories. Emily reflected on the impact of disease prestige on her experience in our interviews, lamenting:

> I don't mean to get angry with anyone like MND [motor neuron disease] or cancer and all that sort of thing, they all deserve their time in the spotlight, I totally get that and I accept it. But there's other diseases that out there that also need research, you know, and just because we're a little unknown autoimmune disease doesn't mean that my death should be any less than someone who is dying from cancer. And I think that's what really gets my goat at the moment, it's that why should my life mean less than someone who has cancer? And that's how we're made to feel by the governments. So that's my biggest thing. And I'm actually, we've got a local election coming up soon and I'm already talking to the local members here telling them, 'what can you do? what can you do to help people that have got terminal illnesses that aren't the big ones?' We get no assistance from Centrelink, we get no assistance from any of the medical [private health] funds, they go, 'what? What have you got?' . . . It should not be weighted on which celebrity [who brings attention to a disease] is more popular, or which disease has got more recognition. You know, a human life is a human life, regardless . . . Why should my family have to suffer because I've got an unknown autoimmune disease. It just sort of doesn't make any sense, yeah, that's why I've decided you know, if I don't bring it to someone's attention who is?

Disease prestige is implicated in how we decide who is deserving of care, and

in turn the delegitimization of people's suffering; however, the act of denying care appears to also reinforce ideas of disease prestige amongst those with lower prestige disease, as Emily's thoughts illustrate. In some contexts, however, a disease typically considered low prestige may actually be associated with higher prestige in some contexts. Emily herself observed that, while scleroderma is not a commonly known illness, the rarity of her specific diagnosis — systemic scleroderma with heart failure — at times attracted a higher prestige than she usually experienced. For example, in 2016 Emily was taken to the emergency department with a burst cyst on her ovary. She insisted that no one treat her until they had spoken to her immunologist but the emergency staff could not get in contact with them. Emily was sent for surgery anyway, where her nose was broken during intubation because of the tightness scleroderma causes. The surgeon also did not know that they would not be able to use stitches on Emily because the scleroderma had thickened her skin, using an alternative method that quickly led to a staphylococcus infection that took three months to heal. Emily explained her immunologist's response when she found out what had happened:

> My immunologist came into work and she caught up and found out what was happening, she tore strips off them, absolutely went to town on them . . . She absolutely went ballistic saying that they were only trying to big note themselves that they were working on someone who had a rare disease and all that sort of thing. And my file now has, my file, which is like 6-7 inches high, they've been told that no one else is allowed to see me now unless my immunologist gives them the authorisation. But it's just ridiculous what people try and do to big note themselves.

Emily's case demonstrates that disease prestige can be fluid and contradictory. In the context of an emergency, Emily's diagnosis appeared to attract higher prestige but this did not translate into high-quality care, as would typically be expected with a high prestige, and therefore better understood, disease. Instead, it was the rarity of Emily's diagnosis that attracted prestige and was implicated in the decision to go ahead with surgery without consultation with her immunologist. More generally, Emily has experienced the consequences of scleroderma being a low prestige disease, which was exemplified in the surgeons' lack of knowledge of her disease and the associated pain and trauma this caused Emily, as well as the denial of

practical and financial support. These experiences have reinforced to Emily the low status of her illness, and by extension her suffering, within the Australian healthcare system.

Discussion

The women in this chapter sought care in a variety of forms, including peer support, practical and financial support, psychological support, and effective treatment. While many of these can be expected, each woman's story pointed to several underlying needs that appeared to drive their search for these forms of care. These needs are intertwined and include a need to have their suffering understood, acknowledged, and legitimised, and a need for support to navigate the challenges associated with diagnosis and identities. Ironically, women's attempts to access these were sometimes constrained by their diagnoses, despite a diagnosis typically being constructed as a gateway to care (Jutel 2011, p. 4).

Jennifer, Harriet, and Kate all expressed a need to feel understood and have their suffering acknowledged. Each woman attempted to seek this through connecting with others who shared their primary diagnosis. While this was feasible through online support groups, each woman still sought out diagnosis-based, local peer support either as an alternative or complement to online support. Diagnosis can both facilitate and constrain access to peer support. In regional areas, local diagnosis-specific support groups are often unavailable, creating gaps in care. As Kate mentioned, smaller populations in regional areas mean there is less likelihood that enough people with the same diagnosis will come together in a support group setting. Harriet had a similar experience with her diagnosis. Rather than simply accept this though, women reconstructed their illness identities and understandings of shared experience to access peer support.

These strategies demonstrate an alternative avenue for women to engage in biosociality. Originally coined by Rabinow (1996, p. 244) in the context of people with shared genetic conditions and traits, biosociality describes how biological conditions trigger the creation of 'new group and individual identities and practices.' More recently, the concept has been reconsidered to better account for the social

aspect of biosociality (Marsland 2012). Women's experiences of accessing peer support, support this shift in emphasis. While a shared biological condition was the initial starting point in each woman's search for peer support, what eventually facilitated that support were shared experiences, such as those related to symptoms, place, and the Australian health system. In this sense, a shared diagnosis is not always enough for biosociality; it is heavily dependent on 'people working together' (Bradley 2021, p. 3). In regional areas, biosociality may only become possible when people focus on the shared experiences of illness, rather than specific diagnoses. This makes Barker's (2002, p. 284) conceptualisation of an illness identity, which she describes as 'an understanding of self, and affiliation with others, on the basis of shared experiences of symptoms and suffering', more reflective of women's lived experience of illness than definitions that focus on a shared diagnosis. While doctors assign diagnoses and, by association, illness identities, these can end up being somewhat fluid as women adjust and recreate their illness identities in concert with others to access the care they need.

Multiple women also expressed a need to have their suffering legitimised. A diagnosis can legitimise suffering (Barker 2005, p. 21; Bradley 2021, p. 6; Jutel 2011, p. 7; Price & Walker 2014; Price & Walker 2015, p. 68) but difficulty accessing care after a diagnosis can threaten this. These 'diagnostic dead ends' (Bradley 2021, pp. 6-7; Rhodes 2010, p. 195), can occur when a diagnosis brings an initial sense of relief, only to be tempered by the eventual realisation that the care a person needs may not be available or accessible. In some cases, such as Emily and Ellen, this can lead to further delegitimisation, creating a 'recursive cascade' (Manderson & Warren 2016, p. 13) of suffering. A recursive cascade describes how 'chronic conditions . . . are reinforced or exacerbated by social or relational factors . . . which then render the person increasingly vulnerable to other bodily or affective conditions' (Manderson & Warren 2016, p. 13).

In response to these barriers, women engaged in multiple strategies to access the care they needed. For example, Emily fought to access financial support which, while detrimental to her health, ensured she would have some independence. Conversely, she resigned herself to not having access to the practical support she needed during chemotherapy. This resignation, however, led to further feelings of

delegitimization since the only barrier to Emily receiving this support was her particular diagnosis. Lucy had to wait, putting her trust in her rheumatologist and the health system in the hope that she would eventually receive effective treatment. Ellen's case illustrates what happens when the legitimacy of a diagnosis is taken away — treatment is denied and suffering continues with no end in sight. For women who have often gone through decades-long diagnosis periods, or had their symptoms dismissed, these feelings of legitimacy are important. While a diagnosis is supposed to legitimise, in reality it may only offer a temporary reprieve from the moralisation of illness.

These needs, and women's strategies to access care to address them, all intertwined with their identities. It is well understood that chronic illness can challenge valued identities (e.g. Charmaz 1983; Estroff 1993; Frank 2013; Honkasalo 2001; Mendelson 2006), and the women in my study are no exception. Perhaps one of the strongest motivators for accessing care among the women in this chapter was the hope to retain important identities and construct new relational identities with other people with ADs. For example, both Lucy and Emily sought to retain their identities as independent adults (Lempp et al. 2006, p. 112). For Lucy, this meant having enough control over her symptoms that she could continue to do everyday tasks independently. For Emily, financial support was crucial to retaining her identity as an independent adult. Without this, she would have had to remain living with, and dependent on, her parents indefinitely. Independence is highly valued in Australia, and a shift to alternative identities that are more suited to the limitations of chronic illness, such as someone who prioritises rest and relies on others, would typically not be viewed favourably. While illness is often seen as an opportunity for personal transformation (Miles 2013, p. 143), what that transformation looks like is still expected to align with cultural expectations that value the performance of independence and productivity. Of course, effective medical treatment is a primary concern, but I believe that one of the most important aspects of seeking symptom relief is the hope that an individual's sense of self and identities can be maintained. This has important implications for how treatment is prioritised and rationed. While clinical markers may not necessarily indicate a severe disease level, any disease activity can have such an effect on a person's identity that they can no longer fathom life without treatment, as Lucy's case demonstrated.

Withholding this treatment based on economic rationing can have potentially severe consequences. Had Lucy not been accepting of the enforced delay in accessing effective treatment that the health system subjected her to, she may not have been alive to participate in this study.

As the examples in this chapter demonstrate, a diagnosis does not guarantee women the care they need. Instead, it can create the possibility of care (Hardon 2016, p. 27) in a system where care is rationed and some diagnoses are privileged over others (Jutel 2018, pp. 8-9; Stone 2018, p. 60). While Jutel (2018, pp. 8-9) notes that diagnosis 'is the way in which medicine decides what matters', I argue that diagnosis is also a key way biomedicine decides *who* matters, including who is worthy of care and who is worthy of particular levels and forms of care. In some cases, people can matter so little that they have their diagnosis — and only avenue for accessing treatment — taken away. This privileging of certain diagnoses exemplifies the broader impact of moralisation on health and illness. In addition to this, moralisation is implicated in other challenges women face after receiving their diagnosis, including through the judgement and rejection of healthcare providers and the types of identities women feel they must retain.

Women engage in various strategies to attempt to navigate these challenges alongside those autoimmunity already creates. These strategies often aimed to retain valued identities, such as those of someone who is productive and independent, at the same time as addressing other care needs such as emotional and financial support. This points to the importance of considering both identities and moralisation in women's experiences after receiving their diagnoses to better understand the challenges and barriers they face, and how they negotiate care in light of these. Embodied, relational care (cf Sand Andersen et al. 2020, p. 574), in the form of local peer support, was particularly important for the women in my study; however, their diagnoses, coupled with their regionality, sometimes initially presented barriers accessing this. Where these barriers were in place, it was only through women's own labour and identity work that access to local peer support became possible. Similarly, diagnosis also did not guarantee access to resources such as effective treatment and practical and financial support. Despite these barriers, women were able to exercise agency to access care, including through shifting their identities, reconceptualising

their understandings of shared experience, waiting and trusting the system, and self-advocacy. It is a testament to these women that they were able to do this despite being so ill; however, a system that truly cares should not force them to carry this added burden. While this chapter considered women's experiences in the period after receiving a diagnosis, the following chapter explores their broader experiences of life with an AD, with a focus on how they come to make sense out of autoimmunity given continued biomedical uncertainty about its cause.

CHAPTER 6: MAKING SENSE OF AUTOIMMUNITY

Biomedical uncertainty about the cause of autoimmunity means there is no single explanation that women can harness to make sense of their illnesses. Instead, women construct particular understandings of autoimmunity and its causes based on their life experiences, shaping their care needs in the process. In this chapter, I discuss five key ways that women explain or make sense of autoimmunity: (i) as the body attacking itself; (ii) as a systemic bodily issue; (iii) as the outcome of stress; (iv) as triggered by environmental pollutants; and (v) as hereditary. Although the meanings ascribed to autoimmunity are shaped by each woman's life experiences and the particular manifestation of her illness(es), two key themes underpin many of these understandings. First, in making sense of autoimmunity as systemic and caused by environmental pollutants, some women can be understood to be attempting to create order from 'matter out of place', and constructing certain substances or agents as polluting to both explain and manage their illnesses (Douglas 1966). Second, underpinning each narrative of autoimmunity are discourses of personal responsibility, particularly in discussions of autoimmunity as the outcome of stress, environmental pollutants, and genetics. These discourses position women, their choices, and behaviours as the central, if not sole, cause of autoimmunity and its management, inevitably shaping women’s care needs and experiences.

Biomedicine and bodies attacking themselves

First and foremost, each woman in my study understood her illness(es) within biomedical frameworks of disease. Some specifically understood their illnesses as autoimmune, while others understood them as a related biomedical classification. For example, Daisy sees her rheumatoid arthritis as simply 'arthritis' as opposed to an AD. While each woman constructed meaning out of autoimmunity in her own way, this was always grounded in a biomedical diagnosis. In biomedical contexts, the metaphor of the body attacking itself has commonly been used to describe autoimmunity. This metaphor is a legacy of the 'distinction between “self” and “not-

self"' that is foundational to the field of immunology (Napier 2003, p. 59). As Napier (2003, p. 59, emphasis in original) argues:

> Self-recognition is central - and, in fact, crucial - to the understanding of antibody formation . . . immunology's focus on identity has given centrality to the fundamental autotoxic metaphor of *the body at war with itself*.

Also central to war metaphors in immunology are constructions of 'rigid and absolute' boundaries 'between the body (self) and the external world (nonself)'(Martin 1990, p. 411). In these conceptualisations, the nonself is further characterised as 'foreign and hostile' (Martin 1990, p. 411).

Although the relevance of war metaphors and self/non-self dichotomies for immunology have been challenged (Martin 1994, pp. 97-101; Napier 2012), they remain pervasive in descriptions of autoimmunity. For example, the website WebMD (2020) explains that autoimmunity as 'immune system overactivity', where 'the body attacks and damages its own tissues.' Healthdirect Australia (2020) describes ADs as occurring 'when the immune system produces antibodies that attack the body's own cells.' An informational brochure produced by the Autoimmune Resource & Research Centre (2014) in Australia describes autoimmunity in the following way:

> For some people, the immune system does not work properly and some people may get sick when the system is not balanced and becomes overactive. When the immune system is overactive it causes harm to itself by attacking parts of the body as if it was the enemy. The immune system mistakenly begins attacking specific healthy cells and tissues and fails to shut off. This is called autoimmune illness.

Davidson and Diamond (2014, p. 24) define an AD as 'a condition in which tissue injury is caused by T cell or antibody reactivity to self.' This represents a shift in emphasis from an attack on the self to 'reactivity to self.' This definition also encompasses two key stages in the process of developing autoimmunity: (1) the body (antibodies) mistaking its own tissue as 'other'; and (2) the immune system damaging those tissues it mistakes as other. Based on this definition, the body-

attacking-itself-metaphor can be seen to better represent this second stage in the process, rather than the process of autoimmunity as a whole.

Because of the contradiction inherent in metaphors of self-attack, the concept of autoimmunity has also been drawn on as a theoretical and philosophical tool to disrupt the taken-for-granted assumption that the self and body are naturally aligned (Cohen 2004) and to explore how nations respond to external threats in ways that may be ‘self-destructive’ (Ferri 2018, p. 10). Although the body-attacking-itself-metaphor is closely tied to broad discussions of autoimmunity, this does not necessarily translate to an equivalent significance for people with ADs. In fact, the metaphor may be more useful to those who wish to harness autoimmunity as a conceptual tool to think through issues other than actual ADs. Most of the women in my study rarely mentioned the idea that their bodies were attacking themselves, suggesting that this explanation is more significant in biomedical and theoretical contexts than in the everyday lives of women with ADs. Some women only mentioned the metaphor when they were explaining to me what their doctors had told them. For instance, Ellen told me, 'they [doctors] said everything is just the immune system attacking itself. Time and time again the doctors have said it'. In a later interview, she told me, 'it's only probably in the last few years that the doctor sort of started mentioning autoimmune, the body attacking itself, things like this she'd say.'

Jennifer's autoimmunity was explained to her by her doctor in a way that drew strongly on military metaphors. She recalled:

> It was explained to me that it is my own body sending out soldiers to attack what it perceives to be a foreign body within, like something foreign, so my body is sending out soldiers to attack it.

In this explanation of autoimmunity Jennifer also draws on misrecognition to explain what is happening to her body. This becomes important when she attempts to explain autoimmunity to others, who often reject her explanation that her body is attacking itself. Jennifer told me about a common interaction she has had when trying to explain her illnesses to people who have not heard of autoimmunity before:

> There's been people who don't know anything about autoimmune disease, or scleroderma, or any of it, and if they say, 'what is this disease you've got?', if I say, 'scleroderma' or 'Sjögren's', . . . [they say] 'what is that?' . . . [I say] 'it's an autoimmune disease' . . . [they say] 'well what does that mean' . . . [I say] 'well my body is attacking itself' . . . [they say] 'oh don't be stupid, your body can't attack itself, what does that mean?'

In this example, the discomfort inherent in the contradiction of autoimmunity (Anderson & Mackay 2014, p. 13) — that your own body could attack itself — shifts from the theoretical or metaphorical to the everyday, shaping the reactions of other people to Jennifer's illness experience. In these cases, Jennifer attempts to explain autoimmunity again, shifting the emphasis from an attack on the self to misrecognition and healing:

> So, then I'll say something like 'well it's [her body] probably not attacking itself, but it believes that there's some foreign thing in my body or something not well in there so it's trying to fight it off to heal it'. So, I find I have to word my explanation better, yeah.

Jennifer's response illustrates how the meaning of autoimmunity is not static or singular and can be renegotiated in interactions with others who reject the idea that the body can attack itself. For Jennifer, the meaning of her autoimmunity shifts from emphasising an attack on herself, to emphasising misrecognition and an attempt to heal. These are both relevant to the way Jennifer understands her autoimmunity. Even in her initial explanation that focused on her body sending out soldiers to attack itself, she explains that this attack is triggered by misrecognition of the self as other. Reinterpreting autoimmunity as the body's confused attempt to heal something that it mistakenly believes is 'not well in there' also aligns more closely with general understandings of how the immune system works; that is, that the immune system 'fights off' disease (Martin 1994, pp. 65-7). This likely relieves some of the discomfort people might feel over the idea that their bodies could potentially attack themselves, allowing them to retain their unconscious awareness of their bodies (Leder 1990, p. 76; Manderson 2011, p. 24). A mistaken attempt to heal is perhaps less confronting than an assault on the self. However, by centring their own discomfort or disbelief, rather than Jennifer's experience as someone living with multiple ADs, the people involved in these interactions dismiss her knowledge and

experience. They position Jennifer as either exaggerating or being uninformed about her own body and illnesses. These interactions are an example of the broader delegitimisation that people with relatively unknown chronic illnesses experience, particularly if those illnesses are invisible (Masana 2011, pp. 134-6; Moss & Dyck 2003, pp. 88-9; Ware 1992).

Alternative metaphors and personal responsibility

While the body-attacking-itself-metaphor is clear, easy to communicate to others, and legitimised by biomedical practitioners, it tends to be an inadequate explanation for those with an AD. It also does not necessarily reflect the biomedical reality of autoimmunity. In fact, the immune system produces and eliminates self-antigens as part of its normal functioning. Autoimmunity does not occur because of the production of self-antigens, but because of a failure to eliminate them. As Davidson and Diamond (2014, p. 24) explain, 'the hallmark of autoimmune disease is the activation of self-reactive T and B lymphocytes . . . For autoimmunity to develop there must be a lack of stringency in the elimination of autoreactive cells.' This distinction is important because it disrupts the foundation of the body-attacking-itself-metaphor, which is inherently violent, invoking images of an angry body destroying itself from within. However, if the emphasis is shifted to the failure of the immune system to eliminate normally produced self-antigens, at least some of the violent imagery is shifted. Although not drawing on the failure to eliminate autoreactive cells, Ferri (2018, p. 15) similarly questions the relevance of war metaphors for autoimmunity, arguing that ‘we must consider the futility of declaring war on a body that has declared war on itself, in an endless cycle of combat and violence’.

There are other metaphors available for explaining autoimmunity. People draw on mystery, confusion, and malfunctioning machines to name a few (Ferri 2018, p. 13). What these metaphors all have in common though, is a link to discourses of personal responsibility. In a culture where health and illness are considered a personal responsibility, describing autoimmunity as the body attacking itself locates the cause of autoimmunity within the individual/self, positioning it as a disease of your own making; *your* body has malfunctioned, or *your* immune system

is confused. In this sense, it is almost the poster child for personal responsibility — if you have an AD you are attacking yourself (as long as we consider our bodies part of our selves) (Kirby 2017, p. 47).

In Jennifer's case, as well as positioning autoimmunity as a personal responsibility through the body-attacking-itself metaphor, she sees the difficulty some people have comprehending this as a problem with the way she explains autoimmunity. She takes personal responsibility for shifting her explanation to something that other people may be better able to relate to, regardless of what aligns best with her illness experience. In this case, one of the key ways these biomedical understandings of autoimmunity permeate women's experiences is not that they necessarily think of their bodies as attacking themselves, but that it reinforces discourses of personal responsibility. This acts to locate the cause and management of illness within the individual. In the current absence of any biomedically identifiable cause of autoimmunity, it is positioned as the failure of an individual body to function correctly, rather than the failure of biomedicine to identify a cause. This is problematic since, as I go on to discuss, many of the currently hypothesised causes of autoimmunity fall beyond the control of individuals. This theme is something that is embedded in each woman's understanding of autoimmunity. While women drew on varied explanations for their own autoimmunity, at the core of each understanding is the idea that autoimmunity and its management are issues of personal responsibility.

Autoimmunity as systemic

For some women, the metaphor of the body attacking itself manifested as an understanding that autoimmunity indicates a problem with their entire bodies, even if their disease was, biomedically speaking, limited to a particular part of the body. For Kate, this underpins her understanding of the meaning of autoimmunity and I discuss her case in depth here:

> My mum has thyroid disease, she's had it for a long time . . . It's not autoimmune. She has autoimmune [rheumatoid arthritis], but not for thyroid. She takes her pill and she is fine. She said to me, 'I don't get it, I've got thyroid [and I feel fine],' and I said, 'but it's different mum, you just have thyroid disease and you

> take your pill and it balances your levels and you're fine. This is autoimmune. It attacks my whole body, it's just the thyroid they treat, they don't treat anything else' . . . It just constantly, constantly attacks. It never ever stops attacking itself. Because that's what autoimmune means, self, self-attack. And no, it never stops, it never ever stops.

Kate has had a similar experience with doctors, telling me:

> The amount of doctors that have just said, 'oh you've got Hashimoto's, that's a thyroid thing, just take a thyroid tablet' and it's not. It's not. Your body is like all these ecosystems, and one effects it, the other effects it. Because if it was just affecting your thyroid then it would be thyroid disease, like my mum's got, and she doesn't have autoimmune or Hashimoto's or Grave's, and she takes a pill and she's fine, so it's not the same.

Kate understands autoimmunity as a systemic illness, even though her disease is limited to her thyroid. She sees autoimmunity as something distinct from non-autoimmune diagnoses by virtue of the biomedical nature of autoimmunity (i.e. the body attacking itself) and by her experience of the complexity of treatment. In understanding autoimmunity this way, Kate draws on her own understanding that her body is made up of multiple, interconnected ecosystems. If there is an issue with one ecosystem, it can create issues with the other ecosystems. In this sense, Kate sees autoimmunity as something that cannot be isolated to one part of the body, even if that is what a specific biomedical diagnosis indicates. At the same time, Kate sees her mother's experience of autoimmunity as distinct from her own. She mentions that her mother 'has autoimmune [rheumatoid arthritis] but not for thyroid' then later says that her mother 'doesn't have autoimmune or Hashimoto's or Grave's.' However, based on Kate's understanding of what autoimmunity is, someone with an autoimmune disease has a systemic problem. Here, the main difference Kate sees between her mother's experience and her own, apart from the differences in their autoimmune diagnoses, is that her mother's illnesses have been more straightforward to treat, while Kate is yet to find a treatment that gives her a quality of life she feels satisfied with. Even though Kate describes autoimmunity as something that attacks her whole body, this is not necessarily an understanding of autoimmunity that she sees as relevant to everyone with an AD. Rather, it is borne from her specific experience of autoimmunity as highly disruptive and difficult to treat.

Difficulties finding an effective treatment significantly shape Kate's understanding of what autoimmunity means. Kate's thyroid levels are regularly monitored through blood tests and her thyroid medication is adjusted depending on those levels. Kate explains that, in theory, this monitoring process should lead to the prescription of the optimal dose of thyroid medication, which should facilitate a relatively normal quality of life by eliminating, or at least minimising, her symptoms. However, this has not been Kate's experience. Despite regularly monitoring her thyroid levels and adjusting her medication accordingly, Kate is yet to feel any significant improvement in her symptoms and quality of life. There have been occasions where she feels like an adjusted dose is starting to improve her symptoms and she begins to feel hopeful, only to have her hopes dashed. During one interview, Kate's medication had been increased and she felt that the higher dose was starting to improve her symptoms. When she went back to the doctor for her routine monitoring, the new dose had altered her thyroid levels to a point that was considered risky. The dose was reduced, and Kate's symptoms worsened again. This has been a common routine for Kate and is in stark contrast to her mother's experience of being treated for non-autoimmune thyroid issues.

Finally, Kate draws on her understanding that ADs can cluster together in individuals. This was considered general knowledge among most of the women I interviewed. Kate has tested positive for antibodies associated with lupus, but not at levels that indicate a diagnosis of lupus at this stage. This has further influenced Kate's experience of what autoimmunity means and adds to the complexity she already experiences. Not only does she have to navigate the difficulties of treating Hashimoto's, but she is also keenly aware that those lupus-indicating antibodies could increase to a level that results in a diagnosis of lupus by her doctor. As she said above, her experience of autoimmunity is that it 'constantly, constantly attacks . . . it never stops, it never ever stops.' This understanding of autoimmunity might be different if Kate did not have the threat of a lupus diagnosis in the back of her mind. The ever-present risk that her autoantibody levels might rise links to Kate's understanding that autoimmunity represents a constant attack. She has a definite diagnosis in Hashimoto's but no meaningful resolution to her symptoms, and she sees no boundaries around her autoimmunity because 'it never stops.' This further

cements her understanding of autoimmunity as a systemic problem that must be addressed at that level. Treatment that only targets her thyroid does not give Kate much comfort, particularly because up until this point at least, it has not been as successful as Kate and her doctor had hoped. In making sense of her experience, Kate constructs her autoimmunity as complex, systemic, and interconnected. She positions it in opposition to other types of diagnoses that may be more straightforward to treat and which she interprets as being isolated to a specific part of the body.

Autoimmunity as matter-out-of-place

Kate's understanding of autoimmunity can be interpreted within a broader framework where autoreactive cells are contextualised as 'matter-out-of-place.' Douglas (1966, pp. 198-9, 873) famously argued that 'there is no such thing as dirt', rather dirt is relative and 'no single item is dirty apart from a particular system of classification in which it does not fit . . . dirt [is] matter out of place.' Kate's experience of autoimmunity can be seen, in part, as an attempt to order or control matter-out-of-place. While ideas of matter-out-of-place align quite well with germ theory, where the body is considered a bounded system that is at risk of being penetrated by pathogens, autoimmunity problematises the idea of what counts as matter-out-of-place because the body itself produces autoreactive cells. Autoreactive cells do not permeate the boundaries of the body because they are produced within it and they do not leave it. Although the creation of cells by the body that harm the body is not a unique mechanism of autoimmunity, ADs tend to be the primary incurable illnesses that are currently constructed as a self-attack. For instance, while discussing the agency attributed to viruses Napier (2012) asks:

> Might it be that our persistent characterizations of viruses as active agents arises partly from the cultural belief that harbouring otherness within us is principally dangerous, a belief whereby a persistent "self" must in turn always be protected against things "foreign"? Although we all have cancer cells within our bodies, for example, we never say we have cancer until those cells become problematic.

Although war metaphors are prolific in cancer discourses, cancer is often framed as a foreign entity inside the body that a person must go into battle with to survive

(Stoller 2004, pp. 128, 211-2). Autoimmunity, on the other hand, is framed as a battle with yourself, even though the mechanisms of both illnesses involve irregular immune responses that can cause tissue damage and chronic disease (Rahat & Shakya 2016, p. 1).

Autoimmune disease is considered to occur when the immune system fails to eliminate autoreactive cells. Cancer is considered to occur when tumour cells are not recognised as 'foreign', allowing for 'tumour progression and dissemination' (Rahat & Shakya 2016, p. 1). Thinking about these similarities and differences through a framework of matter-out-of-place illustrates that in both instances the body creates matter (either tumour cells or autoreactive cells) that is considered out of place only under certain circumstances. Douglas (1966) argues that whether something is considered polluting changes depending on the social and cultural context, and the same can be said for what is considered polluting within an individual body. The simple creation or presence of autoreactive or tumour cells does not make them matter-out-of-place. If they are eliminated as part of the immune system's normal functioning they are not considered matter-out-of-place. If they remain in the body but do not cause biomedically identifiable cell or tissue damage they are not considered matter-out-of-place. If they remain in the body and cause cell or tissue damage they do become matter-out-of-place. However, if they remain in the body and cause cell or tissue damage but this damage is not reflected in clinical markers they are not considered matter out of place.

In Kate's case, from a biomedical perspective, autoreactive cells that would indicate a lupus diagnosis are ambiguous and this is what positions them as matter-out-of-place. They were not removed by her immune system and they are not causing biomedically identifiable cell or tissue damage (i.e. a diagnosis), but their presence has been identified. The presence of an already diagnosed AD is what contributes to this ambiguity, which is linked to risk. Kate told me multiple times during our interviews that if you have one AD you are more likely to be diagnosed with more in the future. The presence of lupus antibodies in her blood makes this risk very real to her. However, it also creates space for her to engage in strategies to minimise the risk of her antibodies rising to levels that indicate a lupus diagnosis. This creates ambiguity around these cells — Kate cannot necessarily eliminate them,

but she believes she can manage them. From a biomedical perspective, they are not matter-out-of-place until they reach levels that indicate a lupus diagnosis. Until this threshold is reached no action is taken to remedy their presence. For Kate, however, they are constructed as matter-out-of-place because even if they do not meet the levels required for diagnosis, for her they are a general sign and reminder of her systemic autoimmunity, and something she needs to manage. Autoimmunity in this context is 'more about a dynamic and unpredictable negotiation between what is recognised and lived with or alongside as well as what is not recognised and not tolerated' (Ferri 2018, pp. 14-5). For autoreactive cells, matter-out-of-place has intersecting meanings that are broadly relevant in a particular cultural context (i.e. biomedicine) but which are experienced in differing ways by individuals.

These understandings of autoimmunity and autoreactive cells underpin Kate's illness experience more generally, including how she engages in different care strategies to manage her illness. Management involves specifically addressing Hashimoto's disease, while also addressing the broader systemic autoimmune issue. For Kate, managing Hashimoto's disease involves taking thyroid medication and eating a gluten-free diet. Management also involves strategies to dampen her body's general autoimmune response and inflammation levels. Kate takes supplements, follows a relatively strict 'Paleo' diet, and tries to eliminate as many toxins and chemicals from her home as she can. This includes those found in common household cleaning products and personal care products, such as deodorants, soaps, and make-up. One of Kate's main goals is to keep her autoantibodies at low levels to prevent the development of lupus. Taking these additional measures to address autoimmunity systemically gives Kate a sense of control over her future. They also help to manage her Hashimoto's to some degree and leave her feeling that she is as healthy as she can be under the circumstances. For her, managing autoimmunity means managing her diagnosed illness and attempting to prevent further diagnoses. Autoimmunity in this context is understood as necessitating care as a measure of control beyond diagnosis-specific illness management.

The way Kate understands and manages autoimmunity forms a core component of her identity. For instance, she told me:

> And you know everyone in this house had that flu [this year] but me, the autoimmune chick didn't get that virus . . . They all went on double antibiotics and I didn't get a thing, because I am so pumped full of vitamins and eat so well, and they all eat well, but I should rattle when I walk, all these supplements I take, and yeah I didn't get sick.

Kate has embraced the identity of being 'autoimmune', referring to herself as the 'autoimmune chick', which she did often during our time together. Although Kate understands autoimmunity as a self-attack she sometimes positions it as external to herself. For instance, when she says, 'this [Hashimoto's] is autoimmune. It attacks my whole body' she positions it as something external to her body. However, she also consistently sees her whole self as autoimmune. Kate's understanding of autoimmunity and the way she manages it aligns closely with discourses of personal responsibility. By identifying herself as autoimmune, she embodies personal responsibility for her illness and enacts personal responsibility through the multiple care strategies she employs. Kate also takes personal responsibility seriously in relation to others. She strongly believes that people need to take responsibility for their health, both in the context of preventative actions or managing an existing illness. She feels frustrated with members of her family who do not take responsibility for their health to the same extent she does. At one point Kate's sister, Marie, asked her how she managed to avoid catching the flu. Kate recalled:

> My sister said, 'how did you not get sick, everyone got it?' And I said, 'yeah but I watch everything I eat and I take so many supplements that I have got my body working pretty smooth really, considering my issues. So, my body has what it needs to fight infection. Yours don't. You smoke, you live on Coca-Cola and junk food, it's got nothing to fight illness.' So there lies the difference.

Part of this moralising of others stems from Kate wanting to prevent her family from going through the difficulties she has experienced with her health. Marie has noticed symptoms similar to Kate's that Kate feels may indicate she also has Hashimoto's disease, but Marie brushed off Kate's warnings. Kate expressed her frustration over what she perceives as her sister not wanting to confront the possibility of having Hashimoto's:

> You're throwing answers out, saying 'save yourself, change your lifestyle, get your [auto]antibody numbers down, save yourself.' And she's 10 years younger than me and it's too hard [for her to make lifestyle changes] . . . God if I had the chance to go back and you know change some stuff, but no. You [Marie] can't do it.

The way Kate manages her autoimmunity and moralises those who she perceives as being irresponsible with their health, reinforce discourses of personal responsibility. By engaging in care strategies to responsibly manage her autoimmunity, prevent further diagnoses, and warn others, Kate can be seen, to some extent, as redeeming what she perceives as past irresponsibility that may have triggered her diagnoses.

Alternative conceptualisations

While the other women in my study understand their illnesses as autoimmune and have been told that their body is attacking itself, this does not necessarily reflect what autoimmunity means for them. Although they recognise this explanation, for them autoimmunity is contextualised as their specific disease, or set of diseases, and this is often reflected in how they approach the care strategies they engage in. In contrast to Kate, Daisy sees her rheumatoid arthritis as a bounded, as opposed to systemic, disease and does not conceptualise it as an autoimmune problem. She understands that it is an AD because she has been told that it is, but that is not relevant for her. For her, what is relevant is that she has arthritis. Her illness management strategies focus on the disease-specific, such as taking prescribed medication and managing pain. Emily sees her scleroderma and lupus diagnoses in a similar way. She knows that they are ADs because she has been told that they are, but she does not think of them as being signs of a systemic autoimmune issue. Emily thinks of her lupus and scleroderma as two distinct illnesses, and like Daisy, her illness management reflects this. Emily takes her prescribed medications and manages things like pain and energy as well as she can.

Because neither woman sees her illness as a symptom of an overarching systemic autoimmune issue, taking additional measures such as experimenting with diet, supplements, or other therapies does not make sense unless they are in the context of addressing specific symptoms. For instance, Emily started using essential oils to manage the symptoms associated with her illnesses, but not to address a

perceived systemic autoimmune issue. In contrast to those who understand their autoimmunity as an attack by their bodies on their bodies, these women understand autoimmunity more as a label associated with their distinct diagnoses, rather than a significant factor in their management strategies. The different emphases that women place on autoimmunity can have important implications for care beyond illness management, as I discussed in Chapter Five. For instance, for those who identify with autoimmunity as a category, options for peer support were expanded as people with different ADs came together under the shared experience of autoimmunity.

Causes of autoimmunity

Something that was shared between all seven women was a need to have some kind of explanation for their illnesses, a phenomenon that is well documented (e.g. Blaxter 1983, p. 59; Hunt 1998, pp. 298-9; Kleinman 1988). For autoimmunity in particular, Anderson and Mackay (2014, p. 119) argue that:

> Evidently, there are many possible causes or incitants of autoimmune disease, but as yet, none has been identified with precision and authority. The etiological framework is sturdy enough, but it is empty. Those who suffer have to find their own answers to the existential questions Why me? And why now?

This echoes Kleinman's (1988) earlier thoughts on the limits of biomedical health systems. Kleinman (1988) posited that an increasing tendency towards medicalisation, coupled with the 'cultural authority' of science and biomedicine has left a gap between physiologically addressing disease and dealing with 'the problem of suffering.' He argued:

> In contemporary biomedicine and the other helping professions there is no teleological perspective on illness that can address the components of suffering relating to problems of bafflement, order, and evil, which appear to be intrinsic to the human condition (Kleinman 1988, p. 28).

Suffering is seen as ‘a problem of mechanical breakdown requiring a technical fix’, with medical treatments applied ‘in place of meaningful moral (or spiritual) [responses] to illness problems (Kleinman 1988, p. 28). This 'meaning void' means people may seek out explanations that give meaning to their suffering, beyond

explanations provided by biomedicine (Gressier 2018, p. 77). In the case of autoimmunity, people may seek out explanations in the absence of any concrete biomedical identification of cause. The current lack of biomedical knowledge around what exactly triggers ADs, or 'whatever enables them to persist thereafter . . . reveals that *autoimmunity actually names a known unknown* whose (un)knowability continues to befuddle even the best funded attempts to contain it' (Cohen 2017, p. 29, emphasis in original). So, while each woman understood her illness within a biomedical framework, this framework does not account for the need to make sense out of why autoimmunity developed in the first place.

For some women, speculation about the cause or trigger of their autoimmunity was something they pondered in passing. For others, it was something they had spent quite some time thinking about. For some women in particular, the explanation they were most wedded to was tied to the way they managed their autoimmunity and their futures. In all cases, the explanations women drew on integrated biomedical narratives of autoimmunity with their own life stories. These understandings helped women to make sense of their illnesses while also shaping their illness and support experiences. For most women, autoimmunity was understood as emerging from one, or a combination of, several triggers. These included stress, exposure to environmental triggers, and genetic or hereditary factors.

Stress

While several women identified stress as a trigger for flare-ups of their illness, Kate and Jennifer both identified stress as also being implicated in the onset of autoimmunity. Generally, Kate and Jennifer use the term 'stress' to refer to disruptive and traumatic life events, something that is often drawn on to help explain illness (see, for example, Blaxter 1983, p. 64; Miles 2013, p. 83; Price & Walker 2015, pp. 42-3). Kate has a particular interest in the links between stress and autoimmunity. It is something that she has discussed with other women in her Facebook support group and identifies with quite strongly. Kate explained to me:

> In my support group online, we talked about who had a lot of stress in their childhood, which is a nice way of putting it, and so many people said that they did and many of the ones that said that they didn't said that then they got into bad

> relationships and that. I don't ever remember life being calm as a child, having happy families, any of that stuff. It was violent at our house . . . I think that's what made me so determined to find someone [in a partner] who thought like me and wanted to live in a peaceful environment, better ourselves, better our life you know, not have all the conflicts that other people seem to have. Because I grew up with a pretty crappy life. And I remember being probably 8 and remember being super super constipated which is part of Hashi's [Hashimoto's disease], the not sleeping thing, I remember things like that, but all the stomach issues didn't really start until I was probably . . . I think it was just after I'd had my first [child] that I started having my stomach issues, but I'd had glandular fever not too long before I'd had him, so it's sort of like this whole time period, and that was a really bad relationship too so it was this whole . . . I've just had so many things that I just go . . . yep ticking them boxes, ticking them off, you know, infections and drama and stress and crap and just . . . ugh so many things.

Kate understands her autoimmunity as something that was almost an inevitable outcome of multiple disruptions in her life. These disruptions started with a difficult childhood with symptoms accumulating and intensifying as she experienced further stress throughout her life. This has become intimately tied to her identity, with Kate making a conscious decision to be someone who disrupts the pattern of a troubled childhood and family life that she experienced. She strives for a life in opposition to what she experienced — peace instead of violence, happiness instead of stress, self-improvement instead of the perpetuation of destructive patterns. As well as seeing autoimmunity as the bodily expression of accumulated stress over a lifetime, Kate now experiences near-immediate physiological responses to stress that she identifies as Hashimoto's flares. She told me:

> For me, when things go topsy-turvy just as life does, the roller coaster of life, that makes me sick, because the stress of it, I just go *splert* immediately down the tubes. You know you get bad news or something happens and within five minutes I feel myself falling down the rabbit hole. So just life affects me.

For Kate, autoimmunity is the embodiment of accumulated stress that has affected her to the extent that she now feels highly sensitive to any kind of stress, even the stress she considers a normal part of life.

Jennifer also believes that stress is a major factor in triggering her illnesses, telling me, 'I think that stress is a lot of it, I really do.' This was emphasised to her after seeing a television program that suggested there was a correlation between childhood trauma and poorer health in adulthood. Jennifer also took part in a survey some years ago that concluded that people with a background of childhood trauma or neglect may be more susceptible to developing ADs because the stress they experienced as children triggered an inflammatory response. This got Jennifer thinking about her own life and what may have triggered the onset of autoimmunity. Like Kate, Jennifer did not have an easy childhood. One of five siblings, she grew up in a household where money was scarce. Her father was a severe alcoholic and when her parents were living together she remembers a lot of fighting. Jennifer remembers that she also had 'little niggling symptoms', things like fatigue, anaemia, and feeling cold all the time; however, when she was 16 her symptoms noticeably worsened. Her parents had separated and her father was rotating between staying with friends, family, and sleeping under a bridge in town. Around this time, there had been reports in the news about an unidentified man who had been hit by two cars and was in a coma at the local hospital. About a week after the reports started, Jennifer's sister-in-law urged her family to visit the hospital to see if the man in the coma was Jennifer's father. It was. He remained in a coma for six weeks before he died. Jennifer distinctly remembers that at this time all of her 'niggling symptoms' seemed to worsen, telling me that from that point on 'it all sort of accumulated into one big thing all the time.'

Since then, Jennifer has experienced worsening symptoms that have coincided with stressful periods in her life. In about 1996 she had been in a high-profile job that involved long hours and a lot of stress and travel, and she identifies this as a specific point in time where her accumulated symptoms again worsened. In 1998 Jennifer's younger brother, who was 31 at the time, was diagnosed with a terminal brain tumour and her symptoms worsened yet again. Not long after, abnormalities were picked up when Jennifer attempted to donate blood, triggering her diagnosis process (see Chapter 4). During this process, Jennifer's husband was hospitalised for five months and Jennifer was left to run their seven-day-a-week business on her own. Again, her symptoms worsened. In our second-last interview Jennifer told me, 'I think probably now I'm more stable in my health because

everything has been on more of an even keel for years.' Not only does Jennifer link phases of worsening symptoms to stressful life events, but she also attributes the plateauing of her symptoms to experiencing a more stable life over the last few years, without the significant disruptions that had characterised her life before.

Stress, the immune system, and personal responsibility

Kate and Jennifer describe several stressful and traumatic life experiences — poverty, conflict, grief, instability. Those experiences have shaped both women's identities and illness experiences, and they interpret those experiences as becoming embodied as ADs. These intersect with biomedical understandings, which include speculation that chronic stress may have a role in the onset and flare-up of ADs (Miller 2014, p. 291; Porcelli et al. 2016; Sharif et al. 2018; Skopouli & Katsiougiannis 2018) and that stress is known to interact with immune function more generally (Dhabhar 2014; McDade 2005, pp. 509-11; Morey et al. 2015). In a biomedical context, stress is framed as something that should be dealt with at an individual psychological level, regardless of the experiences that may cause or exacerbate stress. Experiences that are considered to potentially induce chronic stress include poverty, abuse, maltreatment, bullying, caring for an ageing or ill partner, loneliness, and 'troubled relationships' (Morey et al. 2015, pp. 2-3). In reality, few, if any, of these experiences can be attributed solely to the individual and many are entangled with broader structural issues, that is, the overarching political, social, economic, and environmental factors that influence women's illnesses experiences. These can include, for example, such as socioeconomic inequality, patriarchal social structures, age, and other power imbalances. However, in discussing future directions for research Morey et al. (2015, p. 5) emphasise the importance of investigating 'individual characteristics that make individuals more or less susceptible' to immune dysregulation. Similarly, Dhabhar (2014, p. 205) hopes that future studies will identify how to 'enhance protective immune responses' and 'ameliorate/eliminate stress-induced exacerbation or pro-inflammatory or autoimmune diseases.' In these biomedical discussions on stress and autoimmunity little-to-no space is created to consider addressing structural factors that contribute to stress, particularly chronic stress. To do so would require that biomedical institutions also face the reality that they often cause and perpetuate chronic stress, implicating biomedicine itself in the stress-autoimmunity cycle. As I discussed in Chapters 4 and

5, for some of the women in my study, biomedical structures and the healthcare providers who operate within them cause and exacerbate (dis)stress through delegitimising or completely rejecting women's illness experiences, rejecting women's knowledge of their bodies, moralising and policing women's bodies, and perpetuating a system that prioritises the visibility of disease-indicating clinical markers over women's expressed suffering.

Again, much of this is connected to the pervasive expectation that individuals are solely responsible for their health and illness, including risk management and illness management. The individual management of stress forms part of this expectation, masking the structural factors that may trigger or exacerbate it in the first place. These factors simply become items on a list of ‘stressful events’ to which an individual must manage their response. Individualised understandings of stress are often internalised by people with ADs. For instance, Miles (2009, p. 9) observes that in online lupus forums:

> Much lupus internet discourse is aimed at ironing out stress . . . defining stress as individual, rather than social, effectively places the responsibility for dealing with it onto the ill individual to 'accept' and transform herself.

This is certainly the case with Kate. Stress is a common response to violence in early life (Morey et al. 2015, p. 2); however, she has internalised individualised stress discourses and taken responsibility for ‘transforming herself’ through activities of self-improvement, such as modifying her diet and the products she consumes. Jennifer also approaches stress as an individual condition. I asked her how she coped with the disruptions in her life that she shared with me, particularly grief over her father and brother, and she frequently responded that she simply had to 'get on with things' and 'keep going.' She would also try to focus on hobbies like reading, crocheting, and craft. It would seem that in these cases, where stress is internalised as an individual rather than a social problem, women may engage in individual-level coping mechanisms such as personal transformation or sheer perseverance.

Despite these issues with the way stress is framed as an individual problem and a matter of personal responsibility, understanding autoimmunity as the bodily expression of stress has helped Kate and Jennifer to make sense of their illnesses in

the context of lives that have been characterised by considerable disruption. As Sontag (1978, p. 55) argues, 'psychologizing seems to provide control over the experiences and events (like grave illnesses) over which people have in fact little or no control.' Reinterpreting stress, and stressful events, as triggers of autoimmunity helps Kate and Jennifer to answer those 'why me and why now?' questions that biomedicine cannot answer. In the current absence of a definitive cause of autoimmunity, attributing it, at least partially, to stress can also provide a sense of control. If stress exacerbates autoimmunity, controlling stress might minimise it.

While stress management as a strategy to control autoimmunity reproduces the personal responsibility discourses that can make women's illness experiences more difficult, ultimately Kate and Jennifer must navigate their illnesses within the very system that values individual-level action. Adherence to this system is something that is policed through biomedical health systems generally, but also within illness communities. As Miles (2009, p. 9) observed in her study of online lupus communities, attempts to discuss structural issues such as environmental contaminants that may be implicated in the onset of lupus, or inaccessible and inequitable healthcare systems are usually dismissed or 'framed as individual concerns.' Although these ways of thinking have been challenged, particularly within the social sciences, biomedical epistemologies that locate the blame for illness, and responsibility for managing or mitigating it, squarely on the shoulders of the individual inevitably continue to shape the way women understand their autoimmunity. This is reinforced by the fact that personal responsibility permeates health promotion and prevention measures more broadly, with people encouraged to, for example, refrain from smoking and excessive alcohol consumption, eat more fruit and vegetables, and avoid gaining weight (Brown et al. 2019; Friesen 2018). While personal responsibility discourse can negatively impact women's illness experiences in numerous ways, women can also find some comfort and agency in performing the values it promotes.

Environmental causes

In seeking an explanation for their autoimmunity, women in my study speculated about the role of anthropogens or non-infectious environmental agents as

possible triggers. In doing so, they again integrated their life stories with biomedical knowledge to understand autoimmunity (Miller 2014). Here, anthropogens are defined as 'human-generated substances and behaviours resulting in poor health' (Gressier 2018, p. 35). For instance, Harriet was diagnosed with lupus within a few months of her starting the contraceptive pill and she believes the associated hormone change triggered her illness. Daisy wondered if the pesticides used to spray crops might be implicated in both her own and her younger sister's rheumatoid arthritis diagnoses. Daisy and her sister married a pair of brothers and spent their early married life on a jointly-owned cultivation and cattle property where they were both exposed to pesticides. Kate also speculated on the role Western lifestyles might play in autoimmunity:

> I blame modern life, I really do. And people think I'm wacky I'm sure, but we just live in this chemical, stressful, chemical world. And it's like, I go, 'I don't like meat that's been fed on grain', and people go, 'why?' And it's because the grain chemicals are still in the meat you know, doesn't that just make scientific sense?

In each of these cases, women have identified certain anthropogens as potential triggers for autoimmunity, including medication, pesticides, and contaminated food. These explanations can be interpreted as shifting the locus of blame for autoimmunity onto an external trigger. In their study of women's explanations for gynaecological cancer, Manderson et al. (2005, pp. 327-8) argue that explaining cancer as the product of the 'inherent hazardous nature of available foods' allowed women to 'deny any responsibility for cancer through their own behaviour.' Linking illness to environmental pollution can also represent a ‘powerful symbol of the boundaries of the body and community being breached by forces of capitalist development’ (Whittaker 1998, p. 314). This can be the case whether a specific contamination event occurred, or whether people retrospectively explain their illnesses as caused by environmental pollution (Whittaker 1998, p. 314).

Despite identifying anthropogenic explanations for their illnesses, for the women in my study explanations of autoimmunity as being triggered by certain anthropogens remained conceptualised as individual problems. Harriet's issue is that *she* started taking the contraceptive pill, not that the contraceptive pill has been associated with worsening lupus symptoms (Quintero et al. 2012, pp. 112-3). Daisy's

issue is that she exposed *herself* to pesticides on the farm, and not that pesticides remain in widespread use despite being increasingly linked to chronic illness (Mostafalou & Abdollahi 2013). Similarly, Kate positions the possibility of ingesting chemicals through food as the product of an individual choice to eat grain-fed meat, rather than a structural issue around how chemical agents are deemed 'safe' for human consumption. In each case, women spoke about these issues in terms of how they put themselves in a position to be exposed to illness-inducing anthropogens, positioning exposure as an outcome of choice, ignorance, or poor decision-making. This positions women's understandings of autoimmunity as a health issue that is triggered by something environmental, but they ultimately take individual responsibility for failing to shield themselves from exposure to those possible triggers. Again, autoimmunity is framed as the fault of the self.

To explore this further, I turn now to talk in more detail about Ellen's understandings of autoimmunity and how they are shaped by the environments she has lived and worked in. Ellen repeatedly recalled an incident that stuck out in her mind. For twenty years Ellen and her husband owned a farm outside a small country town of about five hundred people. Ellen also owned a small shop in this town:

> I had a little shop in town next to the TAB [betting shop] and I was there working one Sunday afternoon and there was a government fellow spraying the TAB for spiders and whatever, non-residential see. And he popped in and he said, 'do you want the shop done' and I said, 'no, but the old farmhouse, the spiders are just something shocking in it,' so he came out and did it . . . To the day I left there, my feet would tingle when there was moisture in the air, raining or anything, or if I washed the floors, because I never wear shoes, and walking around on the floors and that your feet would tingle, and I reckon it was this chemical. The little frogs and geckos died for years, years. So, whatever he used shouldn't have been used in a residential [property]. We thought about getting the house tested but we would have ended up with no house and we couldn't afford to so we shut our mouth and didn't say anything. But my brother-in-law bought it [the farmhouse] after we left, and it's been demolished now so no one else can get [sick].

In making sense of her autoimmunity, this story is important to Ellen. She has suffered from a wide array of symptoms over her lifetime and her family had no

history of illness that might help explain them. For most of her life, those symptoms have either been blamed on her weight, or ignored completely simply because she is considered overweight. Ellen was often made to feel that her symptoms were 'all in her head', or that they were her fault for being overweight. While I have discussed these experiences in Chapters 4 and 5, I touch on them again here because after spending decades having her experiences delegitimised, being able to make sense of her eventual diagnoses was particularly important for Ellen, and one of the key ways she does this is through the notion of anthropogens triggering illness.

More recently Ellen has been told by her doctors that some of her diseases are autoimmune and that her body is attacking itself. However, this explanation is not something she has dwelt on. Speaking about autoimmunity and the body attacking itself, she said, 'I'm not really that into the theories of everything. [I] just get up and get on with it.' After decades of being blamed for her symptoms, it did not surprise me that Ellen takes this approach. It surprised me even less that the idea of her body attacking itself was not something she spent much time thinking about, since it represents a continuation of the life-long narrative that she is personally responsible for her health issues. Coupled with significant disruptive, and in some cases traumatic, experiences throughout her life, Ellen has internalised personal responsibility rhetoric. At one point in our interviews, she wondered quietly if she must be a 'terrible person.' During particularly difficult times in the course of her illnesses she recalls exclaiming to her husband, 'oh well, I must have deserved it [her illnesses].'

Recounting stories about chemical exposure are an important part of making sense of illness, both autoimmune and non-autoimmune, for Ellen. Before we started our interviews she had been diagnosed and treated for breast cancer and wondered how chemical exposure might be implicated in this diagnosis as well:

> I've got a friend who's been a nurse most of her life. When I mentioned where our farm was, she said, 'oh I can't understand why someone hasn't looked into a cancer cluster for that town, the number of people that have been in hospital from there that have cancer.' And that was before I was diagnosed with this one [breast

> cancer]. Which makes you wonder about the chemicals that they use out there on the farms.

Stories of chemical exposure create some space for Ellen to think of her illnesses as being triggered by something external to herself, rather than seeing her illnesses as punishment for some perceived internal immorality, that is, that she ‘deserves it’. In doing so, she integrates 'culturally shared biomedical discourse' with her own experiences, 'giving meaning to otherwise arbitrary events' (Hunt 1998, p. 298; Hunt et al. 1998, p. 960). Having the farmhouse sprayed with insecticide, something seemingly mundane and innocuous, retrospectively becomes imbued with meaning as an event linked to the onset of autoimmunity. By linking this story with the nurse's comments about cancer clusters, Ellen can begin piecing together her sometimes disparate illnesses and symptoms into a coherent explanatory framework that does not leave her completely shouldering blame.

This particular understanding of autoimmunity as being triggered by anthropogens can also be considered as emerging from the intersection of personal responsibility and matter-out-of-place, and this then filters through to the way women manage their autoimmunity. For both Ellen and Daisy, pesticides retrospectively become polluting in light of their autoimmune diagnoses. The same can be said for Harriet and the contraceptive pill, and Kate and the range of 'toxic' household products that she identifies as potentially inducing autoimmunity. For these women, managing autoimmunity therefore also involves managing matter-out-of-place, or agents that are considered polluting. Again, this management is focused on what individuals can do to prevent exposure to polluting matter (i.e. potentially autoimmune-inducing or -exacerbating agents). This obscures any meaningful critique of the structural factors that generate the proliferation of potentially illness-inducing agents. While I discuss the cases of individuals here, these discourses of personal responsibility are often reproduced within communities that are concerned about potentially harmful anthropogens. For instance, a similar phenomenon has been observed in communities of Paleo dieters, which tend to include many people with ADs. Discussing Paleo as a form of resistance, Gressier (2018, pp. 81-2) argues that while Paleo dieters were critical of 'government, medical fraternity, pharmaceutical and 'Big Food'/agribusiness,' change was largely enacted at an

individual level through 'individual consumption choices.' Gressier (2018, p. 81) further explains:

> Paleo proponents are not banding together and using their numbers to actively agitate against the state, medical institutions or food and pharmaceutical corporations. Nor are they attempting to influence policy, or even social structures, but focus solely upon changing their own dietary and lifestyle patterns. In this sense, then, they are reproducing even while resisting neoliberal values and practices.

While anthropogenic triggers can provide important causal explanations for autoimmunity, helping women to make sense of their diagnoses within their broader life stories, their positioning as something that an individual exposed themselves to, or that an individual must avoid exposure to, reproduces discourses of personal responsibility. In Ellen's case, drawing on these explanations has helped her to make sense of her illnesses. However, one of the most difficult aspects of her life-long illness experience has been the personal blame placed on her, particularly by the biomedical community. For Ellen, understanding autoimmunity as having an environmental cause allows her to shift, if only momentarily, away from the idea that illness is her punishment for some innate immorality or irresponsibility. However, these explanations are ultimately framed as being within the purview of the individual, rather than the socioeconomic or political.

Heredity

While the women in my study often sought external explanations for their autoimmunity, some understood autoimmunity as hereditary. Lucy had been diagnosed with ankylosing spondylitis for several years before we met. She told me that, looking back, the first indication that something might be wrong was in 2014 when her fingers began to feel stiff and one of her knuckles became swollen. Although these symptoms did not resolve, she put them down to a possible repetitive strain injury:

> Then I started to have a lot of pain and stiffness when I'd wake up in the morning. All down my legs, I couldn't move my legs very well and it was very painful if I had to suddenly move my legs or if I slipped over and the joint moved really quickly. It was quite . . . painful in a way that I can't really describe . . . When

I would get up in the morning I couldn't stand up straight for the first half-hour, like I'd have to really stand up quite slowly and push myself to be able to straighten my back. I couldn't climb stairs very well and I was walking basically like a penguin waddling . . . I couldn't swing my legs very well. And I went on like this for almost six months before I went to the doctor because I just . . . I didn't think that anything like this [ankylosing spondylitis] was a possibility. I just didn't at all think that it could be something serious or permanent. I thought I'd done myself an injury exercising and it would go away and it didn't go away and it started to get worse and the pain got more and more unbearable.

After visiting a local GP, Lucy was referred to a rheumatologist:

I walked into the specialist's room and he did the whole background, asking me questions and family history and all that. And I'd spoken to my parents the day before, I think, telling them what was going on because they live up here in Queensland [Lucy was living in regional New South Wales at the time], and my dad said, 'oh you know how your uncle walks a bit funny, he's always a bit bent over?' And I was like, 'yeah . . . ', because he's been like that my whole life but I've never really asked why or known much about it. And dad goes, 'he's got this disease, it's called ankylosing spondylitis. You probably don't have to worry about it because when he was diagnosed we all went and got tested for the genetic component.' And my dad said, 'I got tested and I didn't have it so you should be fine but maybe you should mention it.'

Then in the specialist's office I said, 'my uncle has something called ankylosing spondylitis' and the specialist just looked up from his pen and paper at me and said, 'yes, and so do you.' And I was just dumbfounded because I was like . . . it can happen without the genetic component but in my case, for it to happen to me without the genetic component and my uncle has it would be just really unlucky. And then I got the test done and it turns out I do have the genetic component, so my dad's tests were wrong, or they told him the wrong information, which is shit because if he'd known then we would have known to look out for it and I would have gone to the doctor a lot earlier and I wouldn't, maybe, have some of the permanent damage that I now have but . . . whatever. I have a lot less permanent damage than my uncle and a lot of other people, so I don't really get annoyed by that I just think that it's . . . unlucky.

Lucy's understanding of ankylosing spondylitis as hereditary has helped her to answer the 'why me' question people with chronic illnesses often ask themselves. Rather than wondering if her autoimmunity was bought on by stressful events in her life, or exposure to anthropogens, Lucy clearly identifies her autoimmunity as something that was out of her control. Her father had been screened for the HLA-B27 gene that is associated with ankylosing spondylitis and received what her family now suspect was a false-negative result. Although the gene is present in 85-90% of ankylosing spondylitis patients, 'only 5% of HLA-B27 positive people develop ankylosing spondylitis ' (Golder & Schachna 2013, p. 782). In undergoing screening, her father fulfilled his role as a responsible 'moral agent', given the presence of the gene in his brother who has ankylosing spondylitis (Huniche 2011, pp. 1811-2). To Lucy, the onset of ankylosing spondylitis was 'unlucky.' This allows her to set aside much of the self-blame that is often intertwined with making sense out of long-term illnesses. Of all the women who were involved in my research, Lucy's understandings of autoimmunity aligned most closely and consistently with biomedical explanations. It is quite possible that the genetic links in her case meant that biomedical understandings made the most sense. There was no need to re-think her life story to identify a reason or trigger for her illness because genetic links provided that explanation.

While having a hereditary explanation meant Lucy did not blame herself for her illness, this does not mean that she is immune to discourses of personal responsibility. Throughout our time together, she often joked about how she was probably exacerbating her pain by not losing weight, or not following a restrictive diet. She also engaged in alternative discourses of personal responsibility. Lucy's understanding of ankylosing spondylitis as hereditary has altered the possible futures she sees for herself. Before being diagnosed with ankylosing spondylitis, Lucy was not sure if she would like to have children in the future. Since being diagnosed, she has decided that it would be irresponsible of her to have children knowing she could pass on ankylosing spondylitis, particularly since she has experienced the pain and suffering associated with it firsthand. She does not feel any resentment towards her father for likely passing the HLA-B27 gene onto her because he fulfilled his 'genetic responsibility' (Novas & Rose 2000, p. 487) by being screened for the gene and was told he did not have it. In a related way, Lucy is enacting her own genetic

responsibility by using the information she has about her genetic risk to make what she feels is an informed decision about whether or not to have children. Understanding her disease in this way means Lucy does not see ankylosing spondylitis as something she was responsible for getting, but she certainly sees it as something that she has a responsibility not to pass on to potential offspring.

Kate also understands autoimmunity as having a genetic component, at one point telling me ‘all of autoimmune is genetics’. This adds to Kate's other understandings of autoimmunity as a systemic self-attack, as the product of stress, and as something that is triggered by particular anthropogens, demonstrating how understandings of autoimmunity are multiple and fluid, even for an individual. Kate has other family members with ADs, including her mother and parents-in-law; however, this has not led to reciprocal care. The same can be said for Lucy. Although she shares a diagnosis with her paternal uncle, she tells me that it has not particularly changed their relationship, and she would not consider him a source of support. Kate often feels that her family members that also have ADs do not understand her experience, particularly the complexity and unpredictability of her illness, and the importance to her of maintaining strict dietary and supplement regimes. This further demonstrates how a shared diagnosis is not necessarily enough to foster reciprocal care. Of six women who had family members with ADs, Daisy was the only one who expressed having a supportive relationship with a family member with the same illness. As well as providing an avenue for reciprocal care, sharing a diagnosis with her sister helped Daisy to make sense of her own diagnosis as something hereditary. Although a shared autoimmune diagnosis does not necessarily equate to shared experiences and support, the understanding that autoimmunity is hereditary can help women to make sense of their illnesses.

Discussion

Like many illnesses, there is no singular meaning of autoimmunity among the women in my study. Women drew on different meanings at different times, often integrating their own life stories with biomedical understandings of autoimmunity to make sense of their experiences. This helps women to make sense of their diagnoses, but in some instances also helps them to make sense of difficult or stressful periods

in their lives. While some women leaned towards one or two key understandings of autoimmunity, others were engaged in a range of different meaning-making processes. I have used Kate as an example of this throughout this chapter. She draws on multiple understandings of autoimmunity, at different times emphasising autoimmunity as a biomedical disease, as the body attacking itself, as a systemic physiological issue, as embodied stress, as triggered by environmental pollutants and as hereditary or genetic.

Embedded in all of these meanings is an understanding that responsibility for the onset and management of autoimmunity lies within the individual. This might be, for example, because someone exposed themselves to pesticides, did not do enough to manage stress, or because their own body is perceived as attacking itself. Regardless of any negative impacts related to personal responsibility discourses, each woman must negotiate her illnesses within a system that values individual responsibility and devalues and moralises people and behaviours that are perceived as contrary to this. Women often find some comfort and agency in understanding their illnesses through this lens, even if this also means accepting self-blame. In this way, women also reproduce expectations of personal responsibility. This is quite clear in Kate's attitudes towards illness management, and towards people who she moralises as failing to engage in responsible health practices such as diet control. In their study of Australian women with breast cancer, Gibson et al. (2015, p. 142, emphasis in original) similarly found that women often internalised individual responsibility discourses and that some felt empowered by accepting responsibility for their illness, encouraging other women to 'take *ownership* of *your* condition.' As discussed throughout this chapter, however, these discourses also act to obscure structural factors such as environmental pollution and poverty that can significantly influence women's illness experiences. In saying this, I recognise that many behaviours encouraged through personal responsibility discourse can be helpful. Kate, Harriet, Ellen, and Jennifer have all found at least some symptom relief by altering their diets and Emily and Lucy both find that exercise helps, at least momentarily, to relieve some of their pain. Despite this, personal responsibility discourse can place an added burden on people who are already struggling with illness, at the same time as obscuring the structural factors that may be implicated in autoimmunity.

Many of women's understandings of autoimmunity filter through to how they approach the 'responsible' management of their symptoms, as well as their illness experiences more broadly. This included managing current symptoms, managing the future threat of illness, and managing the past. Strategies for managing illness in the present included the use of medication, dietary modifications, and stress minimisation. Strategies for minimising the threat of flares or new diagnoses in the future included deciding not to have children, reducing exposure to anthropogens and, again, minimising stress. Finally, women attempted to manage the past, including dealing with issues of past trauma that they linked to their autoimmunity, through minimising stress in the present. Framing women's attempts at illness management in this way highlights some important implications for the care needs of women with ADs. While the use of particular forms of care to manage the present is expected, the above examples show that women with ADs also sometimes need to manage their pasts and futures to manage their illnesses, pointing to the importance of having accessible care systems in place to support this.

CONCLUSION: LIVING WITH UNCERTAINTY

In this thesis, I have examined three key phases of the illness experience of women with ADs, including how women with ADs find a diagnosis, negotiate care following diagnosis, and make sense of autoimmunity, with attention to how moralisation and identities intersect with these experiences. In doing so, I have used a framework of care to explore women's needs and experiences, including the absence of care and how women negotiate access to the care they need. Here, I continue to draw on these three phases to summarise my findings. In doing so, I consider how biomedical attempts to measure suffering complicate women's experiences in these phases, often creating barriers to care, as well as how women enact agency as they negotiate care. While the uncertainty around autoimmunity contributes to a lack of suitable and available care, it also creates space for women to exercise agency in how they respond to their symptoms and then diagnosis. This includes through normalising and absorbing symptoms into their identities, creating new identities, developing their own understandings of autoimmunity, and fighting for the care they need. Here, I refer to agency as the 'socioculturally mediated'(Ahearn 2001, p. 112), 'intentional and motivated capacity to act' (Hay 2010, p. 260). The emphasis on agency being socioculturally mediated is important because, although the uncertainty of autoimmunity can create more space for agency, how women enacted that agency was shaped and constrained by moralisation. I consider these themes through each illness phase, with women experiencing uncertainty related to undiagnosed symptoms, accessing care after diagnosis, and understanding the meaning of their autoimmunity. In each case, although uncertainty complicated their experiences, the women in this study were able to harness it to have more agency in how they responded.

Illness phases

Women's experiences of autoimmunity included three different phases of illness. These included the diagnosis process, being diagnosed with an AD, and life with autoimmunity**.** While I present these as linear phases here, the uncertainty of

autoimmunity means this is not always the case. Autoimmunity is also often not confined to a single diagnosis, with some women being diagnosed with multiple ADs, and others living with the 'embodied risk' (Panter-Brick 2014, p. 437) of developing additional ADs. Thus, women can shift backwards and forwards through these phases, depending on the specific manifestation of their illness and their doctors' interpretations of their clinical markers. They can also occupy multiple phases at once, learning to live with a diagnosed AD while new or additional symptoms remain unexplained. What is common to each phase is elements of uncertainty that often mirror the biomedical uncertainty that continues to surround autoimmunity. This includes, for example, uncertainty about what symptoms mean, particularly for those who experience a prolonged diagnosis period; uncertainty about how women will access the care they need, despite having a diagnosis; and uncertainty about the causes, and by extension meaning of autoimmunity.

Phase one: Diagnosing autoimmunity

In the first phase, women faced considerable uncertainty in the care they received and the progression of their symptoms, with disconnected care, disbelief, and neglect delaying diagnosis. For some women, this was exacerbated by their regionality, particularly where choice of specialists and access to more than one GP was limited. Women were also sometimes complicit in this uncertainty, delaying help-seeking and unwittingly contributing to the fragmented care they received by visiting different doctors when symptoms worsened or new symptoms arose. These responses were often linked to women's identities. Chronic illness can threaten identities and in the absence of a diagnosis, women often attempted to normalise or ignore their symptoms, explain them away as something that is expected (e.g. due to ageing), or decide that they just have to 'get on with things' despite their symptoms. This may be linked to stoic attitudes to health and illness that are common in regional Australia. Similarly, women sometimes attached their symptoms to socially valued identities as a way to explain them, such as that of a busy mother or student. Doctors often triggered or reinforced this approach to symptoms, dismissing women's concerns, refusing to believe their suffering was real, and making cruel comments about women's weight. Moralisation also impeded diagnosis as doctors harnessed personal responsibility discourse to blame women for their symptoms, in the absence of doctors' own understanding of what was wrong. This was a common

and traumatic experience for the two women who had encounters with doctors who judged them as being overweight and blamed them for their symptoms as a result, positioning them as undeserving of care.

These experiences were often compounded by the privileging of clinically measurable suffering over women's lived experiences, leaving women vulnerable to worsening health outcomes. With the exception of those who were completely denied care, women typically went through clinical testing to aid diagnosis, determine illness severity, and guide treatment decisions. This is something that is expected, and where this does not occur during the diagnostic process women can experience this as a lack of care, since clinical testing tended to be interpreted as a sign that doctors believed women's accounts of their symptoms. Not everyone is afforded this form of care, however, with some women's symptoms dismissed without testing and other's denied access to testing because certain diagnostic technologies do not accommodate diverse bodies. This led to a variety of responses, including 'doctor shopping' and wondering if symptoms were perhaps imagined, all of which can contribute to delaying diagnosis.

To cope with their symptoms and the difficulties associated with obtaining a diagnosis, women enacted agency to normalise and absorb their symptoms into their existing identities. This acted to protect those identities even where this was detrimental to their health. Normalising and absorbing symptoms into their identities may have been more difficult had there been more certainty in the explanations for their symptoms. While the women in my study had varied identities, their stories demonstrated the cultural value associated with being stoic, productive, active, independent, and, for those with children, active and caring mothers. In this sense, women's identities, and their desire to protect them, were inextricably linked to the moral value placed on these attributes, which were at times reinforced by the culture of the regional areas in which women lived. While there is, of course, more to women's identities than these attributes, it is possible that these particular identities came to the fore during our interviews because these were the ones most directly threatened by their ADs. Despite their illnesses, women often prioritised the performance of these culturally valued identities as a way to cope in the absence of a diagnosis. This expression of agency was shaped by moral expectations to remain

productive, despite illness. Women 'kept going' regardless of the consequences for their health, because this is what is expected of those who are ill. To stop or rest for an extended period risks social delegitimisation (Hay 2010, p. 270).

These responses to illness reflected internal and external expectations for those who are ill to 'restore normalcy' (Becker 1998, pp. 45-6), where 'normalcy' predominantly means retaining valued identities and the activities associated with them. Because health and illness are significantly moralised in Western cultures, the onset of women's symptoms and realisation that they are not going to resolve can be interpreted as a point of moral breakdown, where, similarly, there is an expectation to restore a sense of normalcy (Zigon 2007, pp. 139-40). Thus, a primary care need during this first phase was care to help retain those identities. In choosing to keep going despite their symptoms, women engaged in often contradictory acts of self-care aimed at protecting their identities at the expense of their health. At the same time, women still required care more directly related to their symptoms, including understanding from family members, practical help at home, being listened to and believed by doctors, and receiving an explanation or diagnosis for their symptoms. This need to protect identities by normalising, ignoring, or dismissing symptoms and having these strategies reinforced by doctors who similarly normalise and dismiss symptoms can leave women with undiagnosed ADs in prolonged, sometimes decades-long, periods of ill health.

Phase two: Negotiating care for autoimmunity

While the first phase was characterised by attempts to retain valued identities, the second was characterised by the creation of new identities and attempts to mitigate the impact of chronic illness on existing identities. In some cases, this was necessary for women to access peer support in regional areas where this would otherwise be unavailable. It also became important for women to address what their illnesses and associated symptoms meant for their lives, particularly in the face of uncertainty in accessing the care they needed. Women enacted agency in various ways in response to these challenges, in some cases absorbing their illnesses into their existing identities and using them to reinforce their moral worth as productive people. This included being active in the organisation of peer support groups as a

means of maintaining a sense of productivity. Women also created new illness identities, often at the same time as they aligned their illnesses with their existing identities. In some cases, these identities were linked to a single diagnosis, while in others the meaning of shared experience expanded into broader and more encompassing identities as women with an AD.

In this phase, women also enacted agency to protect existing identities, for instance, fighting to access financial care that would help them retain identities as independent adults. The particular agency women enacted, however, was shaped by a desire to maintain positively moralised, and thus socially valued, identities. In contrast to the first phase, this agency occurred through diagnosis, rather than in an attempt to normalise symptoms. This fluidity in illness identities, which mirrors the fluidity of identities more broadly (Goffman 1990 [1959]; Taylor & Spencer 2004, p. 4), allowed women to protect against threats to their existing identities while also facilitating access to local peer support that would have otherwise been unavailable.

More apparent than in the first transition, was the impact of women's illnesses on their social worlds, particularly their relationships with family and friends. For some, a chronic diagnosis led to the fracturing of friendships that were formed and sustained based on being able to actively participate in shared hobbies. For others, illness solidified their existing relationships, as partners and families drew together to provide, fight for, and support women to access care. Women's partners and families often did also support them in the first phase, although this was not everyone's experience. For instance, Ellen and Kate's husbands have supported them through their symptoms and advocated for them when faced with less-than caring doctors. Conversely, Jennifer told me that her husband did not have much understanding of, or consideration for, her symptoms until he attended a scleroderma support group meeting with her and listened to other people's experiences. Where a diagnosis challenged women's relationships with others, being able to access peer support became particularly important.

In response to the challenges diagnosis presents to social worlds, and the continued challenges chronic illness poses to identities, women articulated a range of care needs in this second phase. These included local, face-to-face peer support;

practical support, such as help with domestic duties and transport; financial support; and effective treatment. While clinical testing was experienced as a form of care in the first phase, in the second and third phases it became apparent that it can also facilitate the denial of effective treatment and delegitimisation of women's suffering. When prescribing medication to treat autoimmunity, the type and dosage of medications available were often dependent on disease severity, with severity typically determined by clinical markers. This approach fails to consider women's lived experience of autoimmunity and ignores suffering that is not necessarily visible physically or through clinical markers, such as pain, fatigue, and significant identity challenges that can leave women at the risk of depression. In Lucy's case, the denial of effective treatment based on clinical markers left her suicidal. This reflects the more general privileging in biomedicine of the clinically observable, and thus 'objective' or 'scientific', over the subjective (Cassell 1999, p. 533; Good 1994, p. 8), as well as the primacy of imaging technologies that divorce people from their bodies (Samson 1999, p. 16). Such technologies 'reconfigure' suffering people into bodies represented through 'landscapes, graphs, maps and colour resonates' (Samson 1999, p. 16). Were approaches to care available that considered these types of clinical markers alongside the lived experience of illness and subjective accounts of suffering, it is perhaps more likely that effective treatment would be made available to women with ADs sooner, preventing additional adverse health effects. While there were no examples in my study where women's subjective suffering was considered equally as important as clinical markers, in encounters where women had a positive experience with a doctor, this was always because they felt that they were listened to, believed, and had their explanation of their suffering taken into account when determining a diagnosis or treatment options. This reinforces the importance of adopting more holistic approaches to care (Allen et al. 2015, p. 53) that embrace women's accounts of illness, rather than ignoring them in favour of clinical markers that do not necessary reflect lived experiences of suffering.

Surprisingly, despite having a diagnosis women continued to face delegitimisation and as such their care needs were often also shaped by the need to have their suffering acknowledged, heard, and legitimised. I had expected that women's care needs during this phase would differ considerably from those in the first, but the relative lack of acknowledgement and legitimisation women

experienced despite being diagnosed (i.e. biomedically 'legitimately' suffering) meant that those same needs, and the effects of moralisation on women's identities, tended to carry through to the second phase. Thus, being denied care, such as practical and financial support, has implications for day-to-day life but is also an assault on women's identities, feelings of legitimacy, and sense of being deserving of care. In response to these challenges, women often had to navigate this by engaging in additional labour to access the care, usually while incredibly ill, to access the care they need. They created their own peer support groups, worked to 'prove' how sick they were, and fought for access to financial support.

In contrast to the first phase, the presence of a diagnosis opens up new pathways for accessing care beyond symptom management; however, as diagnoses intersected with moralisation, barriers to accessing care are simultaneously created. Here, the relative uncertainty and lower-prestige that tend to characterise ADs seem to create barriers to receiving the care and legitimacy that a diagnosis is typically promised to bring. This creates an artificial moral hierarchy that determines who is most deserving of care. Thus, what became key in this second phase were the tensions between the perceived biomedical and social significance of a diagnosis, the paucity of care actually delivered, and the labour women often have to go through to access the care that is available or create the care environments they need.

Phase three: Life with autoimmunity

In the third phase, the biomedical uncertainty around the causes of autoimmunity provided space for women to develop their own understandings of autoimmunity that made sense to them in the context of their life stories. In doing so, they often developed multiple, overlapping understandings of autoimmunity to counteract the moralisation they faced and integrate their illnesses into their identities and life stories. For instance, for those who experienced difficult childhoods, explanations focusing on stress as a trigger made the most sense, while others focused on environmental and hereditary causes. These explanations were not mutually exclusive, with women often drawing on multiple understandings to make sense of their autoimmunity. Explanations were also fluid, with women drawing on different explanations depending on the context of a conversation. This, again, reflected the fluidity of identities more broadly, how those are connected to a

consistent narrative self (Flanagan 1998, p. 66), and how that narrative self is maintained in the face of illness through meaning-making processes (Barker 2002, p. 282; Ewing 1990, pp. 258-9). For instance, environmental causes were often emphasised when discussing changes women had made to their diets and household products, while stress tended to be emphasised when discussing women's early lives. What was common among explanations for autoimmunity were how they were imbued with personal responsibility discourse. Women tended to identify how their own actions may have contributed to their illnesses rather than considering the implication of structural issues over which they have little, if any, control. The way women construct their understanding of autoimmunity then contributes to shaping their care needs and management of their illnesses.

Women's understandings of autoimmunity shaped how they managed their illnesses through different acts of self-care. For example, those who understood autoimmunity as being triggered by stress placed more importance on managing and minimising stress to prevent flares. An understanding that autoimmunity has environmental triggers often led to dietary changes and the swapping out of common cleaning and beauty products with those perceived as 'natural' and therefore safe. In cases where autoimmunity was considered hereditary, management strategies tended to remain within the biomedical, such as adhering to medication regimes. Often, of course, women's overlapping understandings meant that they adopted self-care strategies across all three categories. Thus, the ambiguity inherent in autoimmunity and the related fluidity in explanations of its cause meant that women negotiated and accessed care in a variety of forms. This points to the importance of attending to women's understandings of autoimmunity when identifying care needs.

In considering the care needs of women in this phase, I had again anticipated that women would no longer face the delegitimisation they experienced before diagnosis. This was not the case. Despite their diagnoses, women continued to experience delegitimisation, disbelief, and discrimination, in some cases due to the lack of awareness of ADs in the community. For example, when explaining her illnesses to a neighbour, Jennifer was told that the idea that her body could attack itself was 'stupid.' Because of this, women's care needs in this phase reflected an amalgamation of previous care needs, with the addition of more specific self-care

strategies. In each illness phase, an examination of how women enact agency highlights the care that is most important to them, while also illuminating the importance of agency for care. This was enabled by a focus on care across women's lifetimes with autoimmunity, which adds to approaches that concentrate on daily care practices (Buch 2015, p. 279; Kleinman 2009; Mol 2008). Where care is otherwise unavailable, agency becomes an important vehicle for women to access the care they need. It can also allow women to maintain socially and morally valued identities, which is important across all three illness phases.

Agency, relationality and care

While I have focused more heavily in this thesis on women's individual, rather relational, experiences with ADs, this is not to suggest that they always enacted agency or sought care independently. Care is relational (Heinemann 2014; Sand Andersen et al. 2020; Thelen 2015, p. 509), and my study supports this while also adding a layer of understanding to how agency and the relational properties of care interact. Women's agentic responses to their symptoms and diagnoses were often intertwined with their sense of responsibility for caring for others, particularly their children and spouses. Thus, their decisions to keep going despite their illnesses were also an avenue through which they could retain their ability to care for their families and, perhaps, reduce the burden that illness can create (Heinemann 2014, p. 67).

This can position women's care choices in some contexts as 'part of a moral orientation toward others' well-being' (Heinemann 2014, p. 68). This was the case for Emily, whose distressing and illness-worsening fight for financial support was as much about retaining independence from her parents as it was about maintaining some sense of stability and security for her husband and children in the wake of her terminal diagnosis. Another aspect of this relationality, however, involves supporting women's agency, rather than, or in addition to, traditional 'caregiving' practices (Tronto 1993, p. 107), such as administering medication or providing personal care. This is demonstrated when Emily's mother supports her fight to access financial support, accompanying her to appointments and advocating on her behalf when Emily could not do so herself. Thus, women's moral obligations to others can create

demand for particular forms of mutually beneficial care, with women acting simultaneously as both caregivers and care receivers as they enact agency to access care for both themselves and others.

Attention to how agency intersects with care also highlights the tensions in care outcomes for women, illuminating an alternative understanding of self-care. Self-care strategies are commonly underpinned by moral imperatives to either actively prevent illness or manage illness responsibly (Clarke & Bennett 2013, p. 212; Guell 2012, p. 518). Common self-care practices include restrictive or modified diets, exercise regimes, complementary and alternative medicines, meditation, and relaxation techniques (Clarke & Bennett 2013, p. 212). For the women in my study, dietary modifications, home remedies, essential oils, and homemade cleaning products were all important forms of self-care, particularly after receiving their diagnoses. Dietary modifications were also important for some before diagnosis, as they engaged in this form of self-care in the absence of effective care from their doctors. As described in the first illness transition, however, women often prioritised the protection of their identities in acts of care that were beneficial for their sense of self at the expense of their health. This form of care — the protection of identities — is as much a form of caring for oneself as it is a form of caring for others. This is because protecting their identities meant that women were often also protecting their ability to continue to care for others. The fact that this often occurred at the expense of women's health does not call into question whether this is still care, since care does not always have exclusively positive outcomes (Garcia 2010, pp. 121-8; Stevenson 2014, p. 3; Thelen 2015, pp. 504, 5, 8). Rather, it highlights women's priorities for care when symptoms remain unexplained or undiagnosed and how those are inevitably tied to their obligation to care for others. This particular form of self-care also carries through the second and third illness phases, in concert with biomedical treatment and other forms of self-care. This points to the importance of having care available in response to illness, and not just specific diagnoses. Without this, women are often left to engage in difficult balancing acts of care, at the expense of their health, as they attempt to maintain morally valued identities and meet their obligations to others.

Diagnosis and care

The illnesses and experiences of the women in my study were diverse; however, they all shared common care needs that transcended diagnostic boundaries. These also largely transcended women's regionality, with key themes such as diagnosis, ambiguity, identity, and moralisation emerging as more significant than regionality. These themes and their related care needs reflect those that women prioritised in their diagnosis stories and form an important contribution of this research. These included being listened to and believed, having their symptoms taken seriously, including through investigation via clinical tests, and having their suffering legitimised, including through a diagnosis. Women need access to effective treatment, financial, and practical support. They require care to manage the identity struggles associated with chronic illness, including through peer support, counselling, and related forms of care (such as practical support) that can help them to retain valued identities. Care needs also include the use of self-management strategies such as adjusting diets and minimising exposure to environmental pollutants and stress. While women often faced barriers to accessing these forms of care, either because their symptoms were undiagnosed or because their diagnosis did not facilitate access, I argue that, with the exception of medical treatment (i.e. the use of prescription medications), none of these forms of care should be restricted to particular diagnoses. While diagnosis-specific care is important, rethinking the dependency of care on diagnosis would facilitate better access to care for women with diagnosed and undiagnosed ADs. This is particularly important in regional, rural, and remote areas where disease-specific care for ADs is typically unavailable, but also transcends geographic boundaries, with improved access to care also possible for those with poorly understood or rare illnesses. This should focus on needs in response to illness, rather than diagnosis, which requires a more equitable understanding of who is considered deserving of care. This is crucial since, as Emily's story shows, an absence of care can be fatal.

The women in my study have demonstrated through their agency that it is possible to facilitate needs-based care by decoupling care from diagnosis. For instance, they have created peer support groups based on more encompassing understandings of suffering. For some, needs-based care might simply mean

symptom management. For others, it might include support to navigate threats to their identities in a way that does not compromise their health. A needs-based approach to chronic illness care should also incorporate broader conceptualisations of care, including caring for identities and being able to care for others. Any alternative approach to care must be underpinned by a willingness and ability to listen to women's stories and concerns without judgement and to acknowledge their suffering. This can occur as an act of care in itself, and also through other acts of care, such as investigating rather than dismissing symptoms. Needs-based models could also better account for the uncertainty that surrounds autoimmunity and the availability of care, and this could extend to other poorly understood and rare illnesses. Shifting our understandings of what counts as care, who is deserving of care, and how care could be uncoupled from diagnosis would contribute to creating environments where women with ADs are more likely to have access to the care they need.

Future directions

Further research is required to identify how needs-based models of care can be developed and implemented in both medical and non-medical settings. This should include models that do not require significant labour from those who are already ill. Because this study sampled women from regional Australia, further research that included urban and remote populations, children, and other genders and ethnicities would also be beneficial, as would international comparisons. This may lead to new insights into how moralisation in autoimmunity is experienced.

Adopting approaches that consider the experiences of those in women's care networks, such as family, friends, and healthcare providers in more depth would also illuminate discrepancies between a care provider and care receiver's perception of the quantity and quality of care they are giving or receiving (Jacobson 1987). I had initially intended to interview those in women's care networks; however, time, resources, and my own health constraints soon made it apparent that this was beyond the scope of this project. Since identity involves both a projection of oneself to others, as well as the reception of that projection by others, it would also be beneficial to understand how participants' identities are received by those in their

networks. In the context of morality, the way a woman's network moralises their illness and its management can affect how women view and respond to both their illness and their sense of self. This is not to suggest that women's experiences of these cannot be collected through their own narratives. Many women in my study had stories about having their illnesses moralised and the use of a life story approach did provide some access to understanding the perspectives of those in women's networks. However, including those in women's networks as formal participants could provide an extra layer of nuance and understanding.

Research with a dedicated focus on autoimmunity and comorbidity would also be beneficial, particularly as ADs tend to co-exist, and those with multiple chronic conditions are at increased risk of severe illness, disability, poverty, marginalisation, and death (Manderson & Warren 2016, p. 4). This may also lead to insights into how the experience of moralisation may differ for those facing the complexity of managing multiple chronic conditions.

Finally, further research on autoimmunity as a category of disease, with a focus on a political economy of autoimmunity, would likely shed additional light on care needs and barriers and would complement the lived experience approach taken in this thesis. This is particularly important as the incidence of ADs has continued to increase globally, particularly in 'rapidly developing countries' (Bach 2018, p. 06). At the same time, ADs continue to disproportionately affect women while women continue to be subject to routine sub-standard care.

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APPENDICES

Appendix 1: Ethical approval

OFFICE OF RESEARCH
Human Research Ethics Committee
PHONE +61 7 4687 5703| FAX +61 7 4631 5555
EMAIL human.ethics@usq.edu.au

UNIVERSITY OF SOUTHERN QUEENSLAND

2 June 2017

Ms Leith Heyman

Dear Leith

The USQ Human Research Ethics Committee has recently reviewed your responses to the conditions placed upon the ethical approval for the project outlined below. Your proposal is now deemed to meet the requirements of the *National Statement on Ethical Conduct in Human Research (2007)* and full ethical approval has been granted.

Approval No.	**H17REA068**
Project Title	Women, autoimmunity and support worlds: Exploring identity, gender and moralisation in regional Queensland
Approval date	2 June 2017
Expiry date	2 June 2020
HREC Decision	**Approved**

The standard conditions of this approval are:

(a) Conduct the project strictly in accordance with the proposal submitted and granted ethics approval, including any amendments made to the proposal required by the HREC
(b) Advise (email: human.ethics@usq.edu.au) immediately of any complaints or other issues in relation to the project which may warrant review of the ethical approval of the project
(c) Make submission for approval of amendments to the approved project before implementing such changes
(d) Provide a 'progress report' for every year of approval
(e) Provide a 'final report' when the project is complete
(f) Advise in writing if the project has been discontinued, using a 'final report'

For (c) to (f) forms are available on the USQ ethics website:
http://www.usq.edu.au/research/support-development/research-services/research-integrity-ethics/human/forms

Samantha Davis
Ethics Officer

Appendix 2: Recruitment flyer

Are you a woman with an autoimmune disease?

I am seeking participants for my PhD project:

Women, autoimmunity and support worlds: exploring identity, gender and moralisation in regional Queensland

The purpose of this project is to understand the life stories, illness experiences and support experiences of women with autoimmune diseases in regional Queensland in order to identify how support systems can be developed or enhanced to better suit their needs. The project also aims to understand how identity, gender and moralisation influence these experiences.

Participation will involve a number of in-depth interviews over the course of 12 months, as well as some optional participant observation. This will involve me observing and participating in some of your everyday activities to gain a more in-depth understanding of your illness and your support needs and experiences. Please note that you do not need to be involved for a full 12 months in order to participate.

If you are a woman who is aged 18 years or older, has an autoimmune disease, and currently resides in the Toowoomba or Southern Downs regions I would love to hear from you. Women who have multiple autoimmune diseases, or other chronic conditions in addition to an autoimmune disease, are encouraged to participate.

For further information on the project, including how to participate, please contact Leith Heyman on 0400 068 471 or (07) 4631 2218, or email leith.heyman@usq.edu.au

All enquiries will be treated privately and confidentially

Human Research Ethics Approval Number: H17REA068

Appendix 3: Consent form

University of Southern Queensland

Consent Form for USQ Research Project Interview

Project Details

Title of Project:	Women, autoimmunity and support worlds: exploring identity, gender and moralisation in regional Queensland
Human Research Ethics Approval Number:	H17REA068

Research Team Contact Details

Principal Investigator Details
Leith Heyman
Email: leith.heyman@usq.edu.au
Telephone: (07) 4631 2218
Mobile: 0400 068 471

Supervisor Details
Dr Lara Lamb
Email: lara.lamb @usq.edu.au
Telephone: (07) 4631 1069
Mobile: 0407 694 580

Statement of Consent

By signing below, you are indicating that you:

- Have read and understood the information document regarding this project.
- Have had any questions answered to your satisfaction.
- Understand that if you have any additional questions you can contact the research team.
- Understand that the interview will be audio recorded.
- Understand that I will be provided with a copy of the transcript or summary of my interviews for my perusal and endorsement prior to inclusion of this data in the project if requested.
- Understand that you are free to withdraw at any time, without comment or penalty.
- Understand that you can contact the University of Southern Queensland Ethics Coordinator on (07) 4631 2690 or email ethics@usq.edu.au if you do have any concern or complaint about the ethical conduct of this project.
- Are over 18 years of age.
- Agree to participate in the project.

Participant Name	
Participant Signature	
Date	

Please return this sheet to a Research Team member prior to undertaking the interview.

Page 1 of 1

Appendix 4: Participant information sheet

University of Southern Queensland

Participant Information for USQ Research Project
Interview & Participant Observation

Project Details

Title of Project:	Women, autoimmunity and support worlds: exploring identity, gender and moralisation in regional Queensland
Human Research Ethics Approval Number:	H17REA068

Research Team Contact Details

Principal Investigator Details

Leith Heyman
Email: leith.heyman@usq.edu.au
Telephone: (07) 4631 2218
Mobile: 0400 068 471

Supervisor Details

Dr Lara Lamb
Email: lara.lamb @usq.edu.au
Telephone: (07) 4631 1069
Mobile: 0407 694 580

Description

This project is being undertaken as part of a PhD project that explores the support systems of women with autoimmune diseases in the Toowoomba and Southern Downs regions of Queensland.

The purpose of this project is to understand the life stories, illness experiences and support experiences of women with autoimmune diseases in regional Australia to identify how support systems can be better tailored to suit their needs. The study also aims to understand how identity, gender and moralisation influence these experiences.

The research team requests your assistance because it is important that support systems are developed based on the needs and firsthand experiences of women with autoimmune diseases. Your thoughts and experiences are vital for understanding how support systems can best be tailored to suit the needs of women with autoimmune diseases in regional areas.

Please note that you must be 18 years or older to participate in this study.

Participation

Your participation will involve participation in a number of in-depth interviews over the course of 12 months (2017-2018). Each interview will take approximately 1-2 hours of your time, depending on what you would like to discuss. The total number of interviews that occur over this period will also depend on how much of your life story you would like to share. Please note that you do not need to be involved for a full 12 months in order to participate in this study. The length of your involvement will depend on how much you would like to share, and how often you would like to meet.

Each interview will take place at a time and venue that is convenient to you.

Questions will cover topics such as significant life events; your illness experiences, including how your illness may have affected your identity and relationships with others, as well as how you manage your illness; your experiences of seeking or accessing support for your illness, and your support needs and desires.

Interviews will be audio recorded for research purposes only, but if you do not wish to be recorded please indicate this.

In order to gain an in-depth understanding of your experiences, your participation may also involve the researcher observing and participating in your day-to-day support activities over 12 months. For instance, the researcher may attend support group meetings or appointments with you; join online forums or support groups that you engage with; or participate and observe support-related activities that occur in your home. This will only occur with your permission and the times, locations and frequency that this occurs will be at your discretion. These interactions will not be audio or video recorded. Please note that this is an optional component of the study. You can participate only via interviews if preferred. If you do choose to participate in this aspect of the study, please note that you do not have to participate for a full 12 months. For instance, you may invite the researcher to attend only one support group meeting with you, or you may invite them to attend several meetings over the course of 12 months.

A third component of the study involves the researcher interviewing individuals in your support networks, based on your recommendation. Once again, this is an optional component of the study and will only occur with your permission. Your involvement in this aspect of the study will include you recommending people from your support networks who you feel would be suitable for one-on-one interviews with the researcher. The topics discussed in these interviews will include the person's understanding of your illness and the difficulties you may face, their own experience of your illness, and their experiences and thoughts on the provision of support for women with autoimmune diseases.

Your participation in this project is entirely voluntary. If you do not wish to take part you are not obliged to. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage. You may also request that any data collected about you be destroyed. If you do wish to withdraw from this project or withdraw data collected about you, please contact the Research Team (contact details at the top of this form).

Your decision whether you take part, do not take part, or to take part and then withdraw, will in no way impact your current or future relationship with the University of Southern Queensland.

This project will be carried out in accordance with the National Statement on Ethical Conduct in Human Research.

Expected Benefits

It is expected that this project will directly benefit you by contributing to a stronger understanding of the support needs of women with autoimmune diseases in the Toowoomba and Southern Downs regions. This understanding will provide a foundation for improving the support available to women with autoimmune disease in these areas, as well as other regional areas in Australia.

A summary of the results of the study will be provided at the conclusion of the study upon request.

Risks

There are minimal risks associated with your participation in this project. It may be emotional or difficult to revisit past events or experiences, however the topics discussed in interviews will be at your discretion. You will not be expected or encouraged to discuss any topics you do not feel comfortable discussing or that you find upsetting. You are free to withdraw or amend any statement made during interviews at any time. You are also free to end an interview at any time.

If you choose to participate in the third component of the study, which involves the researcher interviewing members of your support network who have been recommended by you, there is a small risk that a member of your support network may disclose information about your experiences that you would prefer not to disclose. This risk is considered small as members of your support networks will only be interviewed based on your recommendation and with your consent. The researcher will not discuss details of your own interviews with other participants. Members of your support networks will be reminded that they are not obliged to answer any questions that they feel may breach your privacy, and any interview segments that may breach the privacy of another participant will be removed from the data record. You will also be encouraged to discuss this process with the members of your support networks who you have recommended for interviews to ensure they are aware of any information you do not want disclosed in interviews. As part of this process, you will also have the option to view the interview schedule and veto any questions or topics you would prefer the researcher not to discuss.

Sometimes thinking about the sorts of issues raised in the interview can create some uncomfortable or distressing feelings. If you need to talk to someone about this immediately please contact Lifeline on 13 11 14. You may also wish to consider consulting your General Practitioner (GP) for additional support and/or referral services.

Privacy and Confidentiality

All comments and responses will be treated confidentially unless required by law.

- You will have the opportunity to verify your comments and responses prior to final inclusion if requested.
- Only the principle investigator will be able to access recordings.
- Recordings will only be used for research purposes.
- Data collected during the study will be published in a thesis, and may also be published in journal articles, books, reports or conference proceedings.
- Participants will not be identified in any publication. All identifying details will be replaced by pseudonyms or codes.
- Audio recordings will not be destroyed after the completion of the project, but will be stored securely in accordance with the University of Southern Queensland's Research Data Management policy.
- Data collected during the study will be retained for possible future use.
- You may still participate in the project even if you do not consent to be recorded.
- You may still participate in the project if you choose to be involved in interviews only.

Any data collected as a part of this project will be stored securely as per University of Southern Queensland's Research Data Management policy.

Consent to Participate

We would like to ask you to sign a written consent form (enclosed) to confirm your agreement to participate in this project. Please return your signed consent form to a member of the Research Team prior to participating in your interview.

Questions or Further Information about the Project

Please refer to the Research Team Contact Details at the top of the form to have any questions answered or to request further information about this project.

Concerns or Complaints Regarding the Conduct of the Project

If you have any concerns or complaints about the ethical conduct of the project you may contact the University of Southern Queensland Ethics Coordinator on (07) 4631 2690 or email ethics@usq.edu.au.