

Coping with Chronicity: Exploring women's experiences living with autoimmune diseases that fluctuate and flare

Tayhla Ryder

Masters of Research

Department of Anthropology, Faculty of Arts

9th October 2017

Macquarie University

Contents

Summary.....	3
Statement of Originality	3
Introduction	4
1. Through Sickness and Wellness	12
“It strains you as a person”	13
Double Lives	14
Living Wellness and Thinking Illness.....	16
2. Loss and Learning	20
Loss of Anticipated Future.....	20
Life on Hold.....	23
“A Well-Oiled Machine”	25
3. Control and Hope.....	29
Disease Management and Hope for the Future.....	29
Cutting Corners	33
Learning to Let Go	35
4. Silences and Stigma	38
The Burden of Proof.....	39
Guilt and Pity.....	41
“But you don’t look sick”	43
Conclusion.....	46
References.....	49
Appendix A – Ethics Approval Letter	55

Summary

This thesis examines the illness experience for Australian women with autoimmune diseases with a relapse/remitting or fluctuating disease course. Drawing on ethnographic interviews, I explore the impact of chronicity and the shifting between sickness and wellness on their lives. I address how participants responded to the disruptive force of disease onset and diagnosis, and their tactics to manage and seek control of their illness. In sum, I seek to demonstrate that the women's approaches to living with chronic illness are not static, but reflect the shifting grounds of their disease experience, changing sense of self, and support received from others.

Statement of Originality

This work has not previously been submitted for a degree or diploma in any university. To the best of my knowledge and belief, the thesis contains no material previously published or written by another person except where due reference is made in the thesis itself.

(Signed) _____

Date: 09 / 07 / 17

Introduction

In early 2016, as graduation ceremonies were being held on the other side of campus, I overheard a young woman talking to her friend as we waited in line at a café. I had missed their earlier conversation, but the following remark caught my attention.

...everyone around me is getting in relationships, moving out, getting jobs and I am just stuck doing illness

What did it mean to be “stuck doing illness”? In comparison to their peers whose lives were undergoing change, the speaker said they were stuck. Yet the verb ‘doing’ implied an active involvement with illness as a *task*, quite different from the representation of illness as a passive state.

Her words sparked my research interest in the experiences of young people with chronic illness. I wanted to understand more about how chronic illness, and the work it entails, impacted the everyday lives of young adults and how cultural assumptions about youth, health, and sickness might arise in specific ways during this stage of life. Young adults are typically thought to be “too young” to be chronically ill, to be sick for the rest of their lives (Wendell 2001). The cultural images of what kinds of people get sick makes it difficult for young people to convey the reality of their illness in the face of scepticism and stigma (Bury 1982; Micallef-Konewko 2013). I wondered if it affected how they thought of themselves in relation to their ‘healthy’ peers and if illness shaped how they imagined and planned for their future. I began my research with the aim of understanding how young people navigated their way from adolescence to adulthood with this additional aspect of their lives - an illness that will never go away.

Recent qualitative health research has begun to focus specific attention on the limits and borders of the concepts of ‘health’, ‘illness’ and ‘disability’ and illuminate the ‘third space’ between them (Jackson 2005; Lightman et al 2009; Orlando 2012; Stone 2005; Vick 2012). Both scholarship and everyday language make a clear distinction between disability and illness, but what is the relationship between these for people who are chronically ill?

The distinction between disabling chronic illness and ‘disability’ is a contentious one as there are multiple conceptualisations of the relationships between disability and the environment (G. Williams 1996). For Williams, there is “no neutral language to begin the process of discussing chronic illness and disability” (G. William 1996: paragraph 2) for it is a problem of representation. The disability rights movement has fought against the identification of disability with disease, as this would imply the need to prevent or cure disability (Wendell

2001). A separate model of 'impairment', as an abnormality in the structure or functioning of the body (WHO 1980), allowed for 'disability' to be spoken of in separate terms as a *social* phenomenon (S.J. Williams 1999). In this framework, the social model of disability, people suffer from structural inequality more than from the materiality of their bodies. This aligns with Herndl's assertion that disability is relational – constructed through a matrix of duration, discourse, agents, goals, and representation – with the body at the centre (Herndl 2005:594).

What then, of those who *do* suffer from their bodies? The experiences of the 'healthy disabled' have predominated in disability research while the 'unhealthy disabled' whose bodies are medicalised because of their suffering or who are disabled *by* sickness have been the domain of medical sociology (Wendell 2001). Research in medical sociology has examined chronic illness experience through frameworks of adaptation, identity transformation, and illness as biographical disruption (Asbring 2001; Bury 1982; Charmaz 1983, 1994, 1995; Sanderson et al 2011; S. J. Williams 2000). Disability and chronic illness have been the subject of several auto-ethnographies and personal accounts (Murphy 1987; Wendell 1996; Defenbaugh 2008). These works provide a reflexive account what it means – in the writers' own social contexts – to find oneself with an uncertain, ongoing chronic condition.

My work grows out of the literature in medical anthropology which focuses on the meaning of illness, how it is experienced, and on cultural healing practices (Young 1982; Good 1994). Kasnitz and Shuttleworth suggest that anthropology as a discipline has overly focused on the 'transformation' of healing (2004:142). This is an important point of difference in my research, as there is little to no expectation of a 'cure' or full return to health through healing practices in the case of chronic illnesses.

Chronic illness is an enormously broad term encompassing any range of conditions that last longer than six months and that lack a reliable cure. I limited the scope of this research to a subset of chronic illness: autoimmune disease, which are caused by the body's immune system attacking its own healthy cells as though they were foreign or diseased. I chose to focus my research on autoimmune diseases as they often emerge in late adolescence to early adulthood.

To narrow the avenues for participant recruitment, I selected a small range of diseases to focus on: Crohn's disease and ulcerative colitis (both inflammatory bowel diseases), systemic lupus erythematosus (also called 'lupus'), and multiple sclerosis (MS). As my research aim was to explore the experiences of young people with chronic illness, the specific symptoms and manifestations of these diseases were not the basis for their selection. However, a brief description of each disease is provided below.

- Crohn's disease is an inflammatory bowel disease that can affect any part of the gastrointestinal tract from mouth to anus, and can affect all layers of the intestinal wall. Ulcerative colitis is also an inflammatory bowel disease but it affects only the lining of the large intestine (Crohn's and Colitis Australia 2016).
- Systemic lupus erythematosus can affect almost any organ or system of the body, which makes it highly variable among those with the condition. Commonly affected organs include skin, kidneys, lungs, and heart (Australian society of clinical immunology and allergy 2016).
- Finally, Multiple sclerosis is characterised by lesions within the central nervous system (i.e. brain and spinal cord) caused by the immune system attacking and scarring it. These scars interfere with nerve impulses and, depending on where they are located, have a wide range of possible symptoms (MS Australia 2017).

Treatments for these diseases most often include immune suppressants and corticosteroids, often with severe side effects. Treatment must be ongoing to avoid relapse but even with treatment and monitoring people experience flares and fluctuations of the disease symptoms. These 'ebbs and flows' are often part of long-term conditions but this fluidity is obscured by the acute-chronic dichotomy (Manderson and Smith Morris 2010). In the case of multiple sclerosis, the degree of recovery after a varies between individuals but overall the disease is progressive over time (MS Australia 2017).

I recruited participants using respondent-driven sampling to minimise the pressure to participate. I posted introductory information about the research on the private Facebook pages of state-wide support groups and organisations. I decided to advertise the research outside of the medical system to distance the research from the 'medicalised' aspect of people's lives. Anyone who saw the online advertisement was interested in being involved was invited to contact myself directly. Those who contacted me were given further information about the aims of the research and how they would be involved if they chose to participate. This recruitment method was stipulated in the ethics application for this research and had been granted approval.

I aimed to recruit participants aged 18-30 years. I hoped that with this age range several participants would be in the process of 'transition into adulthood'. However, I was contacted by a number of people who were interested in participating but who, because of their age, fell outside the inclusion criteria for participants. Given that I had a limited amount of time to conduct my research and that responses to the advertisement had been few, I submitted an amendment to the ethics application and received approval to include participants up to the age

of 40. Another outcome of using respond-driven sampling was that all participants were women. To some degree this may have reflected the fact that autoimmune diseases disproportionately affect women. As a result, the role of gender in the illness experiences of these women formed a larger part of the data than initially anticipated.

The participants in this study were not intended to be a representative sample. The small number of participants allowed me to focus in greater depth on the meanings that each participant attributed to their illness and how they navigated living with chronic illness. In total, I completed 14 interviews with 10 participants. Table 1 provides general information about these participants.

Table 1. Overview of Participants

Pseudonym	Diagnosis	Age	Age and life stage at time of disease onset or diagnosis
Alice	Crohn's disease	25	17, in year 11 at high school
Selena	Crohn's disease	29	13, in year 7 or 8 at high school
Catherine	Crohn's disease	28	22, studying at university, living with family
Michelle	Crohn's disease	28	22, recently married and graduated from university
Amelia	Crohn's disease	38	17, in year 12 of high school
Emily	Ulcerative colitis	29	25, in long-term relationship, completed education and working full-time
Kelly	Multiple sclerosis	32	28, married with an 8-month-old baby
Madeline	Multiple Sclerosis	28	26, married with 4-year-old child, working fulltime
Nora	Systemic lupus erythematosus	33	22, living with family, studying at university
Karen	Systemic lupus erythematosus	35	25, living with housemates away from family, studying at university

I invited those that were interested to participate in semi-structured interviews, which were then conducted between February and April 2017. Most interviews were conducted in person at a place of the participant's choosing, although some participants had moved across the state and in these cases participated via telephone interviews.

My primary method was semi-structured interviews. While I started with a list of questions, I aimed to elicit an "illness narrative" (Kleinman 1988), that is, an account of the person's holistic experience of illness including how it impacts on their work or studies, how it intersects with their relationships, and how they have navigated healthcare providers and bureaucracies to seek diagnosis and treatment. Through the process of narrativisation, people attempt to make sense of their experience, recounting and connecting events, describing them

not only 'as they were' but as they were felt to be and imbuing the story with meaning (Good 1994:139, Kleinman 1988; Mattingly and Garro 200).

There are limitations to the use of illness narrative and my reliance here on interview data. What people do frequently differs from what they *say* they do. The ethics approval granted to this research allowed for participant observation in addition to interviews, but this was dependent on the preference of each participant. Ethnographic fieldwork with participants in their daily lives or in the contexts of support groups and meet-ups would have offered one way to balance this and to provide richer descriptive accounts of how people manage their illness (through medications, monitoring, appointments etc.).

However, I found that often my participants didn't want me to 'see' their illness. One participant told me outright that she would never let me or anyone apart her partner see her take her medication, which is injected, and other than that there was nothing to see. This idea that there was nothing worth seeing came up frequently as participants declined nearly all of my attempts to spend time with them outside of the context of a formal interview. This is a limitation of my research and I regret that I didn't have the skill, or perhaps time, to get to know participants well enough to spend time with them in a less formal manner.

My regret is balanced by the satisfaction that participants were able to take control of their engagement with the research. It is empowering for participants to not only talk about their experiences but to take control of the format in which they participate in the research. Although I had hoped to do participant observation, participants preferred only to do interviews – which allowed them greater control over the kind of personal information they revealed and gave me access to. As I later heard the ways in which many of the women strove to keep their illness in the backgrounds of their lives and identities, I wondered to what degree their decision to refuse me access to their daily life was motivated by this goal.

The interview questions covered a range of topics, but most were open-ended and respondent-driven to allow participants to speak about their personal experience in whatever way made sense to them (Levy and Hollan 1998). As a result, the questions were often changed or discarded as interviewees moved into unanticipated areas in response to questions, prompts, and their own interests. The planned questions attended to the following themes; a) their experience of disease onset and diagnosis, b) their sense of self in relation to chronic illness, c) their relationship to peers and family and, d) their thoughts and plans for the future.

Emily was the first woman I interviewed and before I even brought up the topic of age, she reflected on the significance of the timing of her disease onset and diagnosis, saying,

I think there are three things that getting diagnosed getting before and after can have a massive effect on... I got diagnosed when I was 25, so I was at the upper end of the typical 15-30. So, the big things for me were; I had already finished my education, that is huge, I could see how having [ulcerative colitis] or anything would really mess with that... I was in a long-term relationship already, I can see how that could really get messed with real quick. And I already had a stable job. So, I am really lucky with my timing

Emily pinpointed the issues I had been interested in since the start of my research, and yet they were not relevant for her. This was the first of many instances that demonstrated that many of the questions and areas of interest I brought with me to the field did not resonate for my participants. My questions about “becoming an adult” didn’t have a lot of meaning for people who became sick after finishing studies, gaining employment, or moving out.

In the anthropological tradition of inductive research, I sought to follow the interests of my research participants and not impose my predetermined notion of what my research project should discover. The directions that the participants took the interviews and the ideas and moments they spoke of with the most emotional intensity have become central to the development of my newer set of research questions.

When I began reviewing my notes and analysing the interview data, I was struck by the changing relevance and unsettled meanings attributed to illness by the women in their narratives. In one moment illness would be a mere afterthought or minor nuisance, and in the next be a source of suffering and distress impinging on all areas of life. The *changing* severity and impact of the diseases through flares and relapses clearly played an important part in how the women in this research both related to their illness and navigated their everyday lives, and this connected their experience across the different physiological impacts of the diseases. My new research aim was to explore what it meant for these women to be ‘ill’ or ‘well’ within chronic illness and how the fluctuation of illness impacted on their everyday life.

This research brings together the illness narratives of women with Crohn’s disease, ulcerative colitis, systemic lupus erythematosus, and multiple sclerosis to address these questions. Though these diseases vary between one another in significant ways, it is also vital to recognise that no two women even with the same diagnosis share the same experiences. What they have in common is the fluctuating nature of their diseases, which move unpredictably from acute symptomatic episodes to periods of no or few symptoms.

Toombs argued that it is vital to consider illness experience as a temporal event in the light of the horizon of the past and future. Illness, as a “present-now”, is made meaningful in its relation to past meaning and future anticipation (1990:238). In my research, I bring this

consideration to how the women characterise and respond to their current state of health, in the context of past experiences of illness and wellness as well as their anticipation (and hope) for future states.

In 2013 the first *Annual Review of Anthropology* piece to address disability as a central topic was published (Ginsburg and Rapp 2013). It highlighted that despite disability being one of the most fundamental forms of human diversity there has been a lack of explicit attention to it in anthropology (Ginsburg and Rapp 2013; Kasnitz and Shuttleworth 2001, 2004). My preparatory reading of the literature included work on disability because of the overlap with chronic illness in discussions of bodily impairment, stigma, self-identity, and the problem of invisibility or erasure. Due to the prevalence of disability in the literature, the term is used in this thesis when drawing on the findings of research with people with disabilities and when discussing issues of stigma and discrimination. However, no participants identified themselves by the term 'disabled' and as such I do not describe any participant as a person with a disability.

There is a growing body of literature on chronic illness stemming out of global and public health research (Manderson and Smith-Morris 2010; WHO 2011). This area of study investigates the impacts of health care disparities across regions and populations, considering how inequalities manifest in people's everyday lives and how structural forces shape health trajectories. Although the primary focus of my research is not to examine chronic illness through this framework, the impact of social determinants on health trajectories cannot be understated.

The socioeconomic circumstances of the research participants play an important role in their experience of illness. Most participants in this research project were middle class white women, except for one Chinese-Australian woman. In terms of education, all had graduated from high school and most had a bachelor's degree. Some explicitly referenced their education for giving them the skills to better understand and research their disease and the advice of their doctors, which in turn empowered them to advocate for themselves and make informed decisions.

All the women had had quick access to primary health care providers and, following a diagnosis, could access and afford appropriate treatment. Although most of their medications were subsidised through Medicare, a few women had to pay out-of-pocket for additional medication. The women who did not work were supported financially by their families and could rely on their partner's income. One woman with multiple sclerosis (MS) made a total permanent disability claim on her superannuation (i.e. her retirement savings), whilst another woman with MS received a disability pension. Family also played an essential part in helping to

look after children and assisting with household tasks, especially during extended hospital stays and flares. These familial and financial supports meant that the disruptiveness of chronic illness was mitigated to a degree and were one less problem the women were forced to face.

The first chapter of this thesis shall explore how participants experience illness and wellness and how both may coexist within the experience of chronic illness. Guided by the vast literature on the liminal experience of chronic pain, biomedically contested illnesses, and disability (Bruce et al 2014; Deegan and Willet 2001; Glenton 2003; Honkasalo 2001; Jackson 2005; Murphy et al 1988).) I anticipated that someone living chronic illness that ‘comes and goes’ would occupy a liminal state between sickness and health. Speaking with participants, I came to see a slightly different picture.

The second chapter focuses the capacity for chronic illness to upend an individual’s imagined future and ‘put the breaks’ on life, and in turn how participants found ways to re-establish a sense of control and a vision for their future. For some, this centred on learning to manage symptoms and cope with the illness while also striving to maintain one’s career - a respectable hallmark of ‘normality’ (Hay 2010) – which is enable in large part due to the invisibility of their illness. Therefore, in chapter 3 I explore the tactics women use for managing their fatigue and seeking to gain control over their bodies and lives. I also consider how a change in values against the cultural valorisation of action and productiveness may prove to be a rewarding avenue for women whose illnesses could not be contained and sidelined.

Chapter four focuses on the problems of disclosure and the invisibility of illness, as mentioned above. Many illnesses are non-apparent to external observers which enables a choice of whether or not to disclose one’s illness. However, disclosure is not as simple as “tell them or don’t tell them” but is continually having to be reconsidered and performed in multiple contexts over time.

This thesis examines how chronic illness and the shifts between sickness and wellness impact the everyday life of Australian women with autoimmune diseases. By looking across more than one kind of chronic disease, this research considers the commonalities within the illness experience for women living with diseases which fluctuate and flare. Their stories show how approaches to living with chronic illness are not static, but reflect the shifting grounds of their disease experience, changing sense of self, and support received from others.

1. Through Sickness and Wellness

The women whom I spoke with were all well at the time of our interviews, with the most recent flare-up being two or three months earlier in the case of one participant. It is important to bear in mind that it was from a position of wellness that these women spoke about their past experiences and anticipated futures. Narratives are always told from the temporal perspective of the present and present experience inflects how one apprehends the past (Ochs and Capps 1996:25). As Good writes, stories change as they unfold through time and “often maintain several provisional readings of the past and present” (Good 1994:144). I believe that the responses given in the interviews are shaped significantly by the prospects each participant saw for themselves given their current health/illness state (Mattingly and Garro 2000). Therefore, although this research does not focus narrowly on the experience of acute sickness, it is important to acknowledge that dimension of the women’s lives and examine how its recurrence shapes the overall experience of chronic illness.

In the biomedical model, autoimmune diseases are considered chronic because there is no projected future in which a patient will be disease-free. Though they can be treated, there is at present no cure for autoimmune diseases. However, the biomedical classification of autoimmune diseases as *chronic* does not imply that people living with them are constantly ill.

Disease is not equivalent to illness. Whilst ‘disease’ refers to a pathological state or abnormality of the body (Kleinman et al. 2006:140), illness is defined by Kleinman et al. as, “experiences of disvalued changes in states of being and in social function; the human experience of sickness” (2006:141). Individuals living with disease may not always experience sickness, as the disease is asymptomatic or the symptoms may not be experienced as abnormal or worrisome. Given that autoimmune diseases often have extended periods of remission or little symptoms, individuals are not always sick or perceive themselves as ill.

However, a simple coupling of relatively asymptomatic periods with ‘wellness’ and symptomatic episodes with ‘illness’ is reductive, as illness as a disvalued state of being and is not reliant on the presence of a sick body. In what ways does chronic illness go beyond immediate symptoms and manifest as a state of being? On the other hand, what may health or wellness mean beyond the absence of sickness? What exactly the terms ‘illness’ and ‘wellness’ mean for people who live *through* them recurrently, to draw upon Toombs’ emphasis on the temporality of illness (Toombs 1990:228), is the central question of this chapter.

“It strains you as a person”

Emily had a boisterous laugh that filled the room as we spoke over Skype. She sat in her living room, light from the window silhouetting her shape bundled up on the couch, while we talked for two hours about her life in the past few years. I had felt overly stiff and formal before the call, but Emily soon won me over with her frankness and warmth.

It strains your relationships, it strains you as a person, and if you can't - for lack of a better word - get your shit together, you know, you cannot function in all the other levels of life let alone the physical levels of life.

This was how Emily described her illness a year prior to our meeting. Her ulcerative colitis had flared severely and taken over her life in a way she felt utterly unprepared for. It was an episode that lasted 18 months and nearly ended with her bowel being removed, until a last-ditch attempt with a new medication was successful in getting the flare under control. During her flare, her ability to engage with the world was suddenly mediated by a body in pain and sickness.

Merleau-Ponty wrote that, “to be situated within a certain point of view necessarily involves not seeing that point of view itself” (1963:217)– and as such, our bodies as our means of being-in-the-world frequently recede from view. In everyday experience, the body is often absent from awareness (Kleinman 1988:45; Leder 1990). In sickness, the body reemerges, exerting a telic demand to be recognised (Leder 1990:77) and one loses “one’s normal occupancy of everyday reality” (Jackson 1994:215).

Since it is such an aversive and disruptive sensation, pain can create the sense that the (painful) body is happening *to* the self rather than *being* the self (Leder 1990:73-77). Leder suggests that in the case of pain that cannot be removed, the separation of the self from ‘it’ “yields some relief and reestablishes one’s integrity in the face of an overwhelming threat” (Leder 1990:77). Similarly, Jackson writes that, “something that can virtually obliterate consciousness of anything but itself... is clearly an ‘it’ existing apart from the self in some fashion” (Jackson 1994:206). Emily reflects this notion in her repetitive use of ‘it’ to refer to her flare, or more precisely, her ‘flaring’ body.

Just as pain and illness can alter our experience of space as “we are no longer dispersed out there in the world, but suddenly congeal right here” (Leder 1990:75), so to can it impact the experience of time. When I asked one of the younger participants to describe the time before diagnosis, they reflected that, “[it] is weird for me to remember because there are whole blank spaces and I sort of jump from thinking, ‘oh I felt really bad that day,’ then I don’t remember

anything in between and then I remember the next really bad day". This was not a unique experience, as many of the women had difficulty remembering and expressing what their illness had been like a few years prior, but could vividly recollect the times they had been hospitalised or been through a bad flare.

Leder argues that among the "amorphous time of health" the punctuation of illness comes to the foreground (Leder 1990:81). But this suggests that in chronic illness it is also moments of *acute* illness that stand out in memory. Reflecting on the comparison between the everyday and the worst moments of illness may shape how a person with chronic illness perceives the impact of the disease on their life.

Double Lives

I met Amelia on a sunny afternoon at an art gallery she had chosen as our meeting place. I had taken public transport across the city for nearly two hours to get there, but in planning for possible train delays I ended up arriving twenty minutes early. Amelia sent me a text to say to say she was on her way and soon after I spotted her outside the gallery, her daughter skipping in a tutu by her side and her husband – though on crutches – was just managing to keep up. I thought it ironic that her husband was the one visibly unwell, given that I was here to interview her about her chronic illness. Amelia was acutely aware of just how 'normal' she looked, in part because she put forward effort to make it so.

It really is that secret double life! I think it is perhaps unbelievable that someone could be being tube-fed one day and standing in front of a class the next –it does seem very surreal maybe?

What is even equally surreal – in May it's Crohn's and Colitis Awareness Month and I had organised a breakfast at a waterfront restaurant for our local support group, and it was a perfect day, sunshine, everybody came – it was brilliant and there is a photo of me sitting up and they published it in the magazine, of our little group, sitting up, 'this is what we did to recognise May' and it was that night at midnight I was on the tubes.

So, I've took a selfie of myself, I think the next day, and what is so funny is the difference between the two photos. This is 24 hours, not even, this was less than 24 hours and it's like – there's a tube coming out my nose, there's a bag of vomit that I'm holding, like is just hideously – disgusting, it's ugly, it's gross, it's messy, it's embarrassing, it's not nice – you know, I don't know if there is a nice disease out there but this is not it.

As she speaks her tone turns from quiet revulsion into open laughter.

There's nothing sexy about this, nothing sexy about any of it! Yeah, so not good. But, really, once you're back on your feet—well, a version of you is back on their feet, yeah...

She let the end of her sentence drift off. I find it is easier to imagine *two* of her than it is picture the one in front of me, so bright and quick to smile, hospitalised and intubated. I ask whether she ever forgets about being sick and before I can finish my sentence she hums “*mhmm!*” and begins nodding.

I do! I feel sad like I've been re-diagnosed sometimes, so—I've said that to my gastroenterologist, I think one of the last times I said, “this is going to sound ridiculous but I kind of forget that I'm sick until I end up in front of you again,” and I said, “and it makes me really sad”

Corbin observed that people with chronic conditions often only consider themselves ill when there is a high degree of interference with daily activities, or feel that they have lost control over their body or life (Corbin 2003:263-264). The recognition of oneself as sick only during acute phases reflects an approach to illness as an ‘interruption’ to one’s real life (Charmaz 1991:11-16). This approach is viewed by medical practitioners as evidence that a patient is in denial about their disease (Charmaz 1991:16). Amelia’s gastroenterologist responded incredulously, telling her, “don’t be ridiculous, of course you’re sick, you should be used to this by now, this is your whole life.” On the contrary, she told me,

When I'm well I am well, it's not like someone who is going through cancer treatment who is sick 24 hours a day, they have to give up their whole life—you're not like that, you're living a half-life—well, you're trying to live a full life and sometimes you're not living a life so maybe you're averaging 80%, I don't know, overall in five years.

Amelia’s self-correction that she is *not* living a half-life but living both a full- and non-life at once reflects her view of illness as a double life, rather than a liminal or adjusted one. The double life metaphor suggests multiple concurrent identities which Amelia shifts between; the ‘full life’ of wellness and ‘non-life’ of illness. In attempts to narrate ourselves, we may “multiply along dimensions as past and present, subject and ego... normal and aberrant” (Ochs and Capps 1996:22) and, I suggest, as healthy and sick.

Whilst Bury’s (1982) concept of ‘biographical disruption’ in which people with chronic illness adapt to re-establish a sense of continuity in their lives after the ‘disruption’ of illness may be useful to describe the onset of illness, it has limited application to the recurrence of acute episodes of illness. Rather than looking at someone’s life as a singular linear course

through time, we may consider how illness – particularly *recurrent* episodes of illness – may be felt as one dimension of experience running alongside ‘normal life’.

Researchers working with people with autoimmune diseases note how manageable flares or brief periods of hospitalisation were experienced as suspensions of normality rather than usurpers of it. Sanderson et al.’s (2011) research on women with rheumatoid arthritis found that those whose disease fluctuated resisted the ‘normalisation’ of being ill into their everyday life. Instead the women’s narratives were “dominated by the fluctuation between disrupted normality and normality” (Sanderson et al 2011:625). Similarly, Saunders describes the “ongoing cycle of recurrent biographical disruption and subsequent biographical reinstatement” reported by a young man who had been living with IBD for close to a decade (Saunders 2017:17). The biographical course in which wellness is the norm is ‘disrupted’ and then reinstated.

Although diagnosis and the initial onset of illness was disruptive in many ways, their later relapses back into illness are not best understood as ‘biographical disruptions’ but as one dimension of their ‘double lives’. As Vick argues, illness does not bring about the “dissolution of any one identity”, but is just one of the transient “embodied states and identities” the women live through (Vick 2013:178).

Living Wellness and Thinking Illness

Not all people with autoimmune disease experience symptom-free remission as part of their illness. Those with less stable remission and ongoing symptoms, such as fatigue, are caught in the precarious space of not-quite-sickness. For the women I spoke to in this position, the ability to entirely ‘forget’ about illness is a blessing and a risk, both alleviating the fear of illness and potentially jeopardizing wellness.

After years of symptoms that went untreated and were taken to be indicators of irritable bowel syndrome, Catherine was diagnosed with Crohn’s disease in 2011 while in her final years at university. Although she had aspired to become a barrister, she hadn’t pursued the career because of concerns about how self-employment would jeopardise her health and remove the ‘safety net’ afforded by paid leave. She worked as a solicitor, which she enjoyed, but residual disappointment about the impact of her illness on her career lingered. Our interview stuck with me for weeks after we spoke because of her response to one particular question. Catherine had been having more good days than bad since she started on Humira, an injected medication, six months earlier. I asked her what it meant to have a good day now, and she replied,

A good day is probably one where you almost forget that you've got it, you know, you don't have to worry about— on an ultimate good day you don't have to think about it and if you forget for a day that's... a blessing

Catherine felt burdened by her inability to forget about her disease both because of the symptoms of fatigue that she contends with daily and because of the necessity to consider the impact of everyday decisions on her health. She was frustrated at her 'need to worry', explaining that:

Even if you're having a good day but then you start the panic of "oh, but what happens if I don't?" I mean, I went on holidays last year, we went water-skiing up the river and had a great day and then later than night, you know, 2am I was in agony... and so off to the nearest hospital and everything like that. So, I was going there again over the Christmas holidays and then there's just this panic of, "what if this happens again?" and you're completely unreasonable in that sense, but there was one morning that I woke up and my gut was just not well and I missed out on, you know, half a day because I was just feeling very, very ordinary and needed to be close to a toilet

She juxtaposes her panic as both 'completely unreasonable' and somewhat justified, given that she was briefly unwell during the holiday. The "half a day... close to a toilet" was perceived as a moment in which illness again took the foreground – if only momentarily. Catherine remains involved in illness as a *possibility* despite considering herself rather well or having a 'good day'. Wellness and illness are not mutually exclusive states but processual and permeable.

The ability of illness to 'bleed into' wellness was also part of Nora's experience of lupus. I met Nora and her son at a café after she had picked him up from kindergarten. With her wavy black hair and fashionably large framed glasses, she appeared younger than her thirty-three years, even with her young son in tow. Nora had been diagnosed with systemic lupus erythematosus at twenty-one years old when she was in the middle of her exams at university. She spent much of her twenties with excessive fatigue but still managed to work full-time up until the birth of her son five years ago. After giving birth, her lupus worsened severely and she required intermittent hospital stays to treat nephritis of her kidneys. During our interview, she quietly mentioned that she was probably depressed at the time and has only recently got back on her feet.

Nora considered herself to be back in good health and living a "completely regular normal life" which involves taking her son to and from school, volunteering in the city as well as for her local church, and cleaning and cooking at home. I asked if she ever forgets about lupus and she paused for a moment, her face frowning in thought, before answering:

You can sometimes, um.... yes and no, you're body won't let you forget for very long!

She laughed, and I prompted her to keep going:

If you don't take your medication or if you – if I don't get the sleep that I need, yeah my body lets me know. I will get a rash or I will feel a bit sore or I will feel really exhausted... so um, my body lets me know. I can probably get by for a day or two being neglectful but even just a day, one night... Yeah but I think the tiredness doesn't let you forget, you have to keep on top of that.

Through its emergence as pain and discomfort, she engages her body as “the object not just of perception and interpretation but of action... instead of acting just *from* the body, [she] act[s] *towards* it” (Leder 1990:79). Nora listens to and remembers her body. She responds to aversive sensations but also anticipates them; whether they take “a day or two... even just a day [or] one night” to arise. Illness is not a bounded category but one with a permeable border and for those with chronic illness it is easy to shift into.

The following moment in our interview parenthetically shows the shifting ground between illness and wellness. As will be explored in chapter four, people with chronic illness often face difficulties in gaining recognition of their illness from others. Nora explained that she struggled to talk about her illness and suffering with her friends who would often avoid the topic:

*I might tell them about it but then they'll say, "but you're okay right?"
"well, not really".... they want to pretend that I'm alright - and I am now!*

That Nora can be both ‘not alright’ and ‘alright now’ is reflective of the ambiguity of wellness for those living with chronic disease. ‘Health’ as the absence of disease may be unattainable, but the presence of illness does not preclude the possibility of wellness for people with chronic illness.

Much of the literature on chronic illness and disability draws heavily on the concept of liminality. The concept was first developed by Van Gennep (1960) in relation to rites of passage, a ritual process that moves an individual or cohort of initiates from one social status or role to another. The initiates undergoing this transformation pass through a liminal stage in which they are no longer who they *were* but are not yet who they will *become*. This threshold moment was further elaborated upon in the work of Turner, who wrote that “liminal entities are neither here nor there; they are betwixt and between the positions assigned and arrayed by law, custom, convention, and ceremonial” (Turner 1969:95).

The concept of liminality has been applied to describe the situation of people with chronic illnesses and disabilities (Bruce et al 2014; Deegan and Willet 2001; Honkasalo 2001; Murphy et al 1988). In the final stage of Van Gennep's model of rites of passage, an individual is reincorporated into the group with their new social status. People with disabilities may find this re-entry is unavailable to them; in a society that limits 'wellness' to the able-bodied, people with disabilities cannot be recognised as sick nor well. Liminality becomes an ontological state rather than a temporary stage, and this has been used to describe the way many people with disabilities lapse out of the social world and the normal currents of life (Deegan and Willet 2001; Glenton 2003; Murphy et al 1988).

MacArtney et al. highlight the ambiguity of the concept of liminality as it has been applied, interchangeably as being in-process (or the state of being in-between) and as an experience of two states simultaneously (MacArtney 2015:625). The authors propose the concept of 'parallax' as a refined subtype to refer to the multiplicity of states, in this instance, of wellness and being not well. 'Parallax' typically refers to "the change in perspective of a singular object that is brought about by a shift in position" which offers a perspective from which to consider "how people engage with multiple spheres, discourses, or possibilities" (MacArtney 2015:625). In this way, illness and wellness exist concurrently, revealed through shifting contexts and perspectives.

Chronic illness and episodic disability are not a "merging of opposite states of being nor an oscillation between polarities"; instead people are "multipositioned as different versions of the self correspond with different versions of the body at any given time" (Vick 2012:46). In holding two orientations to the world, women with autoimmune diseases "embody two shifting worlds" (Vick 2013:184), being both well and ill in a single moment. Brody neatly captures this duality as the way sickness "can make us different persons while we remain the same person" (Brody 1987:x)

When binary categorisation (i.e. healthy or sick, entirely able or entirely disabled) is expected and enforced, the illness experiences of these women is easily misplaced or reduced. Illness and wellness are not mutually exclusive but processual, describing ways of relating to oneself and the world. The varied ways these diseases manifest over time, whether through severe relapses interspersed with remission or disruptive ongoing symptoms, produce different experiences of the interplay between illness and wellness. Yet, what is shown through each of the women's illness narratives is the fluid and responsive ways in which they relate to their chronic diseases.

2. Loss and Learning

The diagnosis of chronic illness can upturn the anticipated future young women envisioned for themselves. Many of the women attributed their early symptoms to a temporary illness that would soon pass on its own, a simple case of the flu or some strange stomach bug. Those who had more severe symptoms anticipated a diagnosis of cancer and a terminal prognosis. The diagnosis of chronic disease is difficult to bear *because of* its chronicity. Life will not go back to exactly as it was before. As one participant said, “it really used to get to me when I was first diagnosed that it is chronic and it was something that was never ever going to go away.”

Charmaz argues that the loss of self is the main source of suffering for people with chronic illness, as their new self-image is devalued. As people require greater support and assistance to manage their illness they often become simultaneously more isolated and their activities restricted. The social devaluing of disabled people prompts a diminished view of oneself as illness and impairment worsen and contributes to the fear of becoming a ‘burden’ (Charmaz 1983). Therefore, maintaining a ‘normal’ life is invested with the symbolism of a valued self (Charmaz 1983:169). How women respond to the disruption and losses brought about by illness is revealing about which identities are socially valued.

Loss of Anticipated Future

In comparing their current ‘ill’ self to their former ‘healthy’ self, people with chronic illness experience a devaluing of their identity. They are worse off than before. They may no longer have the energy or participate in the activities and relationships that filled their life earlier. Charmaz (1983) argued that this perceived ‘loss of self’ was a fundamental form of suffering for the ill person. Just as one’s former activities and relationships become curtailed as illness demands more time and energy, the anticipated future is obscured by the immediate preoccupation with getting well.

Asbring’s research (2001) with women diagnosed with chronic fatigue syndrome and fibromyalgia showed how illness, and the withdrawal from social life it engendered, prompted a loss and reshaping of identity. Unable to further their education or career, and struggling to maintain relationships or start a family, the women felt a “strong sense of dissonance between [their] expectations ... and the realities of their lives (2001:465). This loss of an anticipated self was expressed by several women in my own research as they reflected on the enormous impact of one’s life ‘stage’ at the time of disease onset on the nature and severity of this disruption and loss.

Anxiety about one's ability to find a partner and continue on their career path swelled following diagnosis. Many of the women who were already married when they became sick mentioned how difficult it would have been for them to find a partner if they had gotten sick earlier. A number had also both graduated from university and begun working before the onset of their disease and two had already had children before becoming sick. Their lives were already 'on track' as they had imagined them and illness was, in varying degrees, a kind of 'derailment' or – perhaps more positively – a change of route.

In contrast, Alice, who was the youngest participant I spoke with, reflected on the ways her disease had impacted her plans for her life before she had even the chance to follow them. Alice was in her second last year of high school when her suspected 'stomach bug' worsened to a point that it could no longer be ignored. One trip to the doctor quickly led to a diagnosis of Crohn's disease.

It still hits me every so often, you know, that in five years' time I am still going to be quote unquote 'sick', and in ten years I am still going to be sick, and when I am my Mum's age I am still going to be sick, and when I am like my Grandpa's age I am still going to be sick. It is hard to get a grasp on what that actually means and how it will actually affect my future as well.

(...) So it can be [a] really frustrating, almost demoralising thought because if it was just something that would be a couple of years or would just take a big surgery to fix or whatever, I think that is something that is a little easier to mentally map out. But I don't know if in five years I will even have a bowel...

If her illness was passing or quickly resolvable, Alice believes it would be easier to visualise her future. As acute illness brings about only a temporary disruption, the imagined future extends ahead of it full of the same possibilities that came before. But with the realisation of her disease as a *chronic* illness, Alice was made to "look at the future from a totally different angle" (Hydén 2008:52). At the time of the disease onset her plans for what she would do after high school were not fixed. In her words, "anything could go anywhere", until – suddenly - it couldn't.

Although Alice considered herself very lucky that her form of Crohn's disease did not impact her day to day life as severely as it had her grandfather, who in his old age had stopped going to new places out of fear of not having access to a bathroom, she felt the limitations that it imposed on her ability to venture out into the world.

(...) there were things that I wanted to do with my life that I wasn't sure any more if I could do. Like some of the travel plans I had wanted to do, like go away for years on end and be a bit of a hobo, that sort of thing. It is a bit hard to do that when you need to get regular prescriptions and check-ups. I had wanted to be a doctor when I was that age, that was my

plan, but I guess spending that much time in hospital changed it (...) The plan was to either go to central America or Africa or somewhere in Asia and work for Médecins Sans Frontières - that was the dream, and that got cut down quite a bit by having a chronic illness. I don't think it is necessarily impossible, but it was just going to make things too hard - I felt at the time - and then I was also very sick for year 11 and 12 and I just didn't want to try.

The future Alice anticipated for herself prior to diagnosis – while still possible – became less desirable. As her final year at high school came to an end, instead of leaving to travel with nothing more than a backpack and a map, Alice stayed at home and enrolled in university.

I kind of thought, I will give myself these years and figure out the future later on.

It had been seven years since her diagnosis when I met her for our interview and in that time, she had finished her bachelor's degree and begun working at the university. She was happy in her role, which was not too demanding, as it allowed her to have her “defining stuff” outside of her work. Alice talked often about her friends and going out to dinner, and her hobbies which included gardening and baking. Her life was on a different path than the romantic vision she had for herself a teenager as an international doctor, but was not any less rewarding for it.

This is not to say Alice had simply acquiesced to the impact of Crohn's disease in her life. Even after getting her first flare under control, Alice had almost constant fatigue as a side effect of two of her medications, so she decided to stop taking them without telling her doctor. She explained, “I was trying to be independent and take control of my health and all of that. I was sick of feeling tired.” It was an action of reclaiming her body, away from disease and the purview of biomedicine, and giving it back to herself. Whilst she was proud of her rebellious moment there was also the nagging thought that if she hadn't stopped her medication she may not have needed surgery so early. Two years later, Alice had part of her bowel removed.

The onset of disease brought about a reshaping of future possibilities for Alice. Her plans to backpack in her ‘gap year’ after high school were usurped by the need to monitor her health and learn how to deal with her Crohn's following diagnosis. Furthermore, all her time spent in hospital and around doctors changed her attitude towards going into medicine herself at university. It was not the disease per se but it's rambling impacts that precipitated a shift in her priorities. Her response to illness demonstrates the ways in which Alice could reimagine her future and work towards a different kind of life, while at the same time the areas in which the impacts of illness remains an ongoing burden and source of frustration.

Life on Hold

Emily's approach to living with her disease had changed drastically in the two years prior. She had been diagnosed four years earlier after an eighteen-month struggle of being passed from doctor to doctor without a diagnosis, which she attributed partially to being located rurally. There had been a three-month waiting list to see a gastroenterologist in her regional city, and waiting without any answers was unbearable. Emily was convinced she was dying. She could hardly eat and was dropping weight rapidly. She would run to the toilet twenty times a day and lost a lot of blood; more than once she passed out in the bathroom.

I remember, I had gone to the doctor in the morning – gone from to the doctor and come home after the doctor because it was lunchtime, and I said to my partner what had happened and I mean, I don't cry very much, I am not a particularly... fragile isn't the right word, but I am not an über emotional person – but I just lost it.

Her partner, also fearing the worst, insisted she could not wait three months and so they had sought a specialist with a shorter waiting time. The gastroenterologist conducted an endoscopy¹ and colonoscopy² on the day of her appointment, confirmed a diagnosis of Ulcerative Colitis, and prescribed anti-inflammatory medications to calm the active flare. Not long after, her disease went into remission. She explained that at the time, she thought she had “gotten away with it... I was in a lull sense of security, I just went back to doing everything normally again, just taking these drugs”.

It was the recent flare that finally forced her to confront the chronic nature of the disease. For close to two years, she suffered from a flare which seemed resistant to most medications. Her patience was pushed to the limit.

So much of it is waiting for things to work. Like I said, for the drugs to work. Waiting for test results. Waiting for the doctor's appointment. And I am not good at waiting, I am the most impatient person (...) that limbo period was probably some of the hardest psychologically for me to deal with. I can almost deal with the symptoms and all of that, but the fact that we weren't moving along, we weren't getting anywhere.

Unlike the trepidation and fear Emily felt during her diagnosis, she responded to her next flare with stubborn pragmatism. She wanted to solve the problem and move on, but it was not the kind of problem which could be rapidly fixed. Instead, she was forced to wait. Hay argues

¹ Endoscopy here refers to the procedure in which an endoscope, a flexible instrument with a light and lens, is inserted down the oesophagus to allow an examination of the upper gastrointestinal tract.

² In a colonoscopy procedure, an endoscope is inserted into the anus in order to examine the colon.

that in a meritocratic society, there is a “moral compulsion for adults to act, to do, to manage, and to withstand” (2010:269). In this sense, Emily’s greatest source of suffering during the long months of her flare was her inability to act to resolve it.

The thing that I probably dislike the most about the disease, what I feel it has taken from me, is that I have had to put my life and my career on hold for the best part of two years or more.

(...) I have to accept that this stuff takes time, and now that I am in a good place I can start looking for a new job and looking to moving somewhere else and that kind of stuff, yeah. That is probably the biggest detractor for me.

Although Emily was frustrated that she needed to put her career on hold, her illness had not been financially devastating or brought an end to her career progression. Her husband, who worked from home, financially supported the family during the periods Emily could not work. Moss and Dyck have shown that the financial status of women with disabling chronic illness is mediated by marital status and class (1996), and this is clearly true for Emily during her flare, and other participants who had stopped working and could rely on their husband’s income. Furthermore, not only did Emily’s husband provide material support, he also helped care for her while she was sick and made sure the household kept running.

The fact that we don't have family around, when I was really sick and at home all the time and fainting on the toilet (...) him being around and being able to keep a check on me, and being there to calm me down and simple running the house shit like making sure we have clean clothes, because I couldn't. That is huge.

Many women described their personality as fiercely independent but that they were learning to ‘get over’ their reluctance to accept help. The assumption that is achievable and desirable to entirely autonomous is bolstered by a cultural emphasis on individual agency, which lessens the significance of interpersonal relationships and cooperation. This taken-for-granted way of living can quickly unravel when one is finds themselves being cared for due to sickness and impairment. Being ‘out of control’ (or being unable to fulfil ones normal ‘duties’) because of illness can create a feeling of reverting to a state of childish dependence on others (Corbin 2003:261; Luborsky 1994; Herskovitz 1995; Ramirez et al 2014). The fact that several participants mentioned that they disliked being ‘babied’ attests to the perception that receiving care is infantilising.

Although Emily lived in a different state to her natal family, the support she drew from her husband was vital to her sense of self-worth during the worst months of her illness. Although she recognised the strain it occasionally put on him, Emily did not feel like a burden to those

around her because of her illness. I got the picture that rarely did she have to *ask* for help, instead her husband offered her the space to *accept* help by asking directly if she needed to book an appointment or needed to be taken to the hospital.

When looking through my notes months later I realised this was the complete inverse to the short description Catherine, the young solicitor, had offered of her mother. Catherine recalled an instance when she had told her mother she was bleeding (likely from the large intestine) and her mother simply replied “oh” and walked away. Catherine was less confident in her ability to move forward in her career and spoke of far fewer ‘illness gains’ – or positive outcomes from the experience of illness – than Emily. Being cared for by others and learning to accept that help, without the connotation of childish dependence or being a burden, played an important role in ability of the women in this research to establish a valued identity amid illness.

“A Well-Oiled Machine”

While denial of illness may prevent mastery of situations that are likely to be repeated (Williams and Koocher 1998:330), the women who had accepted the chronic nature of their diseases could begin to find ways of controlling and skilfully navigating through recurrent illness. Although flare-ups were dreaded, many women expressed confidence in themselves to not only cope but to actively navigate through periods of sickness. Just as beginners learning to skateboard are taught how to fall ‘properly’ to minimise injury, the women I spoke to had learnt how to be sick ‘properly’.

Part of what this entailed was learning how to navigate medical bureaucracies and to be active patients. Emily spoke at length about the importance of self-advocacy and learning to speak up for oneself to doctors. Both Michelle and Amelia gestured towards the idea that they knew their body better than anyone and were thus confident in disagreeing with their doctor. However, most often the women expressed the importance of finding a ‘good doctor’, a doctor who one could work *with* and who *listened* to them.

Selena instantly caught my eye when we met for our first interview. Despite being petite, she stood out from the crowd, with her back tattoo peeking out across her shoulders and brightly dyed hair. Her appearance made her seem younger than her 29 years, though she described herself as being mature for age the result of having to “deal with stuff that nobody should really have to”. Selena had lived with severe Crohn’s disease since childhood and during

the past two decades has had a number of flares requiring hospitalisation. She was also the only participant who had a permanent ileostomy³ and her damaged bowel entirely removed.

I had [my temporary ileostomy] reversed the day after my 22nd birthday... even though the eighteen months was probably the healthiest I have ever been I hated it, I absolutely hated it, and I was pushing pushing pushing for reversal, and my surgeon gave it to me. But then two weeks later I was back in hospital, really unwell again. So, that is when they- that was the time I decided to make it permanent.

I noticed that she corrected herself to say that *she* made the decision, not the unspecified “they”. Although she had been insistent on having her temporary ileostomy reversed, she also positions herself as the one in control of her surgery to make it permanent.

It was like switch in my head where I kind of suddenly realised "shit, I have had literally the healthiest time of life because of this and not even two weeks after it was gone I am back in hospital".

(...) so I went through all the surgery because really it was a no-brainer, it was the only option I had if I wanted to get a little bit better, and you have a stoma therapy nurse who helps you transition and the first time I changed my appliance - she took me to the bathroom to do it - and I had this overwhelming feeling of like, [whispering] I can't fucking do this and she is like, "of course you can! don't be stupid!". I just thought, "no, I can,"

Selena credits the nurse with being able to read her personality and giving her the push she needed to realise “it’s not that bad!”. She described it now as “second nature” that she hardly gave thought to. Selena’s change in attitude towards her ileostomy is characterised by the shift towards regaining *control* over her body after a long period of feeling at its mercy. Her initial temporary ileostomy, despite providing a respite from severe flares, was emblematic of losses and fears. Selena recalled worrying if she could ever have a family or even have a relationship, and how she stopped going to the beach or wearing midriff baring clothes to hide her appliance during the 18 months she had her temporary ileostomy. As she spoke her voice sounded strained, as if this was not something she talked about often.

³ An ileostomy is a surgically made opening in the abdominal wall, which the end of the small intestine is diverted through. Digested food, rather than passing down to the large intestine, comes out through this intestine opening on the abdomen and caught in a bag or pouch (referred to here as an ‘appliance’). A temporary ileostomy can be reversed because the rectum is kept in place.

However, the total colectomy⁴ and creation of a permanent stoma⁵ (this time, lower on her abdomen and easy to conceal) granted her greater control and freedom.

I understand people are afraid, because I was afraid too and I didn't want it and I did hate it for a little while there, but you have to do shit in life that you don't want to do - shit being the operative word!

The tension of her story and the pain in her voice dissipated into the air as she broke out in scattered laughter. Many of the conversations I had with participants were punctuated by bouts of giggling. Some of the women would smile jovially as they told stories in which they were crying, and I was always unsure what tone I ought to take. I was reminded again and again of Emily's remark that, "you have to be able to laugh about it because it is *so* not funny sometimes" and Michelle's admission that, "if I didn't laugh about it I would be crying."

"I guess in control would be a good way to describe it," Selena replied when I asked how she would characterise her disease now. Since her colectomy, Selena's main trouble with her Crohn's (which affects the entire gastrointestinal tract) has been a recurring abscess, "but then I am on a first name basis with my surgeon and my surgeon's nurse!" she added.

When I feel it popping up I just call Breanna and say, "can you put my on Nick's list for next week because I have an abscess," and she is like "no worries, I will put the paperwork in and call you back with an admission time." We are like a well-oiled machine now - it is not perfect and it is not 100% healthy but we have a good system down for managing it.

Often, I felt Selena spoke with a slight air of detachment, giving me a very 'matter-of-fact' account of her disease. But her tone became lightened and she smiled as she explained the ways she could call of her nurse, as one would a close friend, to request surgery. The scenario was almost comical. She regarded herself as far from a passive patient simply *receiving* treatment, but as a member of the 'well-oil machine' alongside her surgeon, nurse, and GP working collectively to manager her disease. I asked her what a flare was like now that her disease is mostly under control;

So, if it is in-the-bed in-a-flare bad day that doesn't require hospitalisation it's generally just lots of pain and fatigue (...) I can handle the general cramps when your intestines are inflamed, my issue is when I get an abscess (...) Sometimes I can smooth it out with steroids

⁴ The surgical removal of the colon.

⁵ A stoma is a surgically made opening which connects to an organ, in this case, it is the opening on the abdomen which the small intestine is attached to. The stoma is permanent because the ileostomy cannot be reversed.

and sometimes, like I was in hospital in the first week of Feb, it can come on really hard, really fast and that is when I need to go to hospital and it is excruciating pain.

Her differentiation between levels of severity adds to the sense of her as a manager of her own body, categorising and responding appropriately to a given set of symptoms. Selena is able to manage the pain on her own up to a point, but abscesses sometimes require surgical intervention if they arise too quickly for her to self-medicate with a short course of prednisone. Finding a doctor who allows her this “hands on” approach to the management of her Crohn’s had been important, and she had recently found a young doctor who respected her ability to manage her disease without constant oversight.

Selena’s experiences of multiple flares and abscesses as part of her Crohn’s over the course of nearly two decades has afforded her the knowledge and confidence to know how to respond in times of sickness. The ‘familiar feeling’ of shifting into illness is less frightening than it once was – a sentiment also expressed by Michelle – because of the routines and skills one has learnt to cope through it.

It was like yeah familiar feeling, I know how this is, and you just fall into old habits, routines, to get it sorted, I guess.

A review of the literature by Michie et al (2003) showed that chronic illness patients who were encouraged to be active in both the consultation and management of their illness had greater satisfaction and physical health outcomes than patients whose beliefs were discussed with the doctor and simply ‘understood’. The authors note that the self-reported improvement in health and quality of life may improve because of how people assess and rate these as “a result of being, and feeling, more in control” (Michie et al 2003:8).

The onset of disease and the diagnosis of a chronic condition are disruptive and disorienting events that alter the expectations one has for their life. In the case of autoimmune diseases with recurrent flares, the ongoing re-emergence of illness can undermine the ability to plan and act to achieve one’s goals. Becoming engaged with the management of one’s own health and finding ways to regain control were valuable ways of achieving a sense of wellbeing for the women in this research.

3. Control and Hope

The flares and relapses that come with autoimmune diseases can be unpredictable and unpreventable. Chronic illness often leads to a sense of having lost control over one's body and life particularly when there is little action one can take to effect health outcomes (Charmaz 1983; Corbin and Strauss 1985; Williams and Koocher 1998:325). In everyday speech, people use the language of 'control' in ways that incorporate ideas of agency and self-efficacy (Warren et al 2013:325). The following stories shows what kinds of goals are important to the women and what – through control – they are trying to achieve.

Disease Management and Hope for the Future

Michelle and I were both 5 minutes late to our prearranged meeting place, a small café at her local shopping centre, a short drive from her home. It was noisier than I had hoped, with only a short half-wall separating our two-person table from the relentless foot traffic. Michelle was gentle yet animated and bright, an outward appearance that, she said, frequently belies her chronic fatigue.

Michelle had been diagnosed six years ago with Crohn's disease. The diagnosis was a relief after months of struggling with on-and-off symptoms and terrible stomach pain, but she was yet to achieve very stable health and had frequent flares. A large part of our interview centred around how she managed these flares and her fatigue and I quickly found that her search for control and stability was powerfully motivated by her goal of becoming a mother. When I asked how she felt about the chronic nature of the disease, she immediately responded saying,

I am 28 and I don't have any kids, that is the hardest thing, because at the moment I couldn't do it with my fatigue. That is what gets me down, it is like, "will my fatigue get better? will I get off the medication that is causing it?"

(...)That would be the biggest thing, it affects all of that - like a spiral effect, like dominoes

Michelle was disappointed and saddened that she had not had children despite being married for six years, and the uncertainty of *if* or *when* she might have children in the future weighed heavily on her. Her husband also worried it would be dangerous to continue taking medication whilst pregnant, despite reassurances from her specialist that the risk was minimal. Thorne et al. argued that women with disability face scrutiny for their choices related to reproduction and mothering and made to feel irresponsible (Thorne et al 1997:6). Michelle was caught between risking her own health and stopping medication or taking medication and being perceived as risking the baby's health.

A year earlier, her doctor had lowered her dosage but soon after she began to flare. Since then she has been concerned about trialling a lower dose again or changing medication because of the risk that she may require even stronger medication to get a flare under control. Although she resented the impact of the fatigue on her life, Michelle had conceded that she could live it while she sought stable good health. How exactly to manage chronic fatigue on a day to day basis, while also working fulltime as a primary school teacher, was a skill she had learnt slowly.

I have only just got that down now - knowing my limits! It feels good now, I know my limits! Like I know I need to have Sunday as a sleep day and nothing [day]. I just stay in my pjs all day and I do nothing, I sleep and I read and that is pretty much all I do on a Sunday. And I know that I need that day, like, to get ready for the week. You know, I know I need to be in bed at 8 - as hard as that is!

Michelle laughed briefly before my question cut her off – “is it was hard?” I asked. She hesitated and I could see her searching for words.

It... Ah... I kind of think I just sleep on the couch at 7:30 but I haven't come to the fact that I just... I can't bring myself to go to bed before 8 O'clock... But that took a long time to come to terms with, that I don't have a life in that respect because I am in bed so early and I can't stay awake.

“What would be different if you didn’t need so much rest?” I asked.

Well, I think I would be spending more time with my husband. We could be spending more times out with friends and be doing a bit more with the week, and on the weekend doing a bit more as well. Like Saturday is often taken up with things I can't do during the week because I am too exhausted, like cleaning and shopping, because I just can't do it during the week - I get home and I am done, you know.

Michelle had reorganised her time to allow for restful evenings and at lengthy sleeps, but she has done so at the sacrifice of other aspects of her life, namely social connections and even her relationship with her husband. Michelle later explained how she had recently declined an invitation to a friend’s baby shower because, simply, “I just won’t be able to do it, I just won’t have the energy”. Learning to work within schedules and planning is a necessary skill to manage unrelenting fatigue.

Michelle’s ability to manage her symptoms, including fatigue, had improved in the past few years. She explained how she monitors her pain and visualises her inflamed and ulcerated intestines. Prior to diagnosis she was afraid of her symptoms, but now, she says “I know that that is exactly what it is.” She gestured to her lower abdomen, saying:

I know where the pain sits and I know that if I eat this - and I kind of, when I come to a flare up, my husband laughs but I actually eat the food I am not meant to eat just to see if that is what it is! It is really bad, but that is what I do! Just to make sure that it is my Crohn's before I go to the doctors and say look I am flaring up and I need strong medication... Just to make sure it is not a bug, because I could get a bug from work so easily

Michelle attempts to closely monitor her diet to avoid foods that 'trigger' her symptoms of cramps or urgency of bowel movement, while paradoxically purposefully consuming the same triggering food at the suspected onset of a flare. What connects these two oppositional behaviours is that in both cases, Michelle positions herself as the one in control of the body. In wellness, it is her dedication to 'clean' eating that helps to sustain her health and in illness, her desire to determine the cause of sickness (and what action she should take in response) lead her to 'provoke' flare by eating triggering foods. Michelle's provocation of her symptoms when she suspects a flare-up goes against her doctor's advice and steps away from the utilisation of biomedical technologies to control symptoms. What is more important for her is her own sense of control over her body. If she is going to get sick, she will do it herself.

(...) I am having a salad and I know that if that has gone through me in an hour and I've got pain then I know that it is the Crohn's... I can, I don't know how to describe it, I can feel my body. Does that make sense? I know the pain, I know where the pain is doing to sit, like it sits right down there.

This visualisation of her inflamed intestines and experimentation with food reflect Michelle's objectification of body as an "it" which can, and must, be worked on by the 'self' (Leder 1990:77). Through recurrent flares, Michelle has gained a familiarity with the location and texture of her pain and can differentiate between a "bug" and the inflammation and cramps that accompany Crohn's. In the case that it is a flare up, Michelle then follows a new routine, saying "I know what to do now, it is like a habit".

Michelle drew my attention to her 'pot belly' and the dress she was wearing to avoid the discomfort of a waistband against her abdomen, and pointed out that she had bought a soy coffee; all so that she could talk to me pain-free. I asked what milk she normally drank at home (the answer being lactose-free milk) and found that she also regularly made her own almond milk, kefir (a fermented milk product), and bread. I had asked earlier if she had time for any hobbies and now she exclaimed, "that is probably a hobby - I love cooking!".

I visit her at her home a few weeks later so she can show me how she makes kefir. There are cooking books and food magazines stacked in the kitchen and open across the dining table. The kefir had been growing in a small plastic container wrapped up in a tea towel, it looked very

unappealing and I began to regret my request to try some. Michelle poured the mixture through a metal sieve, pressing the spoon against the sieve and collecting the remaining clumps in a waiting container of room-temperature milk. When it was time for tasting Michelle kindly warned that I should only eat a little. Ironically, the probiotic cultures might make me feel sick.

Although Crohn's cannot be cured or reliably treated through dietary means, diet may play a part in minimizing symptoms for people who have 'trigger' foods. No specific diet is recommended for everyone with IBD because their trigger foods are so idiosyncratic. In addition to making her own milk and bread, Michelle also doesn't eat take away and minimises her consumption of processed foods. She tentatively refers to her diet as "clean" eating. Michelle's syntax for categorising food is congruent with Australian lay understanding of 'good/healthy' eating. Lupton's research on Australians' lay discourses and beliefs about food found that in addition to the central opposition to good/bad foods, other prominent distinctions made were between low-fat/fatty, natural/artificial, and pure/contaminated (Lupton 2005:463). In each of these, the latter term builds on connotations of 'danger' and 'risk' to one's health (Lupton 2005:463).

The classification of some foods as polluting and dangerous to the integrity of the individual can serve to uphold moral rules within a given culture (Douglas 1966:160). Caplan argues that in Western societies "health... is often interpreted as a sign of good moral character and individual worth, whereas disease is often equated with moral failure" (Caplan 1993:234; Greco 1993). Good health is sign of "virtuous conduct" (Caplan 1993:234), but when lacking the former a healthy or 'virtuous' diet may help to demonstrate to others and oneself that their disease is not their 'fault'.

Karen was another participant who incorporated a specific diet as part of her illness management. She was tall and blonde, and looked strikingly professional in her work attire when I interviewed her over dinner at a local restaurant. Her order to the waitress was full of questions about the ingredients list and I wondered if she felt self-conscious about asking for changes, as I knew my own friends with dietary requirements were. However, she seemed proud of her health-conscious behaviour. Karen explained that her lupus made getting through the day more exhausting and painful for her than her peers – but not to such a debilitating degree that she received sympathy or recognition. Nevertheless, lupus also made her appreciate her health and to take seriously the role of diet and exercise in keeping healthy. As such, Karen loosely adheres to the 'paleo' diet, which attempts to approximate the diet of humans during the Palaeolithic era. This includes lean meat, fruit, vegetables, and nuts and excludes legumes, dairy and grains (Frassetto et al. 2009:1). The central argument for the benefits of this diet is that the

human body has evolved for such a diet and that ‘returning’ to this way of eating will improve health, a discourse Knight refers to as “nutritional primitivism” (Knight 2015:442).

Warren et al. write that while biomedicine gives people a way to seek control over their *symptoms*, many people with chronic diseases look for ways to gain control over their bodies and their lives (Warren et al. 2013:325). Diet is one of the ways that people seek control over themselves outside of biomedicine. Michelle’s diet was less strictly defined than Karen’s, but both utilised these dietary practices in the hopes of improving their health and gaining greater control over their bodies. Likewise, Michelle worked towards her goal of achieving stable health and reducing reliance on medication by routinizing her fatigue management. The management of her disease was not only for her sake in the present but was central to achieving her goals for the future which centred on becoming a mother.

Cutting Corners

Amelia and I sat inside gallery café, watching as her little girl danced and frolicked around the garden. If Amelia was tired from her day out with her daughter at the zoo she hid it remarkably well. During the week, she worked as a teacher in a fulltime role but her ability to rest over the weekend was complicated by the fact she has two energetic daughters under the age of five.

Amelia was the only participant to mention ‘spoon theory’ over the course of our interviews, a term which has emerged from online chronic illness communities. Spoon theory is a metaphor to describe the finite energy, both physical and cognitive, one has for daily activities when living with a disability or chronic illness. A ‘spoon’ is a unit of measurement. High-energy tasks require more spoons and once all spoons have been used one has no choice but to rest. The term ‘spoon’ in this usage was coined by Christine Miserandino in 2003 after she used spoons as a visual aid to explain to her friend the ‘cost’ of daily activities when living with Lupus. Amelia used spoon theory to explain to me how she rations her energy and finds ways of making do.

So, suppose you wake up with three spoons but because you've set your life up to be normal – you haven't put your hand up and said, "I'm sick, I'm sorry I can't do this", you've set your life up to be normal - if you've only got three spoons you have stretch those three spoons out to get through a normal work day, and look after your kids, or cook dinner or... I cut corners if I have to, I've given my kids, you know, like party ware? Like paper plates to eat dinner on before.

She laughs and I join her – it seems like an ingenious solution.

I've done lasagne in the oven, put it on the paper plates and gone, "yeah we are having a party!". Sometimes you've got to do what you've got to do, and if that's the worse thing you do to your children, it is fine. I've fallen asleep once whilst minding my second child, she just walked up and whacked me on the head, "wake up Mummy! wake up!" so I thought no it is okay, she has got this! Between the two of us, we are good!

You know what's funny, the only days I've ever taken sick days was literally when I was in hospital. The other sick days I've had were for things like I've had a cold and it has floored me - which is understandable too because of all the meds and things - so if I had a cold that floored me so I took a day off, like, which is a normal thing, someone might get a cold and have a day off.

Amelia's connection between 'cutting corners' at home to get through the day with also not taking sick days unless absolutely necessary suggests that it is only at home, literally behind closed doors, that she has the freedom to cater to her health. She was happy with her ability to work fulltime and to do the 'normal thing'. This sense of accomplishment at behaving normally was evident across my interviews with women who continued to work fulltime despite ongoing symptoms, which many only managed by limiting activities outside work and getting lots of rest over the weekends. Their skilful impression management (Goffman 1963) enabled them to manage their public identity and shape the perceptions others had of them if they chose to disclose their illness. Having a sense of control over one's public identity can increase self-esteem and sense of autonomy (Valeras 2010).

Bury uses the term 'strategy' to refer to the actions people to take to mobilise their resources in the face of illness (Bury 1991:462). The ways in which people reallocate their time, energy, and money (and social resources) in response to chronic illness highlights the "greater degree of consciousness and calculation" needed to maintain everyday life (G. Williams 1996:35). Demonstrable busyness is the badge of 'normality', taken to signify health and vitality notes (Lingsom 2008:7). Lingsom argues that the most common passing strategy for people with invisible impairments is to concentrate their effort into a specific time and space, that is, the part of the day in which one is visible to others (2008:6).

De Certeau's concept of tactics is a useful tool to think about these kinds of skilful reorganisation of time. For de Certeau, tactics are the techniques of the powerless, who must always watch for opportunities and manipulate events in order to gain a momentary upper-hand from a structure that is ultimately against them (1984:xix). For the women who worked fulltime tactics are employed to sustain not only their health, but also, perhaps more, to ensure their involvement in the workplace. Unless one had a particularly understanding employer or had negotiated for flexible hours, one needed to "make use of the cracks" (De Certeau 1984:37)

and find ways to cope while appearing 'normal'. Tactics do not disrupt or overturn a system, but they find cunning ways to work within it.

Catherine, who worked as a solicitor, was ambivalent about disclosure but wanted her co-worker to be aware of her illness. She did not want to be seen as lazy if she was having a 'rough day,' as she had had the day of our interview. She said,

I work hard, but there are days you can't. There are days like today where you go to the toilet twenty or so times in an hour – you sort of want a little bit of understanding.

People with invisible chronic illnesses may be seeking to distance themselves from an image of malingers or lazy welfare recipients who play up the severity of their sickness to avoid doing work (Vickers 1999). The invisibility of their illness makes them more vulnerable to such criticism on the basis of being assumed able-bodied and healthy.

Hay argues that the expectation to be productive and push through illness and adversity regardless of circumstance – a cultural model she terms the 'John Wayne model' - creates greater suffering for those who cannot achieve it. Hay writes that, "people who cannot be productive while chronically ill are at best pitied and at worst condemned, their suffering delegitimized and their worth devalued" (Hay 2010:268). Working around and against illness can be a Sisyphean task. Even as the women devote time and planning every day to limiting the intrusion of their fatigue and other symptoms; bad days can still throw off plans and flares can still arise. Illness cannot always be 'dealt with' and, for some, this realisation helped move them towards a new way of relating to their illness.

Learning to Let Go

Kelly was 28 years old and only eight months on from giving birth to her son when she noticed her vision deteriorating and began having trouble with her balance. The disease onset progressed so quickly and with such intensity that within two days she was paralysed and blind in an intensive care unit; it was a hospital stay that lasted six months. She has a rare and extreme form of Multiple Sclerosis which usually kills a person within two years of onset. Fortunately, her specialists now doubt the recurrence of such a severe relapse and her disease is not expected to be imminently fatal.

Multiple sclerosis differs from the other diseases in this research because it typically progresses over time towards severe impairment. The physical impairments and neurological symptoms that characterise a relapse can become the new normal even in remission with some forms of MS. Given the knowledge of how her disease may progress, I asked Kelly if she ever thought much about the future.

To be honest I try not to... my mum and I struggle with this, because Mum's version of the disease, she has the progressive form, so she progresses and she gradually gets worse to the point where it will eventually kill her.

Kelly uses her mother's approach to the disease as a counterpoint to her own. Her mother has "always been thinking she is going to get better", a belief which has frustrated Kelly who thinks she should be more realistic, having worked as a nurse throughout her life and seeing the impact of the disease on others. Her mother puts a lot of faith in her physio treatment and is frequently trying vitamins and supplements that are recommended to her by friends and acquaintances.

As she spoke, Kelly switched back and forth from being frustrated with her mother's attitude and commending her for her positivity. This tension may reflect her personal frustration with the disease and the cultural emphasis on 'staying positive'. The expectation that people should 'stay positive' has been shown to be prevalent in discourses around cancer (Gibson et al 2014), however the expectation of this mentality was also felt by the women in this research. Del Vecchio Good et al.'s research showed the extent of the belief prevalent in American society that "if one has enough hope, one may *will* a change in the course of disease in the *body*" (1990:61). This belief in the individualised will is one expression of the broader notions about personhood and autonomy in Australian and American culture (Gibson et al 2014; del Vecchio Good et al 1990).

Kelly rejected her mother's persistent optimism, concerned that it led to unhelpful denial about the reality of the disease. During her recovery in hospital she thought often about her future, but since then has come to the realisation that worrying is a pointless exercise when dealing with a disease which is both unpredictable but also getting greater attention and funding towards treatments. Her main concern was for her son, but she took comfort in the fact that a cure is expected to be found within his lifetime.

I do worry about that as far as the future and how it is going to affect my son but not so much about how it's going to affect me. I suppose I've been to hell, I've seen what it is like, I don't ever want to go back there again but if it happens - I don't know - what can you do, you've just got to get on with getting on.

(...) I just think there is no point in, I don't know, dwelling on it I suppose and then thinking into the future- I don't know. Like, I am not being negative in any way, it's just, you take it one day at a time

Seeking to take control of illness through action is easily recognised as agentive, by demonstrating the ability to affect change in one's own life, however the choice to "let go" is also

an act of agency and can also confer wellbeing. Ironside et al. found that many participants living with chronic illness described themselves as “letting go” (2003:179). Rather than giving up and becoming passive, this act of ‘letting go’ meant knowing and accepting when trying to control a situation was unhelpful and creating new ways of living. This change in attitude, when changing behaviour has little or no effect on improving or controlling the symptoms of disease, is an internal means of coping with the uncertainty of illness (Williams and Koocher 1998:329-330).

Kelly had been unable to continue working because of her MS but in the last few months, as much of her impairment was in remission, she starting was getting bored at home. During the weekdays when her son was in childcare, Kelly found she had little to do but – now – had the energy to do something other than rest. She was considering volunteering and finding her “*own purpose*” outside of caring for her family. The world that had shrunk down during her relapse was opening up again. Moving on to new goals and finding other forms of personal fulfilment is an important part of learning to move on and working with what one has in the present.

As Hay neatly expresses, “the ways in which people approach living with chronic disease are not static” (Hay 2010:270). This is especially true for those whose illnesses move through flares, relapses, and remissions. For the women whose health allowed, continuing with work and managing illness in the margins of daily life granted a powerful sense of control and wellbeing. Others, like Kelly, may be led to a reappraisal of the value of control because of their experiences of unpredictable and incapacitating illness. Instead, they find a way to suffer successfully by valuing the ability to endure and be open to the possibility of new ways of living (see also Honkasalo 2008). My interviews with these women captured their attitude at that moment in time, but their occasionally contradictory responses and stories of past emotions towards their illness suggest that, far from being fixed, these approaches emerge in response to the changing tides of illness.

4. Silences and Stigma

The vast majority of the time autoimmune diseases are invisible to observers. Ulcerated intestines or lesions on the spinal cord cannot be seen without specialised cameras and scans, and pain and fatigue can be hidden with a smile. Behaviours and signs that would hint at illness, such as taking medication or having frequent diarrhoea, are managed in the privacy of one's own home or behind locked bathroom doors. Deciding whether to disclose one's illness to others - to what degree and in what circumstances - was a choice the women in this research wrestled over frequently. The difficulty of verbalising the chronic nature of their illnesses while also avoiding stereotypes and stigma impacted the women's ability to communicate their experience and to receive understanding and support.

The visual field is privileged as a source of information (Lingsom 2008:3; Peters 1993) and this cultural assumption (that 'appearance is everything') is used by participants to hide their illness. Like the legal axiom 'innocent until proven guilty', people are assumed to be healthy until proven sick (Masana 2011:131). However, Myers argues, this assumption of health is generally practical unless there is a particular reason for one's health status to be known (2004:257). Myers therefore draws the distinction between the "person who does not mention illness because there is no particular need to do so" and the person who "deliberately conceals his condition because he perceives a threat of stigmatization" (Myers 2004:257).

Goffman describes an attribute as a stigma when it reduces someone "from a whole and usual person to a tainted, discounted one" (1963:3). Illness and disability are thought to 'reduce' a person, make them less than whole, less than perfect. The threat of stigmatisation is related to the degree to which an attribute, in this case illness or disability, is discrediting. In the case of illness, the disruptiveness of the condition, whether real or merely assumed, is tied to the threat of stigmatisation. Myers' argument that "a person can more safely admit to having a debilitating disease because she does not actually appear disabled" (Myers 2004:260) supports Jones et al.'s research which identified concealability as the foremost dimension of stigma (Jones et al 1984).

Unlike those with physical disabilities who are quickly recognised by others as being different and immediately discredited on that basis, people with autoimmune diseases are faced with the decision of whether or not to disclose their health condition - and potentially accompanying impairments - to others. The terms invisible, non-apparent, and hidden are all used to describe these kinds of 'unseen' illnesses and disabilities with slight variations on meaning. The distinction between visible and invisible is most commonly used to describe whether a health condition is immediately apparent to others, presumably in public (Joachim and Acorn 2000; Stone 2005; Micallef-Konewko 2013; Hay 2010; Masana 2011).

Orlando (2012) uses the term 'non-apparent' to convey that it is not necessarily that these illnesses and impairments are *invisible*, but that the observable cues often go unrecognised by others. 'Hidden' implies more purposefulness of the part of the sick person, describing the purposeful covering up of illness or disability that may otherwise be observable to others (Fitzgerald and Paterson 1995; Valeras 2010). What all these analyses have in common is the impact of being presumed healthy or able by others when living with an illness or disability, and the ways in which those with illness or disability work to maintain that public identity or struggle against it.

The Burden of Proof

Although "not as easily stigmatised", people with invisible disabilities are subject to "rejection, humiliation, and social disapproval" (Davis 2005:154). I extend this to include people with invisible chronic illnesses, which may cause chronic or episodic impairment. As discussed in Chapter 3, Amelia was very determined to maintain her 'normal' life and minimise the disruptiveness of her Crohn's disease on her work. The deeply held assumption that there is an obvious and discernible difference between "normal" people and people with disabilities (Davis 2005:210) is both utilised by Amelia and others, and presents itself as a painful obstacle towards recognition.

She had been transferred to her current school as a 'care case' through the Human Resources department. Although her illness was acknowledged at this level, she did not want to be identified as 'sick' in the workplace – a decision made possible due to the invisibility of her illness (Fitzgerald and Paterson 1995:18). I asked her if this invisibility had ever caused problems, and she immediately told me of an incident a year earlier after starting her new job;

It was a brand new job I had only been in it a few months and we'd had a few hiccups with the job-share situation and because we were both new they didn't know who was telling the truth and what the situation really was, and you don't want to look like 'he-said-she-said', like that is not professional either.

So, I had said "I will step up to fulltime work and let's just forget this whole thing ever happened" (...) then of course, what do I do? I land myself in hospital, because I've stepped up to full-time work and all the stress of the whole situation and I had to really come back and prove I was sick, because I had day surgery on the Saturday and I was at work on the Monday. And I did that because I am pretty bloody determined to look normal and to not let the pieces all fall apart...

Her voice quieted and slowed, it seemed to hurt her to remember. When she had returned to work on the Monday after being hospitalised on the weekend, she was abruptly pulled into a meeting,

(...) they basically sat me down and said, "why were you in hospital" and I said, "well, I handed you my hospital certificate" but again that had gone to HR level, it was not at that level. So, I was requested to provide information and proof, which is illegal - it is unethical - it is illegal but if I didn't do it I would actually be causing myself a lot more stress.

(...)I was just like, "this is ridiculous but if I don't do it these people are maybe going to think I'm making it up, or maybe I'm not really sick," so, I gave them as much evidence as I could but it really shouldn't have been necessary (...) And so I did- it was awful, I ended up in tears in my boss's office because they were pushing and pushing and pushing it, and I'm like, "I may be losing my bowel, I may be ending up with a colostomy bag, I may not even be working in twelve months' time, I might be losing my independence as I know it, the idea that I have prove to you..."

Again, the end of her sentence drifted off. Later, she described it as a 'witch hunt' – the idea she had to provide proof of her illness struck the line between prosecution and persecution.

Disclosing is not always a freely made choice. Amelia felt forced to provide 'evidence' of being legitimately sick to her employers although she recognised that their request was not only unethical, but illegal. Since her hospitalisation came after a long period of stress and interpersonal conflict in the workplace, she felt she would only be adding to her own stress if she denied their request and made a complaint. For people with invisible disabilities it is often insufficient to only verbally disclose that they are disabled. Passing as healthy or at least not physically ill means they "may also have to convince people that they really are disabled, not seeking some special – unfair – advantage: thus, what they must do is meet a burden of proof" (Davis 2005:154-155).

Amelia was made to "endure the discomfort of subjecting [herself] to strangers' interrogations" (Davis 2005:155) on top of the suffering she was experiencing from her flare and the uncertainty of her future. The likelihood of being scrutinised is an added source of anxiety for people with invisible illnesses. For women whose symptoms fluctuate and whose needs and abilities change on a day to day basis – despite often *looking* to the same from the outside – receiving understanding is likely to be even more challenging (Vick and Lightman 2010).

Amelia brought her story to a conclusion by reflecting on her relationships with those co-workers now.

(...) But now I am in a great relationship with those same people, so it really baffles me now looking at them, they are really hard working, normal, lovely people - and I look at them now and think, "why? why did you put me through that?"

Her experience highlights how relationships can shift alongside the fluctuations in illness. People with chronic illnesses are often categorised as completely disabled or completely able despite the fluid and episodic nature of their illnesses (Lightman et al 2009, Vick et al. 2010, Vick 2012). Amelia's chronic illness is still there, but how she is recognised and treated within the workplace has changed. Peters' (1993) argues that people with permanent and unwavering disabilities are often able to anticipate the responses of others, but this relative consistency is unavailable to those who sometimes pass as healthy and sometimes don't. As her illness has once again receded into the background, it is likely that the chronicity of Amelia's disease has been largely forgotten by her colleagues.

Guilt and Pity

People may intentionally avoid self-disclosure because they believe that other people will not be able to understand their situation (Charmaz 2002:309), or, I argue, that people will not be able to understand their situation on their terms.

When Madeline was 27 her life was drastically changed by the onset of relapsing Multiple Sclerosis. She had been energetic and active, working long hours at her job in aged care - a profession which she loved but had since been forced to retire from. At the worst point in her relapse she couldn't walk unassisted and was sleeping for up to 22 hours a day. When I spoke to her in March her relapse was over, but she pointed out that that didn't necessarily mean much beyond a medical classification, since "the symptoms can remain... there's absolutely zero changes in how you feel."

Although she sometimes uses a cane for support, Madeline now walks unassisted, but her other remaining symptoms are less visible. In addition to her chronic 'pins and needles' which she describes as feeling like "thousands of needles under the skin trying to rip open out of the skin", she has chronic fatigue and her memory is impaired. Without her cane it is difficult for others to perceive that Madeline is sick unless they live with her. But she is conflicted about the need to disclose her illness to others,

It is kind of difficult with making new friends because, you know, our- like our next door neighbour, their son is in the same class as my son and he wanted to come over, so I felt like I had to explain to the mother that I had MS because if something were to happen and I didn't say something I would feel really guilty.

Madeline felt compelled to tell her neighbour about her health to justify why she couldn't supervise the two children. The need to justify actions and choices is a common situation for people with chronic illnesses who appear healthy (Masana 2011:134), particularly when matched with feelings of guilt. The expectations put upon mothers to be "protective, considerate, supportive, and patient, whilst looking out for her children's development and well-being" can generate guilt for mothers whose illness imposes limits on their ability to look after and play with their children (Plumb-Parlevliet 2015:10, 35). Madeline explained to me her hesitation about telling her neighbour about her MS,

...because we all know, you tell somebody that you have a degenerative brain disease and people are going to give you that look like, "oh my god, you're so young, that sucks"

(...) I almost feel like I have to justify why I am so tired all the time and why, you know, people's kids can't come over when I don't have the energy to deal with it. So, there's almost this internal conflict of do I say something - which I don't really want to do because I don't want the pity - or then do I not say something and then if it all falls apart I then have to explain why I didn't say something. So it is quite difficult.

People may also be motivated to delay disclosure of their illness to avoid being labelled as sick or disabled before others get to know them "as a person first" (Braithwaite 1990:475, Onley and Brockelman 2003:48). Madeline is forced to make the decision between not disclosing and potentially being regarded as deceptive or disclosing and being treated with pity. This fear of being judged was noted by Plumb-Parlevliet in their thesis on the experiences of mothers with MS, who wrote that, because of its invisibility, "people do not realise the situation these mothers are in" (Plumb-Parlevliet 2015:37).

In addition to being invisible, many of the symptoms of autoimmune diseases are immeasurable and subjective such as chronic pain or cognitive fatigue; the wide-ranging and substantial impact these symptoms may have is hard for others to appreciate (Micallef-Konewko 2013:7). The fact that pain and fatigue are felt by everyone at some point, to varying degrees, makes communicating the severity and chronicity of these sensations more difficult and requires practice and skill (Lingsom 2008:11).

One incentive to accurately convey one's experience of illness through self-disclosure is to achieve the preferred presentation of self (Goffman 1959; Myers 2004) and the avoidance of stigma. For Madeline, as well as Kelly, this was the label of being 'disabled'. Madeline does not consider herself disabled, although she says her disability pension and disabled driving permit all "tell" her she is. I asked her if she knew whether other people with MS would consider themselves disabled, and she replied;

I think they would...although I think most people would hate to say so, you know, obviously (...) I don't think any body ever really wants to label themselves 'disabled' because it is such- it has such like a negative feeling behind it?

“So, it is about the label?”, I asked.

I think it's just... you know, you don't feel good when you get told you're disabled. Being impaired is slightly better, it doesn't seem to feel as bad as being called disabled. You know, whether that is my own weird logic, I don't know

Madeline sees the label of ‘disabled’ as something applied to her, not as something she identifies with herself, and the negative feeling that comes with being told – as if with authority– that one is ‘disabled’. Kelly, who also used a walker during her recovery from a relapse of MS, was frustrated and upset at being seen in public. Kelly said,

“I didn't want the pity party, like, for people to feel sorry for me (...)I knew I was walking weird and, I don't know, I knew that I'd gone through a huge ordeal but I didn't want to be disabled (...) I guess I let myself feel sorry for myself for a while but I didn't– I never thought of myself as disabled...”

Stone writes that when it comes to deciding whether or not to acknowledge their disabilities, most people think of the stigma associated with it (Stone 1995:418). The term ‘disabled’ is attached to a stigmatised stereotype of someone weak, dependent, unintelligent, and worthless (Galvin 2003: paragraph 23). Therefore, in “accordance with the dominant culture, to ask everyone to acknowledge their own disabilities would seem tantamount to asking them to see themselves as helpless” (Stone 1995:415). This ascribed attribute of helplessness can be seen in the pitying of people with disability.

Pity stems from stereotyping and making assumptions about the sort of life someone has because they are ‘disabled’. In this way, pity is a form of enacted stigma which “has a way of neutralising positive qualities and undermining the identity of stigmatised individuals” (Galvin 2003: paragraph 26). In Saunders’ research with young adults with IBD, he found that pity was the most commonly reported form of enacted stigma. Pity, although perhaps well-intentioned, “emphasises... ‘differentness’, implicitly representing the condition as removed from the normalcy of non-IBD others” (Saunders 2014:1032).

“But you don’t look sick”

One risk of disclosure is social rejection and the ‘loss of a legitimate world’ (Kleinman 1992, Masana 2011) through the denial of social and cultural recognition. Social rejection can be a

consequence of the “non-acceptance of a known illness situation, either because of an apparently healthy appearance or because of the type of illness” (Masana 2011:133) meaning that even in the event of being *believed*, one may still be undermined. As Masana goes on to explain, this is “... the phenomena of ‘not wanting to see, nor to recognise, nor to accept, *despite knowing*” (Masana 2011:134 emphasis mine).

Selena was frustrated by the ignorance she encountered in relation to the invisibility of her Crohn’s disease, which, despite being considered very severe by doctors was often minimized and dismissed by coworkers and friends. When I asked if the invisibility of the illness made it harder to have her experience recognised by others she nodded in frustration.

Yes! "But you don't look sick"

She mimicked, clearly frustrated at how often she heard it, and then replied scathingly,

"really? would you like me to display my intestines out on the table for you so you can have a look?"

It is very frustrating, for me, so some people lose a lot of weight, I am one of those, like it doesn't take a lot - I am at a good weight now, 52kgs, and that only happened because I spent two weeks in Italy eating pizza for every single meal, like before that I was 42kgs and that was no matter how hard I tried I couldn't get that up, it was very, very difficult.

“Do people recognise that you’re sick then?” I asked.

At 42kgs no, they just think I am very, very thin, they don't pick up on the sickness (...) When I am little bit thinner than that you can see it, but something that pisses me off about that is that people say "oh, you're so lucky, to be so thin", or, "you're so lucky you can eat whatever you want" and it's like, I don't want to get into it and tell this random stranger that they are being completely inappropriate...

She was either forced to tolerate inappropriate comments or ‘come out’ and explain her illness, again, at risk of being treated with scepticism or having her troubles minimised. Participants also frequently referred to the taboo nature of discussing certain kinds of illnesses, in particular symptoms like diarrhoea and problems with one’s bowel were noted as being unacceptable to discuss openly (Defenbaugh 2013; Saunders 2014; Vickers 2000:143).

Disclosure is not a single event but occurs repeatedly, in both new encounters and continuing relationships (Dindia 1998). However, people do not necessarily progress to revealing more and more about themselves (Dindia 1998:90). The anticipated responses in future disclosures are all drawn from the experiences of past disclosures. When these are

negative and dismissive, one may begin to refrain from disclosure altogether to avoid the possibility of repeated delegitimization, which may “cause moral and social suffering and can entail feelings of guilt, shame, humiliation or vulnerability” (Masana 2011:131).

I had a friend that said "Oh, my uncle's got Crohn's disease and he doesn't need to take medication, so how bad can it be?" and because, at the time I was a teenager, but now I would explain to them this is why but I was 16 and I was upset by the fact that my friend didn't believe me. A lot of situations like that, it makes it a little bit difficult, and because the perception varies so much (...) I did tell some friends but after that incident I talked about I stopped telling friends, mostly because I don't need people's judgement, frankly

Disclosure may be received by others as excuses or complaints and respond by demanding silence (Charmaz 2002:317). When Selena was first diagnosed with Crohn’s disease in high school, she chose to tell only a few of her friends about the reason for her absence (due to hospitalisation) and her new diagnosis. It was at this time that she started having problems with her friends, and she highlighted it specifically as “what contributed to [her] trust issues and not telling people about [her] condition”. There is an indistinct line between choosing to stay silent and being silenced.

Selena’s point that “perception varies so much” calls attention to one of the reasons why disclosure is a difficult decision for people with invisible chronic illnesses. The uncertainty about how others will respond and how the revelation of illness may change the relationship can cause a great deal of anxiety, particularly in the workplace where a number of women mentioned the risk of disability discrimination. Even for those who didn’t work, such as Madeline, these concerns highlighted the subtle biases and stereotypes that persist about the lives of people with disability.

What these narratives also demonstrate is how the stakes of disclosure change as diseases flared and remit. Many of the women used their ability to pass as healthy to avoid stigma or discrimination and to continue ‘as normal’ in the workplace. But passing is a double-edged sword, as is shown when attempts to gain understanding, support, or accommodations through disclosure of illness are undermined the appearance of being healthy/able.

Conclusion

This research has aimed to explore Australian women's experiences of autoimmune diseases and, in particular, how the flares and remissions of their illnesses impacted their lives and relationships. Through ethnographic interviews with women living with a range of autoimmune diseases, this research reflects and critiques the 'cultural imaginaries' (Shildrick 2009) of what illness *is* and what it *looks like*, and impact of this on the lives of those who don't fit the picture.

The problems with drawing a definitive line between sick and well, or able and disabled, particularly for those whose bodies or subjectivities are rendered "unintelligible" (Vick 2012) by these false distinctions have been explored by number of researchers (Broom et al 2015, Jackson 2005, Lightman et al 2009, Lingsom 2008, Micallef-Konewko 2013, Vick 2012). This work often draws on the concept of liminality to describe the state of being caught in-between legitimate classifications and as such may "fall out of culture" (Hilbert 1984). My research contributes by examining how women living with fluctuating illness interact and locate themselves within these categorisations of sick and well. I argue that the concept of 'parallax' as a form of liminality (MacArtney et al 2015) is a useful way to consider the multi-positioning experienced by the women in my research.

The medical classification of autoimmune diseases as 'chronic' is not enough to understand the experience of these diseases, which, for those who live with them, are often everchanging and unpredictable illnesses. Rather than considering themselves as 'chronically ill' in the sense of 'constantly ill' participants described their experience of illness as though it were one thread running through their life. Having an autoimmune disease did not mean they were constantly sick but it was the force that brought one back into sickness again and again. Illness could be the 'double life' existing alongside 'normal life', or it could be interwoven with wellness and shifting between the background and foreground of experience. Listening to how people with chronic illness make sense of their experience is important for understanding the unique challenges and perspectives imparted by the fluctuation of illness.

The onset and diagnosis of chronic illness as a young person can be an alienating and frightening experience, particularly as one's vision for their future becomes clouded by the unknowns of illness. How women respond to the disruption and losses brought about by illness is revealing about what cultural means of coping are available and accessible to them. Biomedical treatment plays the central role in disease management, but it provides limited avenues for individuals to feel personally in control of their bodies or lives. Developing skills for how to 'be sick properly' and gain a sense of mastery was central the way of responding to the

unruliness of illness and a valued ability that many of the women encouraged others, through online forums and support groups, to learn for themselves. Establishing a respectful and cooperative relationship with one's doctors and specialists was important to all participants as a means of stepping beyond a passive role as a patient.

Finding tactics that help to 'pass' as normal and healthy in the workplace was important to a number of participants to help maintain a sense of continuity with their life before illness and a feeling that they are not so different from others despite their illness. Efforts to manage fatigue by regimenting rest and find control over one's body through diets were important parts of everyday life for a number of participants. But they also formed part of a greater pursuit of good health and the attainment of future goals which were highly personal and gave meaning and purpose to their lives.

The cultural values of productivity and success (narrowly defined) shaped and curtailed the ways in which women could define themselves in the idleness of sickness and recovery. Yet, some women had decided that striving for 'normality' and continuing to chase their goals made prior to illness was not worth the continual struggle or sacrifice of their time with family and friends. Establishing new goals for oneself in the present and letting go of the need to control also provided a sense of wellbeing although it often came when no other option was available.

Living with chronic illness exposed the women to ableism and underbelly of the valorisation of health within our culture. Although the participants in this research could and frequently did pass as healthy, they had seen firsthand the reactions of others for 'failing' to live up to the assumptions of their 'normality'. The expectations that all young people are healthy and in the 'prime of their lives' led to a number of the women being accused of lying, of complaining about nothing, and being publicly scorned for using disability services.

The problem of invisibility runs throughout the stories presented in this thesis. Though at times it appeared as an advantage to those who wish to pass as healthy, this utility of invisibility highlights the stigma and limited understanding of disability and chronic illness in the public sphere which, in other moments, is a burden to those who live with unseen impairments. The undermining of personal experience because their illness was not visually apparent to others was an upsetting and all too common experience among participants. Furthermore, being perceived as disabled was strongly avoided and participants were concerned that following disclosure people may regard them with pity, pointing again towards entrenched beliefs about the tragedy of disability and stigmatising assumptions about the diminished lives of people with disabilities.

Research into women's experience of autoimmune diseases is important for better understanding the "continuity of illness and health *together* in lived experience" (emphasis mine, Smith-Morris 2010:35). Fluctuating illness is an experience of unpredictability, making it impossible to know how you will feel tomorrow or in a year from now, how long medication will continue to work, or how others will respond to the knowledge of your illness. While the transformation of healing has been a focal point of anthropology (Kasnitz and Shuttleworth 2004:142), this research brings to light ways illness may be experienced as non-transformational and lacking in resolution. For the women in this research, learning to cope with chronic illness encompassed not only accepting the permanence of the disease, but learning to live their 'new normal' and coping with the rising and receding tides of illness.

References

- Asbring, Pia. 2001. "Chronic Illness – a Disruption in Life: Identity Transformation among Women with Chronic Fatigue Syndrome and Fibromyalgia." *Journal of Advanced Nursing* 34 (3): 312–19.
- Australian society of clinical immunology and allergy. *Information for patients, consumers, and carers - Systemic Lupus Erythematosus (SLE)*, accessed 07 Jan 2017, <https://www.allergy.org.au/images/pcc/ASCIA_PCC_Systemic_Lupus_Erythematosus_2016.pdf>
- Braithwaite, D.O., 1990. From majority to minority: An analysis of cultural change from able-bodied to disabled. *International Journal of Intercultural Relations*, 14(4), pp.465-483.
- Brody, H., 2002. *Stories of sickness*. Oxford University Press.
- Broom, A.F., Kirby E.R., Adams, J., and Refshauge, K.M., 2015. On Illegitimacy, Suffering and Recognition: A Diary Study of Women Living with Chronic Pain. *Sociology*, 49(4), pp.712–731.
- Bury, M., 1982. Chronic illness as biographical disruption. *Sociology of health and illness*, 4(2), pp.167-182.
- Bury, M., 1991. The sociology of chronic illness: a review of research and prospects. *Sociology of Health and Illness* 13(4), pp. 451–468.
- Caplan, A.L., 1993. The concepts of health, illness, and disease. *Companion encyclopedia of the history of medicine*, 1, pp.233-248.
- Charmaz, K., 1983. Loss of self: a fundamental form of suffering in the chronically ill. *Sociology of health and illness*, 5(2), pp.168-195.
- Charmaz, K., 1991. *Good days, bad days: The self in chronic illness and time*. Rutgers University Press.
- Charmaz, K., 1994. Identity dilemmas of chronically ill men. *The Sociological Quarterly*, 35(2), pp.269-288.
- Charmaz, K., 1995. The body, identity, and self. *The Sociological Quarterly*, 36(4), pp.657-680.
- Charmaz, K., 2002. Stories and Silences: Disclosures and Self in Chronic Illness. *Qualitative Inquiry*, 8(3), pp.302–328.
- Corbin, J., and Strauss, A., 1985. Managing chronic illness at home: Three lines of work. *Qualitative Sociology*, 8(3), pp. 224–247.
- Corbin, J.M., 2003. The body in health and illness. *Qualitative health research*, 13(2), pp.256–267.
- Crohn's and Colitis Australia, accessed 22 Dec 2016, <<https://www.crohnsandcolitis.com.au/about-crohns-colitis/>>

- Davis, N.A., 2005. Invisible disability. *Ethics*, 116(1), pp.153-213.
- De Certeau, M., 1984. *The Practice of Everyday Life*, trans. Steven Rendall, Berkeley.
- Deegan, M.J. and Willet, J., 2001. Liminality and Disability: Rites of Passage and Community in Hypermodern Society. *Disability Studies Quarterly*, 21(3), pp.137-152.
- Defenbaugh, N. L. 2008. "‘Under Erasure’: The Absent Ill Body in Doctor--Patient Dialogue." *Qualitative Inquiry*, 14(8), pp.1402–24.
- Defenbaugh, N.L., 2013. Revealing and concealing Ill identity: A performance narrative of IBD disclosure. *Health Communication*, 28(2), pp.159–169.
- del Vecchio Good, M.J., Good, B.J., Schaffer, C. and Lind, S.E., 1990. American oncology and the discourse on hope. *Culture, medicine and psychiatry*, 14(1), pp.59-79.
- Dindia, K., 1998. Going into and coming out of the closet: The dialectics of stigma disclosure. In B.M. Montgomery and L.A. Baxter (Eds.) *Dialectical approaches to studying personal relationships*, Mahwah, NJ: Lawrence Erlbaum Associates, pp. 83-108.
- Fitzgerald, M.H. & Paterson, K. a., 1995. The hidden disability dilemma for the preservation of self. *Journal of Occupational Science*, 2(1), pp.13–21.
- Frassetto, L.A., Schloetter, M., Mietus-Synder, M., Morris, R.C. and Sebastian, A., 2009. Metabolic and physiologic improvements from consuming a paleolithic, hunter-gatherer type diet. *European journal of clinical nutrition*, 63(8), p.947-955.
- Galvin, R., 2003. The making of the disabled identity: A linguistic analysis of marginalisation. *Disability Studies Quarterly*, 23(2), pp.149-178.
- Gibson, A.F., Lee, C. and Crabb, S., 2014. 'If you grow them, know them': Discursive constructions of the pink ribbon culture of breast cancer in the Australian context. *Feminism & Psychology*, 24(4), pp.521-541.
- Ginsburg, F., and Rayna R., 2013. "Disability Worlds." *Annual Review of Anthropology* 42 (1), pp. 53–68.
- Goffman, E., 2009. *Stigma: Notes on the management of spoiled identity*. Simon and Schuster.
- Good, B.J., 1994. The narrative representation of illness. In *Medicine, Rationality and Experience - An Anthropological Perspective*. Cambridge University Press, New York, pp. 135–166.
- Greco, M., 1993. Psychosomatic subjects and the 'duty to be well'. Personal agency within. *Economy and society*, 22(3), pp.357-372.
- Hay, M.C., 2010. Suffering in a productive world: Chronic illness, visibility, and the space beyond agency. *American Ethnologist*, 37(2), pp.259-274.
- Herndl, D.P. 2005. Disease versus disability: The medical humanities and disability studies. *PMLA*, 120(2), pp.593-598.

- Hilbert, R. A. 1984 The Acultural Dimensions of Chronic Pain: Flawed Reality Construction and the Problem of Meaning. *Social Problems* 31(4), pp.365-378.
- Honkasalo, M. L., 2001. Vicissitudes of pain and suffering: Chronic pain and liminality. *Medical Anthropology Quarterly*, 19(4), pp.319-353.
- Honkasalo, M. L., 2008. Enduring as a mode of living with uncertainty. *Health, Risk & Society*, 10(5), pp.491-503.
- Hydén, L.-C., 2008. Illness and narrative. *Sociology of Health & Illness*, 19(1), pp.48-69.
- Ironside, P. M., M. Scheckel, C. Wessels, M. E. Bailey, S. Powers, and D. K. Seeley. 2003. "Experiencing Chronic Illness: Cocreating New Understandings." *Qualitative Health Research* 13 (2), pp.171-83.
- Jackson, J., 1994. Chronic pain and the tension between the body as subject and object. In: Csordas, T. J. ed. *Embodiment and experience: The existential ground of culture and self* (Vol. 2), Cambridge University Press, pp.201-228.
- Jackson, J., 2005. Stigma, liminality, and chronic pain: Mind-body borderlands. *American ethnologist*, 32(3), pp.332-353.
- Kasnitz, D. & Shuttleworth, R., 2001. Introduction: Anthropology in Disability Studies. *Disability Studies Quarterly*, 21(3), pp.2-17.
- Kleinman, A., 1992, Pain and resistance. The delegitimation and relegitimation of local worlds. In Good, M.J.D., Brodwin, P., Good, B. and Kleinman, A. eds. *Pain as Human Experience: An Anthropological Perspective*. Berkeley: University of California Press, pp. 169-197.
- Kleinman, A., 1988. The illness narratives: Suffering, healing, and the human condition. Basic books.
- Kleinman, A., Eisenberg, L. and Good, B., 2006. Culture, illness, and care: clinical lessons from anthropologic and cross-cultural research. *Focus*. 4(1), pp. 140-149.
- Knight, C., 2015. "We Can't Go Back a Hundred Million Years" Low-carbohydrate Dieters' Responses to Nutritional Primitivism. *Food, Culture & Society*, 18(3), pp.441-461.
- Leder, D., 1990. *The absent body*. University of Chicago Press.
- Levy, R.I. and Hollan, D.W., 1998. Person-centered interviewing and observation. *Handbook of methods in cultural anthropology*, pp.333-364.
- Lightman, E., Vick, A., Herd, D. and Mitchell, A., 2009. 'Not disabled enough': Episodic disabilities and the Ontario disability support program. *Disability Studies Quarterly*, 29(3).
- Lingsom, S., 2008. Invisible impairments: dilemmas of concealment and disclosure. *Scandinavian Journal of Disability Research*, 10(1), pp.2-16.

- Luborsky, M. R., 1994. The Cultural Adversity of Physical Disability: Erosion of Full Adult Personhood. *Journal of Aging Studies*, 8(3), pp. 239–53.
- Lupton, D.A., 2005. Lay discourses and beliefs related to food risks: an Australian perspective. *Sociology of health & illness*, 27(4), pp.448-467.
- MacArtney, J.I., Broom, A., Kirby, E., Good, P., and Wootton, J., 2015. The Liminal and the Parallax: Living and Dying at the End of Life. *Qualitative Health Research*, 27(5), pp.623-633
- Manderson, L. and Smith-Morris, C.. 2010. Introduction: Chronicity and the Experience of Illness. In Manderson, L. and Smith-Morris, C. eds. *Chronic conditions, fluid states: Chronicity and the anthropology of illness*, pp.1-18.
- Masana, L., 2011. Invisible Chronic Illnesses Inside Apparently Healthy Bodies. In Fainzang, S. and Haxaire, C. eds. *Of Bodies and Symptoms: Anthropological Perspectives on their Social and Medical Treatment* (Vol. 4). Publicacions Universitat Rovira i Virgili. pp.127–150.
- Mattingly, C. and Garro, L.C. eds., 2000. *Narrative and the cultural construction of illness and healing*. University of California Press
- Micallef-Konewko, E., 2013. Talking about an invisible illness: the experience of young people suffering from inflammatory bowel disease (IBD).
- Michie, S., Miles, J. and Weinman, J., 2003. Patient-centredness in chronic illness: what is it and does it matter?. *Patient education and counseling*, 51(3), pp.197-206.
- Moss, P. and Dyck, I., 1996. Inquiry into environment and body: women, work, and chronic illness. *Environment and Planning D: Society and Space*, 14(6), pp.737-753.
- MS Australia, 2017, accessed 09 Jan 2017, < <https://www.msaustralia.org.au/what-ms>>
- Murphy, R.F., 1987. The body silent: a journey into paralysis. *New York: Henry Holt*.
- Murphy, R.F., Scheer, J., Murphy, Y., and Mack, R., 1988. Physical disability and social liminality: A study in the rituals of adversity. *Social Science and Medicine*, 26(2), pp.235–242.
- Myers, K.R., 2004. Coming out: considering the closet of illness. *The Journal of medical humanities*, 25(4), pp.255–270.
- Ochs, E. and Capps, L., 1996. Narrating the Self. *Annual Review of Anthropology* 25 (1): 19–43.
- Olney, M.F. and Brockelman, K.F., 2003. Out of the Disability Closet: Strategic use of perception management by select university students with disabilities. *Disability & Society*, 18(1), pp.35–50.
- Orlando, R.J., 2012. 'Gimp Anthropology: Non-Apparent Disabilities and Navigating the Social', Master of Arts, Rice University, viewed 24 March 2017, < <https://search-proquest-com.simsrad.net.ocs.mq.edu.au/docview/1266049298/>>
- Peters, S.L., 1993. Having A Disability 'Sometimes'. *Canadian Women's Studies*, 13(4). Pp. 26-27.

- Plumb-Parlevliet, A.M., 2015. 'The lived experience of mothering for women with multiple sclerosis', Bachelor of Arts (psychology) Honours, Edith Cowan University, viewed 15 March 2017, <http://ro.ecu.edu.au/theses_hons/1465>
- Ramirez, M., Altschuler, A., McMullen, C., Grant, M., Hornbrook, M. and Krouse, R., 2014. "I Didn't Feel Like I Was a Person Anymore": Realigning Full Adult Personhood after Ostomy Surgery. *Medical Anthropology Quarterly*, 28(2), pp.242–259.
- Reynolds, F. and Prior, S., 2003. "Sticking Jewels in Your Life": Exploring Women's Strategies for Negotiating an Acceptable Quality of Life with Multiple Sclerosis. *Qualitative Health Research*, 13(9), pp.1225–1251.
- Samuels, E., 2003. My body, my closet: Invisible disability and the limits of coming-out discourse. *GLQ: A Journal of Lesbian and Gay Studies*, 9(1–2), pp.233–255.
- Sanderson, T., Calnan, M., Morris, M., Richards, P. and Hewlett, S., 2011. Shifting normalities: interactions of changing conceptions of a normal life and the normalisation of symptoms in rheumatoid arthritis. *Sociology of health & illness*, 33(4), pp.618–633.
- Saunders, B., 2014. Stigma, deviance and morality in young adults' accounts of inflammatory bowel disease. *Sociology of health & illness*, 36(7), pp.1020–1036.
- Saunders, B., 2017. "It seems like you're going around in circles': recurrent biographical disruption constructed through the past, present and anticipated future in the narratives of young adults with inflammatory bowel disease. *Sociology of Health & Illness*, 39(5), pp.726–740
- Shildrick, M., 2009. Dangerous discourses of disability, subjectivity and sexuality. Springer.
- Stone, D. S., 2005. Reactions to invisible disability: the experiences of young women survivors of hemorrhagic stroke. *Disability and rehabilitation*, 27(6), pp.293–304.
- Stone, S.D., 1995. The Myth of Bodily Perfection. *Disability & Society*, 21(2), pp.413–424.
- Thorne, S., McCormick, J. and Carty, E., 1997. Deconstructing the gender neutrality of chronic illness and disability. *Health Care for Women International*, 18(1), pp.1–16.
- Toombs, S. K. 1990. "The Temporality of Illness: Four Levels of Experience." *Theoretical Medicine*, 11(3), pp.227–41.
- Valeras, A., 2010. " We Don't Have A Box ": Understanding Hidden Disability Identity Utilizing Narrative Research Methodology. *Disability Studies Quarterly*, 30(3), pp.1–18.
- Vick, A., 2012. Theorizing episodic disabilities: The case for an embodied politics. *Canadian Social Work Review/Revue canadienne de service social*, 29(1), pp.41–60.
- Vick, A., 2013. The embodied experience of episodic disability among women with multiple sclerosis. *Disability & Society*, 28(2), pp.176–189.
- Vickers, M.H., 1999. Sick Organizations , Rabid Managerialism : Work-Life Narratives from People with Invisible Chronic Illness. *Public Voices*, 4(I), pp.59–82.

- Vickers, M.H., 2000. Stigma, work, and “unseen” illness: a case and notes to enhance understanding. *Illness, Crisis & Loss*, 8(2), pp.131-151.
- Warren, N., Canaway, R., Unantenne, N. and Manderson, L., 2013. Taking control: Complementary and alternative medicine in diabetes and cardiovascular disease management. *Health*, 17, pp.323-39.
- Wendell, S., 1996. *The rejected body: Feminist philosophical reflections on disability*. Psychology Press.
- Wendell, S., 2001. Unhealthy disabled: Treating chronic illnesses as disabilities. *Hypatia*, 16(4), pp.17-33.
- Williams, G., 1996. Representing disability: some questions of phenomenology and politics. *Exploring the divide: Illness and disability*, 11, pp.194-212.
- Williams, J. and Koocher, G.P., 1998. Addressing Loss of Control in Chronic Illness : Theory and Practice. *Psychotherapy*, 35(3), pp.325-335.
- Williams, S. J. 1999. Is Anybody There? Critical Realism, Chronic Illness and the Disability Debate. *Sociology of Health and Illness* 21(6), 797-819.
- Williams, S. J. 2000. Chronic Illness as Biographical Disruption or Biographical Disruption as Chronic Illness? Reflections on a Core Concept. *Sociology of Health and Illness* 22 (1): 40-67.
- World Health Organisation (WHO), 1980. *International Classification of Impairments, Disability and Handicaps*. Geneva: World Health Organisation
- World Health Organization, 2011. *Global status report on noncommunicable diseases 2010*. Geneva: World Health Organization.
- Young, A., 1982. The anthropologies of illness and sickness. *Annual review of anthropology*, 11(1), pp.257-285.

Appendix A of this thesis has been removed as it may contain sensitive/confidential content